

ASSESSING NURSE PRACTITIONER PREPAREDNESS WHEN CARING
FOR CHILDHOOD CANCER SURVIVORS

by

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As members of the DNP Project Committee, we certify that we have read the DNP Project prepared by Mariel De la Paz Martinez entitled Assessing Nurse Practitioner Preparedness When Caring for Childhood Cancer Survivors and recommend that it be accepted as fulfilling the DNP Project requirement for the Degree of Doctor of Nursing Practice.

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SIGNED: Mariel D. Martinez

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Nursing is an accomplishment of wholehearted initiative. Yet, initiative extends beyond the individual, and I have found that it is a reflection of the support and guidance granted unto me. I am grateful for all of the encouragement and opportunities I have received, especially from the people I never had to ask.

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DEDICATION

I dedicate this project to all of the youth and families of whom I had the privilege of caring. I had never known strength like that of a child, parent, or sibling going through the journey of cancer. You inspire me to instill the same spirit in my practice now. My heart will always remain with all of you.

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ABSTRACT

Background: The rate of childhood cancer survivors has grown to nearly 80% in the past few decades. Current evidence reveals that primary care providers report feeling unprepared with inadequate knowledge about the variable types of late effects and diagnostic screenings recommended for childhood cancer survivors (Dulko et al., 2013; Potosky et al., 2011).

However, the current evidence reflects data mainly from physicians. None of the current literature addresses the specific preparedness of primary care nurse practitioners. Such data would be helpful in better understanding how education and current resources affect nurse practitioner preparedness for such a narrow, but growingly prevalent, patient population.

Purpose: To assess primary care nurse practitioner preparedness when caring for childhood cancer survivors.

Methods: This descriptive study obtained data using a survey disseminated to primary care nurse practitioner members of the Puget Sound Nurse Practitioner Association in Seattle, WA.

Analysis was conducted by calculating the means and modes for each survey item.

Results: This sample (n=5) revealed that 50% of nurse practitioners identify as feeling adequately trained to care for childhood cancer survivors. Time and insurance coverage were not found to be barriers to care. Less than 50% of nurse practitioners utilized guidelines from the Children's Oncology Group. The most wanted resources included the Children's Oncology Group guidelines, survivor care plans, and electronic health record prompts.

Discussion: According to the results of this study imply that nurse practitioners in the Seattle area feel adequately prepared to care for childhood cancer survivors. In addition, nurse practitioners identify that clinical practice guidelines may be beneficial in guiding their care.

However, certain limitations, including small sample size, may affect the trustworthiness of the results. Thus, more research is warranted to gather more comprehensive knowledge and understanding regarding nurse practitioner preparedness when caring for childhood cancer survivors in the primary care setting.

CHAPTER I: INTRODUCTION

Background & Significance

Cancer is unexpected. Approximately 15,000 children and adolescents are diagnosed with cancer each year in the United States (Cure Search, 2016). Most commonly, children and adolescents are presented with a diagnosis of acute lymphoblastic leukemia (ALL), Hodgkin's lymphoma, and tumors of the brain and central nervous system (Cure Search, 2016). With little haste, they are given a central line and expected to start treatment. Depending on their diagnosis, prognosis, and age, their treatment protocols can include chemotherapy, radiation, immunotherapy, a transplant, or any combination of each (Choi et al., 2013). With the continual advent of trials aimed at building and modifying effective treatment protocols, nearly 80% of children and adolescents with cancer will achieve survival (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014; Cure Search, 2016). Yet, after a journey of worry revolving around treatment and acute monitoring, there remains an irresolute conclusion for those who reach survival. This conclusion is accompanied by uncertainty in the primary care sector outside of the confines of the oncologists, worries about the reintroduction into their lives, and concerns for their emotional and physical well-beings (Thorne & Stajduhar, 2012; Berg et al., 2015; Cure Search, 2016). Cancer survival starts a new journey for children and their families to endure.

Due to the toxicities of the treatments introduced during therapy, survival comes with its own health risks. By the age of 30, approximately 75% of childhood cancer survivors (CCSs) will acquire a chronic health issue after reaching remission (Volerman, 2015). These chronic health issues can target any body system, including but not limited to cardiac health, reproductive health, renal health, and mental health (Cure Search, 2016). Each category of treatment includes

variability in the effects it can cause. For example, in the category of chemotherapy, an alkylating drug results in high risk of affecting sterility unlike anthracyclines, which carry high risks of damaging cardiac tissue (Cure Search, 2016). Yet, not all CCSs carry the same history or risks. Variability in the dosing and frequency of each treatment, as well as individual genetics, further diversifies the types and magnitude of effects that individual CCSs may experience. In addition to the chronic effects that can occur, approximately 20% of CCSs will develop a second cancer by the age of 30 years (Voleran, 2015). That likelihood depends on various factors, including the treatment they received and their genetic predisposition (Voleran, 2015).

There are approximately 370,000 childhood cancer survivors in the U.S. (Cure Search, 2016). With the continual rise in survivor rates and volume of CCSs re-entering the communities, primary care providers (PCP) are tasked with caring for more survivors with a wider range of risks associated among them (Potosky et al., 2011). A growing number of PCPs will be responsible for monitoring pediatric cancer survivors for cancer recurrence, development of a new malignancy, screening for residual effects from treatment, and proactively preventative or delaying future morbidities. Yet one of the most common challenges for PCPs caring for pediatric cancer survivors is having insufficient knowledge about the sequelae of health conditions that could arise in survivorship (Dulko et al., 2013; Potosky et al., 2011). In addition, during a time of anxiety and concern, families may perceive uncertainty, discomfort, and mistrust in the primary care sector after survivorship is reached (Thorne & Stajduhar, 2012; Berg et al., 2015). Cancer survivorship should not be inflated with unnecessary concern about the abilities of their PCPs to manage their care, particularly as nurse practitioners are expanding in the primary care sector.

Local Problem

The Seattle area is home to many CCSs. It is an urban city rich in academic research aimed at pediatric cancer survival with participation from several institutions, including Seattle Children's Hospital (SCH), the Seattle Cancer Care Alliance, and the Fred Hutch Cancer Research Center. Children and adolescents are welcomed from all over the U.S. and foreign countries to participate in the research studies and treatment protocols centralized at SCH. The survival rates for childhood cancers treated at SCH either reach the national averages or exceed them (SCH, 2016). For example, survival rates for ALL at SCH is 88%, whereas the national average survival rate for ALL is nearly 90% (SCH, 2016; American Cancer Society, 2016). This data indicates that Seattle and the surrounding area contain a growing number of CCSs that equate the national average. A risk assessment is prevalent to appropriately accommodate the growing number of CCSs in the Seattle area.

Purpose

CCSs are a special population who will benefit from receiving care from the primary care sector. However, with evident concern from PCPs and families of discomfort and impaired preparedness for managing care for CCSs, there warrants the need of further investigation and local assessment (Potosky et al., 2011). However, no studies have focused on assessing nurse practitioners (NPs) and few have included them in the assessments of primary care physicians. Yet, approximately 80% of NPs practice in the primary care setting and are prepared to assess, diagnose, and manage care for children and adolescents with and without chronic health conditions (American Association of Nurse Practitioners, 2015). With the exponential rise in CCSs and NPs in the primary care setting, an isolated assessment of NPs can contribute

knowledge to the comprehensive perspectives of PCPs. Thus, the purpose of this descriptive study was to explore the comfort and perceived preparedness of primary care NPs caring for CCSs in the Seattle area. In order to achieve this goal, a community-wide assessment was conducted of NPs in the Seattle area. The stakeholders involved included all PCPs, oncologists, CCSs, and their families, all of whom will benefit from expanded and comprehensive research.

Study Questions

This project sought to answer the following questions:

1. How NPs feel prepared to care for CCSs?
2. What barriers hinder NPs ability to care for CCSs?
3. What resources do NPs utilize when caring for CCSs?

CHAPTER II: FRAMEWORK & SYNTHESIS OF EVIDENCE

Theoretical Framework

The framework established in the Total Quality Management (TQM) theory guides this study. The TQM theory embraces the necessity of continuous quality improvement for the benefit of patient outcomes and is centered on the belief that inadequate performance is related to problems within a system (Grol, Bosch, Hulscher, Eccles, & Wensing, 2007). Although fairly new to the healthcare scene, TQM is patient-centered and responsive to the fluidity and ever-changing nature of the healthcare system. It is concurrent with the systems theory in that a system (ie. primary care clinic) is a product of the interdependent interactions between its components (ie. providers, staff, policies, patients, demands, available resources, etc.), as defined by Cordon (2013). However, the TQM theory incorporates a goal of quality improvement within a system based on identifying and targeting problems within that system.

The TQM theory identifies quality performance as a product of interconnected parts that include people, planning, and processes (Oakland, 2014). The TQM theory refers to people as the leadership, education, training, and teamwork that fuel a system. Planning refers to the proactive creation of a strategized design complete with a mission, goals, policies, and active interventions. Processes refers to the analyses that occur from audits, performance reviews, and benchmarking that help identify any gaps in delivery of care (Mosadeghrad, 2014). Discrepancies in any of these parts can contribute to a problem that results in lesser quality outcomes. Thus, the TQM theory emphasizes how system performance affects quality outcomes.

However, these three parts can be further influenced by more abstract and intangible factors, including culture, communication, and commitment from all parts of the system (see Figure 1).

Cultures that are transparent, respectful, and include effective communication create innovative and advancing environments (Mosadeghrad, 2013). Communication affects how plans are developed and transgressed, how people become motivated, and how strong or weak a team can become. Likewise, commitment influences the adherence and motivation for complying with the processes and plans. Although the TQM framework mirrors the systems theory, its foundation is based on how people influence and control the infrastructure, whereas the systems theory is grounded on how external factors and infrastructure influences people. Furthermore, the systems theory requires that all participating individuals be system thinkers to correctly identify the influence each part has on each other (Cordon, 2013), whereas the TQM theory requires participants to understand the problems that become identified within a system as motivation for change.

Within the last 30 years, the TQM theory has been successful in improving outcomes and system efficiency by influencing the identification of patients' needs, benchmarking best practices against national standards, and improves policies to reduce errors (Mosadeghrad, 2013). However, the TQM theory has been challenged for ineffective use within the healthcare sector. A meta-analysis by Mosadeghrad (2013) revealed that the barriers to success included the variety of loose definitions of the TQM theory that render application difficult, inappropriate implementation of the model, and application in an unsupportive setting. Instead, successful implementation requires commitment and motivation for organizational structure change as well as specific interventions and tools to guide that change.

