

EXPLORING THE ROLE OF NURSE PRACTITIONERS IN LONG-TERM FOLLOW UP
CARE OF ADULT SURVIVORS OF A CHILDHOOD CANCER

by

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Abstract

Treatment of childhood cancers has made significant gains in recent decades, leading to overall 5-year survival rates increasing to approximately 80%. As childhood cancer survivors (CCS) age, they are at risk for late effects – treatment-related health problems that occur at least 5 years after cancer therapy completion. It is estimated that at least 80% of CCS will develop at least one late effect, which can affect multiple body systems, normal growth and development, and psychosocial wellbeing. The need for long term follow up (LTFU) care to detect, mitigate and treat these late effects is widely recognized and endorsed, but unfortunately, remains suboptimal. There is limited evidence of the optimal model of care for these survivors, and to date, much of the literature has focused on the actual and potential roles and responsibilities of physicians. What appears to be lacking is consideration of nurse practitioner (NP) integration into LTFU of CCS. The aim of this paper is to provide an overview of LTFU needs of CCS and suggest ways in which NPs could support optimal care delivery. NP advanced education and clinical experience, grounded in nursing fundamentals and guided by medical knowledge, allows for both autonomous and collaborative practice in a variety of settings and models of care. NPs are well positioned to support LTFU of CCS by: providing patient-centered care with a health promotion focus, applying strong communication and collaboration skills to support continuity of care and utilizing advanced assessments to direct patient care based on relevant guidelines.

Keywords: childhood cancer survivor, long term follow up, late effects, nurse practitioner

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Exploring the Role of Nurse Practitioners in Long-Term Follow up of Adult Survivors of a Childhood Cancer

The incidence of childhood cancer has risen over the last few decades (Statistics Canada, 2015). Fortunately, the advancements in childhood cancer treatment have produced dramatic declines in mortality, such that the overall 5-year survival rate is currently approximately 80% (Oeffinger et al. 2006, Freyer, 2010). However, this increased survival has come at a cost. It is estimated that up to 80% of childhood cancer survivors (CCS) will face at least one long-term complication related to their treatment (Oeffinger et al., 2006). Many of these late effects, side effects that occur at least 5 years following treatment, are not seen until years or decades after treatment is complete and after specialized care is terminated. With both incidence and survival rates increasing, and the prevalence of late-effects, a larger number of CCS are requiring long-term follow up (LTFU) care.

Late effects are dependant on the type of cancer and treatments and can affect multiple body systems such as cardiovascular, pulmonary, endocrine, musculoskeletal, neurological and genitourinary (Oeffinger, Hudson & Landier, 2009). Blaauwbroek, and colleagues (2007a), found that 39% of patients who were treated in a pediatric oncology department in the Netherlands and then recalled to a LTFU clinic at least 5 years after treatment, had moderate to severe late effects. Furthermore, those with more severe late effects had a lower perceived health quality of life. Information gathered from the Childhood Cancer Survivor Study indicates that some late effects can be prevented or managed if screened for appropriately (Oeffinger et al., 2009). Szalda et al. (2016) collected data from young adult cancer survivors from The Children's Hospital of Philadelphia who had been transferred from pediatric oncology to adult care and

found that unfortunately, many CCS are not receiving adequate LTFU care. For example, 45% of patients reported having no cancer related follow up care in the last year (Szalda et al., 2016).

Primary care providers (PCP) including nurse practitioners (NP) can provide LTFU care and act as significant advocates for adult CCS. Authors of a recent systematic review concluded that most PCPs are willing to care for this population and monitor for late effects provided they have the necessary education, support and resources (Lawrence, McLoone, Wakefeild & Cohn, 2016). Additionally, in a Norwegian study involving focus groups, CCS were willing to be followed long term by a PCP who could provide timely patient-centered care utilizing appropriate resources and supports (Lie et al., (2017)). To date, much of the literature has focused on family physicians as PCPs for LTFU of CCS or family physician integration into shared care models. Given that NPs are consistently considered an essential component of the multidisciplinary team in oncology settings, the limited exploration of the potential integration of NPs into LTFU of CCS is remarkable. Accordingly, the purpose of this paper is to explore the potential role of NPs in LTFU care of adult CCS. Knowledge and information of the ways in which PCPs, particularly NPs, could be involved in the provision of care for CCS is essential for developing effective, quality health services.

Description of the Problem

Increasing numbers of adult CCS will require primary care (Murphy, 2013). Studies from PCP perspectives and Childhood Cancer Survivor Studies suggest that LTFU and health maintenance in this population is suboptimal despite the multiple benefits of LTFU care (Berg, Stratton, Esiashvili, Mertens & Vanderpool, 2016; Oeffinger, 2006). Authors of a systematic review concluded that CCS who engage in LTFU care have better knowledge of their treatment

and potential late effects, understand their risk, are more engaged in screening and, therefore, have higher rates of late effects detection (Signorelli et al., 2017).

An opportunity exists for PCPs to advocate for and encourage this patient group to be engaged in LTFU care that includes screening and management of late effects. Nathan et al. (2008), reported that more than 88% of adult CCS, who were part of a Childhood Cancer Survivor Study from the United States (US) and Canada, had accessed medical care in the last 2 years. However, only 31.5% of those participants reported their visit as being focused on survivorship care and only 17.8% reported survivor focused care that included a discussion of late effects screening or risk reduction. Szalda et al. (2016), using participants from The Children's Hospital in Philadelphia who were transferred to adult-focused follow up care, reported that 83% of young adult survivors who were not engaged in cancer related follow-up had seen their PCP for other reasons. Similarly, Kirchhoff et al. (2014) conducted telephone interviews of adult CCS from the Utah Cancer Surveillance, Epidemiology, and End Results (SEER) Registry, and reported that 83% of cancer survivors had seen a PCP at least once in the last 2 years. Unfortunately, visits to their PCP did not routinely address LTFU needs related to their cancer history. In some instances, conversation about cancer history only took place during initial visits with a new practitioner during the general history discussion. Kirchhoff et al. (2014), also noted that only 45% of patients who were diagnosed with cancer 10 or more years ago, discussed their cancer history with their PCP. These examples highlight the situation wherein CCS are accessing primary care, but not necessarily receiving late effects screening and management, suggesting that opportunities for LTFU in primary care exist but are not being fully utilized.

