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Development of a Patient and Family Educational Document Following Cancer Treatment

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Walden University

College of Health Sciences

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Debbie Slipkovich

has been found to be complete and satisfactory in all respects,
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the review committee have been made.

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Walden University
2016

Abstract

Development of a Patient and Family Educational Document

Following Cancer Treatment

by

Debbie Slipkovich

Master of Science in Nursing, Youngstown State University, 2006

Bachelor of Science in Nursing, Youngstown State University, 2000

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Nursing Practice

Walden University

November 2016

Abstract

New pharmacological interventions for oncology patients have resulted in longer lifespans after treatment completion and a large population of cancer survivors in communities. When patient's complete treatment regimens for cancer, they leave the oncology practice with minimal knowledge of community resources that may assist them during this time of transition. These patients may not interact with care providers again until they return for a surveillance appointment in the future. Guided by Bandura's social cognitive theory, this project's aim was to develop a community-specific brochure that described the variety of services available to oncology patients and their families. The practice-focused question that steered this project asked if the developed patient education brochure on community specific resources was easy to understand and if it contained information pertinent to the oncology population. A comprehensive review of community-based resources was undertaken and placed into a brochure for the cancer survivor and their families. Eleven participants, oncology nurse practitioners, and chemotherapy infusion nurses from the local outpatient community clinical practice were invited to be content experts. They each reviewed the brochure using the Patient Education Materials Assessment Tool for Printable Materials reporting 100% satisfaction with the content and applicability for the intended patient population. This project promotes social change by providing easy-to-understand transitional care informational for cancer survivors using a community-based brochure approach in a practice setting.

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Dedication

This DNP project is dedicated to my parents and my son Robert.

Acknowledgments

I thank my parents and my son Robert for their enduring, supportive comments and understanding of the time I needed to complete my education. Without all of you, I would have never have achieved this educational goal.

I additionally thank the many Walden educators I have had through my DNP education. I especially thank my Chair, Dr. Dana Leach, for always being there for me when I needed assistance with course concerns whether they were day or night as you always responded to my requests for help. Additionally, I thank Dr. Allison Terry for her input and sharing of suggestions as well as Dr. Anna Valdez for her guidance with document development and revision. Without these three faculty members, I could never have succeeded.

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Section 1: Nature of the Project

Introduction

Cancer is a disease with the incidence rising over the lifespan (Williams et al., 2014). Those aged 65 and older comprise 60% of the new diagnoses and represent 70% of the cancer deaths (Williams et al., 2014). The prevalence and incidence of cancer continues to escalate in the United States. The American Cancer Society predicted that 1,658,370 new cases of cancer would be diagnosed in 2015 with 589,430 deaths projected (American Cancer Society, 2015). It was estimated that of the men in the United States being diagnosed with a malignancy in 2015, 26% of those cases would be of a prostate origin, and in women, 29% would be breast carcinomas (American Cancer Society, 2015), being the most prevalent according to gender.

Cancer is a disease seen in all socioeconomic groups and populations. Its presence transcends all age groups and is sometimes discovered in the healthiest of people. As an example, with known causation of the direct link to smoking and the development of a carcinoma, lung carcinoma is sometimes apparent in those without a smoking history. It is by such understanding of disease etiology, the realization is apparent we have a large population of people who will undergo oncology treatment for their disease and receive medical care at some point in their life (American Cancer Society, 2015).

With the integration of primary preventative services, a neoplastic process is likely to be confirmed at an earlier state and treatment initiated accordingly, providing enhanced outcomes. Additionally, the many diagnostic tools that are now available allow diagnoses in earlier stages of the disease process, which optimize survival outcomes.

Statistics from the American Cancer Society (2015) reported that nearly 14.5 million Americans were alive on January 1, 2014 with a past history of cancer. These people were newly diagnosed, in treatment, or were diagnosed many years ago and had no disease recurrence. In the United States, there is a large population of patients in different phases of the illness trajectory. Even with the staggering statistics and the many modalities to treat the disease, many cancer patients are managed from a chronic illness paradigm of care.

An example of a chronic illness of oncological origin may be seen in a patient with a prostate cancer diagnosis. Before the advent of the prostate specific antigen (PSA) blood test, men were rarely diagnosed in early stages of the disease as there were essentially no reliable diagnostic screening tools. With integration of the PSA into standards of care during wellness visits, the healthcare provider may see an elevation in the PSA. Realizing there may be glandular pathology with the serological rise, the patient can be referred out for further management. It is through such situations that disease is discovered in early stages, treatment regimens are initiated, and the long-term outcomes are enhanced in this group. The surveillance of these men over time, takes on a chronic illness model as the disease is discovered early and they are considered cured. These patients do well with treatment regimens and maintain follow up care with providers over time (McCorkle et al., 2011). Survivorship issues with patient and families are vital components of the continuum of care and need to be integrated into standards of care during these intervals.

With the statistics from the American Cancer Society (2015) describing nearly 14.5 million Americans being alive on January 1, 2014 with a past history of cancer, healthcare providers have a large population group who have ongoing needs. An oncology survivor is defined as a person who is recently diagnosed or is undergoing treatment, as well as those patients who have completed treatment regimens (American Cancer Society, 2015). The psychosocial concerns in the oncology survivor overarch the domains of depression and ineffective coping skills, resulting in suboptimal self-efficacy (Deshields & Nanna, 2010).

The navigation of community resources may present as a formidable task to the patient. There may be a myriad of resources for the patient, but no direct description of the availability of these resources. The objectives of this evidence-based project are to broaden the understanding of community resource availability for the cancer patient and their families to impact a positive social change.