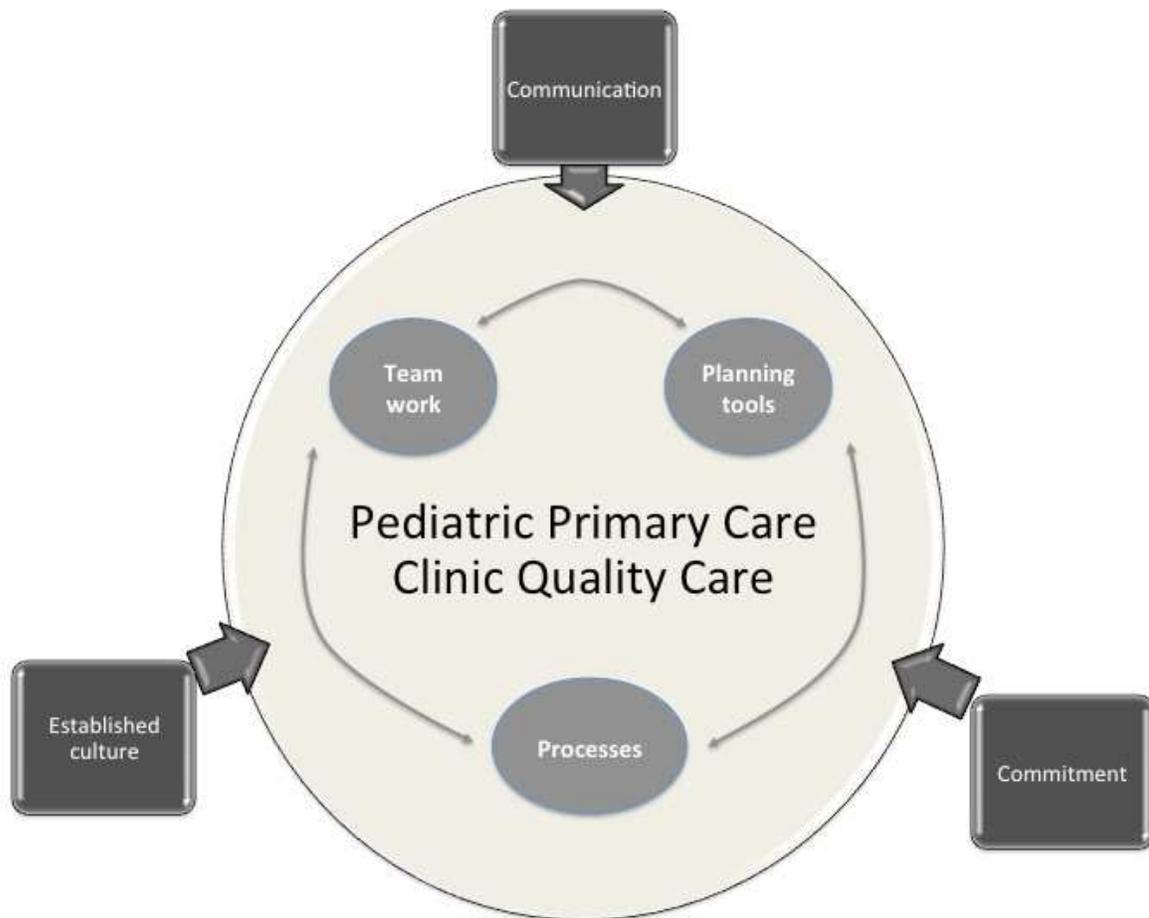


FIGURE 1. Illustration of the Total Quality Management Theory for the pediatric primary care setting. The large central circle depicts the whole system of a pediatric primary care clinic. The darker circles within the system depict the 3 core interconnected parts that affect quality care. The external influencing factors are shown to be impactful on the type of quality care provided by that clinic. This illustration further demonstrates how individual human characteristics influence the infrastructure within the system.

In an attempt to overcome the barriers identified by Mosadeghrad (2013) for successful TQM implementation in this study, the TQM theory definition as presented by Oakland (2014) will be used due to its precise definition and identifiable influential factors. Secondly, the study objectives align with the TQM theory to assess any gaps or failures within the primary care system. The people in this study will focus on primary care NPs. The study will assess if any current planning is being followed and what processes are in place for continual quality analysis. Lastly, the survey will assess whether the primary care sector is supported for change by exploring any cultural, communication, or commitment barriers for NPs caring for CCSs. With the guidance of the TQM model, this study will identify gaps within the current system of caring for CCSs in the primary care setting.

Concepts

The following items further develop upon the concepts that will be addressed in this study. This study has no affiliation with the Children's Oncology Group (COG). Instead, this study will include an assessment of the use of COG materials by NPs in the Seattle area.

Children's Oncology Group

The Children's Oncology Group (COG, n.d.) is a federally funded clinical trials organization devoted to research for diagnosing, treating, understanding disease processes, and monitoring pediatric cancer patients. Pediatric cancer services, including care for survivors, are heavily regulated, tracked, and guided by the Children's Oncology Group (COG), which is a group supported by the National Cancer Institute but devoted solely to pediatric cancer research (COG, n.d.). The COG coordinates research for more than 90% of all pediatric cancer patients in the United States through more than 200 COG-affiliated institutions (COG, n.d.). They contain task

forces dedicated to literature reviews and revising guidelines constantly to remain current with evidence-based recommendations. The COG also recognizes primary care providers within these task forces to incorporate primary care perspectives and helps make implementation feasible (American Academy of Pediatrics, 2009). Although some institutions are equipped with COG guidelines and support, other primary care institutions are not fully prepared to provide competent care for the growing number of pediatric cancer survivors.

Several different institutions provide recommendations for the treatment and care of pediatric cancer patients. The National Comprehensive Cancer Network (NCCN, 2013) is an organization devoted to cancer research for all ages through 26 dedicated cancer centers. Although the NCCN provides guidelines of care and resources for pediatric oncology patients, their focus encompasses a broader age span within a limited group of institutions. They do not have an affiliation with any hospitals within the Seattle area. However, the COG (n.d.) focuses primarily on childhood cancers and is utilized by over 200 institutions for research based, consistent, and comprehensive guidelines. Due to its accepted resource within 2 hospital sites in the Seattle, WA area and affiliation with the local Seattle Cancer Care Alliance, the guidelines produced by the COG will be used for this study.

Childhood Cancer Survivors

This study focused on survivors between the ages of 0 and 25, who would still be considered eligible to be seen by pediatric providers. According to the statistical data gathered since the 1970's through the Surveillance, Epidemiology, and End Results program, the most common pediatric cancers include leukemia, lymphoma, kidney and renal tumors, and central nervous system tumors (National Cancer Institute, 2011a). Since 2011, approximately 388,000 pediatric

cancer patients have been identified to be cancer free due to the growing number of survival rates that have reached nearly 80% since the 1970's (National Institute of Health, 2015). Furthermore, the 5-year-survival rate for children who reached remission less than 19 years of age was 84% in 2003, and the 1-year-survival rate had climbed to 93% by 2007 (National Institute of Health, 2011b).

Remission. Remission is defined as the time that physiological evidence of the cancer is not identifiable and all manifestations of the cancer have disappeared (COG, 2016; National Institute of Health, 2016). Remission does not mean a cure has been reached or that the originally diagnosed cancer cannot return.

Survivorship. The true definition of survivor in the academic sense remains unclear. According to a systematic review of how cancer survivorship is defined in the current literature, the term has carried various definitions, including someone who has reached remission for a specific time frame or someone who is alive regardless of whether they are currently battling cancer or are in remission (Marzorati, Riva, & Pravettoni, 2016). The meaning of cancer survivorship has altered based on culture, education, and inconsistencies in establishing one true definition. However, for the purpose of this study, survivorship will be defined as any child or adolescent, previously diagnosed with cancer, who has reached remission.

Late Effects. Each cancer diagnosis carries an array of different best available therapy protocols that may differ in treatment exposures and duration of treatment. The most commonly used treatments include a multimodal combination of chemotherapy, radiation, biotherapy, and transplants (American Academy of Pediatrics, 2009). Common problems include cardiovascular disease, pulmonary complications, and renal disease (COG, 2013). Due to the life-altering effects

and lifestyle changes that cancer and treatment can produce, survivors are at risk for mental health disorders, including depression, anxiety, and suicidal ideation (COG, 2013).

Follow Up Care

CCSs typically transition to primary care once they are considered fully recovered from immediate treatment-induced effects, which is typically about 2 years after reaching remission (COG, 2013). Due to the lack of a defined time frame in which survivors should seek primary care, there is current debate and inconsistencies regarding when primary care should be accessed by CCSs (Barthel, Spencer, Banco, Kiernan, & Parsons, 2016).

COG Long Term Follow Up Guidelines. The sequelae of effects that can occur are based on the diagnosis, age during treatment, types of treatment that were utilized, and length of treatment. Due to the magnitude of protocols available, the COG (2013) had developed guidelines that address all possible therapies (including radiation, chemotherapy, and surgery) and provides descriptions of what effects they can cause. It is comprehensive and includes specific recommendations of what routine tests can be implemented. It is intended for clinician use and is available free of charge through their website.

Survivor Care Plans. The COG (2013), as well as the Commission of Cancer (2012), highly recommend the use of survivor care plans for PCSs to facilitate transitions between oncologists and PCPs. Survivor care plans (SCPs) contain information on past treatments, recommendations for early detection, and outline possible effects induced by oncology treatment (Warner et al., 2015). Different organizations provide different templates, but implementation of SCPs has not been universally adopted for use by oncologists or PCPs.

Synthesis of Evidence

To gather a foundation of evidence to support the purpose of this project, multiple searches were conducted using the databases Pub Med and the Cumulative Index of Nursing and Allied Health Literature. The following key words were comprised in these searches: cancer survivors, pediatric oncology, childhood cancer, primary care provider, primary care, survivor care plans, Children's Oncology Group, perspectives, and preferences. Inclusion criteria stipulated articles published within the past 5 years, using the English language, and including human subjects. Initially, age was filtered for patients less than 23 years of age. However, due to the limited amount of articles generated, the search was expanded to include all adult-aged childhood cancer survivors (CCS). Furthermore, due to the limited return in NP samples, the search was expanded to include all PCPs. Articles that did not address primary care were excluded. Twenty-three articles were yielded from these searches. The ten most substantive articles are synthesized and discussed based on the most common themes, which PCP and CCS discomfort, common barriers, and inconsistent care coordination (see Table 1, Appendix A).

Discomfort

Providing care for CCSs can induce concern from the providers delivering the care and the patients and families receiving the care. A conceivable disconnect is apparent in the articles discussed below that reveal feelings of concern and inadequacy from all of these parties.

Primary Care Providers. Although PCPs are trained to care for patients with and without chronic conditions, the following articles support the likelihood that some PCPs see CCSs so infrequently that they do not always feel comfortable providing adequate care for them. Cheung et al. (2013) and Sima, Perkins, and Haggstrom (2014) identified that PCPs were more likely to report feeling comfortable caring for CCSs if they had the previous experience. Only one fourth of PCPs felt adequately trained to care for CCSs, whereas three fourths of PCPs felt inadequate, particularly for survivors with residual cognitive issues, reproductive issues, and treatment effects (Sima et al., 2014; Meacham et al., 2012; Berg et al., 2015). However, even though COG guidelines are available online to reference survivor care, PCPs have reported underutilizing them by 93% (Sima et al., 2014). Furthermore, PCPs may not even be aware that some of their patients are cancer survivors because approximately 25% of patients choose to withhold their cancer history from their providers due to discomfort (Sima et al., 2014; Kirchoff et al., 2014). These findings indicate that CCSs may not be receiving proper survivor care in the primary care setting whether due to provider discomfort, PCPs underutilizing available resources, or a lack of communication between patients and their providers.