A systematic review revealed that PCPs are willing to care for CCS and believe it is part of their scope of practice (Lawrence et al., 2016). Yet, a recent study by Sima et al. (2014), found a large majority of PCPs surveyed in the US perceived their medical training as inadequate to prepare them to identify chemotherapy (72.5%), cancer surgery (63.5%) or radiation (61.9%) related late effects in CCS. Perhaps even more concerning is the 93% of PCPs who never used the Children's Oncology Group (COG) Guidelines despite 86% of the participants stating they would follow the recommendations. Similar studies from both Canadian and US populations conclude that PCPs are not using recommended guidelines despite recognizing their importance and usefulness (Suh et al., 2014; Nathan et al., 2013). Furthermore, a survey of US and Canadian family physicians reported only 1% preferred to care for these patients independently, perhaps highlighting a lack of comfort or experience with this population (Nathan et al., 2013). Data from multiple sources suggests that having increased knowledge, open lines of communication with the treating oncologist, a treatment summary, as well as access to guidelines, would be most beneficial for PCPs who care for CCS (Suh et al., 2014; Nathan et al., 2012; Lawrence et al., 2016).

LTFU of CCS is complex and multidimensional, with numerous patient, system and provider barriers and facilitators. Addressing the many barriers and facilitators to successful LTFU care is beyond this scope of this paper, however, the subsequent literature review will: provide a brief overview of CCS late effects risks and outline LTFU needs within different models of care. This literature review provides the foundation for suggestions on the ways in which NP involvement could improve LTFU for CCS. This work will form the basis for developing a manuscript for submission to a relevant journal, such as the Journal of Pediatric Oncology Nursing, The Journal for Nurse Practitioners, or The Nurse Practitioner.

Literature Review

Summary of Late Effects

The late effects associated with childhood cancer treatments can affect many systems including cardiovascular, pulmonary, endocrine, musculoskeletal/bone and reproductive, as well as increase risk for secondary cancers (Schmidt et al., 2010; Oeffinger et al., 2009; Koop, Gupta, Pelayo-Katsanis, Wittman & Katsanis 2012; Murphy, 2013). Hudson et al., (2013), used data from CCS enrolled in the Saint Jude Lifetime Cohort Study and found the most prevalent late effects included pulmonary, auditory, endocrine/reproductive, cardiac and neurocognitive dysfunction. As CCS age and time since diagnosis increases so does the risk of late effects (Landier et al., 2004; Oeffinger et al., 2009; Nathan et al. 2008; Schmidt et al., 2010). It is assumed that some of these late effects effects can be prevented or well managed, more so if detected early, leading to improved outcomes (Oeffinger et al., 2009).

A full review of late effects of treatment and recommendations is beyond the scope of this paper, rather, a brief overview of late effects follows.

Radiation effects. Children and adolescents are particularly vulnerable to the effects of radiation treatment because of their rapid growth and development. The severity of late effects from radiation depends on a number of factors including radiation dose, fraction size, time between fractions, type of radiation, location, and age at treatment. The most common areas of radiation can be divided into cranial, chest, and abdominal/pelvic radiation (Oeffinger et al., 2009).

Cranial radiation therapy can lead to cognitive and neuroendocrine dysfunction, obesity (especially in females), risk for seizures, cerebrovascular accidents, secondary tumors, cataracts, hearing loss and dental complications. Children who have received high dose, whole brain

radiation are at increased risk for several cognitive dysfunctions including impairment with memory, verbal IQ, attention, somatosensory functioning and visual-spatial functioning. The level of cognitive dysfunction can impair the ability to function independently as an adult (Oeffinger et al. 2009). Furthermore, the hypothalamic-pituitary axis, which constitutes a major neuroendocrine system that controls growth hormone, can be damaged by radiation treatment and result in impaired growth and development. These effects become more prevalent as time from treatment increases, making LTFU essential (Mostoufi-Moab & Grimberg, 2010).

Chest radiation increases the risk for breast cancer and cardiovascular disease and may also have a potential association with lung cancer in the presence of other risk factors. Those who have had either mediastinal or abdominal radiation have a seven-fold higher risk of mortality related to cardiovascular disease than those who have not (Koop et al., 2012). Chest radiation may also impact lung and thyroid function in addition to posing a risk for thyroid cancer (Oeffinger et al., 2009).

Abdominal and pelvic radiation can have a wide impact relating to treatment of the gastrointestinal system, liver, spleen, kidneys and gonads. Symptoms can range from gastrointestinal upset to increased risk of gastric cancers. Furthermore, the radiation can lead to renal insufficiency, bladder changes, hypertension and fertility complications (Oeffinger et al., 2009).

Chemotherapy effects. Chemotherapeutics are also associated with late effects risks depending on the specific agent. For example, alkylating agents may lead to gonadal dysfunction, secondary cancer, pulmonary changes, as well as genitourinary changes (Oeffinger et al., 2009). Risks of infertility may be heightened depending on age of treatment. For example, testis are more sensitive to alkylating agents at a younger age. For women, there is an increased

risk of premature menopause that can result in increased risk for osteoporosis and coronary artery disease later in life (Koop et al., 2012). Anthracyclines are well known for cardiotoxic effects, even at low doses, which may develop into heart failure and cardiomyopathy (Oeffinger et al., 2009). These cardiovascular late effects risks are even higher in blacks (Seehusen, Baird & Bode, 2010). Antimetabolite chemotherapy, especially in conjunction with steroid therapy, can hinder peak bone mass development and lead to osteoporosis. Finally, platinum analogues can also pose risks to gonadal and renal dysfunction, treatment related cancer, hearing loss, peripheral neuropathy and dyslipidemia (Oeffinger et al., 2009).

