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Janelle Coleman-Smith
janellecolema00@yahoo.com

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Cancer Survivorship: Promoting a Lifetime of Health

Janelle Coleman-Smith RN

University of San Francisco

Abstract

Introduction Cancer survivors can face post-cancer treatment effects that need addressing throughout their care trajectory. Education provided to stakeholders and patients will be beneficial in preventing fragmented care, increasing patient satisfaction, and expanding ongoing supportive clinical survivorship care. *Methods* An adapted Dr. Joanne Lester survivorship needs survey was given to n=7 post-cancer treatment patients within a northern California cancer patient advisory committee. The survey results were analyzed to identify common underserved chronic long-term survivorship needs. Based on the data, an evidence-based educational component was included within a booklet to enhance future survivorship care. Additional surveys were sent to stakeholders within the oncology clinic and to the committee survivors to ensure that the educational information for the booklet was accurate and supportive to patients. *Results* The Lester adapted survey had a 71% completion rate by the patient committee. An analysis of the survey results determined the most prevalent unaddressed symptoms after treatment including post-treatment skin issues, fatigue and depression. Overall, the results of the follow-up surveys were positive with most participants either strongly agreeing or agreeing with the evidence-based research and interventions within the booklet component. 20% of those surveyed felt that the material on skin care could be expanded further, which was addressed by incorporating additional researched information into the post-treatment skin care section. *Conclusions* By integrating informational literature for post-treatment patients improvements in survivorship care were made, which reduces educational deficits within an oncology clinic setting. The results from the original and follow-up surveys highlight the need for ongoing support in the cancer survivorship population.

Keywords: survivorship, post-treatment, oncology, support

Clinical Leadership Theme

Clinical nurse leaders (CNL) have a responsibility to assist and support patients through the continuum of care to meet their ongoing health needs. “Cancer Survivorship: Promoting a Lifetime of Health” includes an educational component of a booklet to assist patients to become empowered advocates in their own health and wellness through the post-treatment phases of their cancer care transition. Evidence-based research proves that cancer patients need support as they shift from the acute phase of treatment into the survivorship phase. Additionally, applying clinical nurse leader competencies allows for a patient-centered framework to increase overall patient satisfaction and to deliver clinically supportive educational resources to facilitate patient knowledge. Competencies that align with this project are as follows: Communication, advocacy, and education (AACN, 2007). After a review of the American Association of Colleges of Nursing clinical nurse leader essentials (2013, p. 18), it was determined that using evidence in developing and implementing teaching and coaching strategies “to promote and preserve health and healthy lifestyles in patient populations” and “advocating for patients within the healthcare delivery system to effect quality, safety and value-based outcomes”, will be beneficial approaches to communicating, advocating, and educating the survivorship population.

The process began by distributing a survey to gain a qualitative perspective of what needs patients’ would like more education on and/or support in regards to common long-term post-treatment effects (see Appendix A for survey questions and results). This was followed by the design and development of a health maintenance and healthy lifestyle component of an

educational survivorship booklet. The process ended with a follow-up survey given to the same population of patients, assessing that qualitative health maintenance needs were addressed properly, and then to continue to build a complete educational booklet within two months.

Working closely with the oncology clinic interdisciplinary team, the aim of the survey and data analysis was to create a health maintenance intervention and healthy lifestyle section of an educational survivorship booklet to encompass the needs of those who are considered post-treatment cancer survivors. Three common physical post-treatment health concerns within the literature, through informal trend data, and within the distributed survivorship needs survey results were as follows: Fatigue, depression, and skin issues (see Appendix B). These three long-term side effects from various treatments were addressed with a short description of the potential effects and evidence-based interventions to help survivors dealing with the chronic ailments. By working on this process, the expectation is to a) improve patient satisfaction, b) create efficient transitions post-treatment, c) address the ongoing psychosocial, physiological, and spiritual needs of the patients, d) create a section of an educational booklet to address ongoing health maintenance needs, and e) assist patients in finding adequate resources or interventions to deal with the ongoing chronic or adverse symptoms that can potentially plague these survivors.

By collaborating with the patients being surveyed and the stakeholders within the oncology clinic microsystem, the expected results will create a supportive environment of transitional care and enhanced patient education, leading to improved patient satisfaction. This project is embarked upon as an evidence-based enhancement to current survivorship care within an oncology clinic located in northern California.

Statement of Problem

The principle problem within the northern California oncology clinic microsystem was the lack of post-treatment care for patients after the acute phases of their treatment are finished. After a leadership and CNL review of informal data trends, it was found that deficiencies in post-treatment care often leave patients with feelings of lack of support and decreased satisfaction. It is profoundly important for clinicians to provide care and advocate for patients throughout their entire cancer care trajectory. The cancer journey doesn't end at the conclusion of treatment, especially considering that survivors can face long-term side effects that can chronically influence their lives. According to Ferrel and Grant (2008) the physical, psychological, spiritual, and social well-being of cancer survivors can be affected long after the treatments are completed. The purpose of this project is to improve cancer survivorship education and treatment by initiating a change in the current model of care provided to patients post-treatment. The intended provision will improve patient satisfaction and qualitative feelings of support and advance the current standards of care to focus on health maintenance and potential chronic long-term adverse effects of treatment.

The quality of one's life following a cancer diagnosis can change dramatically and the effects of therapy can linger onward, sometimes for the rest of a survivor's lifespan. Many aspects of normal life can be affected long after the treatment phase. Research studies on survivorship show similar findings with chronic ongoing needs that afflict post-treatment patients. Imagine beating cancer, only to be left with an array of prolonged symptoms and a lack of support and resources. After treatment once the cancer is in remission, the oncology team has limited appointments with the patient, which typically consists of monitoring for recurrence.