Survivors and Their Families. Transitioning away from the oncology realm can be just as distressing for CCSs as when they first enter. Berg, Stratton, Esiashvili, and Mertens (2015) highlight how transitioning from oncology care to primary care can be difficult for patients due

to the resulting stress and confusion that can occur. A study by Thorne and Stajduhar (2012) further describe common themes in how survivors commonly feel discomfort, insecurity, confusion, and abandonment when faced with transitioning away from their oncologists. These feelings hinder their initiatives to advocate for their own needs. Survivors were found to be most interested in seeking care for social support, reproductive issues, changes in physical appearance, academic delays due to treatments, and consequential illnesses (Berg et al., 2015). Yet, they often feel uncertain about whether PCPs were capable of providing adequate survivor care, especially if their oncologist cast a negative light on PCPs' abilities to detect cancer in a timely manner (Thorne & Stajduhar, 2012; Chubak et al., 2014).

Commonly Identified Barriers

PCPs have also discussed systematic barriers that may hinder their abilities to provide adequate care to CCSs. The most commonly cited barrier included the limitation of patient time 65% of the time and not receiving a survivor care plan from oncologists more than 20% of the time (Berg et al., 2015; Chubak, et al., 2014; Sima et al., 2014). These barriers can be destructive in allowing PCPs to gather a full history and understanding of their patients. Furthermore, inadequate administration of SCPs by oncologists can be detrimental for patient care in the primary care setting. According to Warner et al. (2015), only half of oncologists are familiar with survivor care plans, depending on their institution, and nearly 40% of oncologists actually implemented survivor care plans for their patients. These findings correlate with data collected from other studies that only 47% of CCSs actually receive a survivor care plan and that 55% of survivors do not receive survivor care plans (Berg et al., 2015; Casillas et al., 2014). However, patients and providers could benefit from SCPs, particularly since they have been significantly

associated with higher confidence in managing care for PCPs and higher confidence of quality of care for patients (Shalom et al., 2011; Casillas et al., 2011). Furthermore, patients and providers have reported interest in using survivor care plans for the benefit of long-term primary care (Kirchoff et al., 2014; Shalom, Hahn, Casillas, & Ganz, 2011; Sima et al., 2014; Warner et al., 2015). Yet, despite the prevalence of studies assessing provider and patient perspectives about survivor care plans, there are limited studies aimed at establishing protocols for their use.

Inconsistent Care Coordination

There remains an even larger discrepancy on whether CCSs should transition solely to PCPs for their main care or whether they should receive a shared model of care from both their oncologists and PCPs. According to the study by Cheung et al. (2013), CCSs are more likely to receive evidence-based care if they see both oncologists and PCPs. Although separating specialty care from primary care appears ideal, Cheung et al. (2013) and Werner et al. (2011) further reveal that providers less prefer the shared model and that only 10% of patients actually see both a PCP and oncologist. This warrants further investigation into how comfortable and prepared PCPs feel when caring for CCSs. Berg, Stratton, Esiashvili, and Mertens (2015) further reveal that nearly 70% of CCSs report having an established PCP who they see regularly, whereas 30% of CCSs reported either not having an established a PCP or only seeing a PCP once in the past two years (Berg, Stratton, Esiashvili, & Mertens, 2015). Such variability in practice can lead to inconsistencies in care continuity.

Strengths and Weaknesses

The majority of articles in this literature search are descriptive and qualitative in nature, with few including mixed-methodology. The mixed-method studies provide well-rounded insight

from objective and subjective data, and the descriptive studies provide insight from PCPs and patients through interviews and surveys. Yet, the lack of quantitative studies reduces the strength of evidence that can arise from more controlled, unbiased data. Instead, one limitation identified in this literature review is that most of the articles pose the risk of participant bias and sampling bias due to recruitment from eligibility rather than randomization. However, recruiting all eligible participants does increase the sample size and power of their responses. With the lack of intervention in these cases, these articles are appropriate and contribute towards a strong foundation in evidence. The focus on qualitative methodology in these studies may be due to the absence of a strong foundation of need, description, and evidence regarding CCS care from PCPs. Generalizability was another limitation due to the prevalence of small sample sizes, constrained settings, diversity in urban and rural settings, and one study with foreign data. However, the range of sample sizes and nature of descriptive studies warrants these articles a substantial contribution to understanding the framework of CCS care in the primary setting as well as identifying potential barriers in their care.

Gaps and Limitations

Most of the studies revolved around adult-age survivors of childhood cancers rather than pediatric-age survivors. Childhood and adolescence is a vulnerable time for development. Thus, disruption from a cancer diagnosis and treatment can instigate different needs than survivors who have already become adult-aged. As a result, most of these articles are not truly representative of the pediatric population, which warrants a need for pediatric-based research on CCS care in the primary care setting. Lastly, few of these studies focus specifically on physician input and were minimally inclusive of other primary care providers, including nurse practitioners. This literature

review reveals there are limited amount of studies that have been conducting primarily towards primary care nurse practitioners caring for CCSs, despite their unique perspective to healthcare management and care coordination. Furthermore, there were no studies linking nurse practitioners to the care of pediatric-aged CCSs. Thus, research aimed towards pediatric nurse practitioners in the primary care setting should contribute more comprehensive insight into the current barriers and mechanisms of CCS care.

CHAPTER III: METHODS

Design

The design of this project will reflect a descriptive methodology. Descriptive studies are aimed at describing a particular experience of interest (Polit & Beck, 2012). In this study, the experience in consideration is that of the NP caring for the CCS. The intent is to interpret the occurrence as realistically as it occurs in the natural setting without any manipulation of variables or measurements of interventions (Vaismoradi et al., 2013). Descriptive survey research includes gathering data related to attitudes, behaviors and incidence of events (Polit & Beck, 2012). Thus, using the descriptive methodology and surveys for data collection, this project will contribute the unique knowledge of NP experiences with pediatric CCSs in the primary care setting as a foundation for further study and direct application in the clinical setting.

Concerns for validity and trustworthiness were addressed in the recruitment, data collection, and data analyses of this study. The concern for credibility ensures that the data collected truly reflects the perceptions of the intended population (Polit & Beck, 2012; Elo et al., 2014). Credibility was addressed in the recruitment process for primary care NPs. Only the targeted population was included in the study to confirm that only their perceptions will be assessed and incorporated within the results.

The concern for dependability refers to the likelihood that consistent results will manifest from the same methodology (Polit & Beck, 2012). The intervention of a survey eliminates researcher bias by providing an objective and structured tool for data collection, which will contribute to the conformability and reliability of the results (Polit & Beck, 2012; Elo et al., 2014). In this study, dependability was assumed by using a survey by Sima et al. (2014), which

was designed to assess provider comfort when caring for CCSs. Sima et al. (2014) created the 22 items within their survey with the guidance of the Tailored Design Method and behavioral theories of change. The survey items specifically focus on the perceived awareness, interest, understanding of current knowledge, and attitude towards change of primary care physicians. However, none of the items specifically address physicians and, instead, are generalizable for all providers. Validity and reliability was established in the original study with the rigorous review process of a multidisciplinary board comprised of primary care physicians, primary care NPs, pediatric oncology specialists, and registered nurses (Sima et al., 2014). The survey for this study contained 22 questions and uses a range of response mechanisms, including the Likert-scale, yes or no options, and ranking by importance (see Appendix A). Minimal modifications were made to the survey for this study. These changes included adding four demographical questions were added to the beginning of the survey, which totaled the number of survey questions to 26. In addition, the order of the questions was revised to facilitate the analysis for this study. The syntax of the questions remained intact to preserve their validity from the Sima et al. (2014) study. The authors granted permission via email to use their survey with any additional adjustments that were appropriate for this project.

Lastly, objectivity was ascertained by addressing the concern for confirmability (Polit & Beck 2012; Elo et al., 2014). The survey questions were structured to produce objective measurements that reflect the participants and not the researcher's bias for data analysis (Elo et al., 2014). By addressing these validity concerns, validity can be established for direct clinician use and future research.

Setting

This study took place in the Seattle, WA area due to its inclusion of a children's hospital and academic settings. This location provided a high potential to achieve participants that would provide a rich amount of information for this project (Polit & Beck, 2012). All of the approximately 100 general practice primary care clinics in the area employed with NPs were eligible.

Participants

Primary care NPs were eligible for participation. Inclusion criteria included a valid NP license, primary care certification, and pediatric involvement. Exclusion criteria included NPs working in the acute care setting and those not caring for pediatric patients under the age of 23. These criteria will accurately reflected the intended population and contributed to establishing confidence in credibility (Polit & Beck, 2012). Recruitment occurred through the Puget Sound Nursing Practitioner Association (PSNPA), which currently holds approximately 100 NP members. The PSNPA provided convenience for contacting a large number of NPs through one direct route. Furthermore, the PSNPA sets no geographical boundaries that limit NP participation and currently includes members from the surrounding five counties. Thus, this sample provided opportunity for diversity within participant demographics and patient population.

Data Collection

Institutional Review Board (IRB) approval was obtained prior to initiating recruitment and data collection. A PSNPA board member sent out an initial recruitment email to the NPs within the PSNPA community as part of their monthly newsletter. The email contained the IRB approved Recruitment Email (see Appendix B) which included the purpose of the study, the

expectations of willing participants, and a brief statement about IRB approval- and a direct link to the survey. Convenience sampling was employed to allow participants to partake in the study on a volunteer-basis (Polit & Beck, 2012). The survey was originally scheduled to remain open from July 27, 2016 to September 2, 2016. Due to a low response rate during that initial period, the deadline was extended until September 21, 2016, totaling 8 weeks that the survey was open. The PSNPA board member agreed to send two email reminders for member participation. One was sent two weeks after the initial email, and another was sent 6 weeks after the initial email. Requests for additional reminders were denied due to concern of the PSNPA board for developing email burnout in its members.

The survey was managed using Qualtrics, which provides convenience to participants in the form of usage and anonymity. The survey link in the recruitment email directly opened the survey within Qualtrics. The first page was faced with the IRB approved Disclosure Statement (see Appendix C), which served in lieu of obtaining consent due to the minimal to no risk of participant harm. The Disclosure Statement provided a more detailed summary of the survey, its purpose, the right to agree or disagree to participate, the right to discontinue participation at any time if agreeing to start the survey, and direct contact information to the IRB and the primary investigator. Participant agreement to the survey indicated willingness to complete the survey and understanding of the conditions discussed in the Disclosure Statement. Those participants were automatically directed to the survey questions. Participant disagreement indicated unwillingness to complete the survey, and they were directed to the end of the survey that included a brief statement of appreciation for considering the study (see Figure 2).