Surgery and hematopoietic stem cell transplant. Depending on the location and extent of the surgery, patients can suffer chronic pain, scarring, incontinence, hypogonadism and sexual dysfunction. Additional complications such as risk for seizures and cognitive, motor or sensory impairments can present in patients who underwent neurosurgery. Furthermore, patients treated with hematopoietic stem cell transplant (HSCT) may be at risk for secondary leukemia, hepatic toxicity and osteonecrosis. There are also several long-term complications for those who develop chronic graft-versus-host disease. For example, patients may experience Sjogren's like symptoms of dry eyes and dry mouth, immune system impairment and functional asplenia (Seehusen et al., 2010). Like the general population, adult CCS who received blood transfusions before universal donor screening may have contracted hepatitis B, hepatitis C or human immunodeficiency virus (Oeffinger et al., 2009; Seehusen et al., 2010).

Psychosocial effects. Many adult CCS experience positive psychological development after treatment. However, some individuals appear to be at increased risk for poor outcomes depending on the type of cancer, treatment, age at diagnosis and severity of the disease (Schmidt et al., 2010). Furthermore, gender may also play a role as women have higher rates of functional

impairment and anxiety compared to men (Seehusen, Baird & Bode, 2010). In addition to anxiety, psychological difficulties include depression, post-traumatic stress disorder (PTSD) and social problems for both men and women. These difficulties can contribute to poor relationships and suboptimal employment, which can lead to further challenges (Oeffinger et al., 2009).

Long Term Follow up Care Needs

Screening, surveillance and management of late effects. Increasing knowledge about late effects has led to significant advances in the recommendations and guidelines for LTFU. The most comprehensive and widely endorsed, is the Children's Oncology Group (COG) LTFU Guidelines. These guidelines utilize evidence-based research combined with expert clinical experience to provide practitioners with a resource aimed at improving the quality of life of CCS by identifying and treating late effects. The guidelines are intended to be used for childhood, adolescent or young adult cancer survivors during routine exposure-related medical follow-up after at least 2 years from treatment. The guidelines suggest treatment specific histories, physical exams and additional baseline and follow up investigations to screen for and treat late effects (Children's Oncology Group, 2013). A comprehensive overview of these screening recommendations is not feasible, however, there are some specific examples that highlight the complex nature of CCS follow up which will be discussed.

Chemotherapy effects. Certain heavy metal agents can cause ototoxicity. Annual history and physical exams should include inquiries about hearing difficulties, tinnitus, vertigo, and otoscopic examination. Screening measures require baseline formal audiology evaluation, which can be repeated if evidence of complications arise. Careful attention to effects of hearing difficulties on education and speech and language development should be explored. Appropriate collaboration with community resources, such as social workers and school counsellors, is

essential. Similarly, high doses of antimetabolite cytarabine or methotrexate can also impact education and overall function. Neurocognitive deficits such as poor executive functioning, memory and attention impairments can have effects on IQ and behavior. Baseline and follow up neuropsychological evaluation is recommended (Children's Oncology Group, 2013).

The risk for gonadal dysfunction following treatment with alkylating and heavy metal agents should prompt practitioners to focus on pubertal development and sexual function. Practitioners should be aware of the need for baseline testosterone level screening at age 14 for males and baseline LH, FSH and estradiol screening at age 13 for females (Children's Oncology Group, 2013).

Symptoms of cough, shortness of breath or wheezing in a CCS treated with alkylating agents or bleomycin need to be evaluated for pulmonary fibrosis and toxicity. Annual pulmonary exams along with baseline and repeat pulmonary function tests is suggested. Additionally, symptoms such as chest pains and palpitations may indicate cardiac complications. Further investigations such as ECHO and ECG can be repeated and compared to baseline LTFU investigations (Children's Oncology Group, 2013).

Lastly, due to the risk for multiple genitourinary complications of CCS treated with alkylating agents or antimetabolites, special attention is needed to assess for urinary changes. Screening should include annual blood pressure measurements and lab studies related to kidney function (Children's Oncology Group, 2013).

Radiation effects. Regardless of the area targeted by radiation, CCS can be at risk for various skin changes and secondary malignancies, including skin and bone cancer. Similar to chemotherapy guidelines, targeted screening based on specific radiation treatment areas are required (Children's Oncology Group, 2013).

For example, cranial radiation can have a significant impact on neurocognitive development requiring comparable examinations, screening and referrals as those treated with antimetabolites. Cranial radiation can also lead to impaired weight management. Practitioners need to document height, weight, BMI and blood pressure annually. These measures may also help identify complications of growth hormone deficiency or early/accelerated puberty. Additionally, higher doses of cranial radiation require assessments for symptoms of hypothyroidism, hyperthyroidism or thyroid cancer in addition to TSH and free T4 lab studies (Children's Oncology Group, 2013).

Females treated with chest radiation must be screened for breast cancer. Depending on the dose of radiation administered and the age of the patient, physical exams are required annually or every 6 months in addition to regular mammograms and MRIs. Both males and females who receive chest radiation require assessment for pulmonary and cardiac toxicities. CCS treated with chest, abdomen or whole body radiation need to be screened for glucose intolerance and dyslipidemia by evaluating fasting glucose, HbA1c and lipid profiles. Abdominal radiation may also lead to increased risk for colorectal cancer which requires more frequent screening and at a younger age than the general public (Children's Oncology Group, 2013).