Survivors' physiological or psychological needs may go unaddressed if patients have limited understanding of their symptoms or expectations. The patient at this point can still be facing complications that impact their daily lives. Survivorship is an evolutionary process, with many challenges in reclaiming important aspects of life. Caring and educational support needs to be a continuing process to empower these patients so they can successfully move through the trauma of what they experienced, while feeling supported within a medical context (Sherman, Rosedale, & Haber, 2012). Patients have not always received survivorship care, leading to gaps in medical care and/or lack of information regarding available resources. Multidisciplinary efforts among stakeholders (see Appendix C for stakeholder descriptions), with a focus on education and communication, will be necessary to maximize patient benefits, improve the quality of care, and prevent chronic post-treatment ailments that patients may face. The coordination of survivorship care relies on multiple layers and facets of clinician support. Communication and advocacy are critical tools in the implementation of quality survivorship care across the continuum.

Project Overview

An educational philosophy was employed to assist patients in gaining insight to develop strategies to recognize their needs and techniques to discuss health maintenance and symptoms with their providers, as well as to allow clinicians to recognize the importance of survivorship care. A component of a booklet was incorporated to concentrate on helping survivors meet their essential needs; providing quality patient centered and value-based health care is fundamental. Preventative interventions and health promotion was implemented within the "Life after Treatment" section of the booklet making the evidence-based education well-defined for patients, families, caregivers, and other specialty care providers. Many aspects of health can be affected post-treatment, but based on research and responses from the distributed survey, three

most prevalent symptoms were chosen to research, which included: depression, skin issues, and fatigue. The three symptoms were defined and interventions were provided based on current evidence. Meetings with stakeholders and again with the Cancer Patient Advisory Committee (CPAC) were facilitated to informally evaluate the components of the booklet. A follow-up survey was distributed to both the CPAC committee and the interdisciplinary stakeholders included in the survivorship care process.

This clinical nurse leader project aimed to ensure patient satisfaction and feelings of being supported, which correlates with the more broad aim of providing patient centered, holistic, evidenced-based education to aid patients in transitioning into survivorship. Collaborating with interdisciplinary teams was vital during this transition to enhance their own knowledge and participation as the survivorship booklet is further implemented. Successful implementation will allow clinicians in the future to truly support patients through their complex physiological and psychosocial post-cancer needs.

Rationale

According to the American Cancer Society (2017), cancer is prevalent among the population; one in three people will develop cancer within their lifetime. Cancer changes everything, leaving those afflicted with an uncertainty and need for chronic support, even after the acute phase of receiving treatment. A majority of survivors have completed some sort of cancer therapy, and approximately two thirds of cancer survivors have survived longer than five years after their treatments (IOM, 2006). Improving the quality of care for survivors should be a high priority for clinicians. Education and coordination of available resources positively affect the perceptions that survivors have about their care.

The organization that holds ownership of the oncology clinic this project serves, utilizes Consumer Assessment of Healthcare Providers and Systems (CAHPS) to analyze randomized qualitative data reports from patients. According to the Agency for Healthcare Research and Quality (AHRQ), CAHPS standardized surveys to collect comparable data to evaluate the experience of the care. The major foci within these surveys include coordination, communication, customer service, and accessibility of care and information (AHRQ, 2016). In reviewing the oncology clinic CAHPS scores from the entire year of 2016, there is room for improvement (see Appendix D). The average results from the clinic were overall very positive, but there are always ways to improve on satisfaction and quality. To increase the scores into the 90th percentile for these three categories would be an indication of improving patient satisfaction. Reviewing scores after the project is implemented will be a strategy to monitor long-term patient satisfaction.

A financial incentive for implementing survivorship education is to prevent complications that will accrue costs for organizations over time. If survivors have uncoordinated follow-up care, opportunities to intervene to prevent complications or to provide supportive surveillance may be missed. Addressing needs early can save the organization money by preventing recurrence, or managing chronic ailments in a proactive preventative manner. According to Wolin, Colitz, and Proctor (2011) cancer costs remain along the continuum of care, affecting healthcare institutions financially. Mariotto et al. (2011) determined that the cost of survivorship complications will cost the healthcare system 157 billion dollars by 2020. Savings would be difficult to measure and fall within the light green dollar category based on improving the system that will benefit and promote health. Considering the long view of the financial picture, especially the costs of chronic illness within the system,

the value to organizations in creating health and wellness programs to lower the costs associated with frequent exacerbations of such illnesses exists. Additionally, lateral integration of the roles of the stakeholders in regards to survivorship will further prevent fragmentation allowing for more comprehensive supportive care, which in turn will reduce the costs associated with post-cancer treatment complications (see Appendix E for stakeholder analysis). Furthermore, the healthcare market within the county of this project is competitive with other major healthcare systems. This market allows for choice and options for patients in regards to their healthcare, including cancer and survivorship care (see Appendix F for SWOT analysis). It is important to induce a survivorship program in the oncology clinic to make sure that the organization remains competitive and contains sought-after services to fully support and preserve members.

Methodology

The project of educating and supporting survivorship patients is an emerging concept with minimally available guidelines or standards within health care organizations. Currently, the organization is trying to meet the American College of Surgeons Commission on Cancer Goals (2014), which include survivorship care plans and compliance with cancer surveillance for recurrence within the clinics. The fact that survivorship care is a relatively novel concept creates some uncertainty among both staff and patients. Informal trend data within the microsystem have identified a need that current care is lacking as patients transition into their “new normal” following the acute phases of cancer treatment. Even with the distribution of the Survivorship Care Plan, there are ongoing issues that need long-term follow-up and access to educational resources. The evidence both objectively and subjectively demonstrates that the time has come to focus on implementing standards within the organization, and to support patients as they shift back into a less acute stage of their treatment. The aim of this project is as follows: we aim to

improve patient satisfaction by distributing an educational portion of the booklet for Survivorship by November 29th, 2017. An adapted survivorship needs survey was sent to seven patients within the organizations' cancer patient advisory committee to better understand their perspectives (see Appendix A). The survey, created by Dr. Joanne Lester was originally distributed to nurses to assess their survivorship knowledge, was adapted with Dr. Lester's permission to assess survivors' needs (Lester, Wessels, & Young, 2013). Evidence-based research strategies were initiated to synthesize the literature in order to have a broad understanding of post-treatment needs (Khan, Ward, Watson, Austoker, & Rose).