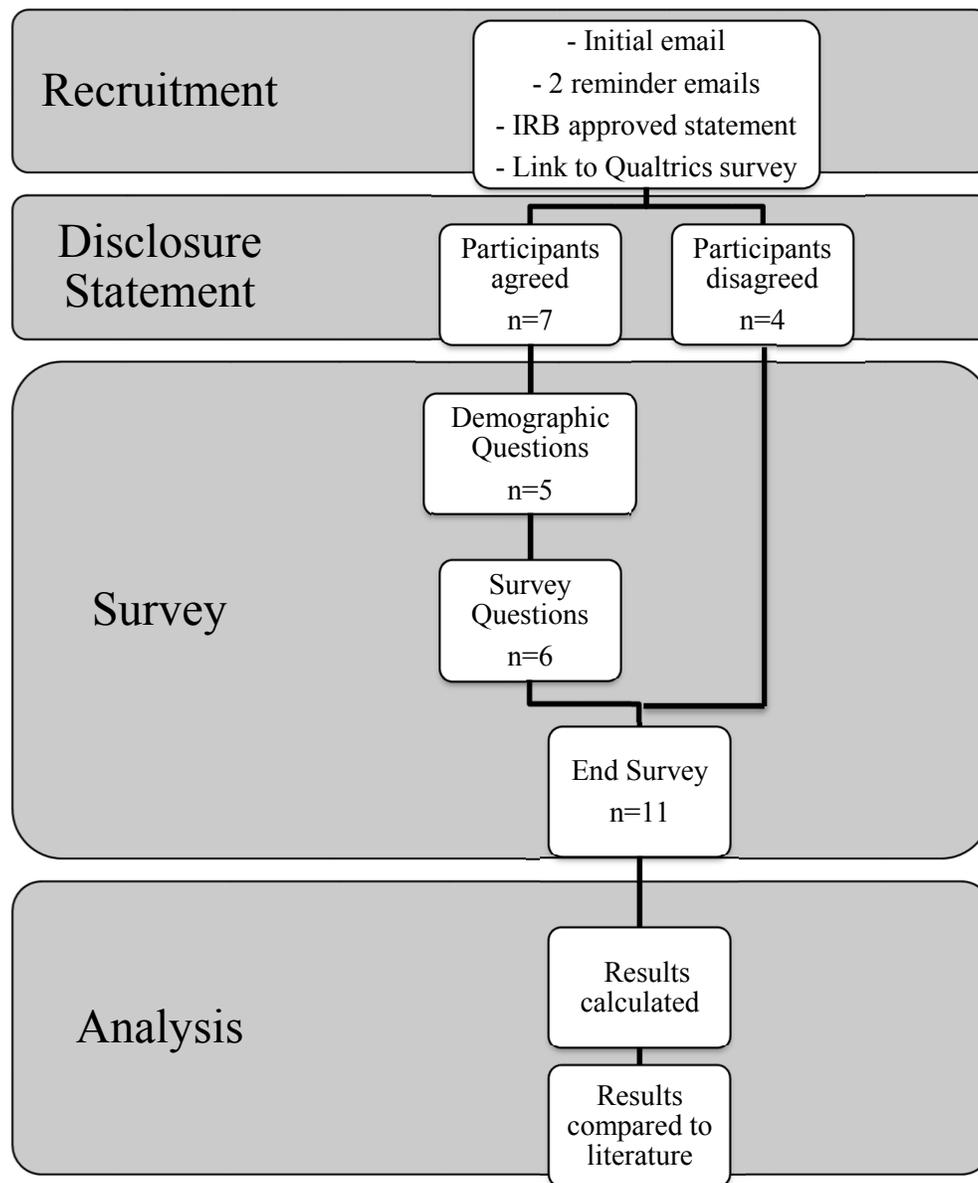


FIGURE 2. Process for Implementing Survey.

Analysis

Descriptive statistics were used for data analysis. Means and modes were calculated for each survey question to provide numerical representations to describe the participants' combined responses (Polit & Beck, 2012). Calculating mean scores is recommended for statistical measurement of more abstract concepts, such as confidence, in surveys (Sullivan & Artino, 2013). Furthermore, it provides a consistent measurement to reflect all answers for reliability of future research (Polit & Beck, 2012). The mode determines frequency of answers to assess what popular answers are chosen. The mode describes an answer chosen most frequently, and the mean describes the average answer chosen between all of the participants (Polit & Beck, 2012).

Ethical Considerations

To ensure compliance in protecting the human participants, this study followed all regulations set by the IRB. This study welcomed the IRB's facilitation and oversight in ensuring human protections of its participants (Office for Human Research Protections, OHRP, 2009). All required training, forms, and applications were submitted for IRB approval prior to commencing the study. IRB granted permission, indicating that the methods of this study reflect ethical considerations to protect the rights and privacy of all willing participants. This study considered high ethical standards for the participants (ie. NPs) and the population of interest (ie. CCSs). Although CCSs comprise a vulnerable population due to their ages and compromised health despite survivorship, they will not be directly affected or included (OHRP, 1979). Therefore, the requirements for a vulnerable population were not needed in this study. Also, the participant group of NPs was not considered a vulnerable population nor required special needs

consideration. However, this study maintained their integrity and respect by incorporating these ethical principles.

Respect

Respect for persons is the ethical principle that people should be treated with autonomy (OHRP, 1979). CCSs may be seen as a group with diminished autonomy due to their pediatric age and likely underdeveloped capacity of self-determination (OHRP, 1979.). However, since this study poses no direct interaction with them, there was no risk to their autonomy. The autonomy of the NP participants was maintained by making the survey voluntary. In addition, informed consent was obtained to verify their decision of participating if they so choose to do so (OHRP, 1979.). Participants were informed that there was no punishment for refusing to participate in the survey. Furthermore, in the setting of Internet research, security was an important aspect to consider. Some email lists may leave a data trail, posing a risk for confidentiality breaches (Williams, 2012). However, the degree of risk is minimal enough that no other special considerations were needed to be made when collecting and storing data (OHRP, 1979). Instead, the mode of survey collection and data storage reflected appropriate security and privacy measures. No identification was obtained and Qualtrics did not store any identifying information.

Beneficence

The ethical principle of beneficence refers to the preservation of an individual's wellbeing and protecting him or her from harm (OHRP, 1979). It maintains the notion of providing benefit to people to its maximum effect while minimizing harm. Harm to the participants may include any repercussions to their professional integrity and practice if their responses from their answers

become exposed and identifiable to them. For example, a NP who states he/she feels uncomfortable about providing care for CCSs or feels ill prepared may face discrimination by patients and colleagues. However, this risk was minimized by maintaining anonymity of responders through the online survey and generalizability of the results. No individual identifiers were collected. Furthermore, there was no risk to the intended population of CCSs. Instead, the possible benefits from this study included improved care and quality of life for CCSs.

Justice

Justice is the principle of fairness. It maintains that benefit is distributed to those who are eligible and protects people from improper, unnecessary, or unjust burden (OHRP, 1979). Although there was no risk of unjust action towards the NP participants for completing the survey, a handout about CCS care was distributed to them to receive the benefit intended to improve their practice when caring for CCS patients. The core of the study was to contribute to the fair distribution of care that CCS patients receive.

CHAPTER IV: RESULTS

Sample Description

The survey was distributed to 100 NPs within the PSNPA community. During the initial 6-week data collection period, a total of five participants entered the survey. Two of the five participants entered the survey, denoted that they agreed to take the survey, and completed the survey. The other three participants entered the survey, denoted that they disagreed to participate in the survey, and did not complete it. After the 2-week extension of the data collection period, five more participants agreed to participate in the survey, and one other participant entered to disagree. A total of 11 individuals responded to both emails (see Figure 2), yielding a PSNPA response rate of 11%. However, only five of the seven participants who agreed to the survey completed both the demographic and survey questions. The remaining two participants did not complete the demographic questions and only completed less than 2 items of the survey questions. Those two participants with incomplete answers were excluded from the results so as to not skew the analysis, leaving a total sample size of five participants. The demographic characteristics of the sample (n=5) are reflected in Table 2.

Survey Responses

Table 3 (Appendix E) depicts the mean scores of responses to the survey. Only four of the five sample participants (80%) completed the entirety of the survey. The remainder participant completed 15 out of the 22 survey questions with a response rate of 68%. The mean score for each survey item was derived from the total number of responses.

TABLE 1. *Participant Demographics*

Characteristic	Frequency n=5 (%)
Specialty	
• Pediatric	3 (60)
• Family	2 (40)
Years of Service	
• 1-5 years	2 (40)
• 6-10 years	3 (60)
• 11+ years	0 (0)
Gender	
• Male	2 (40)
• Female	3 (60)
Degree of Education	
• Doctorate or PhD	1 (20)
• Masters	4 (80)

Training

Sixty percent of participants reported occasionally or frequently caring for CCSs, whereas 40% reported never caring for CSSs. All participants agreed that addressing health care problems in CCSs is an important role as a PCP. Furthermore, more than half of the participants reported feeling adequate training in recognizing late effects of chemotherapy, surgeries, and radiation,

whereas the remainder of participants felt neutral about their training. Of these five questions, two of them (40%) yielded a 100% response rate.

Barriers Encountered

None of the participants found difficulty in obtaining cancer histories from their CCS patients, obtaining cancer histories from oncologists, or locating information about late effects of cancer treatments. Approximately 20% reported time as a barrier to discussing late effects with CCS patients, whereas 80% neither agreed nor disagreed that this was a barrier to providing care. Similarly, 20% of participants found insurance coverage as a barrier for CCS patients to receive the recommended late effects screenings, whereas 80% neither agreed nor disagreed that insurance coverage was a barrier to patient compliance with care. Most of the participants (60%) reported that their CCS patients perceived late effects as serious threats. Each of these six questions had a 100% response rate.

Resource Availability

None of these participants reported using the NGC as guidelines, where as 40% reported occasionally using the COG guidelines. There was wide variability in how frequently participants received cancer treatment summaries and SCPs. However, all participants were in agreement that both of those documents would be useful tools to guide CCS treatment. Of these six questions, four questions (67%) had a 100% response rate.

Future Improvements

All of the participants reported being aware that clinical practice guidelines (CPGs) for CCSs existed, and they were in agreement that they would use the COG guidelines. Furthermore, email reminders, electronic chart access, and telephone communication outlets were reported to be the

most useful way for oncologists to relay CSS information to PCPs. In addition, most participants found the Internet, textbooks, journal articles, and direct communication with oncologists to be the most useful resources to identify information about CCSs. Within these four questions, 2 questions (50%) yielded a 100% response rate.

CHAPTER V: DISCUSSION AND IMPLICATIONS

With the advancement of treatments for pediatric cancers, there is a growing number of CCSs. These survivors are at risk for developing late effects from their life-saving treatments, psychological harm, and recurrent malignancies (Volerman, 2015). PCPs are now experiencing more interactions with CCSs, but report feeling unprepared when caring for CCSs (Dulko et al., 2013). Most research has revolved around preparedness of physicians, as they have historically been the main providers in the primary care setting. Thus, purpose of this DNP project was to explore the preparedness of primary care NPs caring for CCSs. The findings from this DNP project add to the existing knowledge of CCS care in the primary care setting. Furthermore, this DNP project alludes to future research implications and the advancement of the NP role.

Findings Related to Research Questions

Preparedness

The first research question in this DNP project inquired about how prepared NPs are when caring for CCSs. According to these results, over 50% of NPs identify as being adequately trained in recognizing late effects of cancer therapies as compared to the other 50% of NPs who felt neutral about training. These findings are contradictory to the descriptive study by Meacham et al. (2012) that revealed that physicians, NPs, and RNs collectively reported low familiarity in CCS care. In contrast, 88% of oncologists, RNs, and clinical staff reported familiarity of late effects of pediatric oncology treatment in a study by Warner et al. (2015). When compared to the study by Sima et al. (2014) that utilized the same survey, the findings from this DNP project imply that NPs in the Seattle area feel more prepared than approximately 30% of the national sample of physicians from the Sima et al. (2014) study. However, Sima et al. (2014) and this

DNP study revealed that 40% of participants never provided care for a CCS. Despite the growing rate of CCSs, this may be due to the issue that some CCSs do not disclose their full cancer histories, limited healthcare access to CCSs, or that some survivors leave the Seattle area to return home to another location after receiving treatment at a Seattle-based institution (Kirchoff et al., 2014; Sima et al., 2014).