Surgery and hematopoietic stem cell transplant. In addition to radiation and chemotherapy toxicities, HSCT patients require additional assessment and screening. Many examples such as, bone density changes, pulmonary and renal toxicities have already been discussed. Childhood cancer survivors post-HSCT can also be at risk for secondary solid tumors and lymphoma which require relevant assessments. Finally, CCS who have undergone surgery require specific follow up and evaluations based on the type of surgery.

Regardless of the type of treatment or combination, CCS need comprehensive and individualized LTFU that includes appropriate history taking, physical exam, screening and specialty referrals such as neurology, cardiology or endocrinology when appropriate (Children's Oncology Group, 2013).

Health promotion. LTFU care should include counselling and health promotion education. Health promotion for CCS is particularly important because poor health practices can have an increased detrimental effect on health compared to the general population. On the other hand, healthy lifestyle choices have the potential to positively counteract risks for cardiovascular compromise, metabolic changes as well as genitourinary complications (Seehusen, Baird & Bode, 2010). The following section will highlight some important health promotion considerations for CCS.

Self-reports and observational studies of CCS reveal that higher percentages of CCS engage in risky behaviors such as smoking, alcohol use and low levels of physical activity (Murphy, 2013; Overholser, Kilbourn & Liu, 2017). Research from the Childhood Cancer Survivor Study compared smoking rates of CCS to their siblings and found that, despite the health risks, CCS continued to engage in this risky behavior at rates comparable to their siblings (Freyer, 2010). Similarly, CCS experimented with marijuana at comparable rates to their peers (Murphy, 2013). Additionally, CCS self-report consuming almost double the amount of alcohol compared to their peers and engage in binge drinking more frequently (Murphy, 2013). As mentioned, CCS have an increased risk of cardiovascular and pulmonary complications, and therefore, health behaviors that further increase risks can pose significant increase in morbidity and mortality (Overholser et al., 2017).

Cardiovascular complications are the third most common cause of mortality in CCS following recurrent/progressive disease and subsequent malignancy (Mertens et al., 2008). While some treatments are known to be cardiotoxic, a study of CCS in a long-term survivor clinic at the University of Rochester reported that even those treated without cardiotoxic treatments have an increased risk for cardiovascular complications. Furthermore, CCS are eight times more likely to die of cardiac causes than the general population. It is proposed that the increased risk for cardiac complications may be related to ongoing inflammatory processes as well as elevated cholesterol levels, obesity and insulin resistance (Lipshultz et al., 2012).

Treatment can have long term effects on metabolism. Murphy (2013) highlighted that during treatment, children may be required to increase caloric intake to sustain adequate nutrient and energy requirements. Once treatment is completed these practices may continue however, many of the foods are suboptimal leading to nutrient deficiencies and higher risks of metabolic complications.

Risks for skin cancer increase with age and time since childhood cancer diagnosis. Despite already experiencing cancer, CCS are no more likely to engage in sun protection behaviors (Murphy, 2013).

Recommendations. Generalized health promotion education for CCS is not effective (Murphy, 2013). Understanding CCS baseline knowledge and tailoring education needs about late effects risks such as cardiovascular complications and secondary malignancies can be an important first step and motivator for health promoting behaviors (Murphy, 2013; Syed et al., 2016). It is also recommended that annual screening for risk-taking behaviors such as smoking and alcohol use is included in LTFU care (Children's Oncology Group, 2013).

A systematic review revealed some targeted interventions that have shown promise for CCS engagement in health promoting behaviors (Bradford & Chan, 2017). Home training interventions, group based exercise, as well as both paper and online resources have successfully increased rates of physical activity. Interventions aimed at other health promoting behaviours such as dietary changes, optimizing bone health, and reducing tobacco use had variable results with the most positive results centering on education and counselling (Bradford & Chan, 2017).

While there are no specific CCS recommendations for a healthy diet, a DASH style diet has been recommended for children who have familial cardiovascular risks or other conditions that may impact cardiovascular health (Murphy, 2013). The DASH diet has been shown to lower the risk for cardiovascular disease, and consists of four to five servings of fruit, four to five servings of vegetables, two to three servings of low fat dairy and less than twenty-five percent of dietary intake from fat per day (Colditz, 2018). It has also been suggested that CCS may require a lower caloric intake compared to the general population. Furthermore, CCS may be deficient in calcium and vitamin D intake following treatment and need to be counselled accordingly. Practitioners may consider collaboration with nutritionists for support and resources (Murphy, 2013).

There are no standard physical activity recommendations for CCS. In general, aerobic exercise is thought to be safe while strenuous heavy lifting may need to be avoided, especially in patients with cardiovascular complications. Using lighter weights is thought to be generally safe and the number of repetitions should be gauged based on the comfort of the CCS. Resistance training should also be recommended to CCS to maintain bone health (Children's Oncology Group, 2013).

Secondary skin cancer prevention should include common practices suggested to the general population such as avoiding sun exposure during peak ultra violet times, using sunscreen, and wearing protective clothing (Murphy, 2013). For women, screening for secondary breast cancer can include educating women about the risk as well as providing information to assist with self-breast examinations (Children's Oncology Group, 2013).