Implementation of the project began with creating and distributing a section of the booklet that provides common post treatment medical concerns and health maintenance education. Per the responses of the survey, a more detailed focus was utilized to emphasize treating three common late-effects patients experience: depression, skin issues, and fatigue. Statements from the survey were analyzed and combined with data and evidence collected from reliable academic sources to create this section. Additionally, the ongoing educational patient plan includes forming a complete survivorship booklet within three months and a survivorship education and support class within a year. To monitor the effectiveness of three common late-effects health maintenance intervention section, the following measures were instituted: (a) a follow-up survey to participating patients for feedback on completed component of the booklet, (b) Multi-disciplinary feedback to gain stakeholder perspective and input, and (c) further plan-do-study-act cycles to update the educational resource based on reassessment of needs. The results of the feedback survey provided valuable insight into changes and

educational tools that needed to be implemented. Acknowledging the stakeholders review was important to further analyze professional evaluation of the information and other medical needs that should be included or revised within the educational booklet.

A change theory has been included within the plan for both patients and staff. Change can be a difficult process due to habituation or uncertainty (Finkleman, 2012). Utilizing “The Process of Change” theory by Dessler, G., will be important to motivate both patients and staff to be empowered within the processes being implemented. This eight step theory is as follows (Finkleman, 2012):

- (1) Create a sense of urgency
- (2) Create a guiding coalition and mobilize commitment
- (3) Develop and communicate a shared vision
- (4) Empower employees (or patients) to make the change
- (5) Generate short-term wins
- (6) Consolidate and produce more change
- (7) Anchor the new ways of doing things in the organizational unit
- (8) Monitor progress and adjust vision as required (Finkleman, 2012)

This change theory is a valuable tool to assist both staff and patients within the oncology microsystem/survivorship context. The oncology staff are a compassionate group of individuals, but are also very busy in the emotionally taxing and chaotic microsystem environment. It is important to supportively encourage the staff as they actively participate and adapt to the changes within the organizational microsystem (Finkleman, 2012). The staff ultimately wants to do the right thing for the patients; therefore specifically addressing their accomplishments will be beneficial as the

survivorship implementation progresses. This is also an important theory that can relate to post-treatment patients as they embark on their survivorship journey. Depending on the patient's personality or situation, some may have mistrust toward the system, or feel they don't need further treatments and follow-up. According to Lazzara et al. (2017) when patients face uncertainty about their health care, they may shift into a state of vulnerability or develop a lack of trust within the medical establishment. Utilizing the Dessler theory could also help patients embrace the change or become empowered advocates in their own survivorship health and wellness goals.

Patient satisfaction will be measured at the end of the project by giving a follow-up survey to the group of seven patients within the Cancer Advisory Patient Committee. The follow-up survey was one tool employed to further develop the educational interventions for future survivors. Interviews were also utilized with staff in an effort to include them in the change process, receive their feedback, and to communicate and collaborate on a multidisciplinary level. Four months after the completed booklet has been distributed, a review of CAHPS scores will be initiated to more thoroughly monitor patient satisfaction. The clinical patients currently complete randomized CAHPS surveys and looking at these results can be correlated with the project long-term patient satisfaction. The process would require analyzing post-treatment patients that received the portion of the booklet. This process would take organizational effort by the surveyor to identify patients that meet the criteria. Moreover, patient satisfaction would likely be demonstrated with continued research and data collection.

Data Source/Literature Review

In a northern California oncology clinic within a health maintenance organization (HMO) the aim and mission are to treat and support patients facing a cancer diagnosis. It is imperative to continue supportive treatment along the entire cancer trajectory including as patients shift into the survivorship phase. The oncology clinic staff are currently trained to deal primarily with acute phases of treatment. Research provided in this literature review recognizes that survivorship patients continue to deal with complex life-changing issues that affect their existence and well-being. Each member of the oncology team has an important role to assist each patient with their needs at all levels of neoplasm diagnosis and treatment. The educational section of the booklet will serve the dual role of supporting patients and assisting staff clinicians in recognizing some of the post-treatment needs of the patients they serve.

In reviewing the survivorship needs survey and informal trend qualitative data, it was noted that patients have ongoing needs that are not addressed after the acute phase of treatment. The literature demonstrates chronic issues and needs mirror many of the survivorship issues and needs identified on the survey. The CNL focus of this review is to provide education and resources to patients to improve their quality of life, for which the intended outcome is improved patient satisfaction, which aligns with a PICO approach. Employing a PICO strategy to review the research includes: Patients: Post-treatment cancer survivors; Intervention: Creating an educational health maintenance and guidelines section of the survivorship booklet; Comparison: Standard post-treatment care; Outcomes: Improvement in patient satisfaction and feelings of having long-term support. The aim of the oncology clinic is to provide quality care and support for patients facing

a complex life-changing diagnosis. Each member of the oncology team has an important role to assist each patient with their needs at all levels of neoplasm diagnosis and treatment.