Problem Statement

The oncology patient who has just completed treatment for disease begins his or her journey, which has been identified to be a time of uncertainty, with feelings of powerlessness and isolation (Dinkel, Kremsreiter, Marten-Mittag, & Lahmann, 2014). Developed relationships during treatment by the oncology team will culminate until future follow up visits, which could be semiannual in many patients. Those established relationships with the oncology staff during treatment end as treatment is complete. During the interval period between follow up visits post treatment, the nurse practitioner is available by phone for the patient to answer and intervene with any questions or

concerns; however, there are no longer face-to-face interactions. The patient is now transitioning into the interval of follow up care after disease treatment and into another phase of the survivorship trajectory.

Naylor et al. (2013) defined transitional care as the care of complex patients after discharge from the clinical setting to their home environment using evidence-based practice management. Therefore, it is of concern that patients completing their oncological treatment lack transitional care management provided by the oncology healthcare team, after their treatment regimen has been completed.

A report issued by The Institute of Medicine (2013) addressed the current oncology clinical environment being a setting where the standards of care do not reflect the preferences of patients. It was reported that it is imperative that quality cancer care be delivered across the continuum, from the time of the diagnosis to the end of life (Institute of Medicine, 2013). Six strategies to meet quality of care initiatives were addressed:

1. Engage patients into care planning.
2. Ensure adequate staffing, training, and coordination of the workforce.
3. Integrate evidence-based practice into paradigms of care.
4. Maintain cancer-based health care learning technology.
5. Translate the current evidence into practice, performance improvement, and quality measurements.
6. Keep cancer care affordable and accessible to the patient.

These strategies underpin the need for patient and family engagement with the inclusion of current evidence and planning of care with patient involvement. Healthcare

providers develop patient centered plans of care during patient chemotherapy regimens, yet the gap in practice has failed to include the process of navigating community and social resources after discharge when treatment is complete.

Fillion et al. (2012) stated that the role of cancer navigation has never been concisely described for integration into plans of care post treatment. Pederson and Hack (2010) explained that successful navigation of community and social resources does lead to stress reduction, enhanced patient outcomes, and self-efficacy. It is by the current research findings that this doctoral project holds significance for the field of nursing practice to enhance outcomes for patient care.

Purpose Statement

The gap in practice is the attempt to self-navigate the resources at the community level for these cancer survivors and the resultant unknown resources that are available to them and their families. The purpose of this doctoral project was to examine the current evidence that addresses the health disparity and practice gap seen in this population and formulate an intervention that helps to educate cancer survivors and their families on the availability of resources in their community. Through this approach, this project bridges the gap between the end of treatment regimens and the continuity of care for enhanced social outcomes with cancer survivors.

With the 14.7 million cancer survivors in the United States, there is a large population who is attempting to live with their disease as well coping with the myriad of psychosocial manifestations of being a cancer survivor (American Cancer Society, 2015). Involvement with interventional strategies is a priority in all paradigms of care.

Additionally, this segment of the population represents a group who has encountered the emotional journey and the sometimes aggressive treatment regimens for disease cure. Their psychosocial needs do not end at the time of their treatment regimens. The importance of supporting these patients and their families during post treatment intervals is necessary, which is how this doctoral project addressed the gap in practice; the patients and their families need direction and a grounded understanding of the services their community may provide to them in the aftermath of treatment.

Nature of the Doctoral Project

In 2005, (as cited in Hewitt, Greenfield, & Stovall, 2005) the Institute of Medicine (IOM)'s report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, defined the six phases of the cancer continuum of care as prevention, early detection, diagnosis, treatment, survivorship, and end of life issues. The focus of the IOM's report discussed the period of survivorship, which was described as starting at the time of diagnosis and prior to disease recurrence or expiring from disease. This paradigm is beneficial in planning long-term care for the oncology patient as it defines specificity to survivorship concerns of the patients and their families.

As the statistics describe a sizeable group of survivors, there is a need for planning both long and short term goals for these patients and their families. They are now transitioning away from the prescriptive relationships with their health care providers and into a time where they will need to self-manage their post treatment care and begin attempts to empower themselves to achieve personal long term goals.

Collection of evidence to meet the purpose of this doctoral project commenced with a review of the current research on the navigation of community resources after the oncology patient has undergone treatment. Additionally, the sources of evidence underpinned the concept of availability of resources and were analyzed for congruency with the doctoral project content.

The nature of the doctoral project uses the approach of navigating social resources after the cancer patient's treatment has been completed. As described by Fillion et al. (2012), the navigation process originated in the United States as a type of model led by volunteers to overcome the many barriers encountered by groups of people who may have been socially marginalized due to disease states.

A statement of the doctoral project purpose includes the identified practice gap, with perceived inability of the oncology survivor to successfully navigate the community resources after treatment regimens are complete, and the need for the health care provider to formulate an approach to close this gap for positive social changes to occur.

Significance

The exemplary stakeholders of this doctoral project are those members of the community-based healthcare teams who provide the many supportive services for the oncology patients and their families. With their design and development of the existing community-based programs as a component of community infrastructures, they present resources to the local population on survivorship and wellness concerns. The inclusion of these community-based programs has been integrated into the educational brochure.

The target population is those cancer survivors who have completed treatment regimens for their disease and have been released from the oncology clinic until future follow up. They comprise a demographic group of men and women aged 18 and older who are in different phases of the survivorship trajectory.

A navigational tool describing the services provided in a community at the local, state, and governmental level, was developed as an adjunctive medium that provides a benefit as they complete their treatment regimens. A desirable outcome of this intervention was to affect a positive social change on cancer survivors in a community as they make the transition from the oncology clinic to the follow up period a smooth and seamless process, one that will provide a sense of empowerment to the oncology patient and promote self-efficacy.

The educational tool developed through this doctoral research makes a significant contribution to nursing practice as it foundationally moves the cancer survivor from a dependent state, as they incur treatment regimens, into a state of self-efficacy as they know where to turn for the resources they need after treatment completion.