Psychosocial care. The completion of treatment and transition to survivorship may appear to be a positive event, however, some individuals struggle with fear of recurrence and the unknown. There appear to be subgroups of CCS at higher risk for psychosocial challenges, including survivors of acute lymphoblastic leukemia, brain tumors, Hodgkin's lymphoma, sarcoma and bone tumors. Furthermore, age at diagnosis, family dynamics and treatment related side effects may be contributing factors (Oeffinger et al., 2009). Psychological complications can include anxiety, depression and PTSD (Oeffinger et al., 2009; Overholser et al., 2017). Furthermore, PTSD may also affect family members (Oeffinger et al., 2009). PTSD is important to recognize as it may impact CCS encounters with health care. Those with PTSD may be more likely to avoid routine follow up care and engage in risky behaviours that might heighten their late effects risks (Overholser et al., 2017). PCPs should capitalize on each encounter with CCS as an opportunity to provide necessary information about healthy lifestyle behaviors (Kinahan et al., 2015).

According to the COG LTFU guidelines, all CCS should be screened annually for mental health concerns, impaired social interactions and work or school involvement. CCS may also suffer from chronic pain and /or chronic fatigue, which may affect multiple aspects of psychosocial well being (Children's Oncology Group, 2013). Since PTSD can also affect family members, appropriate screening and interventions need to include both the CCS and their family

(Oeffinger et al., 2009). Additionally, PCPs should have knowledge of, and access to, successful treatment. In a systematic review, Bradford and Chan (2017), reported that metacognitive therapy and cognitive behavioral therapy have shown promise in treating anxiety, depression and PTSD in adolescent and young adult cancer survivors.

Patient knowledge and engagement in long term follow up care.

In most cases, CCS transition from pediatric to adult care and away from specialized oncology care. Unfortunately, as time from treatment increases, survivor knowledge of their treatment decreases, as does their engagement in LTFU care (Freyer, 2010; Landier et al., 2004). Authors of a systematic review made the point that patients who are disengaged from LTFU care tend to be less knowledgeable about their late effects risks for long term effects (Signorelli et al., 2017). Furthermore, 33% of previously disengaged patients from the Netherlands, who were recalled to LTFU care clinics, were subsequently diagnosed with late effects that required further management, including secondary malignancy (Blaauwbroek et al., 2007a). It has been reported that more than half of patients at risk for a secondary malignancy were not aware of this late effect (Syed et al., 2016). Syed et al. (2016) found that nearly a third of Canadian patients (aged 15-26) had limited knowledge of both their treatment and the possibility of late effects. Similarly, Kirchhoff et al. (2014) reported that data collected from telephone interviews of participants recruited from the Utah Cancer SEER Registry revealed almost half of CCS were not aware of the potential for late effects. CCS believed that because their cancer treatment took place so many years ago, any health problems related to the cancer or treatment would have already occurred. This perception is important to consider because CCS may consider LTFU to be unnecessary. CSS awareness of late effects risks is especially essential in models of care that require CCS to initiate and engage in care or self-management (Syed et al., 2016).

According to current research, there is large variation in the percentage of patients who engage in LTFU care (McCellan et al. 2013; Szalda et al. 2016; Quillen, Bradley & Calamaro, 2017; Reppucci, Schleien, & Fish 2016). There also appears to be certain marginalized populations who are at increased risk for poor LTFU care, including those of low income and low education levels. Additionally, using data from the Childhood Cancer Survivor Study, it was identified that survivors who were asymptomatic at baseline or had no reported morbidity were less likely to engage in LTFU care (Casillas et al., 2015). Regardless of the percentages, researchers agree that adherence to LTFU care is suboptimal despite various models of care, including speciality survivorship clinics, shared-care or primary care only.

Christen et al. (2016) found adolescent and young adult participants, identified from the Cancer Registry Zurich and Zug, who did engage in follow up, wanted specific information related to cancer recurrence and late effects. Similar results were found by McClellan et al. (2013) using participants from two pediatric oncology programs in the US. Additionally, CCS wanted more information about what tests would be needed to screen for late effects and the impact treatment may have had on their fertility (McClellan et al., 2013). Using data collected from Swiss childhood cancer survivors, Michel et al. (2016) reported clinical reasons outweighed supportive reasons for LTFU care visits.

Care Delivery

Models of care. There is no clear consensus of the best model of care to support CCS LTFU needs, however, there are positive outcomes for CCS who engage in LTFU (Lawrence et al., 2015; Signorelli et al., 2017). It is more likely that models of care need to be tailored to the unique needs of the community, the patients and late effects risk stratification (Kinahan et al., 2015; Signorelli et al., 2017). Regardless of the models of care, Seehusen and colleagues (2016)

and Szalda et al. (2016) support the need for seamless and supportive transitions from pediatric to adult care. Similarly, Baird and Bode (2010) suggest that transition of care from oncologist to community practitioner needs to be a stepwise, well-planned, deliberate process that encompasses the necessary medical background and knowledge, while recognizing the importance of family-centered, culturally competent and compassionate care. The following will provide a brief overview of common models of care.

Oncology led. Oncology led care primarily takes place in a cancer center and may include direction from the primary oncologist or a specialized multi-disciplinary LTFU team. This integrated and specialized model of care may be best suited for those in a high risk category, but also has some drawbacks (Oeffinger et al., 2009; Kinahan et al., 2015). First, oncology led care may hinder relationship building between CCS and PCPs. Second, although LTFU clinics can provide significant benefit, they may not be geographically convenient for patients as they grow older or relocate (Berg et al., 2016; Singer, Gianinazzi, Hohn, Kuehni & Mihel, 2013; Oeffinger et al., 2009; Lawrence et al., 2015). Third, Lie et al. (2017) conducted focus group interviews of adult survivors of childhood lymphoma from the Norwegian Cancer Registry and found that participants had anxiety and fears about returning to a hospital setting that may be associated with bad news. Conversely, Michel et al. (2016) found that Swiss patients had no preference for follow up between adult or pediatric hospital setting or GP practice, but a centralized late effects clinic was least acceptable. This finding may be related to geographic variability as the study was conducted in Switzerland however, this information highlights the importance of conveniently located care.