As cancer survivorship becomes more prevalent, it is important to focus on how these patients can be supported as they evolve from acute cancer patient to long-term survivor patient. Cancer survivorship is becoming a common occurrence as the progression of medical treatments become more accessible and therapeutically effective. According to the National Cancer Institute (2017) there are 15.5 million cancer survivors in the U.S. alone. Furthermore, by 2026 the number of cancer survivors is anticipated to increase to over 20 million people (NCI, 2017). These totals and estimates further confirm that the need for survivorship care will be a necessity as the number of cancer survivors increases, requiring an increase in follow-up care, education, and coordination in all care settings. According to Shapiro et al. (2016) it is necessary that evidence-based interventions and resources be an essential component in assisting patients in dealing with the continuing chronic issues that they face post treatment.

Within the research, there is a common theme that having high quality post-treatment care leads to feelings of being supported and improved satisfaction (Ferrel & Grant, 2008; Peck, 2008). Empowering patients to become educated in their ongoing care is needed so patients can understand and participate in their own treatment and health goals. According to Rushton et al. (2015) a program called “Wellness beyond Cancer” was effective by ensuring collaboration with other clinicians to educate patients about their follow-up care. A study by Dietrich et al. (2016) had positive post-treatment educational follow-up results $p < 0.001$, which showed a correlation between educational support and patient participation in their long-term care interventions. Another study by

Jones et al. (2013) discussed giving patients an educational book post-treatment that focused on potential ongoing needs. Within their study they concluded that patients were more satisfied if their post-treatment needs were addressed (Jones, et al., 2013). Patients provided with emotional and educational support have been found to benefit positively. Peck (2008) discusses how survivorship is a life altering event, which can affect identity and lead to isolation. The study concludes that patients need broad support, and that educational or group support has proven to be helpful to reduce alienation and isolation (Peck, 2008).

Moreover, to substantiate the need for the specified health guidelines and interventions two systematic review articles were analyzed. One systematic review summarized the need for preventative health services and chronic disease management amongst the survivorship population. Findings within the review found that cancer survivors are at risk for developing late-term complications after treatment, and can develop unaddressed co-morbidities (Khan, Ward, Watson, Austoker, & Rose, 2008). The other systematic review concluded that although having guideline evidence for patient education is an effective tool, it is the responsibility of the patients to adopt healthy behaviors on a personalized level. The article also discussed the importance of interdisciplinary teams to prevent wide-ranging chronic issues in the post-treatment stages (Howell et al., 2012).

Additionally, it is important to continue preventative care as patients' progress into survivorship. According to Wilbur (2015) cancer survivors need preventative and health maintenance care, yet they receive less counseling on both diet and exercise than patients with no cancer history. This article continues to predict other morbidity and mortality issues that arise from post-treatment lack of care. Wilbur further describes men treated for prostate cancer are

more likely to face death from cardiovascular disease and cancer survivors with diabetes are 40% more likely to perish from their diabetes than non-cancer patients; teaching patients to be advocates in their own health could prevent unnecessary mortality from treatable chronic conditions. Another journal article discusses the American Cancer Society (ACS) and American Society of Clinical Oncology (ASCO) breast cancer survivorship guide for clinicians. This guide recommends that patients should receive follow-up exam appointments, cancer surveillance, regular imaging, management of long-term treatment side-effects, surveillance for secondary cancers, and health promotion and education for disease prevention (Pandey & Nguyen, 2016; ASCO, 2015).

After reviewing the results of the survey and analyzing the literature, a common pattern emerged. There are common side effects from cancer treatments that need to be addressed. According to ASCO (2017) skin ailments post-treatment is a common occurrence. Chemotherapy, radiation, or anti-hormonal therapy can all cause minor to major symptoms such as, rashes, pruritus, and even malignant wounds (ASCO, 2017). The most common post-treatment effect on the skin is pruritus or itchiness. Finally, it was noted that chronic fatigue is frequently expressed as a side-effect post-cancer treatment. Cancer-related fatigue (CRF) is common, and is often improperly understood and treated by clinicians (Pertl, Quigley, & Hevey, 2013). Between 50-90% of post-treatment cancer patients face chronic ongoing battles with fatigue (Pertl, Quigley, & Hevey, 2013; ASCO, 2017). Furthermore, within the research, depression is a prevalent psychological symptom that can affect cancer survivors. In a study by Phillip, Merluzzi, Zhang, and Heitzmann (2013), it was determined that survivorship patients need ongoing support in areas of psychological support, including depression. According to Fulcher, Kim, Smith, and Sherner (2014) depression among the cancer population occurs in 52%

of patients and the depression can linger into the survivorship phase if it is left untreated. If depression is not acknowledged by either the patient or the clinician, it can cause an increase of medical costs and a decrease of quality of life for survivors (Fulcher et al., 2014). The National Cancer Institute (2017) describes depression as having feelings of melancholy, sadness, tiredness, or moodiness that lasts for longer than two weeks, and is affecting the patients' lives. Additionally, it is important to recognize the signs of depression and to treat the symptoms appropriately to prevent ongoing chronic depression in cancer survivors (NCI, 2017). Overall, it is imperative that patients and clinicians in recognize and treat all three of these common symptoms. Both physiological and psychological care should be an important clinical focus to increase patient quality of life and overall satisfaction with their received care.

Conclusions and data of studies that focused on survivorship and post-treatment cancer care were discussed in this literature review. Articles that described health maintenance and chronic ongoing long-term needs were key words used within the search. The peer-reviewed research articles used were obtained from CINHALL, Google Scholar, and PubMed search engines. This review placed focus on survivorship supportive care, long-term effects of cancer treatment, and studies of the benefits of health maintenance. The overall outcome of the research is to lay an evidenced based foundation for the implementation of interventions that will improve patient satisfaction and feelings of support during post-acute cancer care.