Summary

Due to research for enhanced treatment regimens and enhanced outcome statistics, the patient with a cancer diagnosis may continue to live with a disease considered to be a chronic illness. Survivorship issues become a significant part of the long-term planning process with the patients and their families. As the oncology patient exits the treatment facility, there may be anticipatory anxiety as the developed relationships with the oncology health care team end until the next follow up visit. The patient and their

families are left to manage their care as well as meet psychosocial needs essentially on their own. Without an understanding as to how their community may support them through aftercare treatment for cancer, they are losing a major component of long term disease management.

By the integration of a community resource navigational tool, the desired outcome would be to better meet these needs by a broader understanding as to how their community may serve them in the aftermath of treatment. This tool will assist in guiding the oncology patient into a broader depth and breadth of understanding as to what their community has to offer them to meet their survivorship needs.

Section 2: Background and Context

Concepts, Models, and Theories

With the growing number of oncology survivors in the United States, communities may provide many resources in the aftermath of their treatment regimens. The issue is the failure to efficaciously navigate the resources in a community as the resources potentially available to them are unknown. These survivors are now left to find direction in their community, as they are no longer under the care of the oncology health care team and day to day interactions have ceased. Attempting to determine what social support may be available to them in their community may present as a laborious task to oncology survivors and their families. Bandura's social cognitive theory (1977), which connects people together with their environments, was the theoretical framework for this doctoral project.

The defense for the use of Bandura's theory (1977) is the method the theory describes and predicts the distinctive psychological changes that are apparent with different treatment modalities. The constructs of the theory argue that self-efficacy may be achievable by having specific interventional strategies in place. Hodges and Videto (2011) described self-efficacy as one the most important features seen as influencers of personal behaviors.

It is through self-efficacy that subjective situations perceived as threatening may be approached and found to actually be safe respites. An example is the reluctance of some oncology survivors to engage in the setting of support group environments. It may be hypothesized to be an anticipatory type of threat based on the involvement with

strangers and the expectations of the patient's perceived level of involvement in the milieu.

The concept of self-efficacy may be further exemplified using the act of meal preparation. The cancer survivor must be able to have means of transport to the grocery store, select and pay for the food, then return home and prepare the meal. Some may surmise this as an effortless journey, whereas with the cancer survivor who may have recently completed chemotherapy, this may be a fearful task. The situation may present as an overwhelming venture, with feelings of uncertainty to perform the entire process uneventfully as the patient recovers from the treatment regimen.

It is widely understood that many chemotherapy regimens produce a multitude of treatment related toxicities that impact the quality of life. Going to the grocery store may previously have been an uneventful task whereas it is now become an arduous process, yet one that must be approached. Knowing where to seek assistance during this time of transition is the current gap in practice, as the cancer survivors are uncertain of the resources their communities may provide for them. Bandura's social cognitive theory (1977) is arguably the most efficacious theoretical framework to use to develop strategies to aid the oncology survivor with procuring community resources after they have completed their treatment regimens.

Bandura's social cognitive theory (1977) is imbedded in psychological domains as the theoretical framework assists in the inquiry of psychosocial and psychological alterations seen with different treatment modalities. The theory furthermore guides the heightened understanding of how self-efficacy affects the entire psychological domain of

cancer survivors and is transferable to many standards of care. For example, Hodges and Videto (2011) used the concept of self-efficacy into successful breastfeeding outcomes with women. It was again noted as to how self-efficacy positively influences behaviors, and the more these women felt in control of the process, the more confident they became in their abilities. Their personal achievements of self-efficacy were apparent in their role as they breastfed their infants. It is postulated that people become more engaged and involved when personal achievements are derived from a self-directed action (Hodges and Videto).

Terms that are used in the DNP scholarly project that may have multiple meanings are *cancer survivors*. This segment of the population is people over the lifespan who are newly diagnosed with the disease, currently on oncologic treatment regimens, or those who have completed treatments and return to clinics for follow up visits. The use of the word *communities* is used to describe a local area of residences in a specific part of a town where the oncology survivors reside. *Navigation* of resources is considered the process by which oncology survivors encounter the cancer resources in their local community.

Relevance to Nursing Practice

Absolom et al. (2011) described that emotional distress in oncology survivors is often underdiagnosed and not assessed for its existence and therefore is never able to be managed. Moreover, the oncology team works within the standards of practice; however, the psychosocial needs of the oncology patient are detached at the time of discharge from the oncology practice (Absolom et al., 2011). As depicted by Absolom et al., this time

away from the oncology clinic is a juncture where psychosocial influencers present, and with the face-to-face communication with the oncology team no longer present, patients have described feeling fearful and alone and not knowing where to turn for help.

Mosovel and Sanders (2010) explained that there is a lack of knowledge of the available resources in their community for care issues after chemotherapy completion. The authors described the many effects of cancer therapies and the physiological changes that occurred by cancer survivors, resulting in a need for community assistance. Day to day tasks such as hygiene and domestic tasks may become unimportant duties to oncology survivors after they complete their treatments (Mosovel & Sanders). The toxicities of chemotherapy regimens such as fatigue, malaise, and loss of appetite are known factors of causation. The problem is magnified by not knowing who may be able to help them and where they should go in their communities for assistance.

Local Background and Context

Nearly 14.5 million Americans were alive on January 1, 2014 with a past history of cancer (American Cancer Society, 2015). These numbers describe a vast group of cancer patients transitioning back into their local community with survivorship issues, which describes the relevance of the doctoral project as it adds an educational piece to the shift of care after treatment is complete.

The initial interaction with the patient is in a primary care practice where the patient may have had an abnormal mammogram or computerized axial tomography scan exam warranting further intervention. The patients are referred to a community based freestanding oncology clinic for initial management by the nurse practitioner and

oncologist. The patient thereafter undergoes the necessary tissue sampling for definitive diagnosis to begin comprehensive cancer treatment regimens.