Primary care provider led. PCP led care is follow up care that is managed solely by PCP and may include NP's or family practice physicians (Kinahan et al., 2015). This level of follow

up care is most amendable to those CCS deemed low risk (Oeffinger et al., 2009; Kinahan et al., 2015). There are several advantages and disadvantages to this model of care. PCPs utilize a health promoting focus that can encourage patient autonomy and advocacy for healthy behaviors, both of which are paramount to this population (Singer et al., 2013). PCPs are also in a unique position to provide cost effective follow up for patients in a variety of locations that may be convenient to the patient and promote continuity of care (Berg et al., 2016; Lawrence et al., 2015; Singer et al., 2013). A recent pilot study by Quillen et al. (2017) found that the majority (83%) of US young adult cancer survivors surveyed had follow up with their PCP as opposed to an adult oncologist. Despite the advantages to PCP led care, barriers such as knowledge, lack of communication, workload demands, and patient trust may complicate this model of care (Blaauwbroek et al., 2007b; Lawrence et al., 2015; Singer et al., 2013). Success of this care model may require use of extensive guidelines, which can be difficult due to lack of time and the possibility of unknown treatment histories (Singer et al., 2013; Sima et al., 2014) Furthermore, although the number of CCS is increasing they are still relatively rare, making it difficult for PCPs to stay up to date with current guidelines. It is also unclear when PCP led care should be started. For example, care may be provided by oncologists until there is no longer immediate risk of treatment or 10 years after diagnosis (Singer et al., 2013).

Shared-care. A shared-care model involves both the oncologist or treatment team and a PCP. This model of care requires continued communication between oncologist and PCP to ensure both providers are aware of the patient's health status (Kinahan et al., 2015). Generally, PCPs provide care to the patient and the treatment team is available for consultation. For example, once cancer treatment is delivered, the PCP would perform recommended measures for late effects follow-up and provide the information to the oncology team (Singer et al., 2013).

Usually, shared-care is geared toward patients who are moderate risk. However, some high risk patients may also benefit from elements of shared-care (Oeffinger et al., 2009). Shared-care can be challenging because it requires effective communication between providers and has a potential to be costly, utilizing extensive resources (Kinahan et al., 2015). However, there is potential to mitigate costs of resource use through web-based formats for collaboration (Singer et al., 2013). In a systematic review, Singer et al. (2013) suggest that shared care may be the preferred model of care and allow additional opportunities for research. Furthermore, in a survey of US and Canadian family physicians, Nathan et al. (2013), found that 85% of physicians preferred shared-care models. Lie et al. (2017) also support a shared care model for cancer survivorship indicating that this model would support many of the current perceived gaps in care such as specialized knowledge, shorter wait times and collaboration of services.

Nurse-led. There appears to be limited evidence for nurse-led care. However, a systematic review comparing nurse-led follow-up care to oncologist-led care showed positive outcomes for feasibility, acceptability and safety. It is important to note that these studies were completed in institutions, such as hospitals, and for adult oncology patients. Furthermore, the nurses in the studies had oncology specialty training. The information gathered from the review however, does suggest that models other than oncology-led may be feasible (McCabe et al., 2013).

Risk stratification. In general, risk based care provides screening, surveillance, and prevention strategies based on the patient's cancer history, treatment, and personal factors. Risk based care provides a starting point for optimal survivorship monitoring unique to each patient (McCabe, Partridge, Grunfeld & Hudson, 2013).

Low risk. Patients at low risk of long-term complications are those treated with surgery alone or low risk chemotherapy (Oeffinger et al., 2009). These patients have a low risk for disease recurrence and no or mild persistent effects of treatment (McCabe et al., 2013).

Assuming patients understand potential health risks and necessary future screening, follow up care can generally be provided by a PCP (Oeffinger et al., 2009).

Moderate/intermediate risk. Most CCS fall into the intermediate risk category (Oeffinger et al., 2009). Patients in this group have received low or moderate dose alkylating agents, anthracycline agents, bleomycin or epipodophyllotoxin and would include most patients who have had leukemia, lymphoma or solid tumors. Patients may have had autologous stem cell transplants and/or treatment with low to moderate radiation (Oeffinger et al., 2009; McCabe et al., 2013). Patients in this category have a moderate risk of recurrence and moderate persistent side effects of treatment (McCabe et al., 2013).

High risk. Patients at high risk are those who have undergone treatment with high dose alkylating agents, anthracycline agents, bleomycin or epipodophyllotoxin, received high dose radiation or required allogeneic stem cell transplants (Oeffinger et al., 2009; McCabe et al., 2013). This includes patients who have had central nervous system tumors or Hodgkins lymphoma (Oeffinger et al., 2009). Not surprisingly, patients at high risk for recurrence often have multiple body systems affected by treatment (McCabe et al., 2013).

Patient preferences. Using focus groups and surveys, multiple studies of CCS from Philadelphia, Switzerland and Norway reported CCS felt it was important that the care they received was provided by competent, well informed staff who embraced patient-centered care (Szalda et al., 2016; Lie et al., 2017; Michel et al., 2016). Absolom et al. (2006), compared LTFU in both pediatric and adult clinic settings in the UK and suggested no obvious correlation

between level of satisfaction and clinic type, however, patients valued shorter wait times and clinic appointments that allowed for multiple topics to be discussed. This is important because as the population of adult CCS increases, providing care in a pediatric setting may not be feasible.