None of the previous studies have focused on the NP perspective independent of other providers. Although the findings in this DNP project indicate that NPs are more prepared, it is worth noting that this DNP project uses a small, local sample of NPs in which the results may not be transferrable to the general NP population (see the Limitations section).

Barriers Encountered

The second research question in this DNP project inquired about any barriers that may impact the care that NPs provide to CCSs. The results from this DNP project imply that time during clinic visits and insurance coverage were not barriers to care. However, multiple studies have linked time as a barrier to providing adequate cancer survivor care (Berg et al., 2015; Chubak et al., 2014; Sima et al., 2014). Of note, 80% of the NPs in this DNP project neither agreed nor disagreed to identify time or insurance coverage as barriers. Thus, further investigation is required to explore the meaning behind their neutral stances. Furthermore, usual time allowance during clinic visits should be investigated to provide more insight into whether there is variability in Washington when compared to other places.

A common barrier reported in cancer survivor care is the limited disclosure of histories by patients. According to the descriptive study by Kirchoff et al. (2014), approximately 26% of CCSs did not disclose their cancer histories to their PCPs. This DNP project found that 60% of

NPs reported that their CCS patients perceived late effects as serious. However, these findings cannot truly imply that 60% of CCS patients disclose their cancer histories. Thus, further research into the comfort of NPs in discussing cancer histories may provide more insight into whether communication facilitates or hinders care for CCSs.

Resource Utilization

The final question posed in this DNP project is to determine what resources are utilized by NPs when caring for CCSs. Less than 50% of NPs utilized COG guidelines, and there was no consistency in the availability of SCPs by primary oncologists. This is a contrasting finding when compared to the 7% of physicians who utilize the COG guidelines (Sima et al., 2014). NPs reported that the following resources would be useful: COG guidelines, SCPs, electronic health record prompts, telephone communication with oncologists, and journal articles. These findings align with the findings by Sima et al. (2014) and Kirchoff et al. (2014) that SCPs are underutilized and that nearly all providers would prefer to have guidelines available as useful tools to providing care to CCSs. However, it is unclear whether the use of resource is a result of inadequate training or in response to a need of sustained education.

Impact on Practice

It is clear from this DNP project that most NPs report that having access to additional resources would be useful when caring for CCSs. Since this is consistent with findings from other studies inclusive of physicians, additional resources may be beneficial in most primary care settings. The COG guidelines provide the richest sources of information regarding complete CCS care (Sima et al., 2014). Resources are an important part of the TQM Theory that influences provider performance and patient outcomes. The establishment of policies, direct linkage on

clinic computers, and inclusions in staff meetings may help make the COG guidelines more available for access.

An additional component to the development and sustainability of NPs is to implement clinic-wide education with additional electronic resources. According to the TQM Theory, the performance of people within a system are influenced by education and training. Meacham et al. (2012) implemented an online continuing education program that offered additional evidence-based resources for providers and RNs to access daily to improve their knowledge in CCS care. This particular intervention produced nearly 100% compliance and improvement in CCS knowledge. Although sustainability was not tested, it is a promising effort to provide continued resources to NPs, especially since variability existed in encountering CCSs.

Integration of Theoretical Framework

The preparedness of NPs is integral to the outcomes of CCSs in the primary care setting. The TQM Theory encourages constant qualitative improvement within a healthcare system to improve the performance of healthcare providers and sustain positive outcomes from patients (Grol et al., 2007). This descriptive study aimed to assess the interdependent parts of a system identified by the TQM Theory, including the people and planning. The people assessed in this DNP project refer to the NPs and expands to assess their training and education. The planning that was assessed refers to the available resources available to NPs. There was no focus on processes. This DNP project further assessed how communication may affect care by assessing for time barriers and communication with oncologists through SCPs, electronic email, or telephone. There was no focus on culture or commitment.

It is apparent through this DNP project that multiple factors affect outcomes in both providers and patients. NPs are not only affected by education and motivation, but also by the external resources available to them. The system can provide hindrances of unavailable access to online guidelines or systematic barriers that limit the establishment of communication with oncologists (Kirchoff et al., 2014). With guidance from the TQM theory, findings of this DNP project identify areas of improvement aimed at distinct parts that can be the focus of future quality improvement efforts.

Strengths and Limitations

Strengths

One of the strengths in this project was the establishment of credibility. Using the structured approach of a survey and appropriate inclusion criteria to target NPs caring for the pediatric population. Although there is concern for a small sample size (see Limitations), the recruited participants met the inclusion criteria and are individually representative of the intended population. Furthermore, the use of a survey is an appropriate method for gathering more information about an experience in a population, which is in direct alignment with the descriptive qualitative research (Polit & Beck, 2012). This particular survey was originally tested for validity in the study by Sima et al. (2014) to address similar study questions, which improved confidence in the validity of this tool. Lastly, this DNP project was conducted in a state that allows full practice for NPs, which is likely to be reflective of true NP preparedness without considerations of additional support from collaborative provider models found in more restrictive states.

Limitations

Several limitations hinder the results of this project. There were systematic barriers that affected the ability to send out email reminders. Studies have shown contradictory results as to whether reminders increase survey response rates. According to Glidewell et al. (2012), reminders show no statistical improvement in response rate unless the reminder included an abridged version of the survey. However, this would not be possible for this project as the exclusion of certain questions would skew the results. According to Cho, Johnson, & VanGeest, (2013), a meta-regression analysis revealed that reminders indeed showed improved response rates in healthcare professionals. A hindrance for this project was achieving the ability to email out reminders. Per the PSNPA board member preferences, they did not want to risk email burnout in their members. To comply with the PSNPA and encourage its integrity in its members, their wish to limit email reminders was respected. Thus, the number of email reminders was limited to two. Different modes of reminders, including telephone and mail, have been shown to increase response rates as well (Cho et al., 2013). However, the ethical considerations of respecting the privacy of participants prompted the exclusion of those reminder methods in this project.

Furthermore, there were additional hindrances that impacted trustworthiness, especially the concerns for confirmability, transferability, and dependability. They were likely effected by this project's small sample size and incomplete answers.

Small Sample Size. Confirmability refers to the congruence between the answers provided by the participants and the researcher's interpretations of that data (Polit & Beck, 2012). There is a risk of nonresponse bias due to the small sample size and the inconsistency in survey completion

by the participants leading to the development of assumptions (Cho et al., 2013). The first assumption is that the resulting data is reflective of the intended population. The demographics of this sample reveals 20% male, which is an inflated value compared to both the Washington average of 12% and the national average of nearly 9% (Washington State Nurses Association, 2015; United States Bureau of Labor Statistics, 2016). Furthermore, 20% of this sample held a doctorate degree, which is inconsistent with the national average that approximately 5% of NPs have a doctorate degree (United States Department of Health and Human Services, 2014).

The unrepresentative sample demographic is likely due to the small sample size. Unfortunately, there is a lower response rate in health professionals than in other groups such as patients (Glidewell et al., 2012; Cho et al., 2013). Common barriers include lack of time, perceived long survey items, and lack of monetary incentive (Glidewell et al., 2012). Furthermore, despite the convenience and wide range distribution of electronic surveys, mailed surveys have shown higher response rates (Cho et al., 2013). Although eligibility criteria were set to be inclusive of NPs likely to experience interactions with CCSs during their careers, the small sample size may not support the population's perspective. Qualitative research holds no strict guidelines for the number of participants included in a sample size but is instead guided by the standard of data saturation (Polit & Beck, 2012). The data produced from this project provides insight into NP preparedness and comfort when caring for CCSs, but it may be too immature to have reached data saturation. Considerations of decreasing the number of items within the survey, utilizing mailed surveys, or offering monetary incentives may have improved response rates.

These concerns of demographical inconsistencies and small sample sizes further compromise the transferability of the results to other NPs in the nation. Without saturated data, these results are believed to be too premature and inadequate to indicate transferability to other general constructs. Although this survey was successful in assessing physician preparedness and comfort nationally in its original study by Sima et al. (2014), it may not be a useful tool in assessing NP preparedness nationally due to the variability in state regulated independence that NPs can achieve. In Washington, NPs are allowed full independence in their practice, but different states enforce varying restriction legislations for NPs (Washington State Legislature, 2016; American Association of Nurse Practitioners, n.d.). NPs practicing in reduced practice states or restricted practice states may be required to practice with supervision or in collaborative teams. Having those additional supportive structures may impact their feelings of preparedness.

Incomplete Answers. The second assumption pertains to the inconsistent manner of survey completion by the participants. An assumption is that the incomplete answers would make minimal effects on the results. The 80% completion rate implies question of confirmability of the overall data compiled from the survey. For the survey items with 75% response rates, the calculations of their means are skewed by the difference in summation and total response count. This variability in response rate may be due to the nature of questionnaires being self-administered without regulation by a researcher (Polit & Beck, 2012). Low response rates could induce bias and threaten the trustworthiness of the results (Glidewell et al., 2012).

The participant may have intentionally chosen to skip certain questions or there may have been technical difficulties. The Qualtrics settings enabled the ability to proceed to the next survey item without answering the previous one. However, when reviewing the sole responder

who provided incomplete survey answers, the first five items that were omitted were contained within one page. The advancement to a new page could either have been intentional or accidental without knowing the functions of Qualtrics. That responder also omitted the final two answers on the last page of the survey, which requested that participants number their answers on a scale of 1 to 6. This last page contained three other items requesting Likert-scale answers that were not omitted. The omission of partial answers from this last page may be intentional or related to technical accidents. These flaws in the survey settings question the dependability of whether the unanswered questions provide data that are truly reflective of the NPs (Polit & Beck, 2012). Future settings should consider the enabling of that ability to prevent any accidental or intentional incompleteness of answers.

Future Implications for Research and Advanced Practice Nurse Practitioners

After the completion of this project, future research would benefit the understanding of NP preparedness when caring for CCSs in the primary care setting. This project provided a small window into NP preparedness but does not add complete descriptive knowledge to this topic. Additional research with larger sample sizes may provide more trustworthy results that are more transferrable to NPs across the nation. In addition, since there is wide variability in the diagnoses of pediatric cancers and their treatments, research into the preparedness of NPs pertaining to specific diagnoses can provide rich understanding in whether preparedness is diagnosis-specific. Furthermore, research comparing the different perspectives between NPs practicing under varying state-restricted regulations may provide more insight into how comfort and preparedness of NPs are affected. These future research implications can also expand to different fields, other than pediatric oncology, to better understand the NP experience.

The NP role has developed tremendously over the past years since its initiation in 1965 (AANP, n.d.a). Since then, outcomes for advanced practice nurse practitioners reflect high quality care, safe practices, and at minimum comparable care to physicians (Newhouse et al., 2011). However, there remains a gap between evidence-based research and its translation into clinical practice (Vincent, Johnson, Velasquez, & Rigney, 2010). Doctorate-prepared NPs are expected to integrate the paradigm of scholarship and research to fulfill their role (American Association of Colleges of Nursing, AACN, 2006). The completion of investigative research is encouraged by the AACN (2006) for APNPs to synthesize appraisal skills and research-driven outcomes into scholarly practice. The completion of DNP projects provides additional understanding of appropriate evidence appraisal when considering real-life limitations and hindrances that can affect results. Furthermore, DNP projects offer opportunities of engaging in translational research that can help bridge this disconnect between research and clinical practice (Vincent et al., 2010). NP-driven research is not only beneficial to improve knowledge, interventions, and quality of care, but it is essential for the development the doctorate-prepared NP.