Located in a suburban setting, the clinical facility is fully accredited per the state regulatory guidelines and follows national standards of practice for safe administration and handling of chemotherapeutic agents. The nurses are all oncology certified and are certified in chemotherapy administration from national certification bodies. The facility hosts a patient population of 18 years of age and older with an oncologic diagnosis. The clinic is a paperless facility that uses electronic health care records with its own institution specific software system.

Patients who receive chemotherapy regimens in the facility are often seen in the practice weekly, for sometimes 8 weeks or more, dependent on the diagnosis and medications necessary. Relationships are built with the health care team over the course of treatment and professional associations are developed. In the aftermath of treatment, when chemotherapy sessions have been completed, the patient is discharged from the facility and back into the community. They follow up with the oncology providers at scheduled intervals and with the primary care nurse practitioner who had initially made the referral.

To operationalize the concepts in the doctoral project, the barriers to care must be understood which may be defined as any impediment of accessing needed health care services (Absolom et al., 2011; Burg et al., 2010). In the oncology survivor, barriers to care are in the follow up period, after completion of chemotherapy where they attempt to find resources in their communities to assist them with survivorship issues.

Many state and federal programs have developed support services that are maintained by governmental or local funding. These programs, such as The American Cancer Society, provide a myriad of supportive as well as financial services to the oncology survivors. Many of these programs are in place in communities throughout the United States and desired goal of this DNP project is to assist with a broadened understanding of the many services available.

Role of the DNP Student

After 35 years of working with this patient population, I have seen the negative outcomes when the patient completes treatment. Left to survive in their communities with their families, many know so little as to what their community may provide to them. During treatment for their disease, care planning does encompass some of the community resources to assist them at this vulnerable time, although few choose to use them. An example is involvement in support groups. The patient and families are aware of the existence of these programs, yet seemingly few choose inclusion. These patients strongly bond with health care providers involved in their care and their psychosocial needs are met during these treatment encounters. I add that families are inclusive as well with these statements. The comradery and developed relationships are built as we meet them and continue throughout their treatment regimens.

Patients I have cared for have cried to me, laughed with me, shared personal stories with me, as well as celebrated life events with me. I know them and their families well. Sadly, as their treatment regimens come to an end, and they ring the bell in our main treatment room to mark a sense of closure with chemotherapy completion, we do

part our separate ways. It is this post treatment interval that I feel a need to intervene for better patient outcomes, as their relationship with our oncology team has come to an end until they return for follow up visits.

As I have encountered practicums, I have seen the same behavioral influencers as they return for follow up visits. They have seemingly become lost in the community during these intervals and regain a sense of joy as they return to the facility to see the nurse practitioner. The developed relationships with both the oncology team and the primary care practice cannot be underestimated; they help the patient cope during post treatment survivorship.

Personal motivators for this doctoral project are many. I uphold a sense of empathy with this special population and remain immersed into my practice as I care for them and their families. One area of personal interest, I have yet to understand, is that I remain uncertain as to why this topic has never entered my conscious thought before. As I reflect back on those 30 plus years of clinical practice, I clearly see how outcomes may be improved.

A potential bias I may possess is that I feel they are a vulnerable population from both a psychosocial as well as physiological paradigms and their need for supportive care after discharge. I have addressed this issue with the knowledge there are many vulnerable populations and that a patient's need for support does not come to an end when they leave the health care facility. With this in mind, I am better able to visualize how a doctoral project, such as this one, is easily transferable to other patient populations. Whatever the causation for their needing health care services, it is imperative they have a grounded

understanding as to what services their community may provide them in their time of need.

To summarize, encouraging the concept of self-efficacy, in a cancer survivor, may better assist the patient and their families as they move into survivorship phases. By the integration of Bandura's social cognitive theory (1977) into the theoretical framework, this DNP project was developed. The relevance to nursing practice encompasses a large segment of the population; a group with ongoing needs during survivorship that is inclusive of families.

Communities throughout the United States host programs at many levels to assist these oncology survivors with specific needs that are addressed. The practice gap is the lack of knowledge the oncology survivors and their families may have as to how their local community may assist them for enhanced health care outcomes, as well as helping meet their psychosocial or financial needs. This DNP project has achieved an approach to close the gap by the integration of a community-based navigational document that explains to the cancer survivors and their families, the local services available to them.

Section 3: Collection and Analysis of Evidence

Introduction

For the oncology patient who has just completed a treatment regimen for his or her malignancy, the journey away from the oncology clinic begins, which has been identified to be a time of uncertainty, with feelings of powerlessness and isolation (Dinkel et al., 2014). The developed relationships with the oncology care team during treatment culminate until future follow up visits are made as well as visits to the primary care practice. The cancer survivor is left to seek out the community services with minimal resource availability known to them (Blinder et al., 2013).

Nearly 14.5 million cancer survivors were alive at the beginning of 2014 in the United States (American Cancer Society, 2015). These survivors were either newly diagnosed, on current treatment, or were diagnosed years ago without disease recurrence. This provides a large population of patients in different phases of the survivorship path, which strongly describes the relevance of the doctoral project and the need to maintain a state of self-efficacy in these survivors for enhanced health care outcomes.

Practice-Focused Question

The gap in practice has failed to include the process of navigating community and social resources after discharge when the oncology patient has completed treatment. Comprehensive discharge plans are distributed, yet the availability of community resources have not been part of the discharge plan. The practice-focused question that steered this study is the following: Is the patient education brochure on community specific resources easy to understand and does it contain information pertinent to the

oncology population? As this doctoral scholarly project was a research to practice initiative, this question may be answered with future survivorship research in the field of oncology. Additionally, this research may be considered a prospective pilot study using an educational tool.