There is conflicting evidence of patient satisfaction when comparing care provided by oncologists or PCP (Lie., 2017; Murphy, 2013; Szalda et al., 2016). Using data collected from young adult survivors in the US, Szalda et al. (2016) found no difference in the perceived quality of cancer care provided by subspecialty clinic or oncologist and PCP. However, the young adult survivors perceived PCP as less knowledgeable about CCS diagnosis and treatment. Lie et al. (2017) noted that focus group participants from Norway, felt their PCP lacked sufficient knowledge about late effects and screening recommendations and had difficulty co-ordinating services. While some evidence suggests that the oncologist may be the preferred care provider, patients acknowledged that general practitioners would be a reasonable alternative provided they had necessary knowledge of late effects, short clinic wait times and ongoing support from oncologists. Participants also valued the relationship they had with their PCP and felt confident their PCP would seek necessary advice when needed (Lie et al., 2017).

Regardless of where or by whom care was being provided by, Lie et al. (2017) found that none of the participants could remember receiving written information about late effect or long-term follow up recommendations. Most of the participants felt their LTFU care was fragmented and self-directed, and difficult to manage due to lack of knowledge. Similarly, looking at participants from the Utah SEER Registry, Kirchhoff et al. (2014) found that over 90% of CCS did not have a treatment summary or care plan but many felt it may have facilitated better communication with their practitioner.

Role of Nurse Practitioners in Long Term Follow up Care for CCS

Integrating nurse practitioners into long term follow up care for CCS

Currently, NPs are part of the fastest growing advanced practice nursing roles in Canada, supported by strong public support and patient satisfaction (Staples et al., 2016). The Canadian Nurses Association (CNA) put forth a Canadian Nurse Practitioner Core Competency Framework as a guiding document for regulatory bodies across Canada, to adopt and tailor to the specific needs of the population. While each jurisdiction may have their own adaptations, the document outlines expected competencies of an entry-level NP to allow safe, competent and ethical practice. The framework includes four key areas: professional role, responsibility and accountability, health assessment and diagnosis, therapeutic management and health promotion and prevention of illness and injury (CNA, 2010). The framework, along with additional research, will be used to support reasons why NPs are well suited to provide LTFU care for CCS.

Education and training. NPs are registered nurses who have several years of clinical experience in addition to, at a minimum, masters level education, enabling work as autonomous health care professionals. NPs work in collaboration with clients and other health care members to provide high-quality, holistic, patient-centered care that is grounded in nursing values and guided by theory. Unique to NPs, is their connections between nursing fundamentals and medical knowledge that can be used to care for clients and their families using a health promotion approach (CAN, 2010). Elements of NP training and education including patient-centered care, collaboration, and health promotion focus have all been cited in the literature as important elements of LTFU care for CCS (Murphy, 2013; Szalda et al., 2016).

NPs also work within strict professional, legal and ethical standards in areas of health promotion, disease prevention and chronic disease management across the lifespan. NPs are

responsible for self-reflection, accountability and the safety of their clients. Furthermore, NPs acknowledge broader impacts of the social determinants of health and have key roles in advocacy and leadership while collaborating with key stakeholders and government. The recognition of impacts of social determinants of health may have important implications for marginalized CCS who are at increased risk for late effect complications. NPs can be involved in policy development and research initiatives. Population health trends and impacts of health care delivery are well recognized by NPs and together, with research and policy development, could have the potential to impact CCS both now and in the future (CAN, 2010).

Patient population. Historically, NPs have cared for underserved populations including those whom are marginalized or live in rural communities, thereby enabling increased access to health care services (Staples, 2016). Both Canada and the US have recognized health care shortages and difficulties managing increasing populations of cancer survivors and their unique needs (Nevidjon et al., 2010). An argument can be made that CCS are a marginalized population with unique needs that may benefit from additional NP care.

Currently, NPs are able to work in a variety of settings such as community primary care centers, long-term care, hospitals (including out-patient clinics and emergency rooms) as well as NP-led clinics (CNA, 2010). NPs have also been trained to work in specialty areas with patients that are critically ill or have complex needs. Areas of specialty include neonatal ICU, cardiology, oncology, gerontology and nephrology. The involvement of acute care NPs has led to better continuity of care for complex and critically ill patients (Staples, 2016). NPs ability to work in multiple settings increases access to primary and acute care and therefore strengthens the health care system. Given that NPs work in a variety of specialties and with complex and critically ill patients, it is not unrealistic to assume NPs can be successful within a complex oncology setting

of CCS (Staples, 2016). Furthermore, NPs in the US have been working in oncology settings providing positive outcomes despite lacking specialized training (Nevidjon et al., 2010).

Therefore, it is plausible that even without speciality training, NPs could offer significant value working with CCS.

Providing long term follow up care. NPs are well positioned to perform guideline driven care, such as those described in the COG-LTFU Guidelines. The COG-LTFU guidelines were developed to support a wide variety of care providers, including NPs, with the expectation that those who are unfamiliar with the guidelines or care of adult CCS would consult an oncologist as necessary (Children's Oncology Group, 2013). NP training includes thorough history taking, assessments, diagnosis and treatment for a wide range of acute and chronic illnesses (Staples, 2016). This training is essential for CCS LTFU care since 88% of the screening recommendations from the COG-LTFU Guidelines depend heavily on history taking and physical exams (Children's Oncology Group, 2013).

The COG-LTFU Guidelines are formatted according to therapeutic agent and further cross linked to applicable topics making it inclusive but overly cumbersome. The cumbersome nature of the guidelines necessitates extra time and attention to detail (Nekhlyudov et al., 2017). Fortunately, many NPs have the benefit of longer clinic appointment times, which could allow for a comprehensive review of the guidelines to support individualized LTFU care. Furthermore, it has been shown that CCS value longer clinic appointment times with their care provider, which could make care by NPs a desirable option (Nevidjon et al, 2010; Lie et al., 2017). The COG-LTFU guidelines also suggest multiple scenarios in which referral and consultation may be required. NP scope of practice includes facilitating appropriate referral to community resources and additional health care team members as necessary. NPs therefore, are able to support the

needs of CCSs, ensuring appropriate referrals and maintaining safety while also considering the wider context of resource allocation and cost mitigation (CNA, 2010; Murphy, 2013).