Conclusion

In conclusion, this DNP project addresses the rising rate of CCSs by assessing the preparedness of NPs in caring for CCSs. Although the results of this study imply that most NPs in this survey feel prepared caring for CCSs, it is worth noting that certain limitations may compromise the trustworthiness of that data. However, the question of NP preparedness remains unknown due to the lack of current literature that assesses the preparedness and quality of care NPs provide specific to CCSs. Ongoing research is vital for the continued improvement of CCS

care in the ever-evolving healthcare system and for the supportive advancement of equal practice regulations for NPs nationwide.

APPENDIX A
SYNTHESIS OF LITERATURE

TABLE 2. *Synthesis of Literature*

Reference	Design & Aims	Sample & Setting	Data Collection & Analysis	Findings	Limitations
Berg, C., Stratton, E., Esiashvili, N., & Mertens, A. (2015). Young adult cancer survivors' experience with cancer treatment and follow-up care and perceptions of barriers to engaging in recommended care. <i>Journal of Cancer Education</i> , 30(1), 1-13. doi:10.1007/s13187-015-0853-9	<p><u>Design:</u> Mixed-methods with descriptive focus</p> <p><u>Aim:</u> Examine for any correlations between PCP engagement, experiences with survivorship care, barriers to attaining care, and resources for promoting follow up care in pediatric CCS</p>	<p><u>Sample:</u> (n=106) Young adults now between 18 and 34 years of age previously diagnosed with cancer before the age of 18; avg. age 22 years; 50% male; 75% Caucasian, 20% black; 87% never been married; 33% employed; majority attained at least a college degree; 35% lymphoma, 19% leukemia, 6% blastoma, 10% sarcoma.</p> <p><u>Setting:</u> University-affiliated children's hospital and National Cancer Institute center in southeast region of the USA</p>	<p><u>Quantitative data:</u> Survey regarding demographics, psychosocial factors (PHQ-9), social support (MSPSS), interactions with healthcare system, and resources used.</p> <p><u>Qualitative data:</u> Semi-structured interviews via phone for 60 min, facilitated by one trained interviewer</p> <p><u>Analysis:</u> <i>Bivariate analyses</i> to compare participants who saw PCPs to those who did not <i>Binary logistic regression model</i> to determine associations with PCP interactions <i>NVivo 10.0</i> - determine codes</p>	<p>68.9% reported having a PCP; 17% reported no interaction with a PCP; 14% reported seeing a PCP once in the past 2 years</p> <p>No significance in correlation between patient perceived health threats and PCP use</p> <p>47.2% reported receiving a SCP</p> <p>63% of PCP visits included a discussion of cancer related symptoms</p> <p>Most common barrier to PCP use was limited patient time due to college attendance</p>	<p><u>Participant bias</u> – possible due to monetary compensation</p> <p><u>Generalizability</u> is limited due to the age group of participants being primarily adults and the focused settings.</p>

			independently by two separate coders		
Casillas, J., Syrjala, K., Ganz, P., Hammond, E., Marcus, A., Moss, K., ..., & Friedman, D. (2011). How confident are young adult cancer survivors in managing their care? A report from the LIVESTRONG Survivorship Center of Excellence Network. <i>Journal of Cancer Survivorship</i> , 5(4), 371-381. doi: 10.1007/s11764-011-0199-1	<p><u>Design:</u> Descriptive Method</p> <p><u>Framework:</u> <i>Health Belief Model</i> for developing survey</p> <p><u>Aim:</u> Describe SCP use in primary care setting</p> <p>Define expectation of CCSs and any correlation in confidence with managing survivor care</p>	<p><u>Sample:</u> (n= 376) ages 18-39 years, previously diagnosed with and diagnosed for a pediatric cancer; avg age 28 years; 54% female; 74% Caucasian; 54% earning at least \$60,000; 53% earned at least a bachelor's degree; 62% single; 83% with private insurance, 4% no insurance, 10% public insurance; 20% diagnosed with leukemia, 18% lymphoma; more than 80% had received chemotherapy, radiation, and/or surgery; 34% diagnosed before the age of 14.</p> <p><u>Setting:</u> National Cancer Institute network</p>	<p><u>Survey:</u> 57 items; addressing demographics, experiences with PCPs, knowledge of survivor care, and opinions about available resources</p> <p><u>Analysis:</u> descriptive statistics using 4 point Likert scale; bivariate and multivariate logistic regression; SAS statistical software</p>	<p>20% reported no discussion of late effects</p> <p>55% did not have SCP</p> <p>4% of PCPs provided dominant care and 18% of PCPs most likely knew about survivor symptoms</p> <p>10% used shared model between oncologist and PCP</p>	<p><u>Generalizability</u> is limited due cancer-institute setting that may not be available in other locations for other CCSs and high socioeconomic status of participants that may not be truly reflective of entire survivor population</p> <p><u>Sampling bias</u> is possible due to lack of randomization</p>
Chubak, J., Bowles,	<u>Design:</u>	<u>Sample:</u> (n=230)	<u>Interview:</u> Phone	85% saw oncologist as	<u>Generalizability:</u>

<p>A., Tuzzio, L., Ludman, E., Rutter, C., Reid, R., & Wagner, E. (2014). Perspectives of cancer survivors on the role of different healthcare providers in an integrated delivery system. <i>Journal of Cancer Survivorship</i>, 8(2), 229-238. doi:10.1007/s11764-013-0335-1</p>	<p><u>Descriptive method</u></p> <p><u>Aim:</u> Describe perspectives of survivors 1 year after cancer diagnosis</p>	<p>91% female; 81% Caucasian; 75% at least had college degree; 13% high deductible insurance, 33% traditional HMO, 23% Medicare, 7% self funded; diagnosed with breast, colorectal or lung cancer</p> <p><u>Setting:</u> Western Washington in an integrated healthcare delivery system</p>	<p>surveys with 107 questions focused on receiving SCP, communicating with providers, opinions about care, and perspective on PCPs</p> <p><u>Analysis:</u> Chi-square test for categorical variables; ANOVA for continuous variables</p>	<p>their main provider</p> <p>50% uncertain about communication between oncologist and PCPs</p> <p>50% uncertain about knowledge and ability of PCP caring for survivors</p>	<p>concerning for localized setting</p> <p><u>Sampling bias</u> is possible due to lack of randomization</p>
<p>Kenney, L., Bradeen, H., Kadan, N., Diller, L., Homans, A., & Schwartz, C. (2011). The current status of follow-up services for childhood cancer survivors, are we meeting goals and expectations: A report from the consortium for New England childhood cancer survivors. <i>Pediatric Blood</i></p>	<p><u>Design:</u> Exploratory descriptive</p> <p><u>Aim:</u> Describe available services for pediatric oncology survivors</p>	<p><u>Sample:</u> n=12; pediatric oncologists, NPs, pediatricians, and RNs.</p> <p><u>Setting:</u> 12 academic-affiliated institutions in New England</p>	<p><u>Survey:</u> Sent to each institution and asked about available survivors, structure of clinics, research, and advocacy</p> <p><u>Analysis:</u> Descriptive statistics and inferential statistics</p>	<p>11 survivor clinics within the 12 institutions; all offered SCPs</p> <p>All clinics staff with pediatric oncologists, 7 with nurse practitioners, 9 with social workers or psychologists, 5 with registered nurses, 3 with primary care physicians, and 3 with sub specialists.</p> <p>7 clinics recommended</p>	<p><u>Generalizability</u> – to US geographical area due to foreign setting.</p>

<i>and Cancer, 57, 1062-1066. doi: 10.1002/pbc.22924</i>				long-term follow up care for CCSs	
Kirchoff, A., Monenegro, R., Warner, E., Wright, J., Fluchel, M., Stroup, A., ..., & Kinney A., (2014). Childhood cancer survivors' primary care and follow-up experiences. <i>Supportive Cancer Care, 22(6)</i> , 1629-1635. doi: 10.1007/s00520-014-2130-6	<p><u>Design:</u> Descriptive</p> <p><u>Aim:</u> Explore survivor perspectives related to primary care experiences and knowledge regarding survivor care planning.</p>	<p><u>Sample:</u> (n=53) Adults age 18-56 who were diagnosed at any age less than 21 years; avg. age 39.1; 54% female; 62% diagnosed between 15 and 20 years; 94% Caucasian; 24% lymphoma, 19% germ cell, 18% leukemia; 80% with college degree; 89% insured.</p> <p><u>Setting:</u> Utah SEER registry</p>	<p><u>Sampling:</u> Randomly selected</p> <p><u>Interview:</u> semi-structured via telephone</p> <p><u>Analysis:</u> Coding and themes by two independent members of the team using QSR NVivo</p>	<p><u>Themes</u> <i>Primary health care experiences</i> – 83% had PCP (MD or NP), 9% reported facilitation with oncologist</p> <p><i>Communication barriers</i> – 68% discussed cancer history with PCP of varying length; 26% never disclosed their cancer histories</p> <p><i>Need for more survivorship care and inclusive SCP</i>- 90% did not have a SCP, 62% felt a SCP would be useful</p>	<p><u>Generalizability-</u> concerning due to whether the small sample size provides true representation of all CCSs, particularly with the sample being drawn from one location and being majority Caucasian.</p>
Meacham, L., Edwards, P., Cherven, B., Palgon, M., Espinoza, S., Hassen, L., & Mertens, A. (2012). Primary care	<p><u>Design:</u> Descriptive phenomenology</p> <p><u>Aim:</u> Examine methods for</p>	<p><u>Sample:</u> (n=49) 9 physicians, 15 nurse practitioners, 16 registered nurses, and 9 social workers; no other demographical data provided.</p>	<p><u>Interviews:</u> structured via phone</p> <p><u>Education:</u> In person education provided to PCPs with feedback questionnaires</p>	Providers reported moderate to very low familiarity with survivor management and high level of interest in educational tools	<p><u>Generalizability –</u> due to limited sample size and location within one state.</p>

<p>providers as partners in long-term follow-up of pediatric cancer survivors. <i>Journal of Cancer Survivorship</i>, 6(3), 270-277. doi: 10.1007/s11764-012-0224-z</p>	<p>improving knowledge of pediatric cancer survivorship care and implement them to PCPs</p>	<p><u>Setting:</u> rural and urban primary care settings within Georgia</p>	<p><u>Intervention:</u> 1. Online continuing education resource developed and implemented based on feedback; utilized the Provider Portal of the Cancer SurvivorLink website 2. Evaluation of effectiveness</p> <p><u>Data Analysis:</u> Google Analytics was used to analyze provider registration, number of visits, average time spent on the website, and preferred pages to visit</p>	<p>Providers were most interested in late effects of therapies and easy to use format</p> <p>98% of providers met the objectives of the continuing education resource</p> <p>The most utilized areas were cognitive and school effects, survivor care 101, endocrine issues, and cancer treatment 101.</p>	
<p>Shalom, M., Hahn, E., Casillas, J., & Ganz, P. (2011). Do survivorship care plans make a difference? A primary care perspective. <i>Journal of Oncology Practice</i>,</p>	<p><u>Design:</u> Descriptive</p> <p><u>Aim:</u> Assess PCP interest in SCP and PCP attitudes when caring for cancer</p>	<p><u>Sample:</u> (n=15) primary care physicians who had documentation of receiving a SCP, 60% female; avg. age 48 years; avg. year since medical school 22; 67% internist specialty, 33% family</p>	<p><u>Interview:</u> Semi-structured with open-ended questions regarding the impact of SCPs and their attitudes towards them via phone or in-person</p> <p><u>Analysis:</u></p>	<p>8/10 PCPs reported making changes in care planning when referencing SCPs</p> <p>Greater confidence in providing care to survivors associated with recommendations from oncologists and</p>	<p><u>Generalizability</u> – small sample size as well as academic-affiliated institution may not be truly representative of PCP population</p>