The purpose of this doctoral project was to affect a positive social change in cancer survivors in a community who have completed treatment. To operationalize the purposes, an educational tool was developed to help cancer survivors better understand what their respective community has to offer them as they complete treatment regimens for their cancer. The goals were to develop states of self-efficacy in cancer survivors by having a tool that was easy to understand and had meaningful use. Furthermore, self-efficacy is defined in this population as the ability of the cancer survivor to make decisions using modifiable factors such as social support services to promote enhanced quality of life after treatment completion (Forsythe et al., 2014).

Sources of Evidence

The current evidence strongly supports the large population of cancer survivors who are newly diagnosed, receiving treatment for their disease, or have completed treatment programs. Statistical reports by the American Cancer Society as well as the Center for Disease Control and peer-reviewed research articles were some of the sources of evidence used to address the practice focused question. The evidence was supportive of the purpose of this doctoral project and assisted with answering the project question. The research was analyzed for applicability to the practice concern and supported the purpose of the project. By collecting and analyzing the current research-based evidence, the

inquiry into promoting self-efficacy through education in the cancer survivor was further understood and applied into an information tool for this target population to use.

A systematic review of relevant published outcomes and research applicable to this DNP project was conducted. Sources were broad-based for authors who have presented statistically significant research and presented in peer-review journals for authenticity and reliability. An exhaustive research review was undertaken with the use of grounded and valid search engines that host research focused outcomes related to the practice question in this DNP project.

Search engines such as CINAHL and MEDLINE simultaneous search, CINAHL Plus with Full Text, ProQuest Central and Science Direct were used for the literature review. Key search terms and combinations of search terms used consisted of the following examples:

- *Cancer and survivorship,*
- *Cancer,*
- *Cancer survivorship and self-efficacy,*
- *Cancer survivorship and community resources, and*
- *Self-efficacy.*

The scope of the literature review encompassed research from the past 5 years to maintain current relevancy. Landmark research that was applicable to the proposed area of research inquiry was included in the literature review. The literature review was comprehensive, as the plan was to consider all research that was discovered by the use of the key search terms and combinations to provide a deeper and thorough exploration of

the topic. This systematic review of the literature was reviewed for applicability to the practice issue for support of the final DNP project documents of a community-based navigational tool.

Oncology patients are concerned about the gap in transitional care and the intervals for return for follow ups with minimal resource availability known to them (Blinder et al. 2013). Current, evidence-based research reported that navigating through social resources not only removes the barriers that impede care, but there is overall improvement in the delivery of health care when resources are made available to the oncology survivors and their families (Fillion et al., 2012). Moreover, with cancer survivors, the navigation of community resources after treatment completion may present with a host of obstacles faced as they encounter the diverse social system in their communities (Fillion et al). Van Ryan et al. (2011) described that a major theme reported on questionnaires was that minimal social support had been provided to them after treatment completion. As reported by Hodges and Videto (2011), people become more engaged and involved when personal achievements are derived from a self-directed action. It was by this understanding that an educational document that navigated community resources was developed for this population.

The individuals who contributed information for this doctoral research were the community stakeholders who spearhead the efforts of the survivorship programs and the healthcare providers who care for oncology patients in the clinic. These individuals were from the outpatient oncology facility. The relevance to the selection process was to

include various members of the health care team who provided patient education in different schemas to the oncology population.

After the document describing the community resources available to the cancer survivors and their families was developed and approved by the Institutional Review Board (IRB) approval number 08-05-16-0569089, a content validation of the document was done using oncology expert reviewers. The evaluation instrument of choice was the Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P; Agency for Healthcare Research and Quality, 2013; Appendix C) as it has rigorously been tested for reliability and validity with patient education materials and is available on the public domain. Furthermore, the PEMET-P tool specifically evaluates the understandability of printed patient education materials. The tool also evaluates the actionability of the printed material by allowing those of diverse backgrounds and various levels of health literacy to read the documents and be able to integrate changes with the material presented (Agency for Healthcare Research and Quality, 2013). The tool measures 17 items of understandability and seven actionability items. As I used a developed patient education brochure on community resources, the PEMAT-P provided the most effective content evaluation.

The study process initiated with a request to participate in the review with a project sheet (Appendix A) sent to all potential reviewers describing the processes and determination if they desired inclusion. This document was sent via email messaging with addresses available on the public domain. Additionally, another document was developed should potential reviewers need contacted a second time (Appendix B).

The PEMET-P tool was sent to the group of reviewers via email, with the developed brochure on the navigation of community resources after the reviewers accepted study inclusion. After their completion of the PEMET-P appraisal document, they returned the completed form to me via my email. Additionally, the names of individual participants and were masked on the evaluation documents to maintain confidentiality.

Analysis and Synthesis

Analysis procedures used in the doctoral project, to address the practice focused concern, were compiled by the results of the PMET-P evaluation and its specific methodology to calculate the materials score for both understandability and actionability (Agency for Healthcare Research and Quality, 2013). With conclusion of the PEMAT-P scoring, the results were then interpreted as to what the reviewers determined need changed to make the brochure applicable to the target population of oncology patients. As this scholarly DNP project contains no research, rather document review, there is no inclusion of statistical analysis rather content evaluator findings.

Summary

With a large number of cancer survivors in the United States, there is a vast population of people who have ongoing health care needs to maintain states of wellness. After discharge from oncology clinics, when treatment regimens are complete, many face their futures with uncertainty as to what services their communities may provide to them in the aftermath of an oncology diagnosis. As a practice gap has been identified, since there are no documents to guide the cancer survivor through community services, a

dedicated educational document has been developed to close this gap. The goals are of this scholarly DNP project were for a smooth transition back into their community and with feelings of self- efficacy as they will be adequately navigated into these local resources.

Section 4: Findings and Recommendations

Introduction

This DNP project encompasses the transition of care as the patient leaves the oncology clinic after treatment and the lack of understanding of community resources available to them during this time. The gap in practice was the nonexistence of a comprehensive educational document to guide the oncology patient and their families to the availability of the resources their community has to offer them.