Timeline

The project, "Cancer Survivorship: Promoting a Lifetime of Health", began early August 2017 and will conclude by late-November 2017 (see Appendix G for Gantt chart). The planning phase of the project began mid-August and included researching survivorship evidence-based research to understand common needs amongst the post-cancer treatment population. The

adapted Dr. Lester survey was created late-August 2017. Surveys were distributed to the seven members of the Cancer Patient Advisory Committee (CPAC) on September 27th, 2017. Results from the five returned surveys were analyzed and manually entered into survey monkey to observe trends in survivorship needs on October 7th, 2017. The response rate was 71% with 5 of 7 distributed surveys completed. The rough draft version of the health maintenance, interventions, and guidelines for depression, fatigue, and skin issues within the booklet was created on October 28th, 2017 and then presented to stakeholders within the oncology clinic on November 7th, 2017. The booklet and follow-up survey was sent CPAC Survivors via mail and should have been received by the survivors by November 20th, 2017 in time for them to complete it by the meeting date. The follow-up survey will be collected at the CPAC committee on November 29th, 2017, so that the results can be analyzed and the component of the booklet can be revised as needed utilizing the input from the data. Furthermore, the information collected will then be distributed to the oncology nurse navigator and the clinic manager to support a long-term project goal of creating the entire formal finalized survivorship booklet within two months after the component completion in November, and a class within nine to 12 months. The health maintenance discussing the three potential long-term subjects of depression, fatigue, and skin issues will be included in the booklet and is scheduled to be finalized by November 29th, 2017 after reviewing the follow-up survey results.

Expected Results

This project will be beneficial in enhancing educational care for both patients and clinicians involved in the survivorship continuum. Utilizing the contributed survey data and evidence from the research will allow leadership within the oncology clinic to move forward in forming a complete educational survivorship booklet by January, 2018. The meticulous

implementation of the health guidelines and health promotion interventions for depression, skin care, and fatigue within the booklet will improve communication and facilitate inspiration among both patients and stakeholders involved in survivorship care. After the section of the booklet was completed, it was distributed to staff and the CPAC patients by being mailed on November 8th, 2017. A follow-up survey was allocated to those who had received and reviewed the section of the booklet on November 29th at the CPAC survivorship meeting. The expectation of the survey results are that the information provided will increase patients' knowledge on the subjects discussed and increase feelings of being supported. The impact of having better education available to patients will ultimately improve patient satisfaction and heighten patients' feelings of being supported. To monitor the ongoing patient satisfaction, CAHPS scores will be monitored as the booklet distribution is implemented. In conclusion, the outcome of this CNL project will provide the continuing physiological and psychological support survivors feel they need. The intention of the intervention will prevent patients from experiencing fragmented or incomplete care by providing them with adequate resources to advocate, educate, and empower themselves to deal with the lingering effects of cancer treatment. Furthermore, the outcome will promote an educational resource to provide clinicians with additional approaches to enhance their supportive patient-centered care.

Nursing Relevance

This project is a collaborative effort that affects multidisciplinary staff, including nurses and nursing leadership. Although the three components of the educational booklet are completed now, the finished booklet in its entirety will serve to increase nurses' knowledge in better understanding ongoing health and wellness needs of survivors. Moreover, it is imperative to enhance awareness of the lingering challenges that survivors' face along the cancer trajectory.

Nurses have long had the role of educating their patients, and this beneficial professional skill can be used to influence patient-centered survivorship care and education. A holistic educational booklet is being implemented to not only support patients' physiological needs, but also their psychosocial needs as well. The basis of the nursing model of care is "holistic care", which embodies focusing on the whole person to support all their needs, physical, spiritual, and psychological (Zamanzadeh, Jasemi, Valizadeh, Keogh, & Taleghani, 2015). Additionally, this project allows nurses to understand the deeper quality-of-life issues by focusing on aspects that affect these patients, and by identifying methods to further acknowledge the ongoing or underlying chronic issues. Clinical nurse leadership takes this concept further by promoting health, education, and advocacy with strong evidence-based research and a theoretical foundation to provide quality care. This project will further enhance communication, collaboration, and coordination within the clinic/hospital microsystem, mesosystem, and amongst stakeholders to guide cancer patients in meeting their holistic needs for increased support as they progress into the survivorship stage.

Summary Report

Within the project "Cancer Survivorship: Promoting a Lifetime of Health", creating an educational component addressing survivorship patients' needs based on the results of the adapted Dr. Lester survey aims to improve patient satisfaction by distributing an educational portion of the booklet for Survivorship by November 29th, 2017. The principal goal of this implementation project was to present a section of the booklet to both stakeholders and the n= 7 survivors within the Cancer Patient Advisory Committee with the longer-term goal of creating an entire booklet by January. Follow-up surveys were given to the CPAC survivor patients and to the stakeholders within the oncology

clinic after they received copies of the section of the booklet describing health maintenance, promotion, and interventions for the post-treatment topics of skin issues, depression, and fatigue.

The setting for the implementation was a northern California oncology clinic in the greater San Francisco bay area. The population of survivor patients within the committee is coalesced with oncology clinicians to create the committee. The overall goal of the advisory committee is to generate patient-centered solutions to improve outcomes within the healthcare setting for future survivorship patients by combining patients' and clinicians' knowledgeable perspectives to support healthy living. The clinicians and the patients within the committee work closely with one another to better understand clinical and patient outlooks. The collaborative group contains nursing leadership, physicians, nursing, social work, and a group of survivor patients with various cancer backgrounds.

The results from adapted Dr. Lester survey were examined to determine the most prevalent issues that the survivors described as needing addressing, which included skin issues, depression, and fatigue. Evidence-based research was utilized to create the component of the booklet as an educational tool for future survivorship patients to improve their physiological and psychological experiences post-treatment and to create a sense of self-efficiency and empowerment. Moreover, the expected results will improve patient satisfaction and feelings of support by allowing patients to have an educational comprehension of interventions to address their health issues. The evidence-based published interventions used were the American Society Clinical Oncology survivorship booklet, and four peer-reviewed journal articles with interventions for skin issues,

fatigue, and depression (ASCO, 2017, Fulcher et al., 2014, & Mitchell et al., 2014). The completed section was then presented to both the stakeholders within the clinic and the survivorship patients within the Cancer Patient Advisory Committee. Additionally, another survey was created to analyze professional and patient feedback regarding the booklet component for further development and improvement of survivorship care.