7(5), 314-318. doi: 10.1200/JOP.2010.000208	survivors	<p>physician specialty, and 1% pediatric specialty.</p> <p><u>Setting:</u> LIVESTRONG Survivorship Center of Excellence in affiliation with UCLA</p>	<p>Development of themes, codes, and categories; NVivo-8 used to assist with coding</p>	<p>having SCPs</p> <p>Avg. length of SCPs: 5.3 pages, which was considered appropriate by the PCPs</p> <p>Benefits of SCPs: assisting with insurance reimbursement, organizing problem lists</p>	<p><u>Sampling bias:</u> Sampling was based on eligibility rather than randomization</p>
<p>Sima, J., Perkins, S., Haggstrom, D. (2014). Primary care physician perceptions of adult survivors of childhood cancer. <i>Journal of Pediatric Hematology and Oncology</i>, 36(2), 118-124. doi:10.1097/MPH.000000000000061</p>	<p><u>Design:</u> Mixed methods</p> <p><u>Framework:</u> Behavioral theories were used for survey development</p> <p><u>Aim:</u> Identify barriers and facilitators to CCSs screening and treatment by primary care physicians</p>	<p><u>Sample:</u> (n=351) physicians; 60% male; 94% completed training; 64% specialized in family medicine, 36% specialized in internal medicine; survivors were older than 18 years</p> <p><u>Setting:</u> Participants gathered from American Medical Association Physician Masterfile; data reviewed through University of Purdue</p>	<p><u>Survey</u> – Likert scale 1-5; \$1 incentive</p> <p><u>Analysis:</u> <i>Chi test and t test</i>; binary variables created</p>	<p>93% of physicians had never used COG guidelines, but 86% reported willingness to follow them</p> <p>85% of primary care physicians reported never receiving a SCP, but 90% reported they would be useful</p> <p>40% never cared for CCSs, 44% aware of practice guidelines for CCS, 27-38% felt they received adequate training for late effects of treatments</p> <p>Barriers included: low</p>	<p><u>Generalizability</u> – Limited to physician perspective and not inclusive of nurse practitioners or physician assistants who may also be providing care to CCSs</p> <p><u>Sampling bias:</u> Sampling was based on volunteers rather than randomization</p>

				level of awareness and inadequate training	
Thorne, S. & Stajduhar, K. (2012). Patient perceptions of communications on the threshold of cancer survivorship: Implications for provider responses. <i>Journal of Cancer Survivorship</i> , 6(2), 229-237. doi: 10.1007/s11764-012-0216-z	<p><u>Design:</u> Interpretive descriptive</p> <p><u>Aim:</u> Assess how cancer survivors communicate their needs and preferences regarding the transition to primary care</p>	<p><u>Sample:</u> (n=14) 12 women, 2 men; avg age 53; primary disease sites included breast, hematological, gynecological, prostate, gastrointestinal, and lung.</p> <p><u>Setting:</u> Canada</p>	<p><u>Interviews:</u> via phone or in-person</p> <p><u>Data Analysis:</u> Transcription of interviews via NVivo to determine themes</p>	<p><i>Emotional Themes:</i> confusion, insecurity, vulnerability, loss, and abandonment</p> <p><i>Communication challenges for providers:</i> non-verbal communication, showing anxiety, and sensitivity to normalization</p>	<p><u>Generalizability</u> – Canadian responses may not be reflective of American providers and education</p> <p><u>Sampling bias:</u> Sampling was based on volunteers rather than randomization</p>
Warner, E., Wu, Y., Hacking, C., Wright, J., Spraker-Perlman, H., Gardner, E., & Kirchoff, A. (2015). An assessment to inform pediatric cancer provider development and deliver of survivor care plans. <i>Journal of Cancer Education</i> , 30(4), 677-684. doi: 10.1007/s13187-	<p><u>Design:</u> Mixed methods with focus on exploratory descriptive</p> <p><u>Aim:</u> Assess the needs, willingness and preparedness of an institution to institute</p>	<p><u>Sample:</u> (n=41) 20 oncologists, 37 nurses, 15 clinical staff; 73% female, 92% caucasian; 37% had less than 5 years experience, 37% had more than 15 years of experience</p> <p><u>Setting:</u> children's hospital in Utah</p>	<p><u>Survey:</u> created by experts in pediatric cancer survivorship; 25 open-ended and closed questions; apprx. 45 minutes</p> <p><u>Focus group:</u> supplementary discussions</p> <p><u>Data Analysis:</u> themes and codes were constructed using multiple coders and agreed</p>	<p>88% high familiarity with late effects of cancer treatment and survivor care</p> <p>73% familiar with COG guidelines</p> <p>58% familiar with SCPs; 73% found SCPs useful; 40% implemented SCPs</p> <p>66% training from colleagues, 54% from conferences, 36% from</p>	<p><u>Sampling bias:</u> Participants were determined by the administrative director rather than randomized</p> <p><u>Generalizability:</u> Limited due to single hospital setting</p>

015-0829-9	SCPs		upon after completion	<p>medical journals</p> <p>95% supported idea of instituting a SCP program</p> <p>Most common barriers to delivering SCP included knowledge deficit (67%), lack of significance (54%), no designated champion (48%), and insufficient resources (43%)</p>	
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Note. PCP = primary care provider, SCP = survivor care plan, CCS = childhood cancer survivor

APPENDIX B
PRIMARY CARE NURSE PRACTITIONER SURVEY

Primary Care Nurse Practitioner Survey

Please answer the following demographical information:

1. What specialty are you certified in?
 - a. Pediatric
 - b. Family
2. How long have you been practicing as a nurse practitioner?
 - a. 1-5 years
 - b. 6-10 years
 - c. 11+ years
3. Which gender are you?
 - a. Male
 - b. Female
4. What is your highest level of education
 - a. Doctorate or PhD
 - b. Masters

Please answer the follow questions in relation to your previous or current practice with childhood cancer survivors:

- 1.) How often do you participate in the medical care of a childhood cancer survivor?

1 2 3 4
 o-----o-----o-----o
 Never Occasionally Frequently Very Frequently

- 2.) I feel that addressing the health care problems of childhood cancer survivors is important to my current practice.

1 2 3 4 5
 o-----o-----o-----o-----o
 Strongly Somewhat Neutral Somewhat Strongly
 Disagree Disagree Agree Agree

- 3.) I have had adequate training to recognize late effects of chemotherapy including sterility, endocrine deficiencies, cardiomyopathy, osteoporosis, and others.

1 2 3 4 5
 o-----o-----o-----o-----o
 Strongly Somewhat Neutral Somewhat Strongly
 Disagree Disagree Agree Agree

4.) I have had adequate training to recognize late effects of cancer surgeries (amputation, splenectomy etc...).

1	2	3	4	5
o-----o-----o-----o-----o				
Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

5.) I have had adequate training to recognize late effects of radiation therapy (skin malignancies, local functional complications etc...).

1	2	3	4	5
o-----o-----o-----o-----o				
Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

Please answer the following items in relation to any barriers you may encounter in your practice when caring for childhood cancer survivors:

6.) It is difficult to obtain essential elements of a cancer history from the patient.

1	2	3	4	5
o-----o-----o-----o-----o				
Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

7.) It is difficult to obtain elements of the cancer history that the patient can't provide, i.e. from the treating oncologist.

1	2	3	4	5
o-----o-----o-----o-----o				
Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

8.) It is difficult to locate current information about late effects of cancer therapy for educating myself and my patients.

1	2	3	4	5
o-----o-----o-----o-----o				
Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

9.) In my practice I find there is not enough time to discuss late effects of therapy.

1 2 3 4 5
 0-----0-----0-----0-----0
 Strongly Somewhat Neutral Somewhat Strongly
 Disagree Disagree Agree Agree

10.) In my experience, survivors of childhood cancer do not perceive late effects as a serious health threat.

1 2 3 4 5
 0-----0-----0-----0-----0
 Strongly Somewhat Neutral Somewhat Strongly
 Disagree Disagree Agree Agree

11.) In my experience, cancer survivors often cannot afford or lack insurance coverage for recommended screening for late effects.

1 2 3 4 5
 0-----0-----0-----0-----0
 Strongly Somewhat Neutral Somewhat Strongly
 Disagree Disagree Agree Agree

Please answer the following items in relation to the use of available resources:

12.) How often have you used the National Guideline Clearinghouse to locate any type of clinical practice guidelines?

1 2 3 4
 0-----0-----0-----0
 Never Occasionally Frequently Very Frequently

13.) How often have you used the clinical practice guidelines created by the Children's Oncology Group (www.childrensoncologygroup.org) to guide medical care for a childhood cancer survivor?

1 2 3 4
 0-----0-----0-----0
 Never Occasionally Frequently Very Frequently

14.) A *cancer treatment summary* is a document prepared for an individual cancer survivor that includes the following information: diagnosis, chemotherapy doses and schedules, radiation doses and location, surgical procedures, and toxicities of cancer therapy. How often have you had such a treatment summary available to you when providing care to a childhood cancer survivor?

1 2 3 4
 o-----o-----o-----o
 Never Occasionally Frequently Very Frequently

15.) A *cancer survivor care plan* includes detailed information regarding the potential for late side effects, the recommended screening procedures, and screening intervals. How often have you had such a care plan available to you when providing care to a childhood cancer survivor?

1 2 3 4
 o-----o-----o-----o
 Never Occasionally Frequently Very Frequently

16.) It would be useful to have a *cancer treatment summary* to manage childhood cancer survivors if provided to me by the treating oncology team.

1 2 3 4 5
 o-----o-----o-----o-----o
 Strongly Somewhat Neutral Somewhat Strongly
 Disagree Disagree Agree Agree

17.) It would be useful to have a *cancer survivor care plan* to manage childhood cancer survivors if provided to me by the treating oncology team.

1 2 3 4 5
 o-----o-----o-----o-----o
 Strongly Somewhat Neutral Somewhat Strongly
 Disagree Disagree Agree Agree

Please answer the following items in relation to future improvements that can aid in caring for childhood cancer survivors:

18.) Prior to this survey were you aware that clinical practice guidelines existed for the medical care of childhood cancer survivors?

- a. No
- b. Yes

19.) In my practice I would follow recommendations of the Children's Oncology Group childhood cancer survivor guidelines.

1	2	3	4	5
o-----o-----o-----o-----o				
Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

20.) It would be useful to receive timely reminders to direct late effects screening of cancer survivors.

1	2	3	4	5
o-----o-----o-----o-----o				
Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree

21.) Many primary care practices have a mechanism to remind physicians or other members of the care team that a patient is due for screening of any nature. If you were to receive such a reminder from an oncologist prompting screening for late effects in cancer survivors what form would be most useful in your practice setting? Rank all choices below from #1, most useful, to #6, least useful.