The practice-focused question that has steered this study is the following: Is the patient education brochure on community specific resources easy to understand and does it contain information pertinent to the oncology population? A statement of purpose included the identified practice gap, with perceived inability of the oncology survivor and their families to successfully navigate the available community resources after treatment regimens are complete and the need for the health care provider to formulate an educational approach to close this gap for positive social changes to occur.

Sources of evidence were obtained from an exhaustive review of the current literature. The research inquiry focused on patient education using transitional care models in oncology practice. The literature review further centered on psychosocial needs of the oncology patient and their families after treatment completion. An in-depth exploration of the services that were currently available in the local community to serve the oncology population and their families was also conducted. An Internet search of the larger agencies that provide community resources to the oncology patient was a starting point to guide the inquiry to the community levels. As information was determined from

the larger groups, such as the American Cancer Society and Hospice programs, phone calls were made with community stakeholders to determine local availability of resources.

Incorporation of leadership principles as well as collaborative processes was accomplished by communication with those in the community who spearhead efforts to promote comprehensive oncological support to this group in the aftermath of care. By meeting with the community-based oncology support team within the hospital infrastructure system, newly formed relationships were developed with the oncology care team, and communication processes were shared to support the development of the brochure for this DNP project. This allowed a full spectrum of information as to what the local community could offer this population after they completed oncology treatment. As the educational brochure was in the process of development, the interaction with these stakeholders allowed a time of collegial sharing of the purpose of this collaborative DNP project and assisted with recruitment of a larger group of potential content reviewers for the brochure.

Findings and Implications

After IRB approval, email messages were sent incorporating an IRB approved form to the reviewers (Appendix A) asking for their potential inclusion in the review. A total of 13 email messages available on the public domain were sent with two declining due to current work and time concerns. A reminder letter was developed (Appendix B), should a response not be received after the initial email request, but the document was not needed as all responded. The final The 11 content reviewers were emailed the PEMAT-

P Tool (Agency for Healthcare Research and Quality, 2013; Appendix C) and the developed patient and family brochure on community resources after completion of oncology treatment.

The findings that resulted from analysis of the brochure using the PMET-P tool described PMET-P scoring of 100% in areas of understandability and actionability of the developed navigational printed material. The content expert review of the community brochure was favorable as the reviewers felt the content was comprehensive and easy to understand for the oncology patients and their families (understandability). Additionally, the content was felt to be valid information and the patients and their families could use the information to benefit themselves (actionability). The included narrative box, for reviewers to place suggestions to enhance the tool, were descriptive and constructive to final brochure deployment. As the brochure was initially developed to be a succinct document that narratively described resources, one reviewer felt the need to add more description of each of the support groups. This was considered with final document development, yet the support groups are titles with the disease areas that oversee the group focus.

This navigational brochure has potential implications to affect a positive social change within a community of cancer survivors and their families. Whereas there has been little distribution of supportive services for this group in the past, this brochure provides new understanding of what their specific community may offer them. It is by the integration of research into clinical practice that this transitional care interval is better enhanced by the distribution of this brochure. Additionally, by the use of this patient and

family focused brochure, social change is affected by the desired outcome of enhancing population health in this group. It is widely understood in the practice of nursing that the better educated the patients are, the better they are able to manage their health.

Recommendations

The gap in practice, as previously described, is the lack of understanding the myriad of community resources available to the oncology patient and their families after treatment completion. As there has been no transitional care document to guide this group, a brochure has been developed and evaluated by reviewers for applicability in the clinical setting. With the eventual approval of the brochure by administrative decision makers in the clinical setting, a standard of practice may be developed to incorporate distribution of the material when the patient has completed treatment. This is planned to be facilitated by meetings with administration and the users of the brochure, the nurse practitioners, to further explain the use of this educational tool. As administrators in the clinical setting have been aware of the development of this brochure, these meetings will further support the research to practice component to guide the patients and their families accordingly after treatment.

Contribution of the Doctoral Project Team

I feel the success of a student is strongly correlated with the level of involvement and active participation by faculty. Arguably, the doctoral project team has provided invaluable resources for constructive comments on improvements to comprehensively develop DNP related project documents as well as revisions to submissions sent to the team. Without guidance from the doctoral project team, it is likely I may not have succeeded.

The roles of the committee chair and committee member provided a significant integrative component to this DNP project. Phone conferring discussions further enhanced my understanding of the components necessary to put together a DNP project that followed a logical as well as sequential order. It furthermore brought a “human touch” into this online learning platform as we were able to speak to each other rather than use an electronic platform. It permitted a time of interactive discussion on the DNP project as well as a time of sharing of student concerns with suggestions for improvement, all to my benefit.

The role of the committee URR is yet another component of my success during doctoral work. To have a dedicated faculty member objectively review the work of a student before final submission, once again, precedes the success of a student at course completion. Additionally, the use of the Doctoral Project Checklist provided a marked benefit to me as it succinctly narrated the focus areas I needed to include during the write up of DNP project findings. Moreover, it allowed a place for my committee URR to place constructive comments and suggestions to further refine my submitted documents.

Future research on the benefit of this navigational brochure may be undertaken by having the oncology patients and their families evaluate the document for its inherent value and usefulness to them. It is speculated that a research study such as this could potentially strengthen the need for this type of transitional care information although future research with groups will answer that question.

Strengths and Limitations of the Project

The strengths of this DNP project encourage a positive social change as the foundation of the project overarch community health concerns. By the use of a navigational brochure that identifies community resources to oncology patients and their families after treatment completion, we may positively enhance health outcomes in this population.

Another strength is the use of a printed document for distribution. There are a multitude of computer applications available for patients to use that are directed to specific health concerns. Health care providers must be cognizant of the fact there are populations of people who do not use electronic media therefore these computerized applications will not be used by this group. It is important to consider the target population and the ways we desire to communicate patient education. Should all educational documents be placed into electronic media, we are quite likely to miss a segment of the population, which would be an unfortunate outcome from an educational standpoint.