CCS face significant challenges to LTFU care which can include poor continuity of care and suboptimal transitions from pediatric to adult care. Cooper, Loeb and Smith (2010) commented on the benefits of continuity of care provided by NPs along the cancer continuum, from diagnosis to survivorship care, of adult cancer patients. The benefits included a focus on psychosocial aspects of cancer care as well as improved quality of life. Although extrapolating this data to adult CCS should be done with caution, it may be assumed that CCS may also benefit from improved continuity of care. NPs ability to work in primary care settings, acute care settings and specialty clinics as well as care for patients of all ages means that, depending on the model of LTFU care, NPs could follow a CCS from diagnosis to long term survivorship, thereby ensuring continuity of care. Additionally, Sadak et al., (2017), emphasized the need for effective communication and collaboration for successful transition of CCS into LTFU care. Fortunately, NPs are well positioned to provide excellent communication and collaboration between care providers to further improve continuity of care.

NPs strong communication skills also facilitate the development of patient-centered care. After conducting focus groups with childhood lymphoma survivors, Lie et al. (2017) reported that participants wanted patient-centered care, to feel heard and be taken seriously by a care provider that conveys interest. From an NP perspective, clients are encouraged to be active participants in their care, leading to inclusive decision making and trusted NP-client relationships (CNA, 2017). While some CCS may prefer oncologist provided care, a provider, such as a NP, that can deliver care in a patient-centered model and show authentic interest, may be a reasonable and necessary long term alternative.

In addition to delivering patient-centered care, Nevidjon et al., (2010) acknowledge NPs unique health promotion lens that facilitates patient education and provides significant benefit to the health care needs of adult cancer survivors. While the data reported by Nevidjon et al., (2010) is from adult survivors of cancer, it may be assumed that similar principles could be applied to CCS as well. Similarly, Murphy (2013) suggested strong relationship building as an additional advantage of NPs working with adolescent and young adult cancer survivors. Together, a strong relationship and unique health promotion lens strengthen the ability of NPs to encourage and support health promoting behaviours of CCS. The ability to successfully promote healthy behaviours in a population in which generalized education is ineffective, is paramount in providing LTFU care for CCS.

Current Nurse Practitioner practice in different models of care

The NP scope of practice lends itself nicely to being able to provide care for CCS and their LTFU needs in all models of care. NPs, like family physicians, could be integrated into each of the models of care to support increased access to necessary health care services.

As mentioned, there has been little evidence of the use of NPs as PCP for CCS. However, nurse-led health centers are being utilized outside Canada and the US. These centers are a collaboration of NPs, RNs, and speciality nurses who provide management and surveillance of treatment related complications. This model of care has improved access to services and reduced wait times, enhanced outcomes of symptom management, and provided long term health care services (Cooper et al., 2010).

NPs may also have a significant role to play in shared care models. NPs could act as a facilitator for a successful transition from oncology care to primary care, wherein they would maintain communication with the client's PCP to offer ongoing screening recommendations and

highlight potential risks of late effects unique to the patient (Cooper et al., 2010). Alternatively, NP's could function as the client's PCP and continue ongoing communication with the oncologist or oncology team. Skinner, Wallace and Levitt (2017), suggest that survivors at moderate risk for late effects, with guideline or protocol driven LTFU needs, may be adequately cared for by a nurse or primary care doctor. Given NP's strong communication and collaboration skills, ability to make referrals, and longer appointment times to navigate complex guidelines, this may be a reasonable option. Furthermore, by continuing to serve as the client's PCP, NP's can maintain continuity of care.

In the US and Canada, NP's who specialized in oncology are caring for patients in speciality care clinics for cancer survivors. Similar to results reported by Cooper et al. (2010), Nevidjon et al. (2010) reported improved adult cancer survivor outcomes, including quality of life, patient satisfaction and cost containment, in care involving NP's. These results relate to survivors of adult cancers and, therefore, additional research is needed to discern if the similar benefits could be replicated for adult CCS.

Another approach more specific to adult CCS has been proposed by the National Institute for Clinical Excellence and involves multidisciplinary LTFU teams that include a variety of health care workers including nurse specialists. It is not clear what background or education would be required of the nurse specialist, however, the role may include co-ordination and navigation of services. It is possible that NPs could function within this clinic model as well (Skinner et al., 2006).

Conclusion

Although treatment advancements have dramatically improved survival for childhood cancers, late effects of treatment are being recognized as CCS advance into older decades of life.

Surveillance, early detection and management of late effects is key to promote improved quality of life and reduced rates of morbidity and mortality. Unfortunately, many CCS are not receiving adequate LTFU. Many barriers to LTFU exist including patient knowledge and engagement, provider knowledge, and resources. Each barrier is complex and will require multiple interventions to help facilitate improved LTFU.

To date, there has been limited research specific to the potential role NPs could have in LTFU for CCS. Given the wide scope of practice of NPs, their holistic patient-centered approach to care and focus on health promotion, NPs could act as a valuable addition to the current models of care and perhaps improve access to health care services. Additional research of the potential benefits of NPs caring for adult CCS is needed. Furthermore, ways to disseminate knowledge of CCS late effects to PCP should be an important consideration to support adult CCS in the future.

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Appendix

This culminating project has been submitted as a component of the degree requirements for the Masters in Nursing, Nurse Practitioner program at the University of British Columbia. The information presented in this culminating project has been used as the foundation for the creation of a manuscript for publication. The goal of the manuscript is to bring awareness to the ways in which Nurse Practitioners can be integrated into and improve the long term follow up care of adult childhood cancer survivors.