The stakeholder survey results were critically analyzed to improve the section that was created to address ongoing chronic issues. The stakeholders provided valuable clinical insight and knowledge to help further improve the information. The results of the stakeholder survey did indicate that some changes were necessary to improve the educational material to align with current clinical practices within the organization (see Appendix G and H for stakeholder and CPAC survey results). Overall, the results were positive with 80% of the clinicians surveyed strongly agreed or agreed that the provided information would be helpful and addressed the topics described, while 20% of clinicians surveyed disagreed with the educational material and offered suggested improvements. Two of the surveyed clinicians did recommend necessary changes in regards to the information provided regarding skin care. The over the counter medicated creams were not recommended within the clinic, despite the evidence-based research that had listed it as a treatment for pruritus. Furthermore, a research clinician disagreed with the provided educational information, and felt the skin topic information was too basic. To improve this subject, a sub-heading addressing skin needs post chemotherapy and radiation was added to expand the educational component to address needs earlier in survivorship. A systematic review was analyzed to include patient-centered interventions that would pertain to patients in the initial stages of survivorship post chemotherapy and radiation

(Butcher & Williamson, 2012; Dehaven, 2014). The sub-heading section included various recommended creams to utilize for varying skin ailments and the positive benefits of washing effected areas (Butcher & Williamson, 2012). The booklet was updated accordingly by employing the knowledge of the respected clinicians and peer-reviewed research articles. The project verbiage was adjusted to meet the criteria for the recommended 8th grade level to meet the various health literacy needs of the members within the healthcare organization. Furthermore, an interdepartmental meeting was held with the health education department management team to discuss the educational grade level of materials provided to patients to determine organizational appropriateness. The National Institute of Health (2016) recommends a clear and simple format for health educational material to meet the needs of diverse educational literacy levels within a healthcare setting. To improve the material provided within the component of the booklet, the informational material was adjusted to meet grade-level requirements within the organization and to the standards provided by the National Institute of Health to an 8th grade level (NIH, 2016).

The patient survey results were obtained after meeting with the Cancer Patient Advisory Committee on 11/28/17. Overall, the committee was very satisfied at 86% or satisfied at 14% with the component of the booklet addressing fatigue, skin issues, and depression. Some informal statements from members concluded that the information was thorough, concise, and encouraging to those in any stage of survivorship. The only suggestion was that it was not very gender specific and that is something that could be added as subtitles under each subject as the booklet is further developed as an improvement project. In evaluating the survey results, it was noted that the projection of

the patient perceptions were very positive. This indicates a significant improvement in survivorship care when compared with the previous model of having no follow-up care after treatment. Moreover, this aligns with the aim of this project and research within evidence-based practice that patients are more satisfied and feel more supported if they are given post-treatment educational materials and resources.

Cultivating and incorporating this change within the current survivorship care processes will be achieved by including both the staff and patients. This change will be further implemented by empowering patients and stakeholders in the overall vision and progression of post-treatment care. The change concept within the oncology clinic is further supported by Dressler's eight step change theory, which will continue to be used as the program continues to evolve to support survivorship patients. A plan has been initiated to distribute the educational booklet to patients and staff to continue care across the cancer trajectory into the survivorship phase and will be implemented by the oncology leadership team. Multi-disciplinary efforts will be made to have inclusive survivorship care within other departments by introducing the completed booklet throughout the meso-system when it is completed in January. CAHPS scores will be further monitored in the future to assess survivors' satisfaction and feelings of being supported. Additionally, it will be important to utilize clinical nurse leader skills by continuing to communicate and coordinate this educational component for both patients and stakeholders. Furthermore, survey feedback will continue to be obtained as the project is adjusted and implemented to continue to meet the needs of the clinic and the patient population.

In conclusion, this project has the potential to continue to grow into a comprehensive survivorship program to support patients long after their acute stages of treatment are complete.