The limitations of the use of this community navigational tool is the specificity of resources in a local community. As the local area is a coastal community with a seasonal tourist population, the nurse practitioner must remain aware of the needs of these specific patients. When distributing the brochure, these considerations must be kept in mind as it is likely other communities may offer different services. From a conceptual standpoint, the major service providers to the oncology population are nationwide such as the American Cancer Society. It is believed, the seasonal tourist to the community would

have some local information to expound upon when they leave the area and return to their own community.

Section 5: Dissemination Plan

Analysis of Self

As a nurse practitioner, understanding the many potential psychosocial influencers encountered by the oncology patients and their families assists with making the connections with this DNP project experience. Having cared for this population for over 30 years and having witnessed firsthand some of the stressors encountered, I was better able to conceptualize the need for ongoing support for these patients. As treatments modalities cease, the need for ongoing supportive services does not. As previously discussed, the number of cancer survivors in the United States is continuing to grow and with those numbers comes the need for supportive services for this population.

When I objectively analyze myself as a scholar and project manager during this DNP project, I see myself initially as novice to approaches to begin influencing a social change in this population. However, the integration of new learning from coursework has allowed for an enhanced understanding and has encouraged new insights into long-term professional goals. I am better prepared to see where practice improvements can be initiated and have a solid understanding of how leadership principles factor into enhanced clinical outcomes when working with groups.

As I reflect on the completion of this DNP project, I understand it was not a singular pathway. The challenges were many as not everyone I encountered was interested in clinical change. Some felt that this educational brochure on resources in the county to assist the oncology patient and their families after treatment completion was unnecessary. Again, I restate the positive influencers of past coursework and the

integration of new learning into making it through this DNP journey. Where I started and where I am now are two different phases. I have a greater understanding of working with groups and building teams without acting as a solo entity in the clinical setting.

The insights gained have been many during this DNP project. The value of ongoing communication cannot be overrated when working with groups of people including community stakeholders. It has become apparent to me that all clinicians in the practice need to be part of the intermix of the team concept. I surmise we all need to feel as though we are part of a process and have had inclusion into the desired outcomes.

When encountering a journey such as this, I further the communication process with the absolute necessity of sharing concerns with faculty members. If it were not for contacting my faculty with questions when I did not know where to turn, I believe I may have failed due to feeling overwhelmed. Again, acting as a solo entity and feeling this will increase a student's success, is a fallacy. I cannot imagine how I would have made it through my DNP project without the support of faculty.

Another valuable student insight is to have a preceptor that is desirous of a student's drive to succeed. I have been guided by a DNP degreed preceptor who was always available to me for questions or concerns. She had a thorough understanding of the components need to help me achieve my goals as she had earned the same degree. I realize this may not be something necessary for all students but she understood the research to practice model of the DNP degree and guided me accordingly.

An additional element of my DNP project that was a challenge as well as a superior learning experience was involvement with the IRB. Having had numerous

research classes, I felt comfortable I understood the many underpinnings of the IRB process. I actually questioned the need for IRB approval when, after all, I was only going to ask people to review a brochure I created. What I strongly gained from the experience was something that shall guide me on future research. My involvement with the IRB allowed a book to practice concept to be integrated with a very rich learning experience as I reflect back.

Summary

The institution experiencing the problem is a private practice that provides care to patients with an oncological diagnosis. The transitional care component with symptom management is fully covered, whereas the available community resources to assist the patients and their families in the aftermath of treatment are not existent. After collaboration with the clinic's nurse practitioner it has been determined that the lead, managing partner is the founder of the facility who continues to be actively engaged with daily operations. This physician also remains in active practice seeing patients and plans are to meet with him to discuss the educational brochure before dissemination. Discussion will encompass the usability of the brochure and operability to the patients as derived from the reviewer's evaluation and final document development. This meeting will also include the nurse practitioners, as it is being scheduled.

A proposed approach after approval for dissemination of the brochure is to distribute the brochure by the nurse practitioner to the patient to assist with bridging the gap between the clinical practice site and back into the community. Additionally, the discussion will include the use of this type of education, highlighting the community

resources to the oncology patient and how it sets the groundwork for further research on the benefits of this type of educational tool.

The audiences and venues that would be appropriate for dissemination of the project to the broader nursing profession may be targeted to those who care for oncology patients. It is planned to present the findings of this doctoral project to oncology nurse practitioner colleagues using a poster presentation. The appropriate venue would be at a regional nurse practitioner conference, where there is usually sizable attendance.

Another format for DNP project dissemination would be the use of a podium presentation at a regional conference. As this project has transferability to other practice areas, a prospective wider audience may be included. The potential for future presentation at a primary care conference, as an example, is also a consideration. The format to a larger audience would be based on the transitional care management model in all practice areas and not be solely inclusive of the oncology population. By understanding the audience, a podium presentation could be used to discuss this model with specificity to the patients and the practice itself. An example would be the inclusion of community resources on the management of diabetes, hypertension, hypercholesterolemia, as examples, as many communities provide resources to these patient populations in primary care settings.

Grove, Burns, and Gray (2013) described a thought-provoking example regarding the dissemination of research. They presented the situation of conducting research, formulating the findings, and then placing the study documents in a drawer without

dissemination. As scholar practitioners and nursing leaders we have an obligation to disseminate research to further the evidence into practice for enhanced patient outcomes.

At the initiation of this DNP project the statistics on the number of cancer survivors in the United States was found to be large. Moreover, the review of the current literature on the translational care phase of the oncology patient after treatment completion informed of the need for support services to maintain physical and psychosocial states yet actual interventions were scarce. With a large population of cancer survivors, education on community resources needed developed to assist the patients and their families in the aftermath of disease treatment.