- | | |
|--|--|
| <input type="checkbox"/> Letters sent in the mail | <input type="checkbox"/> Telephone call to your office |
| <input type="checkbox"/> Computer generated flow sheet in the patient chart | <input type="checkbox"/> Email reminders |
| <input type="checkbox"/> Telephone hotline you could call for patient specific information | |
| <input type="checkbox"/> A website you could access for patient specific information | |

22.) What resources would you be most likely to use when looking for information about childhood cancer survivors? Rank all choices below in order from 1 most useful, to 6 least useful.

- | | | |
|-----------------------------------|---|--|
| <input type="checkbox"/> Internet | <input type="checkbox"/> Journal articles | <input type="checkbox"/> Oncologist |
| <input type="checkbox"/> Textbook | <input type="checkbox"/> Colleagues in your specialty | <input type="checkbox"/> Other specialty physician |

APPENDIX C
RECRUITMENT EMAIL TEXT

Recruitment Email Text

Please join in the following survey conducted by a local DNP student for her final thesis. The study is aimed at assessing primary care nurse practitioner perceived preparedness when caring for childhood cancer survivors. The survey consists of 26 questions and is expected to take 5-10 minutes to complete.

An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to the applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

If you have any questions or concerns, you may contact Mariel Martinez at 928-446-3024 or MDM@email.arizona.edu.

APPENDIX D
PRIMARY DISCLOSURE STATEMENT

Primary Disclosure Statement

Assessing Nurse Practitioner Preparedness in Caring for Pediatric Cancer Survivors

Mariel Martinez

This survey is part of a DNP project to assess primary care nurse practitioner preparedness when caring for childhood cancer survivors. You will be asked to complete a survey consisting of 26 questions. It will take you approximately 5-10 minutes to complete this survey. There are no foreseeable risks associated with participating in this research, and you will receive no immediate benefit from participating. However, results from this survey may benefit advanced practice nursing and society by raising awareness of the risks that childhood cancer survivors carry with them and the survivor guidelines that are available. In addition, the results can be used for future research. Participation in this survey is voluntary and will remain anonymous.

If you choose to participate in this study, you may choose to discontinue participation at anytime without penalty. You may skip any question that you choose not to answer. By participating, you do not give up any personal legal rights that you may have as a participant of this study. An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to the applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research. For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at 520-626-6721 or online at <http://rgw.arizona.edu/compliance/human-subjects-protection-program>.

The final date to complete the survey is September 2, 2016. For questions, concerns, or complaints about the study, you may call Mariel Martinez, RN, BSN, at 928-446-3024 or via email at MDM@email.arizona.edu.

By taking this survey, you agree to have your responses used for research purposes.

APPENDIX E
SURVEY RESULTS

TABLE 3. *Survey Results*

Knowledge and Awareness					
1. <i>How often do you participate in the medical care of a childhood cancer survivor?</i> Total response rate: 5 (100)	<i>Never</i> 2 (40)	<i>Occasionally</i> 2 (40)	<i>Frequently</i> 1 (20)	<i>Very Frequently</i> 0 (0)	
2. <i>I feel that addressing the health care problems of childhood cancer survivors is important to my current practice.</i> Total response rate: 4 (75)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 0 (0)	<i>Neutral</i> 0 (0)	<i>Somewhat agree</i> 2 (50)	<i>Strongly agree</i> 2 (50)
3. <i>I have had adequate training to recognize late effects of chemotherapy including sterility, endocrine deficiencies, cardiomyopathy, osteoporosis, and others.</i> Total response rate: 4 (75)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 0 (0)	<i>Neutral</i> 1 (25)	<i>Somewhat agree</i> 4 (75)	<i>Strongly agree</i> 0 (0)
4. <i>I have had adequate training to recognize late effects of cancer surgeries (amputation, splenectomy etc...).</i> Total response rate: 5 (100)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 0 (0)	<i>Neutral</i> 2 (50)	<i>Somewhat agree</i> 2 (50)	<i>Strongly agree</i> 0 (0)
5. <i>I have had adequate training to recognize late effects of radiation therapy (skin malignancies, local functional complications etc...).</i> Total response rate: 4 (75)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 0 (0)	<i>Neutral</i> 2 (50)	<i>Somewhat agree</i> 2 (50)	<i>Strongly agree</i> 0 (0)
Barriers Encountered					
6. <i>It is difficult to obtain essential elements of a cancer history from the patient.</i> Total response rate: 5 (100)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 2 (40)	<i>Neutral</i> 3 (60)	<i>Somewhat agree</i> 0 (0)	<i>Strongly agree</i> 0 (0)
7. <i>It is difficult to obtain elements of the cancer history that the patient can't provide, i.e. from the treating oncologist.</i> Total response rate: 5 (100)	<i>Strongly disagree</i> 2 (40)	<i>Somewhat disagree</i> 1 (20)	<i>Neutral</i> 2 (40)	<i>Somewhat agree</i> 0 (0)	<i>Strongly agree</i> 0 (0)

8. <i>It is difficult to locate current information about late effects of cancer therapy for educating myself and my patients.</i> Total response rate: 5 (100)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 2 (40)	<i>Neutral</i> 3 (60)	<i>Somewhat agree</i> 0 (0)	<i>Strongly agree</i> 0 (0)
9. <i>In my practice I find there is not enough time to discuss late effects of therapy.</i> Total response rate: 5 (100)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 0 (0)	<i>Neutral</i> 4 (80)	<i>Somewhat agree</i> 0 (0)	<i>Strongly agree</i> 1 (20)
10. <i>In my experience, survivors of childhood cancer do not perceive late effects as a serious health threat.</i> Total response rate: 5 (100)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 3 (60)	<i>Neutral</i> 2 (40)	<i>Somewhat agree</i> 0 (0)	<i>Strongly agree</i> 0 (0)
11. <i>In my experience, cancer survivors often cannot afford or lack insurance coverage for recommended screening for late effects.</i> Total response rate: 5 (100)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 0 (0)	<i>Neutral</i> 4 (80)	<i>Somewhat agree</i> 0 (0)	<i>Strongly agree</i> 1 (20)
Resource Availability and Utilization					
12. <i>How often have you used the National Guideline Clearinghouse to locate any type of clinical practice guidelines?</i> Total response rate: 5 (100)	<i>Never</i> 5 (100)	<i>Occasionally</i> 0 (0)	<i>Frequently</i> 0 (0)	<i>Very Frequently</i> 0 (0)	
13. <i>How often have you used the clinical practice guidelines created by the Children's Oncology Group (www.childrensoncologygroup.org) to guide medical care for a childhood cancer survivor?</i> Total response rate: 5 (100)	<i>Never</i> 3 (60)	<i>Occasionally</i> 2 (40)	<i>Frequently</i> 0 (0)	<i>Very Frequently</i> 0 (0)	
14. <i>A cancer treatment summary is a document prepared for an individual cancer survivor that includes the following information: diagnosis, chemotherapy doses and schedules, radiation doses and location, surgical procedures, and</i>	<i>Never</i>	<i>Occasionally</i>	<i>Frequently</i>	<i>Very Frequently</i>	

<i>toxicities of cancer therapy. How often have you had such a treatment summary available to you when providing care to a childhood cancer survivor?</i> Total response rate: 4 (75)	1 (25)	1 (25)	1 (25)	1 (25)	
<i>15. A cancer survivor care plan includes detailed information regarding the potential for late side effects, the recommended screening procedures, and screening intervals. How often have you had such a care plan available to you when providing care to a childhood cancer survivor?</i> Total response rate: 4 (75)	<i>Never</i> 1 (25)	<i>Occasionally</i> 1 (25)	<i>Frequently</i> 2 (50)	<i>Very Frequently</i> 0 (0)	
<i>16. It would be useful to have a cancer treatment summary to manage childhood cancer survivors if provided to me by the treating oncology team.</i> Total response rate: 5 (100)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 0 (0)	<i>Neutral</i> 0 (0)	<i>Somewhat agree</i> 1 (20)	<i>Strongly agree</i> 4 (80)
<i>17. It would be useful to have a cancer survivor care plan to manage childhood cancer survivors if provided to me by the treating oncology team.</i> Total response rate: 5 (100)	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 0 (0)	<i>Neutral</i> 0 (0)	<i>Somewhat agree</i> 1 (20)	<i>Strongly agree</i> 4 (80)
Future Improvements					
<i>18. Prior to this survey were you aware that clinical practice guidelines existed for the medical care of childhood cancer survivors?</i> Total response rate: 5 (100)	<i>No</i> 0 (0)	<i>Yes</i> 5 (100)			
<i>19. In my practice I would follow recommendations of the Children's Oncology Group childhood cancer survivor guidelines.</i>	<i>Strongly disagree</i> 0 (0)	<i>Somewhat disagree</i> 0 (0)	<i>Neutral</i> 0 (0)	<i>Somewhat agree</i> 4 (80)	<i>Strongly agree</i> 1 (20)
<i>20. It would be useful to receive timely</i>	<i>Strongly</i>	<i>Somewhat</i>	<i>Neutral</i>	<i>Somewhat</i>	<i>Strongly</i>

<i>reminders to direct late effects screening of cancer survivors.</i> Total response rate: 5 (100)	<i>disagree</i> 0 (0)	<i>disagree</i> 0 (0)	0 (0)	<i>agree</i> 3 (60)	<i>agree</i> 2 (40)	
21. <i>Many primary care practices have a mechanism to remind physicians or other members of the care team that a patient is due for screening of any nature. If you were to receive such a reminder from an oncologist prompting screening for late effects in cancer survivors what form would be most useful in your practice setting? Rank all choices below from #1, most useful, to #6, least useful:</i>	<i>Rank 1</i>	2	3	4	5	6
<i>Letters in the mail</i>	0 (0)	0 (0)	0 (0)	0 (0)	1 (25)	3 (75)
<i>Email reminders</i>	2 (50)	0 (0)	1 (25)	0 (0)	1 (25)	0 (0)
<i>Electronic access to patient information</i>	0 (0)	4 (100)	0 (0)	0 (0)	0 (0)	0 (0)
<i>Telephone call to the office</i>	0 (0)	0 (0)	1 (25)	0 (0)	2 (50)	1 (25)
<i>Telephone hotline to the oncologist</i>	0 (0)	0 (0)	1 (25)	3 (75)	0 (0)	0 (0)
<i>Electronic access to patient information</i>	2 (50)	0 (0)	1 (25)	1 (25)	0 (0)	0 (0)
Total response rate: 4 (75)						
22. <i>What resources would you be most likely to use when looking for information about childhood cancer survivors? Rank all choices below in order from 1 most useful, to 6 least useful:</i>	<i>Rank 1</i>	2	3	4	5	6
<i>Internet</i>	2 (50)	1 (25)	0 (0)	0 (0)	1 (25)	0 (0)
<i>Textbook</i>	1 (25)	1 (25)	0 (0)	1 (25)	0 (0)	1 (25)
<i>Journal articles</i>	1 (25)	1 (25)	1 (25)	1 (25)	0 (0)	0 (0)
<i>Colleagues in your specialty</i>	0 (0)	0 (0)	1 (25)	1 (25)	2 (50)	0 (0)
<i>Oncologist</i>	0 (0)	1 (25)	1 (50)	0 (0)	1 (25)	0 (0)
<i>Other specialty physician</i>	0 (0)	0 (0)	0 (0)	1 (25)	0 (0)	3 (75)
Total response rate: 4 (75)						

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