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Appendix A
Survey Table

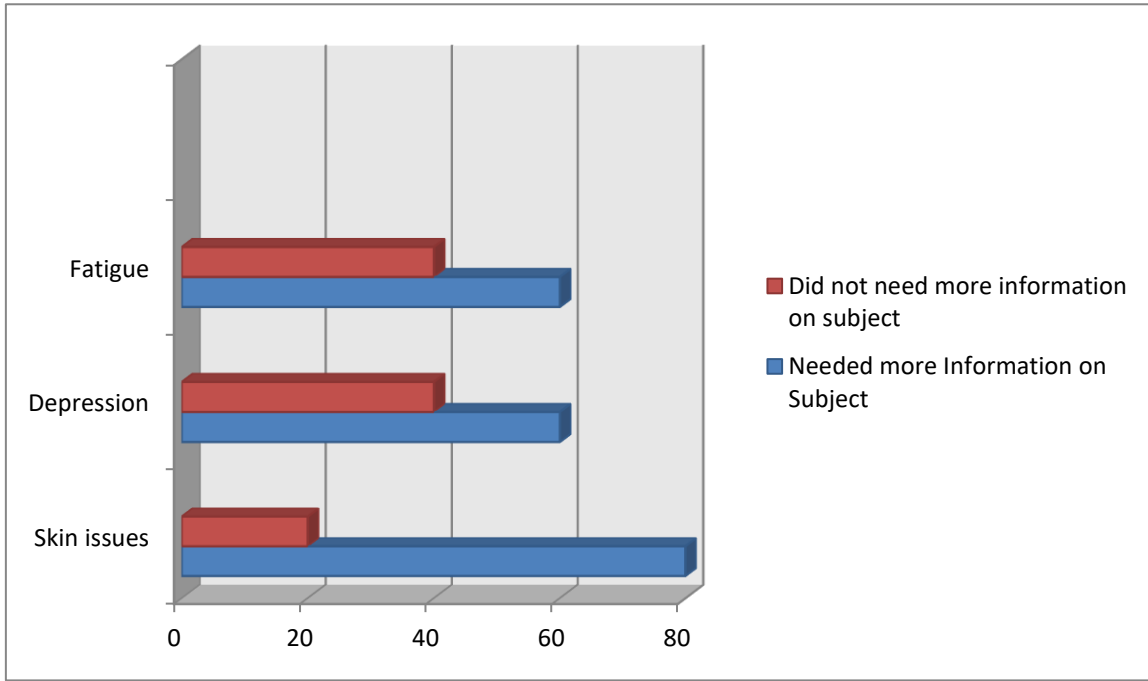
Question	Yes	No	N/A
1. Were skin care needs met?	80%	20%	
2. Were nutrition needs met?	40%	60%	
3. Survivorship exercise knowledge?	80%	20%	
4. Were fatigue symptoms addressed?	40%	60%	
5. Did you need smoking cessation resources?		0%	
6. Were routine cancer screening guidelines given?	100%		
7. Were long-term side effects of chemo guidelines given?	40%	60%	
8. Were depression/anxiety resources or education given?	20%	60%	20%
9. Were there expectations about limitations on ADLs?	80%	20%	
10. Did you need information on oral/dental Care?	40%	60%	
11. Did you receive information to deal with lymphedema?	20%	0%	80%
12. Were you given information to get vaccinations/immunizations?	40%	40%	20%
13. Did you receive adequate information about Long-term surgery side-effects?	60%	20%	20%
14. Did you need information on osteoporosis prevention?	60%	40%	
15. Were you facing financial barriers not addressed by	20%	80%	

Clinicians post-treatment?

16. Did you feel you needed information to communicate needs with family or spouse?	40%	60%	
17. Were you given information on long-term radiation effects?	60%	0%	40%
18. Do you feel you had post-treatment info/knowledge to deal with the effects of treatment on sexuality?	20%	60%	20%
19. Were you given pre/post treatment info on fertility needs/preservation?	20%	40%	40%
20. Were you given info on the post-treatment effects of bone marrow transplant?	20%	20%	60%
21. Did you feel you needed more info on how cancer dx would affect family?	80%	20%	
22. Were you given information on long-term side effects of hormone tx?	n/a	40%	60%
23. Were employment issues addressed?	n/a	80%	20%
24. Did you receive info on genetics risks and testing?	40%	60%	
25. Did you have insurance issues during or post-treatment?	n/a	80%	20%

Appendix B

Survivorship Needs Survey Data



Comparing the most Prevalent Long-Term Issues from the Collected Survey Responses

Appendix C

Stakeholder Analysis Matrix

Stakeholder Name	Impact <i>How much does the project impact them? (Low, Medium, High)</i>	Influence <i>How much influence do they have over the project? (Low, Medium, High)</i>	What is important to the stakeholder?	How could the stakeholder contribute to the project?	How could the stakeholder block the project?	Strategy for engaging the stakeholder
Patients and Families	<i>High</i>	<i>High</i>	<i>To feel supported and have ongoing needs met.</i>	<i>Informal Interviews and Surveys to better understand their perspective.</i>	<i>If they didn't feel patients needed follow-up care.</i>	<i>Committees, interviews, encouraging participation, offering them supportive resources.</i>
Physicians	<i>High</i>	<i>Medium</i>	<i>Preventing late-term physiological or psychosocial complications.</i>	<i>Providing insight into what their patients have been dealing with.</i>	<i>By not participating due to time or workflow restraints.</i>	<i>Information and feedback meetings. Outreach when booklet is completed.</i>
Nurse Navigator	<i>High</i>	<i>High</i>	<i>Coordination of care and prevention of barriers.</i>	<i>By promoting the booklet and presenting services available as patients finish treatments.</i>	<i>By not participating due to time constraints.</i>	<i>Information and feedback meetings to prove that the service is beneficial to the population.</i>
Nurses and Medical Assistants	<i>Medium</i>	<i>Medium</i>	<i>Providing quality care to patients.</i>	<i>By catching patients as they qualify as survivors (as patients near the end of treatment.</i>	<i>Resistance to change, not currently a part of workflow.</i>	<i>Meetings to discuss the importance of survivorship care to the patient. Examples on how the implementation will benefit patients.</i>

Stakeholder Name	Impact <i>How much does the project impact them? (Low, Medium, High)</i>	Influence <i>How much influence do they have over the project? (Low, Medium, High)</i>	What is important to the stakeholder?	How could the stakeholder contribute to the project?	How could the stakeholder block the project?	Strategy for engaging the stakeholder
Nursing Leadership	<i>Medium</i>	<i>High</i>	<i>Patient satisfaction scores and quality care results.</i>	<i>Assisting in the implementation of the project.</i>	<i>Budget and financial concerns.</i>	<i>Meetings to discuss the evidence of the long-term gains of preventing complications</i>
Social Workers	<i>Medium</i>	<i>Medium</i>	<i>To prevent barriers to care.</i>	<i>Providing insight into current post-treatment barriers.</i>	<i>By not having the experience of following patients in later stages.</i>	<i>Meetings to engage the SW in discussing this with current patients</i>
Physical Therapist	<i>Medium</i>	<i>High (for Lymphedema)</i>	<i>Assisting patients regain mobility or preventing lymphedema.</i>	<i>Collaborating with nursing and physicians to find patients that would qualify as needing f/u mobility care.</i>	<i>N/A</i>	<i>Including this stakeholder in meetings to strategically find ways to coordinate.</i>
Other Practitioners	<i>Medium</i>	<i>Medium</i>	<i>Varies</i>	<i>Multi-faceted support measures such as nutrition or complementary therapy to help patients with chronic needs.</i>	<i>N/A</i>	<i>Including these stakeholders in meetings further into the future as the project progresses.</i>

Appendix D

2016 CAHPS Results	
Staff Helpfulness:	82.1%
Care Experience:	87.2%
Needs Considered:	78.6%


The percentages are as follows: (1) staff helpfulness was 82.1%, (2) care experience was 87.2%, and (3) needs considered was 78.6%.