The use of a navigational tool that lists the community-specific resources available to the oncology patient and their families affects a positive social change in an ever-growing group of cancer survivors. Their need to understand the resource available to them in their community is based on a continuum of care to meet their health care needs.

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Appendix A: Project Information

I am writing to invite your participation in the content validation of a new Patient educational tool, entitled Development of a Patient and Family Educational Document Following Cancer Treatment.

I am a doctoral student with interest improving education of community resources by the oncology patient and their families.

The purpose of this study is to evaluate an educational document for its understandability and actionability for use with the oncology population and their families. This is an opportunity to contribute to an educational document designed to help cancer survivors and their families better understand the many resources and services our local community has to offer.

You have been asked to take part because of your experience in oncology patient care and survivorship. You are being asked to take a survey projected to require approximately 10-15 minutes to complete. For the survey, you will be asked to rate understandability of content and design on a proposed educational brochure. You will not be asked any personal or demographic questions. Participation in this study is unlikely to be associated with risks to you other than the possible loss of confidentiality if you reveal something that you wish to be kept confidential. To minimize risk to you, all research records will be de-identified to the extent possible, and research records will be kept confidential to the extent allowed by law. If any new risks become known in the future, you will be informed of them.

While there may not be any direct benefit to you from participation, possible benefits include future use of Development of a Patient and Family Educational Document Following Cancer Treatment brochure to improve survivorship concerns. The alternative to participation is to choose not to participate. Participation in this review is entirely voluntary. You may refuse to participate or withdraw at any time. You will be told if any important new information is found during the course of this study that may affect your wanting to continue. Signed consent has been waived for this study. Your participation in the proposed survey indicates that you consent to participate in this brochure review. If you choose to participate, please reply to this email indicating your desire to receive the Development of a Patient and Family Educational Document Following Cancer Treatment content survey, and the brochure to review, and you will be sent the survey and brochure electronically. Upon receipt of the survey and brochure, you are still not under any obligation to participate. If you have any questions, you may contact me, the principal investigator, as noted below. Thank you in advance for your time.

Sincerely,
Debbie Slipkovich

Appendix B: Reminder Letter

Regarding Development of a Patient and Family Educational Document Following Cancer Treatment evaluation participation.

I sent you an email message 2 weeks ago about a new patient brochure I am creating for oncology patients and their families to invite your participation in the content review of a brochure. As of today, I have not received a response from you. This is an opportunity to contribute to an educational document designed to help cancer survivors and their families better understand the many resources and services our local community has to offer.

If you have any further questions about the brochure review or did not receive the first message on the evaluation I sent, please let me know as I can resend the document to you, if you are interested.
Thank you for your time.

Sincerely,
Debbie Slipkovich

Appendix C: PEMAT-P Tool

Title of Material: Development of a Patient and Family Educational Document Following Cancer Treatment
Review Date: _____

Understandability

Item #	Item	Response Options	Rating
Topic: Content			
1	The material makes its purpose completely evident.	Disagree=0, Agree=1	
2	The material does not include information or content that distracts from its purpose.	Disagree=0, Agree=1	
Topic: Word Choice & Style			
3	The material uses common, everyday language.	Disagree=0, Agree=1	
4	Medical terms are used only to familiarize audience with the terms. When used, medical terms are defined.	Disagree=0, Agree=1	
5	The material uses the active voice.	Disagree=0, Agree=1	
Topic: Use of Numbers			
6	Numbers appearing in the material are clear and easy to understand.	Disagree=0, Agree=1, No numbers=N/A	
7	The material does not expect the user to perform calculations.	Disagree=0, Agree=1	
Topic: Organization			
8	The material breaks or "chunks" information into short sections.	Disagree=0, Agree=1, Very short	

		material=N/A	
9	The material's sections have informative headers.	Disagree=0, Agree=1, Very short material=N/A	
10	The material presents information in a logical sequence.	Disagree=0, Agree=1	
11	The material provides a summary.	Disagree=0, Agree=1, Very short material=N/A	
Topic: Layout & Design			
12	The material uses visual cues (e.g., arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.	Disagree=0, Agree=1, Video=N/A	
Topic: Use of Visual Aids			
15	The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size).	Disagree=0, Agree=1	
16	The material's visual aids reinforce rather than distract from the content.	Disagree=0, Agree=1, No visual aids=N/A	
17	The material's visual aids have clear titles or captions.	Disagree=0, Agree=1, No visual aids=N/A	
18	The material uses illustrations and photographs that are clear and uncluttered.	Disagree=0, Agree=1, No visual aids=N/A	
19	The material uses simple tables with short and clear row and column headings.	Disagree=0, Agree=1,	

		No tables=N/A	
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Total Points: _____

Total Possible Points: _____

Understandability Score (%): _____

(Total Points / Total Possible Points x 100)

Actionability

Item #	Item	Response Options	Rating
20	The material clearly identifies at least one action the user can take.	Disagree=0, Agree=1	
21	The material addresses the user directly when describing actions.	Disagree=0, Agree=1	
22	The material breaks down any action into manageable, explicit steps.	Disagree=0, Agree=1	
23	The material provides a tangible tool (e.g., menu planners, checklists) whenever it could help the user take action.	Disagree=0, Agree=1	
24	The material provides simple instructions or examples of how to perform calculations.	Disagree=0, Agree=1, No calculations=NA	
25	The material explains how to use the charts, graphs, tables, or diagrams to take actions.	Disagree=0, Agree=1, No charts, graphs, tables, or diagrams=N/A	
26	The material uses visual aids whenever they could make it easier to act on the instructions.	Disagree=0, Agree=1	
	Is there any missing content or		

	resources that you feel needs to be added? Please list below:		
	Do you have any document improvements, not listed, that you feel need addressed? If so, please list:		

Total Points: _____

Total Possible Points: _____

Actionability Score (%): _____

PEMAT for Printable Materials (PEMAT-P). October 2013. Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/pemat-p.html>