**Appendix E
Gantt Chart**

2017-2018	Aug	Sept	Oct	Nov	Dec	Jan
Survivorship Needs Survey						
Booklet Component Creation						
Stakeholder/Survivor follow-up survey						
Final Booklet Creation						

Appendix F

SWOT Analysis



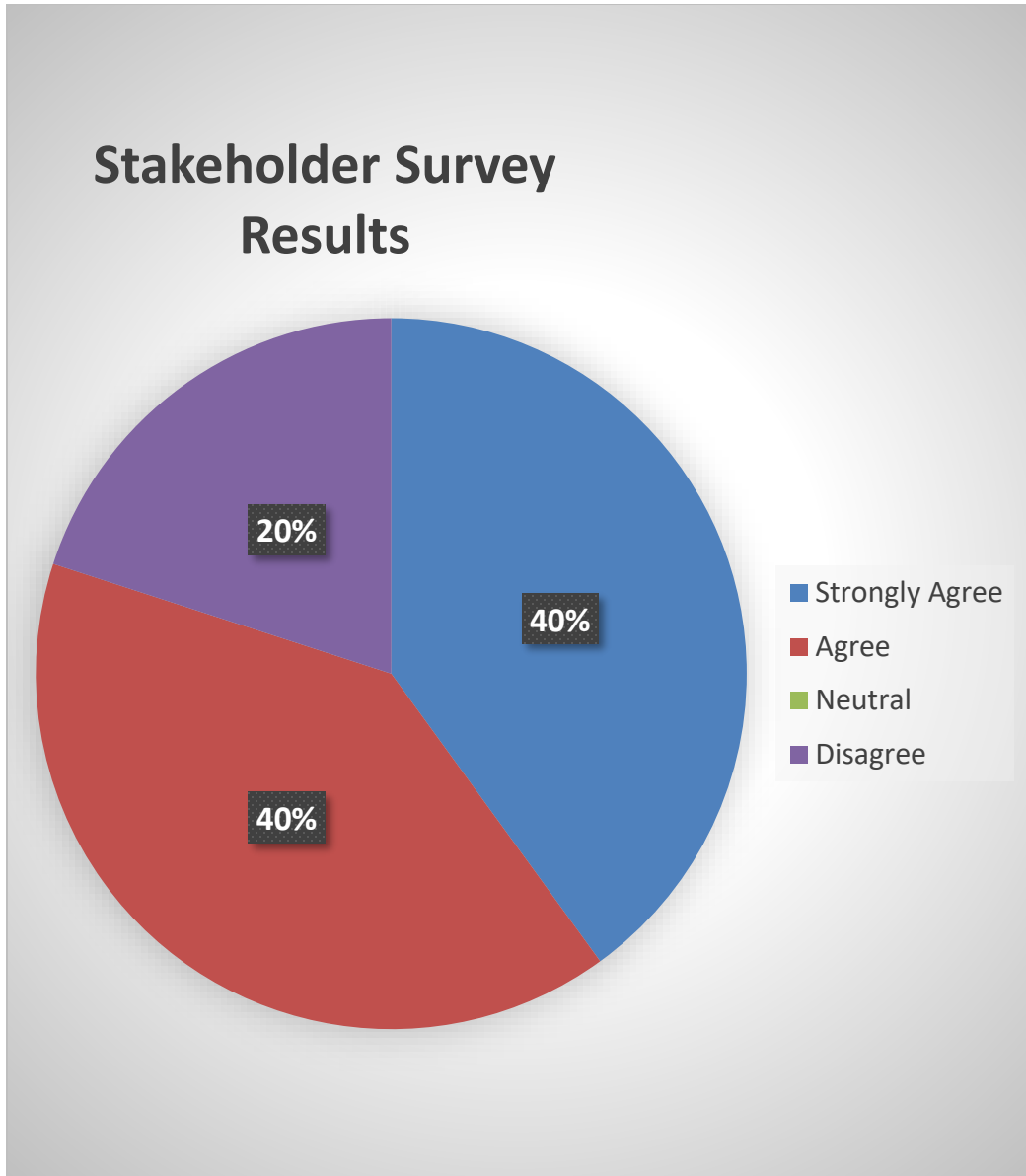
Strengths: Improve patient satisfaction Patients feel supported
Weaknesses: Unpredictable down stream revenue Staff knowledge deficit of long-term effects of cancer treatment
Opportunities: Comprehensive survivorship care provided Working as a team with other stakeholders to provide seamless transitions
Threats: Competition among local hospitals with survivorship programs Potential healthcare reform and loss of reimbursement

Appendix G

Survey Questions for Stakeholders/Patients

1. Do you feel the educational information would be helpful to survivorship patients?
 - a. Strongly Agree
 - b. Agree
 - c. Neutral
 - d. Disagree
 - e. Strongly Disagree
2. Do you feel the material provided had enough information to address the topics described? What do you feel was missing if you stated “No”?
 - a. Yes
 - b. No
3. Are there any other evidence-based interventions for the symptoms that you would recommend from the clinic or from the literature research? If you stated “Yes” please describe below:
 - a. Yes
 - b. No
4. Do you have any further comments or recommended changes regarding the material provided?

Appendix H
Stakeholder Results:



Survivorship Patient Survey Results:

