

Running head: A NURSE NAVIGATOR'S EXPERIENCE

Providing a Culturally Sensitive Approach to Support Indigenous Cancer Patients and Their Families: A Nurse Navigator's Experience

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Thesis Abstract

Cancer among Indigenous Peoples (First Nations, Inuit, and Métis) is disproportionately higher than the overall Canadian population. Many Indigenous Peoples have difficulty accessing care and do not receive culturally safe care due to a longstanding history of marginalization and colonization. The role of a nurse navigator (NN) was developed to improve continuity of care and overall health outcomes for Indigenous Peoples; however, limited research exists on what a NN does or how they are perceived. Using constructivist case study methodology, this thesis explored the experiences of a NN working in a large tertiary care hospital in Ontario, Canada, and the processes the NN used to support Indigenous cancer patients in a culturally safe manner. Six in-depth semi-structured interviews were performed with health care providers and managers, and shadowing of a NN occurred over two weeks allowing direct observations of the NN that was captured in field notes and reflective journaling. Interviews were audiotaped and transcribed; all data was entered into NVIVO 12 qualitative software and coded thematically. Analysis revealed the NN to be an important complement to clinical care and key resource to navigating the health care system, providing mechanisms for building trust, and raising awareness of Indigenous historical and cultural contexts. The NN practiced non-conventional, patient-centered approaches that included engaging with the land and arts, interpreting healthcare information, advocating for and aiding autonomy over healthcare. All participants felt the NN had a positive influence on health and wellbeing. Thesis results inform healthcare delivery and nursing practice to improve quality of care and outcomes for Indigenous cancer patients.

Dedication

*Dedicated to my lovely grandparents (رحمهم الله)
my wonderful parents,
my always-encouraging siblings, and
my ever-supportive future husband (إن شاء الله).*

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May God shower the above cited persons with happiness, health, and success – always.

Statement of Contributions

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Chapter 1

Introduction

Background

Indigenous Health: Disparities in Cancer Burden

Health inequities persist for the Indigenous population (First Nations, Inuit, and Métis¹), as Indigenous Peoples in Canada suffer ill-health at much higher rates compared to non-Indigenous people (Allan & Smylie, 2015; Fontaine, 2012; Tang & Browne, 2008). In fact, cancer among Indigenous People is disproportionately higher than overall Canadian rates, affecting both patients and families alike (Canadian Partnership Against Cancer, 2011; Chiefs of Ontario, 2017; Marrett & Chaudhry, 2003). Although there is less data on the specific cancer burden among Inuit and Métis Peoples in Canada, there is significant data from First Nations reports to show that cancer incidence and mortality rates are elevated among Indigenous Peoples, and cancer survival rates are worse compared to Non-Indigenous Canadians, even while living in the same geographic regions (Cancer Care Ontario, 2015a; Chiefs of Ontario, Cancer Care Ontario, & Institute for Clinical Evaluative Sciences, 2017; Kewayosh et al., 2015; Marrett and Chaudhry 2003; Nishri et al. 2015).

Fundamentally, the intergenerational effects of colonialism, residential schools, and systemic racism paired with health disparities related to the social determinants of health, are the root of the health challenges faced by this population (Adelson, 2005; Kurtz et al., 2008; Wilson & Young, 2008). Accordingly, as explained by Hammond et al. (2017), “across the globe, common barriers to cancer treatment among Indigenous populations include cultural insensitivities; socio-economic disadvantages; mistrust of mainstream health systems founded upon historical and ongoing marginalization; and complexities associated with healthcare systems, procedures, and services” (p. 2) (Haozous, Knobf & Brant, 2011; Olson, 2014; Rainie,

¹For the purpose of this research, the term ‘Indigenous’ is used to represent First Nations, Inuit or Métis Peoples.

Jorgensen, Cornell & Arsenault, 2015; Treolar et al., 2014). As such, the socio-political determinants of health contribute to and further perpetuate the unique cancer burden faced by Canada's First Nations, Inuit, and Métis People (Fontaine, & Health Council of Canada, 2012).

The Dominance of the Biomedical Model in Canadian Health Care

As explained by Durey & Thompson (2012) in describing the impact of the socio-political determinants, the “losses of traditional land and language, social dislocation and cultural fragmentation all negatively impact on Indigenous culture and health” (p. 4). However, the health disparities that stem from these inequities have also been exacerbated by institutions such as the Canadian health care system in that the indiscriminate application of the Western biomedical model, without critical consideration of its applicability, echoes Eurocentric views and ways of thinking, and has stifled and largely excluded Indigenous ways of knowing (Browne, Smye & Varcoe, 2005). Varying between cultures and individuals, Indigenous ways of knowing describe the ways in which Indigenous Peoples perceive, understand, and interact with the world around them (Turton, 1997; Wright et al., 2019). For example, for many Indigenous cultures, health and wellness are intrinsically related to collective well-being and identity, achieved through the balance of body, heart, mind, and spirit (Graham Leeseberg, & Stamler, 2010). The dominance of the Western biomedical model in Canadian health care does not align with Indigenous ways of knowing and has therefore created culturally unsafe and unwelcoming environments for Indigenous Peoples (Arnold & Bruce, 2005; Denzin & Lincoln, 2008; Howell et al., 2016; Smye & Browne, 2002; Sherwood & Edwards, 2006). Together, the dominance of the biomedical model, and lack of culturally sensitive health care services, have resulted in Indigenous Peoples in Canada being less likely to seek health services, thereby affecting their health outcomes (Allan & Smylie, 2015; Kewayosh et al., 2015).

Furthermore, navigating through Canada's complex health care system for cancer care can be "arduous and fraught with uncertainty and fear," and these "difficulties are exacerbated for Indigenous Peoples, who may not always utilize or understand Western health care systems" (Bernardes et. al, 2018, p. 2). Thus, Indigenous Peoples with cancer may have difficulty optimizing their health and getting the care they need, as they face a combination of individual and system level barriers (Burgess, 2017; Canadian Medical Association, 2017; Cancer Care Ontario, 2015a; Interior Health, 2018; Kelly et al., 2015; Walkinshaw, 2011).

Gaps in Health Services: A Lack of Culturally Sensitive Care

Although Indigenous Peoples have been demonstrating resilience in the face of exclusion and marginalization, systemic racism has greatly contributed to the health inequities that are reflective of the broad disadvantage that this population faces in Canada (Fontaine, & Health Council of Canada, 2012). Recent literature reiterates that cultural differences and the inability of health care providers to appropriately address these differences have resulted in lingering racism, which in turn, contributes to the high rates of non-adherence, avoidance and reluctance to seek mainstream health care services when ill (Kurtz et al., 2008; Browne et al., 2011; National Aboriginal Health Organization, 2014). This, in turn, reduces the opportunity for early intervention and prevention of health problems, as well as leads to later-stage diagnoses, and ensues implications in terms of treatment and patient health outcomes (Allan & Smylie, 2015). More specifically, as described by Kewayosh et al. (2015) many First Nations, Inuit, and Métis People "delay seeing a healthcare professional until they are seriously ill because they are afraid their diagnosis will mean they will be sent away for care and never return. If they do seek help and the care is not culturally safe, they may not return for follow up appointments or continue with their treatment plans" (p. 35).

Thus, the lack of culturally appropriate programs and services, paired with the individual and system level barriers, contributes to the poor health status of Indigenous Peoples (Feather, Carter, Valaitis, & Kirkpatrick, 2017; O'Sullivan, 2013). As health care providers, nurses are uniquely placed in the health care system, and therefore providing culturally sensitive patient care can hold promise to reducing health outcome disparities (Nguyen, & Kagawa-Singer, 2008).

Nurse Navigation to Reduce Health Inequities

Globally, existing strategies aimed at improving equity in Indigenous health outcomes continue to suggest use of culturally appropriate health care services, particularly nurse patient navigation, as a potential solution to reducing barriers to service access and use throughout the cancer continuum (Bernardes et al., 2018; Burhansstipanov et al., 2015; Dohan & Schrag, 2005; Eschiti, Burhansstipanov & Watanabe-Galloway, 2012; Fayerman, 2011; Grimes, Dankovchik, Cahn, & Warren-Mears, 2017; Krebs et al., 2013; Meiklejohn et al., 2017; Natale-Pereira et al., 2011; Warren-Mears, Dankovchik, Patil, & Fu, 2013; Wells, 2008; Whop et al., 2012). In Canada, since its inception in the early 2000s, patient navigation programs have been established in hospital settings to support cancer patients (Canadian Partnership Against Cancer, 2012; Fillion et al., 2009; Pederson & Hack, 2011; Psooy, Schreuer, Borgaonkar, & Caines, 2004); however, these programs were not specifically focused on serving the Indigenous population. As such, in Ontario, in an effort to help improve the cancer care experience of Indigenous Peoples, in 2015 Cancer Care Ontario (2015b) created Indigenous cancer patient navigator roles to “facilitate and coordinate access to cancer services for First Nations, Inuit and Métis people with cancer and their families” (p. 3). However, the title and role description vary per region, and therefore these cancer patient navigators are not always Registered Nurses, and instead can be lay workers embedded in their own Indigenous communities, or other health care providers such

as social workers, who help patients navigate within and across the health care system (Canadian Partnership Against Cancer, 2012).

Although the amount of literature on navigation has increased during the past two decades, the role of Indigenous cancer patient navigation carried out by a Registered Nurse remains relatively new and under-explored. In Ottawa, Ontario, Canada, this navigation role was adopted regionally by the hospital's Cancer Program, with goals based on Cancer Care Ontario's Aboriginal Cancer Strategy III (2015b) to address the distinct cultural and spiritual needs of Indigenous patients and families, by using Registered Nurses as Indigenous patient navigators. Thus, based in Ottawa, this study aims to achieve a deeper understanding of Indigenous cancer patient nurse navigation, through the perspectives of a Registered Nurse navigator (NN), and related health care providers, administration, and senior management.

Research Purpose and Objectives

The overall purpose of this study was to describe the experiences and processes of a Registered NN working with Indigenous Peoples living with cancer, in the context of a large tertiary care hospital. The specific objectives were: (I) to understand what a NN does to support Indigenous Peoples living with cancer, and (II) to describe the challenges and supports experienced in the role of nurse navigation (at the level of the patient, the NN, the organization, and the health care system). The research question was: *What are the experiences and processes of a NN working with Indigenous Peoples living with cancer, in the context of a large tertiary care hospital?*

Study Significance

The expected impact is to improve nursing practice for Indigenous Peoples, and to increase the presence of culturally sensitive Indigenous care and quality of life. The findings of

this research will contribute to our understanding of the experiences and processes of the NN role in supporting Indigenous Peoples living with cancer in a culturally sensitive manner. The knowledge gained from this study can help inform nursing practice and assist nurses in providing patient-centered care, helping to close the current gap in health status between Indigenous and non-Indigenous people (Kurtz et al., 2008). Ultimately, as has been iterated by Dr. Harold Freeman, often known as the father of patient navigation, “no person with cancer should be forced to spend more time fighting their way through the health care system than fighting their disease” (Fayerman, 2011, p. 1).

Epistemological Lens: The Constructivist Paradigm

Used as a tool in nursing practice and often referred to as a “belief system,” a paradigm is a “worldview” that acts as a framework of assumptions and principles that guides the researcher and research ontologically and epistemologically, informing the development of knowledge (Guba & Lincoln, 1994; Monti & Tingen, 1999). With roots in philosophy, sociology, anthropology, and psychology, the constructivist paradigm, or way of knowing, is not a new concept (Sridevi, 2008). Constructivism draws back on the work of Thomas Kuhn (1962), rejecting the convergent notion that scientific truth is established solely by objective criteria, and acknowledging that we must account for subjective perspectives. Accordingly, the constructivist paradigm acknowledges multiple socially constructed truths, perspectives and realities, and therefore no single objective reality (or truth) exists (Weaver & Olsen, 2006). This relativist ontology refers to the idea that the mental world, or the experienced reality, is continuously consciously constructed through human sense-making (Scotland, 2012). The process of constructing reality is therefore not a technological progress towards a final state, but rather an active and continuous development, shaped by individual experiences, and influenced by a

multitude of historical and social factors (Guba & Lincoln, 1994; Weaver & Olson, 2006).

Unlike other paradigms, constructivism has no interest in examining causal relationships, but instead its inquiry is qualitative and seeks to facilitate change through the ongoing process of social interaction and interpersonal awareness (Guba & Lincoln, 1994). In accordance with the epistemological constructivist assumption, by interacting with the subjects of investigation, the environment, and surroundings, findings are “literally created” (Guba & Lincoln, p. 111). Thus, knowledge is gathered, refined, and sophisticated through observation and social interaction between investigators and respondents (Scotland, 2012). It is important to note; however, that because the experiences are subjective, they are context-dependent and therefore findings are not often generalizable (Guba & Lincoln, 1994). Though this allows for limited transferability, the insights of constructivism can allow for understanding interesting patterns, such as behaviours, experienced by a specific population within a specific context (Guba & Lincoln, 1994). Valuing aesthetics, ethics and personal knowledge as integral components of nursing, ultimately, research through a constructivist lens seeks to examine and understand a phenomenon through the eyes of the people that live it, allowing for people to transform, reformulate, and enrich their perspectives (Carper, 1978; Monti & Tingen, 1999).

While multiple paradigms within nursing science exist, and although each paradigm has unique principles that contribute to the profession and discipline of nursing, this thesis will incorporate a constructivist lens to facilitate the understanding of Registered Nurse navigation in supporting Indigenous Peoples living with cancer in a culturally sensitive manner, as the inductive nature of constructivism can help fill the knowledge gap by developing new layers of comprehension regarding this topic. Thus, through the engagement of constructivist research, by creating a space for dialogue and learning from both the voices of NNs and health care

professionals, patterns can be recognized that can then help guide nursing practice and assist in providing patient-centered care, helping to improve the quality of care received by Indigenous Peoples (Kurtz et al., 2008).

Theoretical Framework

Madeleine Leininger's Culture Care Diversity and Universality Theory

Developed in the 1960s, Madeleine Leininger's Culture Care Diversity and Universality Theory (CCDUT) is derived from the disciplines of anthropology and nursing (Leininger, 1991b; Leininger & McFarland, 2002). The CCDUT was developed because Leininger felt that "nurses needed to greatly expand their worldview and incorporate new dimensions of care in order to arrive at comprehensive and holistic data to understand cultural care phenomena" (Leininger, 1997, p. 4). Mirroring constructivism (Guba & Lincoln, 1994), the theory acknowledges that individuals should be at the center of care, and ultimately seeks to understand people in terms of their "lifeways, cultural values and beliefs ... and living contexts" (Leininger, 1991a, p. 55), valuing both *emic* (insider) and *etic* (outsider) insights (Leininger & McFarland, 2002).

Major Concepts and Theoretical Assumptions

Culture and *care* are regarded as the two main concepts in the CCDUT (Leininger, 2002). Leininger describes *culture* as "patterned lifeways, values, beliefs, norms, symbols and practices of individuals, groups, or institutions that are learned, shared, and usually transmitted from one generation to another" (Alligood & Tomey, 2010, p. 460). *Care* is defined as "complex, elusive, and often embedded in social structure and other aspects of culture" (Alligood & Tomey, 2010, p. 460). From the two main concepts, Leininger synthesized the concept of *culture care* as a powerful theoretical construct, referring to the "synthesized and culturally constituted assistive, supportive, enabling or facilitating caring acts towards self or others" (Alligood & Tomey, 2010,

p. 461). Culture care, according to Leininger (1985), is universal, but actions, expressions, patterns, lifestyles and meanings of care may differ. Accordingly, Leininger assumes that people of every culture are able to define their understanding of nursing care which is based on experience forming their general beliefs related to health (2006). On this basis, both *emic* (insider) and *etic* (outsider) knowledge are used to differentiate the informant's knowledge with that of professional knowledge – though both are studied as integral parts and held as invaluable insights in order to obtain comparative data (Leininger, 1997).

Leininger (2002b) holds that care is the “essence and unifying focus of nursing” and that it is essential to curing and predicted that “there can be no curing without caring” (p. 87). Nursing care sits between and effectively bridges generic (traditional) health systems and professional health systems, therefore Leininger (2002b) emphasizes that nurses not only be a mediator, but to strive to be “knowledgeable about the client's culture and diverse factors influencing needs and lifeways,” because caring has different meanings for different cultures (p. 119). The theorist postulates that a nurse cannot provide appropriate cultural care without having knowledge and understanding of cultural diversity (Leininger, 1991a). Phrases such as “nursing interventions” are seldom used as Leininger acknowledges that they often refer to cultural imposition practices which may be offensive and ethnocentric with an individual's lifeways, potentially causing pain and conflict (Leininger, 1991a). Essentially, Leininger assumes that clients who experience “nursing care that fails to be reasonably congruent with the client's cultural beliefs and values will show signs of stress, cultural conflict, noncompliance, and ethical moral concerns” (Leininger, 2002, p. 45).

Accordingly, Leininger holds that nurses must consider the individual's worldview, environmental context (physical, geographical, and sociocultural), as well as cultural and social

dimensions in order to provide culturally appropriate care (Leininger, 1991a). Seven cultural and social structure dimensions are described by Leininger (2006) to help researchers inductively discover culturally specific meanings and expressions in relation to care and health; namely, cultural values and lifeways, as well as technological, religious and philosophical, kinship and social, political and legal, as well as economic and educational factors. Leininger (2006) developed the “Sunrise Enabler” (see Appendix A) to visually demonstrate the interrelationships of the concepts in the CCDUT. It provides a cognitive guide for the researcher to reflect on during the discovery process, depicting multiple factors predicted to influence care expression, practices, and patterns (Leininger & McFarland, 2006). Based on the information gathered, three major actions and decision guides can lead nurses in the provision of patient-centered culturally congruent care: culture care preservation or maintenance (assisting cultures in retaining care beliefs), culture care accommodation or negotiation (accommodating to cultures), and culture care re-patterning or restructuring (modifying professional actions) (Leininger, 1991a). The theory has both abstract and practice dimensions offering guidance in culture care research and practice.

Relevance to Thesis

As has been iterated by Ibrahim (1985) and McCormick (1996), it is imperative to understand the worldview and beliefs of a culture prior to applying health-care related techniques and theories in order to avoid cultural imposition practices. The strength of Leininger's CCDUT lies in its ability to guide exploration of people's lived realities and provides a broad scope to inductively investigate Registered Nurse navigation and the manners in which they support Indigenous Peoples living with cancer in a culturally sensitive manner. The CCDUT acknowledges that individuals should be at the centre of care, seeking to understand people in

terms of their values, beliefs, lifeways, and living contexts (Leininger, 1990). The theory consistently focuses on how a patient should be treated individually, and that personal uniqueness should always be considered (Leininger, 2002). These ideas correlate with constructivist's relativist ontology and epistemology, as the theory postulates that personal experience cannot be separated from knowledge, and therefore views an individual within their context (Guba & Lincoln, 1994). As an extension of this belief, the CCDUT provides a holistic means to discover and understand multiple universal and diverse factors that can influence care (Leininger, 1991a). Leininger values an open discovery and naturalistic process to explore different aspects of care and culture; she believed reductionist goals could greatly limit obtaining holistic cultural care knowledge, and that it was necessary to hear informants tell stories about their own health and lifeways (Leininger, 1990; 1991a, 1991b). Being open to different realities of care, could then result in a perspective transformation and could assist nurses in subjective reframing (Garneau & Pepin, 2015; Leininger & McFarland, 2002). Essentially, application of the CCDUT can help establish the "nature, essence, meanings, expressions, perceptions, and forms of human care or caring," which could provide a unique, and highly meaningful body of knowledge for nursing (Leininger, 1991a, p. 35). Although the findings may have limited transferability due to the data being context dependent and culture bound with unique features (Leininger, 2006), application of the CCDUT can uncover in-depth knowledge of what is considered culturally sensitive care from emic and etic perspectives. Using the "Sunrise Enabler," themes of care patterns and descriptors can then be derived, which can be used to guide nursing action in the provision of culturally sensitive patient-centered care to support Indigenous Peoples.

It is important to note, however, that this theoretical lens “should not, however, constitute a strait-jacket and the cases should not be "forced to fit" the particular theoretical framework that is being employed” (Crowe et al., 2011, p. 8). Thus, acknowledging this, the CCDUT underpinned this research study, and was therefore used as a theoretical guide to discover specific and holistic care through the process of nurse navigation, paying specific attention to the sociopolitical factors that influence care, wellness, health, and illness beyond the biomedical and psychological dimensions (Leininger, 2002).

Thesis Organization

This thesis encompasses five chapters. Chapter One includes an introduction to the thesis, the research purpose and objectives, the study significance, an introduction to nurse navigation to reduce health inequities, and an introduction to the theoretical framework and central concepts. Chapter Two provides a detailed literary review to understand current research in relation to Registered Nurse navigation in supporting Indigenous cancer patients and families. Chapter Three describes the methodology of this thesis, including the study design, sample size, data collection methods, data analysis plan, as well as an ethics statement. Chapter Four, is a version of the manuscript entitled “Working with Indigenous cancer patients and families to navigate health care: The role of a nurse navigator” which is formatted for the submission to the journal: *Canadian Oncology Nurses Journal*. Chapter Five provides a general discussion of the overarching findings from this thesis, limitations of the study, as well as recommendations for nursing practice, policy, and research, with a specific focus on culturally sensitive care to support Indigenous patients and families living with cancer.

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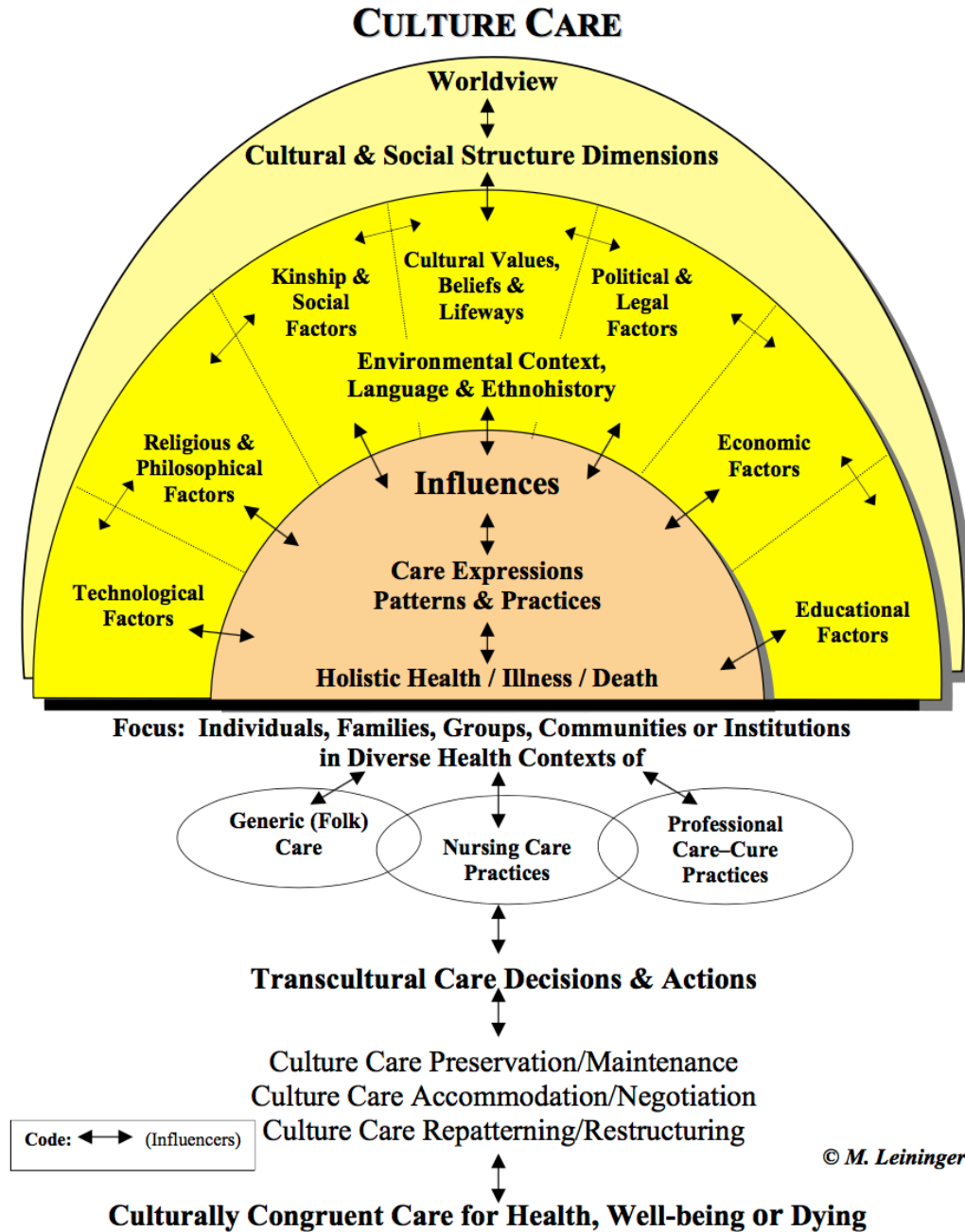
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Appendix A
 Madeleine Leininger's Sunrise Enabler²

Leininger's Sunrise Enabler to Discover Culture Care



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Chapter Two

Literature Review

Introduction

This chapter provides an overview of previous research on Registered Nurse navigation to support Indigenous Peoples living with cancer in a culturally sensitive manner. The purpose of this review was to explore the existing literature on Registered Nurse navigation to support Indigenous cancer patients and to critically evaluate the literature. This chapter outlines the search methods used to identify the literature, search outcomes, literature results and gap, and finally the limitations.

Search Methods

Cumulative Index to Nursing and Allied Health Literature (CINAHL) and MEDLINE data bases were searched because they index nursing and allied health research. The databases (CINAHL and MEDLINE) were searched from the year 1998 to the year 2018, limited to the English language and human. The search was limited to the past two decades because Indigenous health research in the areas of oncology is a relatively contemporary subject. The search was not limited to Canadian studies so as to yield as much information as possible regarding the topic of interest.

It is important to note that, in order to ensure continuous engagement with the literature, the search was repeated throughout the study in order to reveal new research that had been published since January 2019.

Based on the SPIDER tool (see Appendix A, Table 1) that was used to refine the study's research question (Cooke, Smith & Booth, 2012), search terms "nurse navigator," "Indigenous," "cancer" and "culturally sensitive care" (see Appendix B, Table 1) were identified using key words and MeSH headings (Higgins & Greens, 2011). These search terms were then categorized into themes within which the terms were combined with "OR" and each theme subsequently

combined using the Boolean operator “AND” to obtain results (Higgins & Greens, 2011). In order to be included in this review, studies had to: 1) be published in the English language, 2) be focused on patient or nurse navigation, 3) consider individuals with cancer, and 4) specifically target Indigenous Peoples.

All studies were included irrespective of practice setting or country. Both quantitative and qualitative articles were included to ensure a broad range of literature was included. Google Scholar, a general database, was also searched for relevant studies. Reference lists of included articles were also examined for additional applicable studies (see Appendix B, Table 2).

Search Outcome

The search yielded a total of 59 articles, from which duplicates were removed, resulting in a total of 33 unique references. Criteria for data extraction from studies was adapted from the Cochrane Collaboration handbook for Systematic Reviews of Health Promotion and Public Health Interventions (Jackson, 2007). I reviewed the titles and abstracts for relevance and discarded irrelevant articles. I then studied abstracts and full texts of remaining articles for eligibility based on the inclusion and exclusion criteria developed; thus, articles that did not refer to cancer, Indigenous Peoples, or nurse or patient navigation were excluded (see Appendix B, Table 2). Furthermore, to identify other published materials, bibliographies of retrieved references were searched, as well as a hand search of grey literature, yielding an additional 6 references. A final sample of 17 articles were therefore included in this literature review. Please see Appendix C, Figure 1 for a PRISMA flow chart of the search.

Results

All 17 articles included in this literature review were published from 2005 onwards, indicating that research on Registered Nurse navigation in supporting Indigenous cancer patients

is a relatively new role and process. The majority of the articles included were qualitative studies (n=8) (Abbott, Fisher, Greenberg, & Safdar, 2017; Bernardes et. al, 2018; Burhansstipanov, Harjo, Krebs, Marshall, & Lindstrom, 2015; Dohan, & Schrag, 2005; Grimes., Dankovchik, Cahn, & Warren-Mears, 2017; Hohl et al., 2016; Meiklejohn et al., 2017; Warren-Mears, Dankovchik, Patil, & Fu, 2013). Other studies were quantitative or mixed methods (n=3), including randomized control trials (Braun et al., 2015; Fiscella, et al., 2012; Guadagnolo, Cina, Koop, Brunette, & Petereit, 2011). Six knowledge syntheses of the literature were included, four of which were literature reviews (Eschiti, Burhansstipanov, & Watanabe-Galloway, 2012; Krebs et al., 2013; Nguyen, & Kagawa-Singer, 2008; Whop et al., 2012), and two systematic reviews (Cavanagh, Wakefield McLoone Garvey, & Cohn, 2016; Clifford, McCalman, Bainbridge, & Tsey, 2015).

The majority of included publications originated in the United States (Braun, et al., 2015; Burhansstipanov et al., 2015; Dohan, & Schrag, 2005; Fiscella, et al., 2012; Grimes., Dankovchik, Cahn, & Warren-Mears, 2017; Eschiti et al., 2012; Guadagnolo et al., 2011; Hohl et al., 2016; Krebs et al., 2013; Nguyen, & Kagawa-Singer, 2008; Warren-Mears et al., 2013), with some publications included from Australia (Bernardes et. al, 2018; Whop et al., 2012; Cavanagh et al., 2016; Meiklejohn et al., 2017). No articles included originated from Canada. As such, all grey literature was focused, but not limited to, Canadian publications, ranging from news articles to provincial and federal government publications (Burgess, 2017; Canadian Medical Association, 2017; Cancer Care Ontario, 2015; Fayerman, 2011; Interior Health, 2018; Walkinshaw, 2011). A summary of all included publications, including their appraisal, is presented in Table 1 in Appendix D, with grey literature presented in Table 1 in Appendix E.

Discussion

The research found in this literature review reported that Registered NNs can improve continuity of care and coordination, facilitate timely access to services, and improve overall Indigenous health outcomes through improving access to health care services throughout the cancer continuum (Bernardes et al., 2018; Burhansstipanov et al., 2015; Clifford, McCalman, Bainbridge, & Tsey, 2015; Dohan & Schrag, 2005; Eschiti, Burhansstipanov & Watanabe-Galloway, 2012; Fayerman, 2011; Grimes, Dankovchik, Cahn, & Warren-Mears, 2017; Natale-Pereira et al., 2011; Warren-Mears, Dankovchik, Patil, & Fu, 2013; Wells, 2008; Whop et al., 2012). More specifically, although nurse navigation is operationalized broadly in the literature, due to the variation in role, function, setting, and program design across the world, a recurrent theme indicates that Registered NNs have the ability to reduce health disparities by employing a patient-centered approach, helping individuals navigate their way through their cancer journey and the health care system and assisting them to overcome individual and system level barriers in access to and continuity of health care (Burhansstipanov et al., 2015; Clifford, McCalman, Bainbridge, & Tsey, 2015; Dohan & Schrag, 2005; Fayerman, 2011; Natale-Pereira et al., 2011; Warren-Mears, Dankovchik, Patil, & Fu, 2013; Wells, 2008; Whop et al., 2012).

For example, Guadagnolo et al. (2011), in conducting a pre-post survey study of American Indian cancer patients ($n = 52$), reported that those who participated in a culturally tailored patient navigational service during their cancer treatment showed statistically significant improvements ($p < 0.0001$) in levels of satisfaction with health. Similarly, Fiscella et al. (2012) reported from their randomized control trial study ($n = 438$) examining treatment times, psychological distress, and satisfaction with cancer care, that patient navigational services improve experiences and satisfaction with care among breast and colorectal cancer patients. This

finding was also echoed in Braun et al.'s (2015) randomized control trial study, which focused on the use of patient navigators to reduce disparities that Asian and Pacific Island Medicare recipients experience in accessing cancer screening services. Braun et al. (2015) reported a statistically significant ($p < 0.05$) higher level of satisfaction among participants receiving navigational services with "94% reported that they valued working with the navigator, 95% would recommend this service to others, and 93% rated their overall experience with the navigator as excellent (77%) or very good (16%)" (p.5).

Accordingly, Cavanagh, Wakefield McLoone Garvey, & Cohn (2016) in their systematic review on cancer survivorship services for Indigenous People stated that "patient navigator programs have been widely used and have been effective in providing additional support and increasing access to cancer care for Indigenous populations" and that tailoring programs to the needs of Indigenous People will "likely lead to an enhancement of quality of life for this underserved group" (p. 4). As well, Clifford et al.'s (2015) systematic review on interventions to improve cultural competence in health care for Indigenous Peoples of Australia, New Zealand, Canada and the US, suggest that culturally tailored programs such as navigator programs, have shown efficacy at improving levels of patient satisfaction; however, they also note that the majority of the studies were from the US and Australia, and that no studies included were from Canada or New Zealand.

Thus, during the past two decades, multiple studies have been conducted to understand and evaluate the benefits of nurse navigation roles and programs in the field of oncology (Braun et al., 2015; Abbott, Fisher, Greenberg, & Safdar, 2017; Cavanagh, et al. 2016; Fiscella, et al., 2012; Guadagnolo et al., 2011; Hohl et al., 2016). However, few studies exist that have targeted the Canadian Indigenous population.

Literature Gap

Although there is some existing literature on the role of a NN in the field of oncology (Dohan & Schrag, 2005; Natale-Pereira et al., 2011; Wells, 2008), there is limited research exploring nurse navigation with Indigenous People in Canada for the provision of culturally safe care. More specifically, there has been less exploration, from both Indigenous Peoples' and nurses' perspectives, regarding the actual process of nurse navigation, and how navigators who are Registered Nurses go about their role to guide and support Indigenous patients and families through their cancer journey in a culturally sensitive manner. Further clarification of this role can not only help guide nurses in the provision of culturally sensitive and safe care, but also can improve the quality of care received by Indigenous People (Cavanagh et al., 2016; Clifford, McCalman, Bainbridge, & Tsey, 2015). As such, further research is needed to investigate the process of Registered Nurse navigation with Indigenous Peoples in Canada.

Limitations

Limitations of this review include that studies included were only published in English between the years of 1998 and 2018. Although during all stages of the study, especially during data analysis, the search was repeated multiple times to uncover any new relevant research published in the year 2019, all included articles were published between the years of 2005 and 2018.

Another limitation is that a health sciences librarian was not involved in developing the search strategy, which may have resulted in the omission of a broader range of research. Future systematic reviews are recommended that involve a health services librarian that specializes in Indigenous research. Systematic reviews could, for example, use search filters designed to help retrieve articles that are relevant to Indigenous Peoples in Canada such as those developed by

Campbell, Dorgan and Tjosvold (2014). However, given that this literature review was not limited to studies in Canada, the Campbell et al (2014) search filters were not used to avoid excluding relevant studies (Jenkins, 2004).

Conclusion

Despite literature existing on patient and nurse navigation in the field of oncology, this literature review shows that the process of Registered Nurse navigation in supporting Indigenous cancer patients is under researched. Further research is required that focuses on the actual processes and experiences of Registered NNs in providing a culturally safe and sensitive approach to supporting Indigenous patients and families living with cancer.

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Appendix A

Table 1. SPIDER model

Research question: What are the experiences and processes of a nurse navigator working with Indigenous Peoples living with cancer, in the context of a large tertiary care hospital?

SPIDER model (Cooke, Smith & Booth, 2012)	
S (sample)	Defined by case, the sample will consist of 6 participants: <ol style="list-style-type: none"> 1. Nurse navigator 2. An oncologist 3. Administrative and senior management
PI (phenomenon of interest)	The “ <i>how</i> ” piece <ul style="list-style-type: none"> • Interested in the experiences and social process (the role of the nurse navigator) and the manners in which they support Indigenous People living with cancer, in the context of a large tertiary care hospital
D (design)	Case study <ul style="list-style-type: none"> • <i>Method:</i> Merriam’s (1998) case study methodology
E (evaluation)	Views, attitudes, beliefs and experiences of care provided by nurse navigators, from both nurse navigator and related perspectives
R (research type)	Qualitative research

Appendix B

Table 1. Search terms used in databases (CINAHL, MEDLINE)

Concept or Term	Search terms used in databases
Nurse navigator	Nurs* navigat* OR nurs* navigat* role OR nurs* patient navigat* OR personal health navigat* OR care coordinat* OR cancer care coordinat* OR Indigenous nurs* navigat* OR Aboriginal nurs* navigat* OR Native patient navigat* OR community nurs* navigat* OR patient navigat* OR navigation
Indigenous	Indigenous OR Native OR Aboriginal OR Indian* OR First Nation* OR Inuit OR Métis OR Indigenous people* of Canada OR Maori OR Pacific
Cancer	Cancer OR Cancer patient* OR cancer OR oncology OR oncolog* care OR Oncolog* nurs* OR tumour OR malignancy
Culturally sensitive care	Cultural competen* OR cultur* care OR culturally sensitive care OR culturally appropriate care OR traditional care OR native care OR Aboriginal care OR Indigenous care

Table 2. Inclusion and exclusion criteria, and limits.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Written in English • Publications focusing on the nurse navigation role, on nurse navigation, or on patient navigation • Publications targeting the Indigenous population, irrespective of setting (international studies included) • Considered individuals with cancer • Publications between 1998 – 2019 • Qualitative or quantitative 	<ul style="list-style-type: none"> • Other languages • Main focus was not on the nurse navigator role, nurse navigation, or patient navigation • Main sample was not Indigenous • Did not consider cancer • Articles published before 1998 • Duplicated papers
Limits: English language, human, articles published after 1998 (2 decades from present)	

Appendix C

Figure 1. Flow chart of search strategy

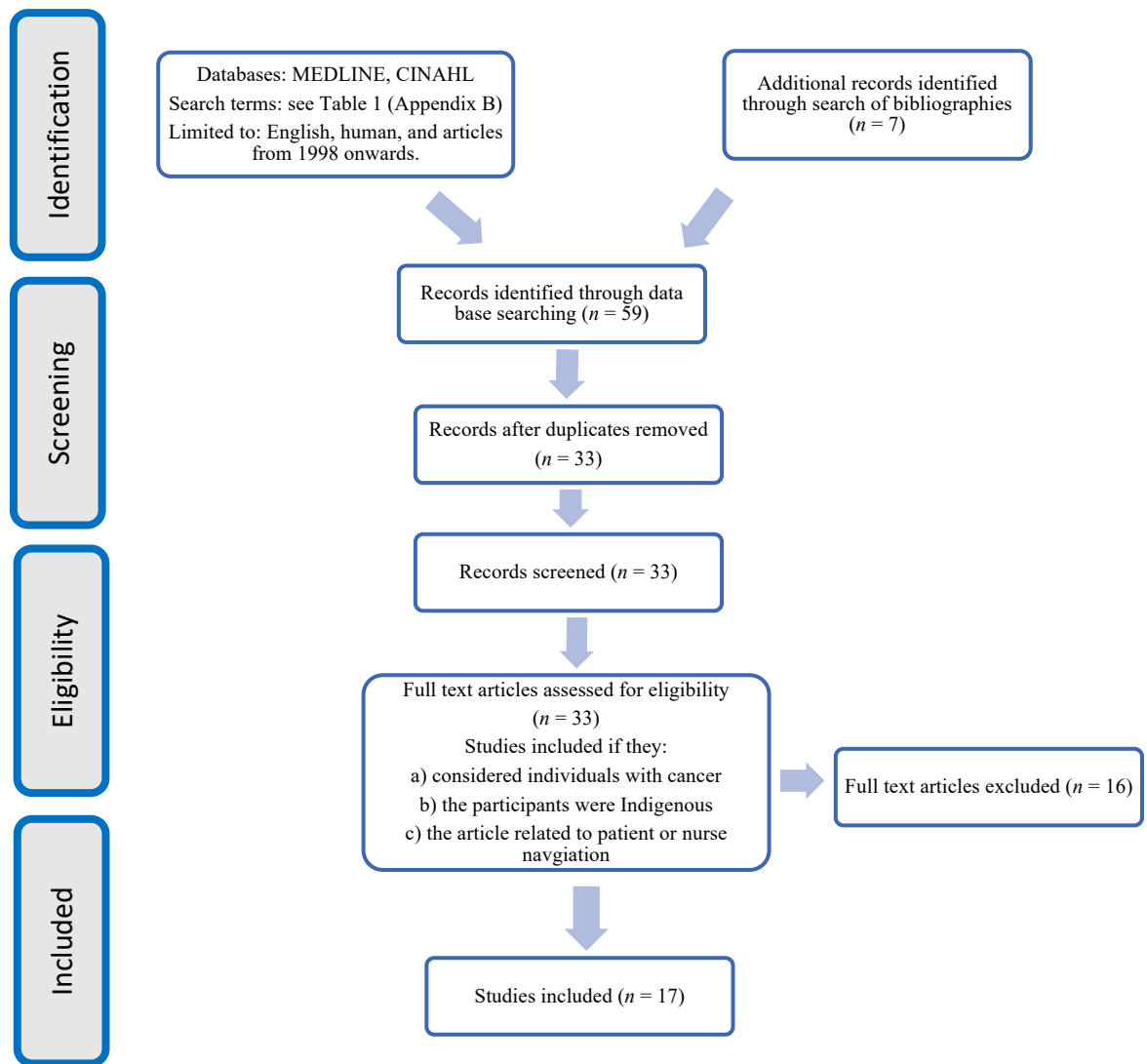


Table 1. Qualitative and quantitative literature review summary

Article (title, author, year, country)	Aim	Methodology & Data Collection	Setting, and Sample	Results	Strengths	Weaknesses and Limitations	Key findings from this study:
Lessons learned from a pilot study of an Indigenous patient navigator intervention in Queensland, Australia (Bernardes et al, 2018) (Australia)	“The purpose of this paper is to describe and reflect upon the experience of training an IPN and implementation of the intervention in the Australian context with Indigenous cancer patients.”	Qualitative “Participants were assessed through a face-to-face interview for their needs using a Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP); distress using the Distress Thermometer (DT)); and on worry using the Worry Chart (CWC)” “Participants were assessed by the IPN at two points in time: at enrolment and 2 months after enrolment.” “A research assistant conducted a satisfaction survey with participants who completed the follow-up questionnaire.”	“A convenience sample of 26 (N = 26) Aboriginal and Torres Strait Islander adult cancer patients receiving care at a major public hospital in Queensland were approached from July, 2013 to March, 2014. Of those, 18 (69%) were interviewed and 8 (31%) declined to participate in the study.”	“Navigating one’s way through the complex health care system for cancer care can be arduous and fraught with uncertainty and fear. However, these difficulties can be exacerbated for Indigenous people, who might not always utilize or understand Western health-care systems.” This study describes and reflects upon the training experience of an IPN and implementation of the intervention in the Australian context with Indigenous cancer patients. By systematically assessing and addressing patients’ needs, IPNs can potentially fill an important gap in the supportive care needs of Indigenous cancer patients currently not covered by the hospital’s IHLOs.	“This study was approved by the Human Research Ethics Committees of Menzies School of Health Research and Princess Alexandra Hospital” Inclusion criteria explicitly stated. Open-ended questions used – enhances credibility Prolonged engagement Participants were assessed by the IPN at two points in time: at enrolment and 2 months after enrolment. 5 key lessons – clear and rich description provided	Limited recruitment (n = 26, but 8 declined leaving a total of 18) Small pilot study therefore impacting generalizability. Limited timing, which did not allow for prolonged engagement	“The people most able or equipped to provide a culturally safe atmosphere are people from the same culture (Williams, 1999). Evidence from previous research shows that Aboriginal and Torres Strait Islander cancer patients place high importance on the relationship within their culture and their relationships with staff can affect their engagement in treatment and follow-up.” “In contrast, the second experience revealed that some patients felt uncomfortable having an Indigenous person as an IPN. Some patients did not like to share their condition with someone known in their community”
Follow-up cancer care: perspectives of Aboriginal and Torres Strait Islander cancer survivors (Meiklejohn et al., 2017) (Australia)	“The purpose of this study was to explore Indigenous Australian cancer survivors’ perspectives of follow-up cancer care and management.”	Semi-structured interviews Grounded theory Yarning methods as defined by Bessarab and Ng’andu were used to conduct semi-structured interviews. Yarning is a culturally appropriate, informal conversational process which emphasises the importance of storytelling. This method is gaining recognition in Indigenous research to cocreate knowledge, share experiences, and develop a deep understanding of the research interest [12, 11]; therefore, it was considered appropriate for this study. “Yarning methods used related to the different types of yarning such as social, topic, collaborative, and therapeutic yarning; the importance of time and place of the yarn; reciprocity and relationship building throughout the research process; and the importance of following cultural protocols [12, 11]. The yarn was held	“This is a qualitative study employing individual interviews with 21 Indigenous cancer survivors (13 females, 8 males) recruited from a rural primary health service and large tertiary hospital in Brisbane, Queensland. Yarning methods were used to conduct semi-structured interviews.”	“Findings describe a range of ways in which follow-up cancer care is experienced with four major categories elucidated, namely: links to tertiary health services, links to primary health services, communication between tertiary and primary health services, and lost in transition. Both positive and negative experiences were described; however, the importance of timely and informative discharge information, continuity of care, good communication between tertiary and primary health services, and strong therapeutic relationships were salient issues raised by participants.”	Ethics approval was obtained Inclusion criteria explicitly stated Semi-structured interviews, open ended questions “Yarning is a culturally appropriate, informal conversational process emphasising the importance of storytelling.” The yarn was audio-taped, and consent was obtained Analysis of interviews identified a number of categories relating to links to follow-up cancer care, which are	“Challenges associated with poor coordination of appointments, time away from family and community, costs of accommodation and travel, and discomfort associated with long journeys were identified.”	“These findings highlight the importance of establishing strong therapeutic relationships between patients and tertiary and primary health professionals. Also important for survivorship is provision of discharge summaries or care plans at discharge for survivors and general practitioners as well as access to a range of allied health services. Alternative means for follow-up could be investigated for regional and rural survivors to facilitate convenient and cost-effective follow-up care. Finally, provision of responsive and flexible follow-up care to cater for the diverse range of needs and preferences of cancer survivors is required. A patient navigator available across the cancer continuum could go some way to addressing this.” “Study results highlight the importance of strong therapeutic

		<p>at a time and place suitable to the participant with partners or family members in attendance if desired. Time was allowed for a social yarn as a shared space to get to know each other outside the ‘researcher-participant’ domain prior to beginning the research topic yarn”</p>			<p>discussed in the article and presented in Table 2.</p>		<p>relationships between patients and tertiary and primary health professionals and the potential role of a patient navigator to link patients to appropriate services and care and improve communication.’</p>
<p>American Indian and Alaska Native Cancer Patients’ Perceptions of a Culturally Specific Patient Navigator Program (Grimes., Dankovchik, Cahn, & Warren-Mears, 2017). (United States: Idaho and Oregon)</p>	<p>“The objective of this study was to explore whether working with a navigator can improve the quality of life and subjective well-being of AI/AN cancer patients, determine the primary barriers to timely cancer care for this population, identify the most effective navigation strategies, and examine participant perceptions of and satisfaction with the program.”</p>	<p>“We conducted a survey of participants enrolled in the Northwest Tribal Cancer Navigator Program”</p> <p>“We developed the survey instrument in partnership with community members to ensure a culturally appropriate semi-structured questionnaire.”</p> <p>“The survey instrument for this study was a semi-structured questionnaire developed by NTCNP research staff, in conjunction with navigators and community members. Navigators and community members reviewed the questionnaire to assess ease of understanding, relevance, and cultural appropriateness. Two respondents then pretested it and provided additional comments. We incorporated feedback from these three sources into the final questionnaire.”</p>	<p>Conducted in-depth interviews with 40 AI/AN patients at tribal clinics in Idaho and Oregon</p> <p>The Northwest Tribal Epidemiology Center implemented the Northwest Tribal Cancer Navigator Program (NTCNP) between 2006 and 2010 as one site of the national Patient Navigator Research Program (PNRP). One patient navigator was placed at each of four tribal clinics in Idaho and Oregon. Interviewers recruited patients from three of these clinics for this study.</p>	<p>“Patient navigation is a good fit for native communities, and a variety of models have shown promise toward decreasing cancer disparities for AI/AN populations. The results of this study reveal the strengths and weaknesses of the navigation model as implemented by the NTCNP.”</p> <p>Primary barriers to timely cancer care were identified and depicted in two tables (table 1, and table 2). Representative quotes were also provided (shows transparency).</p> <p>Navigation services and patient perspectives are depicted in table 3.</p>	<p>The Portland Area Indian Health Service Institutional Review Board approved the study</p> <p>Inclusion criteria clearly stated</p> <p>Included figures that depict the navigation process. “ Fig. 1 This figure shows the role of the navigator throughout the patient’s cancer journey, and how it was changed to adapt the program to tribal communities”</p> <p>Open-ended questions</p> <p>Interview duration was 30 min (prolonged engagement)</p> <p>Provided 30\$ gift card upon completion</p> <p>Survey was developed by research staff, but then brought back to community members and navigators for feedback and adjustment to ensure it was culturally appropriate.</p> <p>Informed consent obtained</p> <p>Interviewers recorded all interviews, and certified professional transcriptionists created verbatim</p>	<p>Result presented are based on a very small sample size, and therefore findings are not representative.</p> <p>“Study data are limited to self-reported opinions and we did not validate the instrument due to the small sample size and few published AI/AN cancer patient surveys. Instead, we drafted a questionnaire based on the literature review of AI/AN survey best practices and guidance from the community.”</p>	<p>“While recent trends have shown decreases in cancer mortality among NHW, high rates for AI/AN have persisted (Espey et al., 2007; Hoffman, Li, Henderson, Ajani, & Wiggins, 2014; Stewart, King, Thompson, Friedman, & Wingo, 2004). Many financial, social, and cultural barriers contribute to these disparities (Petereit et al., 2008). Late stage diagnosis is a primary factor, and is linked to low screening rates and inadequate follow up of abnormal screening tests. Screening rates in the Northwest remain lower among AI/ AN than NHW (Steele, Cardinez, Richardson, Tom-Orme, & Shaw, 2008), and mammography and Pap test screening rates are lower among AI/AN in the region than AI/AN nationally (Indian Health Service, 2010).”</p> <p>“We expected navigator services around accommodating cultural practices within the health care system to be important to AI/AN patients in Northwest tribal communities. However, our data show that few participants surveyed experienced cultural barriers. Some did describe cultural traditions and ceremonies as a vital part of their healing journey.”</p>

					transcripts from the audio files, purging identifying details.		
<p>Native cancer navigation: The state of the science (Eschiti, Burhansstipanov, & Watanabe-Galloway, 2012).</p> <p>(United States)</p>	<p>The purpose of this literature review is to determine the current state of the science for the effectiveness of patient navigation on improving outcomes of cancer care across the continuum among Native Americans. The research will help healthcare professionals ascertain potential evidence-based practice guidelines and gaps in knowledge, which may provide direction for future research.</p>	<p>Literature review</p> <p>The search strategy included a review of cancer-related patient navigation programs published in peer-reviewed journals or online to ascertain potential evidence-based practice guidelines and gaps in knowledge that may provide direction for future research.</p>	<p>N/A literature review</p>	<p>Native navigation has been shown to increase recruitment screening, rescreening, and perceived barriers and facilitators to screening regarding breast cancer. Increases in knowledge were observed regarding Pap tests and cervical cancer, in addition to comfort talking about cancer issues and awareness of cervical cancer issues. Burhansstipanov et al. (2010) found no difference in mammography for women receiving telephone versus in-person navigation. However, 55% of those receiving the navigator intervention had a statistically significant difference in receiving rescreening compared to those who were not navigated. Native navigation was shown to lead to three fewer days of treatment interruption for radiotherapy. Warren-Mears and Ramsey (2007) reported high levels of patient and provider satisfaction with patient navigation.</p>	<p>Clear description of literature review search methods - authors demonstrate transparency.</p>	<p>Limited sample characteristics.</p> <p>Lack of randomization.</p> <p>All of the studies included women; in fact, many of the samples included women only.</p> <p>None of the research conducted included children.</p> <p>None of the studies focused on caregivers or the family of cancer survivors and how navigation might assist them.</p> <p>Limited transferability.</p>	<p>Oncology nurses must have a role in training personnel to serve as cancer navigators.</p> <p>Oncology nurses need to be supportive of culturally appropriate navigation programs. Oncology nurses who serve NAs need to be familiar with the cultural practices and beliefs of the Native people of the area. When a nurse interacts with Native navigators, questions about culture may be asked of the navigators, who often live the culture. Respect for local cultures by nurses will serve to strengthen the relationship with navigators, as well as Native patients who are served.</p>
<p>Reducing cancer screening disparities in Medicare beneficiaries through cancer patient navigation (Braun, Thomas, Domingo, Allison, Ponce, Haunani Kamakana, & Tsark, 2015)</p> <p>(Hawaii: Asian and Pacific Islander)</p>	<p>“The purpose of this article is to present findings from this randomized controlled trial (RCT) of the use of navigators to reduce disparities that Asian and Pacific Islander Medicare recipients experience in accessing breast, cervical, prostate, and colorectal cancer screening.”</p> <p>It was hypothesized that navigators could help increase the prevalence of cancer screening in Medicare beneficiaries with low screening participation and reduce cancer health</p>	<p>Design: Randomized control trial</p> <p>“The program was named Kukui Ahi, a Hawaiian phrase meaning to show the way.”</p> <p>“The Kukui Ahi model was based on social cognitive theory, which guides practitioners to consider how individuals’ knowledge and environment affect their behaviors.”</p>	<p>The program ran from 2006-2010, 6 hospitals participated.</p> <p>Sample size was n=246.</p> <p>The CMS demonstration project required a RCT design.</p> <p>“The study setting was Moloka’i General Hospital on the island of Moloka’i, Hawai’i, which was one of six sites participating in the Cancer Prevention and Treatment Demonstration sponsored by the Centers for Medicare and Medicaid Services (CMS).”</p>	<p>“Navigators helped more than 95% of these Medicare recipients to access cancer screening by providing information about screening, mailing reminders that screening was due, and calling to remind them to schedule screening appointments. For 65%, navigators scheduled initial or follow-up appointments or both. They helped approximately one-third arrive on time for appointments and arranged transportation for approximately 10%. They helped approximately 16%</p>	<p>Randomized control trial design</p> <p>Adequately powered sample size</p> <p>“The institutional review boards of the Native Hawaiian Health Care Systems and The Queen’s Medical Center (parent organization of MGH) approved the study in Hawaii”</p> <p>Chi-square tests were used to analyse the data statistically.</p>	<p>A statistically significant result does not necessarily mean a clinically meaningful improvement.</p> <p>Unclear who the navigators were: “The navigators were not certified healthcare providers, but they completed a 48-hour evidence-based navigator training program and participated in quarterly continuing education sessions to</p>	<p>Findings from this study suggest that navigation services are effective in increasing cancer screening of Medicare beneficiaries from groups experiencing significant disparities and living in medically underserved communities. For this rural cohort, cancer screening navigation resulted in significant increases in cancer screening.</p>

	disparities in the Medicare population.			complete paperwork, 15% talk with doctors and staff, and 11% find ways to pay for care.”	<p>Table 4 presents this data. Appropriate statistical test.</p> <p>Table 2 provided the characteristics of the experimental and control groups.</p>	<p>extend their navigation skills”</p> <p>The CMS demonstration aimed to test the effect of navigation on cancer screening and treatment of older, Medicare-eligible adults. This article reports only on the screening-related findings.</p> <p>“Baseline data were collected before randomization, so no bias was expected, but data collectors were not blinded to RCT group assignment when collecting exit data.”</p> <p>“The analysis relied on self-report of screening behaviors by study participants. In the national analysis, the CMS contractor checked self-reported screening data against Medicare claims data,³ whereas the current analysis was restricted to the self-reported survey data.”</p> <p>Limited generalizability of findings (small isolated and medically underserved island)</p>	
<p>Navigating the cancer journey: A review of patient navigator programs for Indigenous cancer patients (Whop et al., 2012)</p> <p>(Australia)</p>	<p>Review article</p> <p>“ We reviewed the scientific literature on patient navigator programs in Indigenous people with cancer. We conducted a review of the published literature up to 13 April 2011. PubMed, MEDLINE and CINAHL</p>	<p>Review article</p> <p>A search of online peer-reviewed journal articles indexed in PubMed, MEDLINE and CINAHL before 13 April 2011 was undertaken. Citations that included the following terms in either the title, abstract, article or MeSH heading were selected: neoplasm*, Navigat*, Native Sisters,</p>	N/A because it is a review article	<p>“All eight articles reviewed (Table 1), described PNP that were conducted in the USA.”</p> <p>Cultural aspects: “There are several areas in which the PNP incorporated cultural aspects into their programs. Both programs had cultural competency</p>	<p>Compared program details (from the different articles reviewed) and depicted data in a table</p> <p>Cultural aspects, and outcomes of the various patient</p>	<p>The review focuses on PNP For indigenous people with cancer, but there is no consistent definition of navigator characteristics, and therefore its unclear which of these</p>	<p>This review highlights the dearth of published research articles on PNP for Indigenous populations. The eight articles identified to date provided information on two programs. While they vary to some degree, the programs share the common theme of attempting to provide a culturally competent service to reduce cancer mortality</p>

	databases were searched for original articles on Indigenous patient navigation programs. The review produced eight relevant articles covering two specific programs, the Native Sisters Program and the Walking Forward Program”	cancer care coordinator, Aboriginal, Torres Strait Islander, Maori, American Samoa, Indian, North American, Inuit, Metis, Eskimo, Alaska/an Native, Aleut, Oceanic Ancestry Group, American Native Continental Ancestry Group. A short list of these articles was created by reviewing the title and abstract against our inclusion criteria, which specified that the publication had to: (i) be an original article; (ii) focus on a PNP related to cancer care; and (iii) target an Indigenous group. The reference lists of shortlisted articles were reviewed for additional articles that met our inclusion criteria.		components that included acknowledging Indigenous peoples’ history, promoting awareness of diversity among human beings, ensuring the ability to care for individuals and advocating a nonjudgmental openness towards all” “ having a PN with an Indigenous background,3,12–17 a culturally relevant educational materials (e.g., culturally tailored and appropriate brochures),13,15 and the use of the local language or an interpreters15,18 were also deemed to be important features of the PNP reviewed.”	navigation programs are reported.	characteristics are most pertinent to improving health outcomes. “This lack of consistency and the absence of comprehensive program evaluation have resulted in unsubstantiated and generalized conclusions being reported”	in Indigenous people through increasing cancer screening and assisting with follow-up care coordination. The existing articles do, however, provide some important insights into the roles of the PN and the delicate interface they play between the community and the healthcare system.
Interventions to improve cultural competency in health care for Indigenous peoples of Australia, New Zealand, Canada and the USA: a systematic review (Clifford, McCalman, Bainbridge, & Tsey, 2015). (Canada, New Zealand, Australia, United States)	Systematic review “This article describes the characteristics and reviews the methodological quality of interventions designed to improve cultural competency in health care for Indigenous peoples of Australia, New Zealand, Canada and the USA.”	Systematic review Data extraction: Information on the characteristics and methodological quality of included studies was extracted using standardized assessment tools.	A total of 17 electronic databases and 13 websites for the period of 2002–13. Study selection Studies were included if they evaluated an intervention strategy designed to improve cultural competency in health care for Indigenous peoples of Australia, New Zealand, the USA or Canada.”	Sixteen published evaluations of interventions to improve cultural competency in health care for Indigenous peoples were identified: 11 for Indigenous peoples of the USA and 5 for Indigenous Australians. The main types of intervention strategies were education and training of the health workforce, culturally specific health programs and recruitment of an Indigenous health workforce. Main positive outcomes reported were improvements in health professionals' confidence, and patients' satisfaction with and access to health care. The methodological quality of evaluations and the reporting of key methodological criteria were variable. Particular problems included weak study designs, low or no reporting of consent rates, confounding and non-validated measurement instruments.	Clear inclusion and exclusion criteria Tables used to depict qualitative data analysis. Strengths and limitations of the reviewed articles provided. Rich description.	Possibility that the review did not locate all relevant studies. “Since evaluations with statistically significant findings are more likely to be published, it is possible that the published evaluations reviewed overestimate the true effectiveness of interventions to improve cultural competency in health care for Indigenous peoples” A statistically significant result does not necessarily mean a clinically meaningful improvement.	There is a lack of evidence from rigorous evaluations on the effectiveness of interventions for improving cultural competency in health care for Indigenous peoples. Future evaluations should employ more rigorous study designs and extend their measurement of outcomes beyond those relating to health professionals, to those relating to the health of Indigenous peoples.
Cultural Roles of Native Patient Navigators for	The purpose of this opinion article is to clarify cultural roles Native Patient	N/A opinion article	N/A opinion article	What we have learned from AI NPNs is relevant to other populations that live with	A few examples from NACR’s [patient navigation program]	This is an opinion article; therefore, it is subject to bias.	Native patient navigators (NPNs) should come from or be familiar with and trusted by the local

<p>American Indian Cancer Patients (Burhansstipanov, Harjo, Krebs, Marshall, & Lindstrom, 2015)</p> <p>(United States, Colorado)</p>	<p>Navigators (NPNs) perform in providing cancer support. NPNs, who are American Indian (AI), provide many unique services to indigenous patients who are undergoing treatment (radiation, chemotherapy, surgery, adjuvant therapy) for cancer.</p>			<p>health inequities in order to improve patient care and outcomes. Other populations need to adapt their cultural components within their respective navigation programs and use cultural navigators, such as NPNs, to support health, healing, and recovery</p>	<p>experienced demonstrate cultural roles as well as the collaboration with clinical staff. These roles may be comparable for indigenous people living in other parts of the US as well as countries outside the US.</p> <p>The authors provided examples that were illustrations of cultural issues that patient navigators address on the behalf of their Indigenous patients. Navigation is not limited to these examples, but these represent a holistic approach to meeting the patient’s cultural needs.</p> <p>Authors mention transferability – unable to generalize to all Indigenous people but recognize that the culturally sensitive navigation approach may also be appropriate for other Indigenous populations. Authors leave it up to the reader to decide.</p>	<p>Subject to potential misinterpretation of the research, or possible omission of relevant research</p> <p>Limited transferability.</p> <p>This is a problem-based discussion paper, any relevant published papers might be included (but not limited) to support my opinions without a rigorous systematic literature review.</p> <p>No standard critical appraisal instruments for specific study designs were used to critically appraise the level of evidence.</p>	<p>community (reservations, rural or urban settings).</p> <p>NPNs in urban settings should be able to work with AIs who come from many different tribes.</p> <p>NPNs need to be respectful of the local cultures and have cross-cultural skills. All NPNs will encounter AIs from different tribes; because of trust relationships with local communities, inter-tribal cultural differences have not been an issue.</p> <p>NPNs use respect and communication skills to allow AI patients to share personal, cultural, and religious needs related to their health and possible treatment.</p> <p>NPNs are an extension of the medical community and provide services that are not duplicated within most settings. Therefore, they should be paid.</p>
<p>Socioeconomic disparities, financial toxicity, and opportunities for enhanced system efficiencies for patients with cancer (Abbott, Fisher, Greenberg, & Safdar, 2017).</p> <p>(United States: Ohio)</p>	<p>“We identify five subsets of patients with cancer who are at particular risk of inequitably suffering from health care disparities.”</p>	<p>N/A Review article</p>	<p>N/A Review article</p>	<p>5 different categories (identified as subsets of patients with cancer who are at particular risk of inequitably suffering from health disparities):</p> <ol style="list-style-type: none"> 1. The financially challenged 2. Racial, ethnic, and cultural disparities 3. Geographic disparities 4. Educational challenges 5. Veterans 	<p>Figure 1, which depicts the intersection between disparities that contribute to suboptimal cancer care.</p> <p>Table that summarizes current American clinical guidelines.</p> <p>Recommendations provided (strategies to address health disparities).</p>	<p>Article is subject to potential bias, including the influence of the authors' personal viewpoints.</p> <p>Gaps in literature searching practices that may lead to the omission of relevant research, or even errors in the translation of data from the primary</p>	<p>“Moving forward it will be important for us to understand not just what drives geographic disparities, but parsing out actionable targets to affect change, as the multifactorial challenges to the rural populous are likely intertwined. It is likely that simple distance to the center is not the sole determinant of geographic disparities. Improving health literacy, minimizing financial toxicity by understanding ways to decrease out-of-pocket costs, and increasing access to tertiary care</p>

						<p>literature to summarization in the review.</p> <p>Possible misrepresentation or misinterpretation of original source data.</p>	<p>providers (perhaps via telemedicine) are all worthy of prospective evaluation”</p> <p>“Ample evidence exists for marked, persistent disparities in how health care is delivered. Well-documented racial, socioeconomic, and geographic disparities directly impact access to high-quality health care. And when these at-risk populations are given a cancer diagnosis, the risks of poor adherence to diagnostic, treatment, and surveillance guidelines is only exacerbated. Understanding more specifically what defines high-risk populations in a given clinical scenario will be critical to designing and promoting novel interventions to narrow current delivery gaps. The future holds promise in this regard, with telehealth increasingly prevalent and cost-effective across a variety of medical disciplines. Further innovation should be encouraged and implemented to ensure quality medical care for all segments of our population.”</p>
<p>Navigation as an intervention to eliminate disparities in American Indian communities (Krebs et al., 2013)</p> <p>(United States: Colorado)</p>	<p>To identify the role of patient navigation in decreasing health care disparities through an exemplar of a successful patient navigation program for American Indian populations living in the Northern and Southern Plains of the United States.</p>	<p>Literature review</p> <p>Reviewed published literature and data from the Native Navigators and the Cancer Continuum study.</p>	<p>Native Patient Navigators successfully collaborated with local American Indian organizations to provide cancer education through a series of 24-hour workshops. These workshops increased community knowledge about cancer, influenced cancer screening behaviors, and increased the visibility and availability of the navigators to provide navigation services.</p>	<p>The NNACC study is one strategy to overcoming health care disparities in those most in need of coordinated, comprehensive, quality cancer care. Through NNACC, NPNs were made visible to their communities, increasing access to health care resources and services throughout the cancer continuum. Patient navigation offers even the most vulnerable of the US population the opportunity to access cancer care, support services, and community resources.</p>	<p>Inclusion criteria clear and explicitly stated.</p> <p>Table 1: Cancer Incidence Data for Southern and Northern Plains American Indians – this table made the cancer burden among this population clear to the reader.</p> <p>Table 2: Roles and Responsibilities of Cancer Patient Navigator – made it clear to the reader.</p> <p>Table 3: Navigation In-Service Training Topics – made it clear to the reader which topics were covered in in-service training for patient navigators.</p>	<p>Article is subject to potential bias, including the influence of the authors' personal viewpoints.</p> <p>Gaps in literature searching practices that may lead to the omission of relevant research, or even errors in the translation of data from the primary literature to summarization in the review.</p> <p>Possible misrepresentation or misinterpretation of original sources.</p>	<p>Reaching those with health care disparities requires multiple strategies. Collaborating with patient navigators who are embedded within and trusted by their communities helps to bridge the gap between patients and providers, increases adherence to care recommendations, and improves quality of life and survival.</p> <p>Using patient navigators, both lay health workers and health care professionals, to facilitate cancer care has the potential to decrease the overall US cancer burden and increase long-term cancer survival and quality of life.</p>

<p>Cancer survivorship services for Indigenous peoples: where we stand, where to improve? (Cavanagh, Wakefield McLoone Garvey, & Cohn, 2016)</p> <p>(Australia)</p>	<p>There are few support programs with evidence-based practices which address the needs of cancer survivors from indigenous populations. This systematic review analysed the experiences and current support services for cancer survivors from indigenous populations following the cessation of cancer treatment.</p>	<p>Systematic review</p> <p>The data sourced for this article was identified from a systematic search of five databases (MEDLINE, MEDLINE In-Process, PsycINFO, CINAHL, and EMBASE). Studies were selected if they described the experiences of indigenous cancer survivors, their families, and/or clinicians primarily responsible for their care. In total 208 unique abstracts were screened, from which 17 studies were identified as having fulfilled all selection criteria.</p>	<p>N/A systematic review</p> <p>17 studies</p>	<p>Of the 17 articles reviewed, 12 described qualitative data and 5 provided quantitative data. Common themes identified included the importance of family support throughout the survivorship period, the negative effect of community stigmatization, fatalistic attitudes towards cancer, and the importance of spirituality in coping with, and understanding, the cancer experience. Potential barriers to accessing care included distance and difficulties revisiting the survivor's cancer experience due to an associated fear of cancer recurrence.</p> <p>The results from this review indicate that there is a need for survivorship care to be shaped specifically for the needs of indigenous cancer survivors.</p> <p>Indigenous cancer survivors would benefit from survivorship programs more specifically tailored to their individual circumstances, such as personalized spiritual care, facilitation of increased involvement of family members, and connection to other indigenous cancer survivors.</p>	<p>Inclusion and exclusion criteria clear, and explicitly stated.</p> <p>Table 1: outlines the quality of the articles: the authors gave a small critique regarding the quality of the articles.</p> <p>Figure 1: outlining systematic review process, which enhanced transparency and dependability of data.</p>	<p>Gaps in literature searching practices that may lead to the omission of relevant research, or even errors in the translation of data from the primary literature to summarization in the review.</p> <p>Possible misrepresentation or misinterpretation of original sources.</p>	<p>Indigenous cancer survivors have unique needs and experiences that can impact upon their cancer journey. To date, current programs may not be fulfilling these needs. Services should be encouraged to develop programs that assist indigenous cancer survivors with their reintegration into the family, community, and workplace; provide peer-support programs that allow for the sharing of stories from other survivors; provide cancer education services to individuals, their families, and wider community; and incorporate spiritual activities tailored to the needs of the individual.</p> <p>Patient navigator programs have been widely used and have been effective in providing additional support and increasing access to cancer care for indigenous populations.</p> <p>The challenge is how to continue to fund and implement these programs for indigenous people in other countries. Tailoring current survivor care programs to the needs of indigenous survivors may limit the cost and time involved in designing a novel program and will likely lead to an enhancement of quality of life for this underserved group.</p>
<p>Patient navigation for breast and colorectal cancer treatment: a randomized trial. (Fiscella, et al., 2012).</p> <p>(United States)</p>	<p>“ We pooled data from these 2 sites (Denver, CO and Rochester, NY) to examine the hypothesized effect of PN: (i) shorter time to treatment completion; (ii) less psychologic distress; and (iii) greater satisfaction with cancer care. We also expected that patients with inadequate or no insurance, language barriers, lower education, and lower income, would show greater benefit</p>	<p>Randomized control trial</p> <p>The authors “pooled data from two sites from the national Patient Navigation Research Program (PNRP).</p> <p>Trained research assistants administered surveys in preferred language (English or Spanish; ref. 21). Research assistants also abstracted data from medical records.</p>	<p>Participants with a definitive diagnosis of breast or colorectal cancer were enrolled in a randomized controlled trial for PN from September 2006 to June 2010 at the two study sites.</p> <p>Patients (n=438) with newly diagnosed breast (n=353) or colorectal cancer (n=85) were randomized to PN or usual care. Trained lay navigators met with patients randomized to PN to help them assess treatment</p>	<p>Statistical analysis.</p> <p>The sample was predominantly middle-aged (mean age=57) and female (90%); 44% were race-ethnic minorities (44%), 46% reported lower education levels, 18% were uninsured and 9% reported a non-English primary language. The randomized groups were comparable in baseline characteristics. Primary</p>	<p>Significant statistical results, and appropriate statistical tests chosen.</p> <p>Sample was randomized.</p> <p>Tables used to summarize published articles pertaining to native cancer navigation. Enhances transparency of research study.</p>	<p>While positive findings are consistent with the author’s hypothesis, they reflect secondary analyses and therefore should be replicated.</p> <p>Authors studied navigation provided in only 2 communities, and therefore don’t know</p>	<p>“In a randomized controlled trial of PN to reduce barriers to cancer treatment, we observed no overall effect on patients’ time to completion of treatment. Within 3 months of treatment initiation, we also found no overall effect on psychologic distress or satisfaction with care. However, subgroup analysis showed benefits for selected patients. In particular, those with educational, language, and insurance barriers reported greater satisfaction when</p>

	from PN than those with fewer needs”		barriers and identify resources to overcome barriers. We used intent-to-treat analysis to assess time to completion of primary treatment, psychological distress (Impact of Events Scale) and satisfaction (Patient Satisfaction with Cancer-Related Care) within three months after initiation of cancer treatment.”	analysis showed no statistically significant group differences in time to completion of primary cancer treatment, satisfaction with cancer-related care, or psychological distress. Subgroup analysis showed that socially disadvantaged patients (i.e. uninsured, low English proficiency and non-English primary language) who received PN reported higher satisfaction than those receiving usual care (all ps < 0.05). Navigated patients living alone reported greater distress than those receiving usual care.	Clarity in research methods (inclusion and exclusion criteria explicitly stated).	whether these findings generalize to other parts of the country. Findings not generalizability to other cancers – left up to reader to decide transferability. Limitations of articles discussed by authors (ie. Sample size, self reported measures, representativeness)	navigated. These findings, if replicated, suggest that PN may improve experience of care among patients with the greatest needs, which conforms to the original intent of PN.”
Using navigators to improve care of underserved patients: Current practices and approaches (Dohan, & Schrag, 2005). (United States: California)	In this report, the authors have 1) defined patient navigation, distinguishing it from other cancer support services; 2) described how programs are organized; and 3) discussed the need for research on program effectiveness	The authors reviewed published literature on patient navigation. However, after initial search efforts, it became clear that the literature was not developed sufficiently to address our research questions. There appeared to be two primary reasons for this deficiency. First, systematic evaluations of navigation only recently have begun and have yet to appear in the literature. Second, many navigation programs have been oriented toward local quality-improvement initiatives rather than scientific research, evaluation, and publication. Accordingly, the authors approached this review using two simultaneous approaches. First, they conducted a systematic literature review. Second, one author (D.D.) collected original data on patient navigation programs through a variety of qualitative research methods.” Standard anthropologic research methods were used during observation and interview research in all settings.	Information was examined on navigation programs published in the scientific literature and on line. Qualitative research also was conducted, consisting of direct observation of patient care in cancer clinics with and without navigators in northern California, in-person interviews with personnel and patients in the clinics observed, and telephone interviews with navigators at four sites across the United States	The authors found that navigation services have been implemented at all stages of cancer care: prevention, screening, treatment, and survival. Navigators differ from other cancer support personnel in their orientation toward flexible problem solving to overcome perceived barriers to care rather than the provision of a predefined set of services. There are no rigorous demonstrations of the effects and effectiveness of navigation, although such studies are underway. A striking finding from the literature review was the lack of a standard definition of patient navigation. Such a designation is requisite for practitioners and researchers who seek to distinguish navigation from other cancer support services, such as advocacy, outreach, education, case management, and social work.	Clear research methods and rationale for choice. Standard anthropologic research methods were used during data collection. Topics covered during interviews provided. Semi-structured interviews, broad open-ended questions The authors provide graphic figures that illustrate the work roles of navigators and other providers of support for patients with cancer. Table 1 summarizes the characteristics of 11 navigation programs found and described in the limited published literature.	The 11 navigation programs described do not represent an exhaustive list of extant navigation programs. The sample size was very small (n=6) – therefore, transferability questionable.	Logistic, cultural, educational, and other barriers can impede the delivery of high-quality cancer care to underserved patients. Patient navigation services represent one innovation for addressing perceived barriers to care encountered by disadvantaged patients. Currently, patient navigation is understudied, and literature documenting its effects and effectiveness is scant. Rigorous studies are needed of the navigator role and program costs and benefits. Such studies will facilitate an assessment of program effectiveness, feasibility across a range of health care settings, and performance relative to alternative approaches for addressing barriers to care among the underserved.
Overcoming barriers to cancer care through health navigation programs (Nguyen, & Kagawa-Singer, 2008).	To provide an overview of theoretical concepts in community-based, culturally tailored heal	Published articles, reports, book chapters, government documents, research findings.	N/A literature review.	This article has provided a general overview of cancer disparities in AAPI communities, discussed the	Table 1: provided by the authors highlighting the measures of success	Unclear inclusion and exclusion criteria for the articles reviewed – although the authors	Nurses need to be more involved in developing and delivering effective, culturally competent community-based cancer screening

<p>(United States)</p>	<p>th navigation programs that have improved access to health care for ethnic minority populations, particularly for Asian Americans and Pacific Islanders (AAPI).</p> <p>The purpose of this article is to: 1) delineate the major barriers to health care access contributing to cancer disparities in Asian American and Pacific Islander (AAPI) communities; 2) discuss community-based, culturally tailored health navigation programs developed in recent years to improve access to health care for ethnic minority populations; 3) discuss conceptual issues related to cultural tailoring; 4) highlight the development of one particular cancer navigation program focused on seven Southeast Asian and Pacific Islander communities in California (the PATH for Women/REACH 2010 Project); and 5) discuss implications for oncology nursing education, practice, research, and policy.</p>			<p>conceptual issues important in understanding what is needed to culturally tailor health interventions, and highlighted innovative community-based cancer navigation programs that have been developed to address these disparities, particularly the PATH for Women program focused on seven Southeast Asian and Pacific Islander communities in California</p> <p>Community-based patient navigation interventions provide promising strategies for providing culturally tailored programs that are more likely to succeed in eliminating cancer disparities in screening and early detection of cancers for diverse cultural communities.</p>	<p>for patient navigation programs in cultural communities with unique needs and resources.</p> <p>Table 2: Common ecological barriers to breast and cervical cancer screening – makes it clear for the reader (summarizes text nicely).</p>	<p>mention “published articles. Reports, book chapters, government documents, and research findings” – it is very ambiguous.</p> <p>Criteria and methods for implementing and evaluating culturally tailored patient navigation programs for diverse populations “are still in the early stages of development, with most models again reflecting hospital- or mainstream system health care-based services” – therefore the authors are limited in the assessment and evaluation of what constitutes a culturally competent program.</p>	<p>and treatment navigation programs through education, practice, research, and policy improvement.</p>
<p>A Pre- post survey analysis of Satisfaction with Health Care and Medical Mistrust after Patient Navigation for American Indian Cancer Patients (Guadagnolo, Cina, Koop, Brunette, & Peterit, 2011).</p> <p>(United States)</p>	<p>To assess the impact of patient navigation (PN) on satisfaction with health care and medical mistrust among American Indians (AI) undergoing cancer treatment.</p>	<p>This was a pre-post cohort survey study of 52 AI cancer patients who participated in a culturally-tailored PN program during their cancer treatment. Surveys were administered prior to and after cancer treatment assessing medical mistrust and satisfaction with health care using two Likert-type scales.</p>	<p>Small cohort study</p> <p>The authors prospectively surveyed AI patients (adults) presenting for cancer treatment and undergoing patient navigation at Rapid City Regional Hospital’s Cancer Care Institute in Rapid City, South Dakota between March 2008 and February 2010.</p> <p>The data were collected by using a novel instrument developed after review of the literature and meetings with focus groups of AI community members and cancer patients, as well as research program staff of both AI and non-AI background. The domains established for this</p>	<p>Participation refusal rate was 7%. Mean scale scores for satisfaction with health care were significantly improved after PN compared with pre-navigation ($p < .0001$; Wilcoxon signed-rank test). There was no significant difference in the mean scale scores for medical mistrust after PN compared with those observed prior to treatment ($p < .13$).</p> <p>American Indian cancer patients who received PN services during their cancer treatment showed improvement in levels of satisfaction with health. However, no improvements</p>	<p>Inclusion criteria clear.</p> <p>Rich description of data collection provided, including use of culturally appropriate data collection instrument.</p> <p>Study measures clear, as well as statistical analysis procedures-enhancing dependability of the study, as well as transparency.</p>	<p>Limitations related to this small cohort study include: the ability to draw conclusions about the role that patient navigation itself played in the observed improved levels of satisfaction is limited by the fact that the author’s did not have a comparison cohort of patients who did not receive patient navigation against which to compare survey results.</p>	<p>The authors observed improved satisfaction with health care among American Indian patients receiving patient navigation during cancer treatment. This finding suggests that patient navigation may be an effective health care delivery intervention for improving patient-reported outcomes in this population with known cancer-related health disparities. Findings regarding the lack of impact upon medical mistrust after patient navigation among patients in our study suggest the need for programmatic review of our patient navigation effort, specifically with regard to training and cultural competence preparation of patient navigators to address the special historical and cultural concerns of this vulnerable</p>

			study were medical mistrust and satisfaction with health care.	were observed in levels of medical mistrust.		Response bias may have been present in the post-navigation survey in as much as respondents may have been inclined to provide positive answers to the satisfaction scale items in order not to offend or extend negative feedback to the navigators (who often administered the survey). A statistically significant result doesn't necessarily mean a meaningful clinical improvement.	population. Further studies are needed with larger numbers of patients to assess how patient navigation may improve quality of care for this and other vulnerable populations.
Impact of patient navigation on cancer diagnostic resolution among northwest tribal communities. (Warren-Mears, Dankovchik, Patil, & Fu, 2013) (United States).	The primary aim of this analysis was to estimate the effect of navigator services in reducing the time between suspicious cancer-related finding and definitive diagnosis.	Navigation services were provided between June 2006 and August 2010 at four Northwest Tribes and their respective clinics. Four additional Northwest Tribes and their respective clinics were recruited to serve as control clinics. The time interval between abnormal finding and definitive diagnosis (T1) was the primary outcome variable in the study and was dichotomized in the multivariate analysis to estimate the effect of navigation.	The data for the study were collected from various sources. At navigated sites, clinical data were obtained from the clinical database and paper medical charts. Clinical data were collected through chart reviews at control clinics and no contact was made with participants in these communities. Differences in sample size between navigated and control sites arose due to the fact that data were only collected for navigated subjects who were a) identified and contacted in a timely manner, b) agreed to receive navigation services and c) agreed to share their data for the research portion of the study	The initial results of this study show that AI/AN patients who worked with a patient navigator had significantly higher odds of obtaining a definitive diagnosis than their counterparts who did not have navigation. This finding shows a real benefit for tribal communities which may have a positive impact on health disparities in Indian Country.	Clear study eligibility (inclusion criteria) explicitly stated. Demographic and clinical characteristics provided. Statistical analyses methods clear and explicitly stated.	Sample size unclear, and small within the navigated arm – but the authors stated that this was mainly due to difficulty identifying and enrolling eligible patients early, prior to diagnosis. The data is vulnerable to lack of comparability between navigated and non-navigated groups. Therefore, due to limited sample size it is difficult to detect differences between the two study arms, should they exist. Some of the limitations mentioned by the authors are germane to the nature of the community recommendations for enhancement of the study design noted in the approval process. For example the community opted not	Our study found that having a navigator gave patients a better chance at obtaining diagnostic resolution, indicating that navigators were successful in combating loss to follow-up and preventing patients from “falling through the cracks”. This observation suggests navigators improved continuity of care and patient communication with their primary care clinic. Their assistance appears to be crucial in preventing individuals from dropping out of the health care system. Within AI/AN populations, those at highest risk may include those who are older, fearful of the health care system, geographically isolated and with limited transportation. It appears that patient navigators can enhance engagement and follow through with cancer care.

						<p>to randomize patients to navigation at the individual level, so that all members of a particular tribal community would be treated equitably.</p> <p>The participants in this study were from a variety of tribes in the Northwest. Service types – therefore results are likely not generalizable. Caution should be used and the results should be interpreted in the context of the particular community assessing the need for a patient navigator.</p>	
<p>Satisfaction with cancer care among American Indian and Alaska Natives in Oregon and Washington State: A qualitative study of survivor and caregiver perspectives (Hohl et al., 2016)</p> <p>(United States)</p>	<p>To better understand satisfaction with care among American Indian and Alaska Native (AI/AN) persons with cancer, we explored dimensions of the provider relationship that contributed to satisfaction among caregivers and survivors who received cancer treatment in Oregon and Washington State.</p>	<p>Between November 2011 and April 2013, the project team interviewed 11 caregivers and 71 AI/AN cancer survivors residing in Oregon and Washington State. Interview questions aimed to elicit participant experiences with care providers and factors associated with cancer care satisfaction. Interviews were analyzed using an inductive content analysis approach in which concepts were identified and themes derived from interview data.</p>	<p>Between November 2011 and April 2013, 71 eligible AI/AN cancer survivors residing in Oregon (79.4 %) and Washington State (20.6 %) were interviewed (Table 2). All but one survivor had completed treatment or were undergoing treatment at the time of the interview. None reported cancer recurrence. Thirteen (21.3 %) were employed and 46 (76.7 %) were living below 250 % of the Federal Poverty Level (FPL). Eleven eligible AI/AN caregivers were interviewed.</p>	<p>Three overarching themes, each with two sub-themes, emerged from the data: (1) universal factors: bolstering understanding, involvement, and empathy in care; (2) minority-specific factors: incorporating culture and community into care; and (3) AI/AN-unique factors: interacting with Indian health clinics and Indian Health Service (IHS).</p> <p>Our study demonstrates providers’ critical role in ensuring AI/AN patients emerge satisfied with cancer treatment by honoring their AI/AN-specific needs, such as respect for integration of traditional healing modalities and navigation of specialty care coordination. Our study also highlights the need for future research that addresses systemic challenges in coordinating primary care through the IHS and specialty care for AI/ANs. Enhancing providers’ abilities and tools to deliver clear information, demonstrate cultural</p>	<p>Explicitly stated inclusion and exclusion criteria. Rich description of thematic analysis. Examples of interview questions provided – enhancing transparency.</p> <p>Tables and figures provided depicting rich narratives – enhancing trustworthiness (credibility).</p>	<p>The study was based on interviews conducted with AI/AN cancer survivors and caregivers, and all but one had completed treatment at the time of interview.</p> <p>Small sample size - thus similar themes emerged for both survivors and caregivers in this study, and the number of caregiver interviews was limited.</p>	<p>The results of our study suggest that satisfaction with care among survivors and their caregivers must be examined within the context of culture and community, particularly among minority patients. Our study demonstrates providers’ critical role in ensuring AI/AN patients emerge satisfied with cancer treatment by honoring their AI/AN-specific needs, such as respect for integration of traditional healing modalities and navigation of specialty care coordination.</p>

				competence, and assist survivors in navigating specialty care may increase the number of AI/ ANs who complete cancer care once diagnosed.			

Appendix E

Table 1. Grey Literature summary

Title (author, year)	Key findings
Aboriginal cancer strategy III 2015–2019 (Cancer Care Ontario, 2015)	<p>“A network of 10 Aboriginal Navigators was established across the province to guide people with cancer through the cancer system.”</p> <p>“Our Aboriginal Navigator has also been incredible. In order for our work to gain real traction in the region in the field of palliative care, I just don't think it would have been possible without having the necessary resources in place. Our Navigator also helped to educate the team, and provided cultural sensitivity training to 85 per cent of our staff; this has gone a long way to ensuring that the Cancer Centre is a much more welcoming place for our Aboriginal patients and families”</p> <p>“Navigating the cancer system is a significant challenge for patients who are unfamiliar with medical systems, don't speak English or French and/ or must travel from home for treatment and care. Cancer Care Ontario's Aboriginal Navigators provide support and advocacy for First Nations, Inuit and Métis patients and families by facilitating and coordinating access to cancer services for palliative and supportive care, addressing cultural and spiritual needs, and networking with Aboriginal and non-Aboriginal partners to make the cancer journey a culturally safe experience.”</p>
Vancouver Sun: Aboriginal patient navigators bridge divide between Western traditional care (Fayerman, 2011)	<p>“Aboriginal nurse liaison: a position that involves navigating aboriginals through the health care system.”</p> <p>“Doctors don't always understand our environment. There's a certain amount of stereotyping that goes on,' he says, noting that at some hospitals, aboriginals are lumped together as “frequent flyers, alcoholics and people who get everything paid for.”</p> <p>“Cliff Hanuse [an aboriginal navigator] says he helps out with any issues pertaining to medical care, long-term care, mental health, addiction services, the justice system, family services, and the education system. He views his role as bridging the divide between health care providers and their aboriginal patients. In the Western medical system, for example, treatments are based on interventions such as surgery and prescription medications, but many aboriginals also want to use traditional medicine and practises like prayer circles and sweet grass burning.”</p>
CBC News: Nurse navigators – The Ottawa Hospital (Burgess, 2017)	<p>Nurse Roberts answers questions about cancer and treatment, and programs patient's phone with reminders to drink fluids. “And she's been there in dark moments”</p> <p>“Roberts has the support of hospital leaders for her unique approach to care, including spending time with patients outside the building.”</p> <p>“part of a bigger effort to educate hospital staff about Indigenous culture”</p>
Aboriginal patient navigators (Interior Health, 2018)	<p>“The Aboriginal Patient Navigator provides linkage within the local health areas and First Nation communities within the Interior Health region. The APN workers provide support to Interior Health Aboriginal patients, caregivers, and their families while in the health-care system. The APN will collaborate with and assist health-care providers in early identification and assessment of patient needs. They will participate in the discharge planning process to facilitate the timely discharge of patients to support patient care and independence.”</p>
The rise of the patient navigator (Canadian Medical Association, 2017)	<p>“The rise of the patient navigator — sometimes also called nurse navigator or even health care concierge — addresses the need for guides, translators and advocates. These navigators can attend medical appointments with patients to ask pertinent questions and take notes or help seniors research and connect with community care providers. They can organize a senior's health record and help ensure that busy physicians get the right information, at the right time.”</p>
Patient navigators becoming the norm in Canada (Walkinshaw, 2011).	<p>“Unlike the United States, in Canada, the patient navigator role is slightly more regulated, with often-defined roles and responsibilities.</p> <p>Navigators provide a measure of familiarity and security for patients, she adds. “Patients have described the experience as being on a conveyer belt, it stops, you fall off and then you crawl on to the next phase but there doesn't seem to be a connection so they use the navigator as that bridge so they don't have that sense of falling off the conveyer belt quite as quick but it's continuous.” In addition to connecting patients to resources and specialists, navigators also help patients obtain financial resources to cover such costs as transportation to a cancer centre and chemotherapy.</p> <p>Canada has adopted a more regulatory approach to the profession, although programs do vary from province to province</p> <p>“Patient navigators guide people through the health care maze, connecting them with the right doctors and helping them gain access to available therapies.”</p>

Chapter Three

Methodology

Introduction

In this study, I used a qualitative case study design following Sharan Merriam's approach, to explore the processes and experiences of a NN supporting Indigenous People living with cancer. To restate, my research question was: What are the experiences and processes of a NN working with Indigenous Peoples living with cancer, in the context of a large tertiary care hospital? The specific objectives were: (I) to understand what a NN does to support Indigenous Peoples living with cancer, and (II) to describe the challenges and supports experienced in the role of nurse navigation (at the level of the patient, the NN, the organization, and the health care system). Qualitative case study methodology was appropriate to examine the research question, because there is limited understanding regarding the processes and experiences of Registered Nurse navigation, and how they provide culturally sensitive care with Indigenous Peoples during their cancer trajectory. Constructivism guided this study, acknowledging the relativity and subjectivity involved in this research. This methodology led to an abstract understanding of the NN role through the collection and analysis of data obtained from the NN, health care professionals, and senior management.

In this chapter, I provide a historical overview of Sharan Merriam (1998)'s approach to case study, and how this research method was an appropriate fit for my research question. Next, I outline the sample and recruitment of participants, and describe the process of data collection, management, and storage. I then discuss data analysis strategies, criteria used to ensure rigor of this study, and a timeline for conducting this research. Lastly, I discuss ethical considerations.

Study Design

Sharan Merriam's Case Study

In qualitative research, “case study is discussed as a significant qualitative strategy or tradition, along with phenomenology, ethnography, biography, and grounded theory” (Brown, 2008, p. 2). Historically, case study research has “antecedents in anthropology, sociology, and psychology” (Merriam, 2015, p.37); however, it wasn't until the 1980s, where most of the evolution of qualitative research methods occurred, that case studies received attention from a methodological perspective (Crotty, 1998; Creswell, 2003; Denzin & Lincoln, 2005, 2008; Guba & Lincoln, 1994; Mertens, 2005; Patton; 1990). Since then, case study as a research strategy has been explored in-depth mainly by three foundational writers: Robert Stake (1978/2000), Robert Yin (1981), and Sharan Merriam (1985). While each approach reveals and contributes new understandings of this kind of research, Merriam's (1998) approach on case study offers an accessible novice-researcher friendly, and pragmatic approach to understanding complex situations holistically. Thus, this research study was guided by her work.

Case study is differentiated from other research strategies because of the focus of the research being a bounded system, otherwise known as a “case” (Merriam, 1998). The case is therefore described as “a thing, a single entity, a unit around which there are boundaries” (Merriam, 1998. p.27). This in-depth focus on the particular unit within a bounded system, helps provide a holistic understanding of a particular phenomenon within a specific context (Merriam, 2015). Accordingly, Miles and Huberman (1994) graphically present case study as a circle with a heart in the center, where the heart is the focus of the study, and the circle "defines the edge of the case: what will not be studied" (p. 25).

Merriam (1998) further defined case study research as “an intensive, holistic description and analysis of a bounded phenomenon such as a program, an institution, a person, a process, or

a social unit” (p. xiii). Focusing on its unique attributes, case study design is “particularistic (it focuses on particular situation, event, program, or phenomenon); descriptive (it yields a rich, thick description of the phenomenon under study); and heuristic (it illuminates the reader’s understanding of phenomenon under study)” (Yazan, 2015, p. 139). Essentially, case study research provides humanistic, holistic and descriptive details about the complexities of a situation and presents information from a wide variety of sources and viewpoints in a variety of ways, making it a valuable research tool. Thus, given that there is limited understanding regarding the social process of nurse navigation, this methodology was appropriate to examine the research question; specifically, the process by which NNs support Indigenous Peoples living with cancer.

Rationale for Case Study Design

Recent publications in nursing research have noted that case study methodology places emphasis on multiple sources of evidence, in an effort to cover multiple realities (Jones & Lyons, 2004; Brown, 2008), therefore highlighting a method of bridging paradigms (Luck, Jackson, & Usher, 2006). In fact, “the flexibility in definitions and uses of case study research acknowledges the need for paradigmatic flexibility” (Brown, 2008, p. 9). However, while a strength of case study research is its flexibility, its scope is bounded and therefore the findings can rarely be generalized (Merriam, 2015). Despite this, case study research can still provide rich and significant insights into specific activities, events, attitudes and behaviours and can “contribute uniquely to our knowledge of individual, organizational, social, and political phenomena” (Yin, 1984, p. 14). Thus, case study seemed like a natural approach to use, given my desire to understand the process by which the NN supports Indigenous Peoples living with cancer.

Furthermore, case studies “may be approached in different ways depending on the epistemological standpoint of the researcher, that is, whether they take a critical (questioning one’s own and others’ assumptions), interpretivist (trying to understand individual and shared social meanings) or positivist approach (orientating towards the criteria of natural sciences, such as focusing on generalisability considerations)” (Crowe et al., 2011, p. 4). Acknowledging subjectivism, Merriam (1998) notes that the combination of the need for constant interpretation within a case study, as well as the need for deep inspection of an individual’s experience indicate that case study’s particularistic design builds on constructivist epistemology. Thus, the relativity and subjectivity that is inherent in the process of nurse navigation makes Merriam’s (1998) case study design an appropriate methodology to study this research topic. Given that the epistemological framework of this case study was based in constructivism, this research methodology ultimately aligns with the interpretive nature of this study.

Utilizing this approach enables me to research a “bounded system” (Creswell, 2003), otherwise known as a “case,” ultimately using informative and contextual data to interpret my findings about the phenomena that I explore. This methodology therefore allows me to gain a more complete and holistic understanding of a specific aspect of a situation and provides affective information that could not have been collected otherwise (MacNealy, 1997). Merriam’s (1998) design acknowledges the relativity and subjectivity involved in this research, and therefore this methodology can lead to an abstract understanding of Registered Nurse navigation through the collection and analysis of data obtained directly from this study.

Setting and Boundaries of the Case Study

In setting a case study, Merriam (2015) concludes that “the single most defining characteristic of case study research lies in delimiting the object of the study: the case” (p. 38).

The case is therefore described as “a thing, a single entity, a unit around which there are boundaries” (Merriam, 1998, p.27). Thus, a case can further be defined by the number of people, a “finite time frame for observation, or the instance of some issue, concern or hypothesis (Brown, 2008, p. 3). Consequently, it is up to the researcher to rise to the challenge of fully articulating the unit under study, as if the phenomenon of interest is not intrinsically bounded (i.e. there is no end, actually or theoretically to the number of people who may be interviewed or observations that may be conducted), it is not enough to qualify as a case (Merriam, 1998). Baxter & Jack (2008) note that boundaries that indicate what will and will not be studied in the scope of the research study are similar to the development of inclusion and exclusion criteria, in that these boundaries indicate the breadth and depth of the study, and not simply the sample included.

In this study, the unit of analysis was the Registered NN. While 10 other navigators exist in the province of Ontario, under Cancer Care Ontario's Aboriginal Cancer Strategy III (2015-2019), not all navigators are Registered Nurses. This case was thereby selected because this Registered NN's role in supporting Indigenous Peoples was “intrinsically interesting,” unique, and under-researched (Merriam, 2015, p. 38). Thus, this study aimed to achieve a full understanding of the NN role as best as possible. The case, therefore, is identified as the NN, and the health care professionals and senior management that work to support the NN.

Further boundaries were set on this case in terms of time, data collection processes, and place. Regarding time, data collection took place over a period of 3 months, during the late winter and early spring of 2019. The window of opportunity gave the data gathering phase logical and specific boundaries. In terms of data collection processes, methods included face-to-face and telephone interviews, as well as a maximum of two weeks of shadowing of the NN.

This boundary further “fenced in” what I studied (Merriam, 2015). Lastly, in terms of place, the case was limited to a tertiary care hospital in the Capital region of Canada, for two reasons: 1) given that this is a masters level study, for feasibility reasons in order to finish within a one-year timeline, broadening the scope of this case to provincial (i.e. Ontario) or federal levels was not possible; and 2) the case was chosen as this NN role was “intrinsically interesting” and unique in serving as a key resource for navigating the health care system in supporting Indigenous cancer patients and families. Ultimately, by pre-defining boundaries “to clarify the nature, and time period covered by the case study (i.e. its scope, beginning, and end),” this ensured that the study remained in scope (Crowe et al., 2011, p. 5).

Participants and Sampling

Sampling

Merriam (1998) provides significant direction for researchers conducting case study research. She discusses the concept of sampling in case study, where she explains two levels of sampling inherent in the design (Merriam, 1998). Firstly, the researcher needs to select the case to be studied (Merriam, 1998). Secondly, the researcher needs to select the sample of the people within the case (Merriam, 1998). Thus, the researcher needs "to consider where to observe, when to observe, whom to observe and what to observe. In short, sampling in field research involves the selection of a research site, time, people and events" (Burgess, 1982, p. 76). In this case study, purposive sampling was used; specifically, a type of purposive sampling known as snowball sampling, whereby each participant referred the researcher to other participants (Merriam, 1998). By utilizing this strategy, participants were identified “from people who know people...who know what cases are information-rich, that is, good examples for the study, good interview subjects" (Patton, 1990, p. 182). This provided for rich and significant insights into

events, situations, and behaviors experienced in working with or supporting the NN. However, given that this was a master's study with time constraints, for feasibility reasons, and as per Patton's (1990) recommendation of specifying a potential sample size "based on expected reasonable coverage of the phenomenon given the purpose of the study" (p. 186); both the intended and actual number of participants in this study was 6.

Specific Inclusion Criteria

In case study research, what is classified as the "case" influences the inclusion criteria. Purposive sampling was used, and the study sample only consisted of health care providers and administration. The sample consisted firstly of a Registered NN working to support Indigenous Peoples within the Cancer Program at a large tertiary care hospital in the province of Ontario, Canada. Inclusion criteria for the NN included: a) being a Registered Nurse in the province of Ontario who works or has worked as a NN, and b) currently navigating or have navigated Indigenous Peoples living with cancer. An oncologist working within the Cancer Program at the tertiary care hospital was also recruited as a participant. Inclusion criteria for the oncologist included: a) being an oncologist, b) working within tertiary care hospital's Cancer Program, and c) having referred patients to the NN or worked with the NN to support an Indigenous cancer patient and their family. Other participants included people in administrative and senior management roles, who work or have worked within the context of the tertiary care hospital, and who have or have had supportive roles and/or direct interaction with the NN. Thus, this study focused on the perspectives of health care providers and management. It is therefore important to note that Indigenous Peoples living with cancer were not interviewed or shadowed and therefore they were not participants in the study.

Recruitment of Participants

Participants were purposively selected and recruited. I recruited and contacted participants by email. Building on a study that is currently in process (University of Ottawa Ethics #: H12-16-24 and H-06-18-787), a relationship with the NN at the tertiary care hospital had already been established. I emailed the NN a brief synopsis of the study (see Appendix A), including the consent form (see Appendix B), where the NN was formally asked to participate by the researcher.

For all other participants, the manager of the Cancer Program at the tertiary care hospital, sent an email invitation (see Appendix C), with a brief synopsis of the study, as well as a consent form. My contact information was included, and participants were asked to email me directly should they be interested in participating.

Data Collection

Data Collection Methods

Case study research does not claim any specific data collection methods, but “focuses on holistic description and explanation” (Merriam, 1998, p. 29). Multiple sources and methods of data collection and analysis can be used in case study research; however, interviews and observations are the dominant data collection methods (Merriam, 1998). Given that I aimed to explore the process and experiences of NNs working with Indigenous Peoples living with cancer, interviews and participant observations using a technique known as shadowing were used (Quinlan, 2008). In-depth individual interviews were held with all participants ($n = 6$), and data was audio-recorded, transcribed verbatim, stored, and analyzed on a password protected laptop.

In addition, Merriam (1998) further commented that while they are highly subjective and must be used carefully, observations are also an important data source (Brown, 2008, p. 4). As such, shadowing of the NN occurred over a duration of two weeks, where I closely followed the

NN for a period of two weeks to allow for more in-depth observational details than traditional observational methods (Quinlan, 2008). Shadowing as a data collection strategy “entails a researcher closely following a subject over a period of time to investigate what people actually do in the course of their everyday lives, not what their roles dictate of them” (Quinlan 2008, p. 1480). It is a collaborative research methodology, and an accepted qualitative research practice (Ferguson, 2016), where the “shadower and shadowee interact and explore roles, they co-create knowledge and understanding” (Ferguson, 2016, p.16). Thus, the use of this technique provided a fuller picture of the NN’s world, including their verbal and non-verbal behaviors, expressions and body language (Quinlan, 2008). Participant observations were documented through field notes in order to gain an intimate familiarity with the NN and their environment, as well as situate the study within a larger societal and temporal context by explicating the process of navigation “inherent in the social organization of everyday activities” (Quinlan, 2008, p. 1483). Given that the focus of this study was on the social process of Registered Nurse navigation, using shadowing as a data collection method was “particularly suitable to answering research questions where the unit of analysis is not the individual but the social relation; positions are explored within a complex of interrelated processes” (Quinlan, 2008, p.1482).

Data Collection Process

All participants were asked to participate in one individual interview. Each interview was took 30-45 minutes and began with open-ended questions to encourage participants’ stories to emerge. Later, questions became more specific in order to explore emerging concepts. A semi-structured interview guide was used to facilitate keeping the interviews focused on the research topic (see Appendices D and E).

In addition to interviews, the NN was also shadowed for a duration of 2 weeks, as consecutively as possible. During this time, I closely followed the NN throughout their day(s), taking field notes, and writing down observations. This included the NN's interactions with patients; however, no data was collected about the patient as the unit of analysis was the navigator. It is important to note that the researcher (myself) who conducted the shadowing is a Registered Nurse and therefore maintained professional ethical and legal responsibilities regarding confidentiality and privacy of client health information, as well as continuously respects institutional protocols of confidentiality (College of Nurses of Ontario, 2017). The NN was not asked to perform any specific activities, as "shadowing entails a researcher closely following a subject over a period of time to investigate what people actually do in the course of their everyday lives, not what their roles dictate of them" (Quinlan, 2008).

Data Analysis

Merriam (1998) notes that "historically, data analysis in qualitative research has been something like a mysterious metamorphosis. The investigator retreated with the data, applied his or her analytic powers, and emerged butterfly-like with 'findings'" (p. 156). However, she suggests that the data analysis process within a case study is "highly intuitive, and that the learning is the doing" (Brown, 2008. p. 4; Merriam, 1998). Accordingly, as a common trend in qualitative tradition, researchers should conduct data collection and analysis processes simultaneously, as "you can be doing some rudimentary analysis while you are in the process of collecting data, as well as between data collection activities" (Merriam, 2007, p. 1954). Thus, there is no exact point in the research process to start analysis because there is no exact point to start data collection (Graneheim & Lundman, 2004).

To begin the intensive phase of data analysis, all the information was to be together and organized in a fashion where data is easily retrievable for analysis. Firstly, audio-recordings of interviews were transcribed verbatim by the researcher. Secondly, observational findings from shadowing and reflective dialogues from journaling were organized temporally, to facilitate recall of events and experiences (Quinlan, 2008). All interview text, field notes and written observations from the participant observations were then imported into NVIVO 12 qualitative data analysis software. Data was then analyzed in levels, beginning with the use of coding (the process where the researcher defined what is happening to begin to make analytical sense of data) (Miles & Huberman, 1994). An initial coding frame was then used to help capture the emerging data themes (Miles & Huberman, 1994). All qualitative data was then deductively organized and inductively coded to allow the key issues to emerge from the data set (Merriam, 1998). As major and minor categories emerged from the coded data, they were raised to theoretical concepts based on the data (Graneheim & Lundman, 2004). Constant comparative methods were then used to determine analytic distinctions and move towards theoretical concepts (Merriam, 1998). The analysis moved “back and forth between concrete bits of data and abstract concepts, between inductive and deductive reasoning, between description and interpretation. (Merriam, 2007, p. 2144). The researcher simultaneously analyzed ideas through memo-writing to write down thoughts, feelings or questions that arose from the analytic process. These steps allowed for a more holistic understanding of the case and the development of themes that were grounded in the data (Merriam, 2007). Accordingly, reflections on the sub-themes and categories served as relevant headings to unify the sub-themes into themes (Graneheim & Lundman, 2004). Through this process of data analysis, a visual depiction of the results was created to illustrate emerging themes and concepts in the data.

Data Saturation

Qualitative data analysis can go on “indefinitely,” and therefore as suggested by Lincoln & Guba (1985/1994) “practical and theoretical indications for ending a study exist” (Suter, 2012, p. 361). Suter (2012) describes data saturation as the “exhaustion” of sources and “saturation” of categories (limited new knowledge appears to be forthcoming), evidence of “regularities” and a sense of “integration,” and “overextended” findings (new data yields information far afield from the research questions of interest) (Suter, 2012, p. 361). Consequently, as new findings emerged from data, they were checked against other sources of data (from interviews and shadowing observations) until a point of saturation was believed to be reached (Suter, 2012). Observational findings from reflective dialogues were also analyzed, and further qualitatively coded, and nothing that contradicted the themes could be found. Instead, additional “data served only to confirm emerging understanding” (Suter, 2012, p. 350), and combining and collapsing of existing themes occurred. This further suggested that data saturation had occurred, as no new information was forthcoming from the analysis. Thus, after being convinced that there was robust evidence for saturation to cover all that had emerged from data collection, I stopped analysis (Suter, 2012).

Rigour

Researchers must take responsibility to ensure rigour in qualitative studies (Cypress, 2017). Being a qualitative case study researcher requires “knowing what leads to significant understanding, recognizing good sources of data, and consciously and unconsciously testing out the veracity of their eyes and robustness of their interpretations. It requires sensitivity and skepticism” (Stake, 1995, p. 50). Stake (1994) further notes that knowledge gained “faces hazardous passage from writer to reader. The writer needs ways of safeguarding the trip”

(p.241). Accordingly, Merriam (2015) stresses the importance of the audience being considered, as they will judge the quality and usefulness of the study. Thus, several techniques were used to ensure rigour, including examining the credibility, dependability, confirmability and transferability of this study (Lincoln & Guba, 1994).

Credibility

Credibility refers to the “confidence in the truth of the data and interpretations of them” (Loiselle & Profetto-McGrath, 2011, p. 276). Measures to ensure credibility include triangulation (Denzin, 1989), “using multiple investigators, multiple sources of data, or multiple methods to confirm the emerging finding (Merriam, 1998, p. 2447). In this study, investigator triangulation occurred by conducting data analysis independently from the thesis supervisor, with the thesis supervisor auditing data coding and analysis decisions. Prolonged engagement with the data, and personally transcribing and coding the interviews allowed for the immersion and intimate familiarity with the data (Charmaz, 2014). In addition, during the analysis phase, weekly meetings were set up with the thesis supervisor in order to review the evolving coding framework, and thematic data emerging. Extensive feedback was also received on the preliminary coding from the thesis committee. Furthermore, data source triangulation also occurred, by using multiple sources of data, and cross-checking data collected through observations at different points in time and in different places, as well as by collecting interview data from different perspectives (Merriam, 2015). Lastly, member-checking was also used as a technique to enhance credibility of the findings (Merriam, 1998). Participants were invited to review the transcripts of interviews to verify the accuracy and provide feedback about any interpretive errors or deficiencies; however, only one participant responded, and no feedback regarding content was given.

Dependability

Given that this is a qualitative research study, the term “reliability in the traditional sense is something of a misfit” (Merriam, 1998, p. 2475-2477). Lincoln & Guba (1985/1994) therefore suggest focussing on “consistency;” in essence, to consider whether the results obtained are consistent with the data collected (p.288). Thus, “rather than demanding that outsiders get the same results, a researcher wishes outsiders to concur that, given the data collected, the results make sense - they are consistent and dependable” (Merriam 1998, p. 2477-2478). Dependability was therefore achieved through the use of multiple methods of data collection and analysis, as the use of “triangulation strengthens reliability as well as internal validity” (Merriam, 1998, p. 2477). In addition, the development of a retrievable audit trail in the NVIVO 12 qualitative software, allows for transparency of the analysis process. Lastly, because interviews and shadowing were both conducted by the same person, this ensured consistency and dependability of study findings.

Confirmability

Confirmability refers to “establishing that data and interpretations of the findings are not figments of the inquirer’s imagination but are clearly derived from the data” (Tobin & Begley, 2004, p. 392). Lincoln & Guba (1985/1994) suggest that confirmability can be achieved through producing an audit trail, reflective journaling, and triangulation. Confirmability in this study was therefore supported through the use of triangulation, and audit trails as Bowen (2009) notes that an “audit trail offers visible evidence—from process and product—that the researcher did not simply find what he or she set out to find” (p. 307). In addition, throughout each phase of data analysis, discussions with both the thesis supervisor, and thesis committee occurred, during which codes and transcripts were read and discussed in depth, to determine analytic distinctions

and move towards more abstract themes and concepts. These meetings heavily influenced the analysis, and the contribution of all members of the committee allowed for greater confidence in findings.

Confirmability was further established by using reflective journaling throughout data collection and analysis, whereby I documented all events happening and personally reflected during and afterwards with regards to my values and interests. This process of interpretation, otherwise known as reflexivity, also included the “assessment of the influence of the investigator's own background, perceptions and interests on the qualitative research process” (Krefting, 1991, p. 218).

Transferability

Transferability is explained as the extent to which the results of this study can be transferred to other contexts (Lincoln & Guba, 1985/1994). However, Merriam (2015) notes that while a strength of case study research is its flexibility, its scope is bounded and therefore the findings can rarely be generalized. Despite this, the “researcher facilitates the transferability judgment by a potential user through ‘thick description’ and purposeful sampling” (Bitsch, 2005, p. 85). Thus, in order to facilitate transferability of this study, I provide a detailed rich description of the context of the study, specifically highlighting the setting, boundaries, and scope of the case study, from beginning to end.

Timeline

This research project was designed to a maximum of 12 months (see Appendix F). Prior to starting this research project, ethics approval was sought.

Ethical Considerations

Ethical Approval

Approval for this study was obtained from both the University of Ottawa Research Ethics Board (uO REB #S-02-19-1150), and the Ottawa Health Sciences Network Research Ethics Board (OHSN-REB #20180917-01H) (see Appendices G and H). Institutional approval from the affiliated tertiary care hospital was also obtained. The study was also conducted in compliance with the second edition of the Tri-Council Policy Statement (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2014). Informed consent was obtained prior to participating in research activities.

Data Management and Storage

Physical Safeguards. During data collection and study analysis, audiotapes, de-identified transcripts, interview guides, and consent forms were stored separately in a locked filing cabinet in the locked office of Dr. Wendy Gifford, in room 1118, at the Centre for Research on Health and Nursing, at the University of Ottawa, located at Roger Guindon Hall, 451 Smyth Road, Ottawa, Ontario. Audio-tapes, de-identified transcripts and interview guides that were stored on my password-protected computer were then transferred to the University of Ottawa network.

Technical safeguards. All de-identified electronic data collected (i.e. audiotapes, transcripts, interview guides, and consent forms) that were stored on my password-protected computer during the study, were then moved onto the University of Ottawa's network for storage. Audiotapes, transcripts, interview guides, and consent forms will be conserved for 5 years after the end of the study.

Upon completion of the study, analysis, audiotapes, transcripts, interview guides, and consent forms will be stored separately in a locked filing cabinet in a locked office in the Centre for Research on Health and Nursing, at the University of Ottawa, located at Roger Guindon Hall,

in room 1118, 451 Smyth Road, Ottawa, Ontario. After the study, electronic data will be removed from the password-protected computer and stored on an electronic storage device that will be stored in the same locked office at the Centre for Research on Health and Nursing, in room 1118, at the University of Ottawa.

Disposal. All electronic, audiotapes, and printed data will be disposed of per University of Ottawa policy at the end of the conservation period.

Free and Informed Consent

Before each interview, I explained the purpose of the study, and reviewed the consent form, highlighting issues around confidentiality and anonymity and answering any questions asked. Accordingly, study participants were given the consent form prior to the interview. Each participant signed the consent form before commencing and was given a copy for their own personal records. For interviews that were conducted over the phone or Skype, consent forms were signed and emailed to me prior to the interview. An explanation was also given that every best effort will be made to protect participants' confidentiality and anonymity. All participants were given a pseudonym, and any personal information or names of places were removed or changed from the transcripts to protect participant anonymity. Furthermore, participants were reminded that they were able to withdraw their consent at any time with no negative consequences and that they could decide what would happen to the data they had contributed thus far.

Lastly, in order to protect confidentiality, I explained that all data collected (i.e. audiotapes, observations, and field notes) were to be transcribed by myself, or by a professional transcriptionist who has experience working with nursing research and with Dr. Wendy Gifford and stored on a password-protected computer. A copy of my data was to be stored on a password

protected external hard drive locked at the University of Ottawa. I further explained that only myself and my thesis supervisor Dr. Wendy Gifford, and members of my thesis committee would have access to the information, and that the anonymized data would be stored for five years after completing my thesis. Afterwards, I explained that the data will be destroyed.

Benefits

Before each interview, I explained the potential benefits of participating in this study. Specifically, I explained that by sharing experiences, participants would contribute to valuable knowledge to better understand the role of registered NN, their experiences, and the processes behind how they provide culturally sensitive care to support Indigenous patients with cancer and their families. Based on the results of this study, in the long-term, care for Indigenous cancer patients and their families may be improved.

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Appendix A
Recruitment Email (for the NN)

Re: OHSN-REB #20180917-01H

Study Title: Providing a culturally sensitive approach to support Indigenous cancer patients and their families: A nurse navigator's experience

I am a Master of Science of Nursing student at the University of Ottawa pursuing my thesis, focusing on the role of nurse navigators providing care with Indigenous Peoples (First Nations, Inuit, and Métis) living with cancer. To date, limited research exists regarding the role of nurse navigators in the provision of culturally sensitive care to the Indigenous population in Canada. I am interested in learning about your current and past experiences as a nurse navigator working with Indigenous Peoples living with cancer, within the context of a tertiary care hospital.

I am hoping to gain a better understanding of the nurse navigator role and the manners in which they support Indigenous Peoples during their cancer trajectory. As a participant in this study, you would be asked to take part in a confidential interview that would last 30-45 minutes. This interview would be held either in person, or over the telephone. In addition, you would be asked to allow myself to shadow you for a duration of 2 weeks. During this time, I would closely follow you throughout your day(s), taking field notes, and writing down observations.

Attached, please also find a consent form with more detailed information regarding the study.

If you are interested in participating, or for more information, please contact me at [REDACTED] or contact [REDACTED], the principal investigator for this study, at [REDACTED].

Appendix B
English Informed Consent Form

Minimal Risk Informed Consent Form for Participation in a Research Study

Study Title: *Providing a culturally sensitive approach to support Indigenous cancer patients and their families: A nurse navigator's experience*

OHSN-REB Number: 20180917-01H

Principal Investigator: [REDACTED]

Researcher: Tara Abdul-Fatah, [REDACTED]

INTRODUCTION

You are being invited to participate in a research study. You are invited to participate in this study because the researcher is aiming to explore the experiences and processes of a nurse navigator and how they support Indigenous (First Nations, Inuit and Métis) people living with cancer, in the context of a large tertiary care hospital.

This consent form provides you with information to help you make an informed choice. Please read this document carefully and ask any questions you may have. All your questions should be answered to your satisfaction before you decide whether to participate in this research study.

Please take your time in making your decision. You may find it helpful to discuss it with your friends and family.

Taking part in this study is voluntary. Deciding not to take part or deciding to leave the study later will not result in any penalty or affect current or future employment.

IS THERE A CONFLICT OF INTEREST?

There are no conflicts of interest to declare related to this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to explore the experiences and processes of a nurse navigator and how they support Indigenous (First Nations, Inuit and Métis) people living with cancer, in the context of a large tertiary care hospital.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

It is anticipated that about six people will take part in this study, from research sites located in Ottawa, Ontario, Canada. This study is part of a master's thesis, and should take one year to complete. The results should also be known in about one year.

WHAT WILL HAPPEN DURING THIS STUDY?

Participation will consist of attending one **30-45-minute audio-recorded interview** during which you will be asked questions and to reflect on the experiences of a nurse navigator (the

researcher and student Tara Abdul-Fatah) or working with a nurse navigator supporting Indigenous Peoples living with cancer. The interview will take place face-to-face with the researcher at [REDACTED] or over Skype if face-to-face interviews cannot be held. If you choose to participate in an interview, you are encouraged to choose a private, confidential, and quiet space.

In addition, if you are a nurse navigator, your consent for participation would also involve consent for the researcher to **shadow yourself for a duration of two weeks**. During this time, you would allow the researcher to follow yourself throughout your day(s), allowing them to take notes and write down observations. You would not be asked to perform any activities outside of your routine ones, and you would not be audio-recorded during shadowing.

HOW LONG WILL PARTICIPANTS BE IN THE STUDY?

Your participation on this study will last for about 30-45 minutes.

However, in addition, if you are a nurse navigator, your consent to participation would also consist of allowing the researcher to shadow you for a duration of two weeks.

CAN PARTICIPANTS CHOOSE TO LEAVE THE STUDY?

You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason. If you choose to withdraw from the study, you are encouraged to contact the research team.

You may withdraw your permission to use information that was collected about you for this study at any time by letting the research team know.

If you decide to leave the study, you can ask that the information that was collected about you not be used for the study. Let the research team know if you choose this.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

There are no medical risks to you from participating in this study, but taking part in this study may make you feel uncomfortable.

You may become uncomfortable while discussing your experiences. You may choose not to answer questions or leave the interview at any time if you experience any discomfort.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

You may not receive direct benefit from participating in this study. However, by sharing your experiences, you will contribute to valuable knowledge to better understand the experiences of nurse navigators and how they provide care with Indigenous Peoples living with cancer. Based on the results of this study, it is hoped that in the long-term, care for Indigenous cancer patients and their families can be improved.

HOW WILL PARTICIPANT INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the research team will only collect the information they need for this study.

Records identifying you at this centre will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document.

Authorized representatives of the following organizations may look at your original (identifiable) records at the site where these records are held, to check that the information collected for the study is correct and follows proper laws and guidelines.

- The Ottawa Health Science Network Research Ethics Board who oversees the ethical conduct of this study
- [REDACTED] *Research Institute* to oversee the conduct of research at this location

Information that is collected about you for the study (called study data) may also be sent to the organizations listed above. Your name, address, or other information that may directly identify you will not be used. The records received by these organizations may contain your participant codes.

During the discussions, participants will be encouraged to refrain from using names. If names or other identifying information is shared during the discussion, it will not be included in the written records.

The video/audio recordings will be stored in a secure location and viewed only by members of the research team. The recordings will be kept until they have been transcribed (turned into written records), and then they will be destroyed.

If the results of this study are published, your anonymity will be maintained by not including any personal information (name or identification) in transcripts, publications, or conference presentations from this research. All study data and participants would therefore be 'de-identified' in any potential publication.

WHAT IS THE COST TO PARTICIPANTS?

Participation in this study will not involve any additional costs to you.

ARE STUDY PARTICIPANTS PAID TO BE IN THIS STUDY?

You will not be paid for taking part in this study.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study.

You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please contact the research team.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

By signing this form, you do not give up any of your legal rights against the researcher, or involved institutions for compensation, nor does this form relieve the researcher, or their agents of their legal and professional responsibilities.

You will be given a copy of this signed and dated consent form prior to participating in this study.

WHOM DO PARTICIPANTS CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, you can talk to the principal investigator who oversees the study at this institution. That person is:

██████████

Principal Investigator Name

██████████

Telephone

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. Please contact The Ottawa Health Science Network Research Ethics Board, Chairperson at ██████████

Study Title: Providing a culturally sensitive approach to support Indigenous cancer patients and their families: A nurse navigator's experience

SIGNATURES

- All my questions have been answered,
- I understand the information within this informed consent form,
- I have read, or someone has read to me, each page of this participant informed consent form,
- I do not give up any of my legal rights by signing this consent form,
- I agree to take part in this study.

Signature of Participant /

Printed Name

Date

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Signature of Person Conducting
the Consent Discussion

Printed Name and Role

Date

Appendix C
Recruitment Email (for all other participants)

Re: OHSN-REB #20180917-01H

Study Title: Providing a culturally sensitive approach to support Indigenous cancer patients and their families: A nurse navigator's experience

I am a Master of Science in Nursing student at the University of Ottawa pursuing my thesis, focusing on the role of nurse navigators, and how they go about providing a culturally sensitive approach to care in effort to support Indigenous (First Nations, Inuit, and Métis) cancer patients and their families. To date, limited research exists regarding the role of nurse navigators in the provision of culturally sensitive care to the Indigenous population in Canada. I am interested in learning about your current or past experiences working with a nurse navigator, within the context of a tertiary care hospital.

As a participant in this study, you would be asked to take part in a confidential interview that would last 30-45 minutes. This interview would be held either in person, or over the telephone. I am hoping to gain a better understanding of the nurse navigator role and the manners in which they support Indigenous Peoples during their cancer trajectory.

Attached, please also find a consent form with more detailed information regarding the study.

If you are interested in participating, or for more information, please contact me at [REDACTED] or contact [REDACTED], the principal investigator for this study, at [REDACTED].

Appendix D
Semi-structured interview guide (for the nurse navigator)

Title/Role

1. What is your current role/title?
2. Tell me about your background. How long have you been a nurse? How long have you been a navigator?
3. What made you want (or decide) to become a navigator?

Activities

4. What do you do?
 - a. Experiences? Processes? What does your role entail? What does it involve?
 - b. Describe a typical day in your role as a nurse navigator
5. In what ways is it similar to care received from other health care providers? Different or distinct from...?
6. What do you think is the most important part of your nurse navigator role?
 - a. Activity? Processes? Experiences?
7. Why are you there?
 - a. Why do you think your role is important?

Challenges

8. What are the challenges you encounter?
 - a. Personal challenges?
 - b. At the patient level?
 - c. At the organizational level?
 - d. At the health care system level? (i.e. politics, discrimination, prejudices, systemic stigma, lack of adequate services? Others?)
9. How have you been able to overcome these challenges?

Strengths, Facilitators, and Supports

10. What are some of the things that support you in the nurse navigator role?
 - a. Organizational support? (management, physical space – Windòcage room, policies?)
 - b. Working with patients and families themselves? (resilience, their cultural practices, their positive outlooks, their spirituality)

Benefits

11. From your experiences, what are some of the benefits?
 - a. Of the nurse navigator role?
 - b. Of this population?

Wishlist

12. Moving forward, if you had a magic wand, what would you suggest to improve your role as a nurse navigator?
13. Do you have any recommendations in regard to the provision of culturally sensitive care with this population?
 - a. Clinical recommendations? Educational? Administrative? Research?
14. Do you have any questions or comments?

Thank you so much.

Appendix E
Semi-structured interview guide (for all other participants)

Title/Role

1. Tell me a little bit about your background... What is your title?
 - a. How long have you been in your role?

The nurse navigator

2. What are your experiences working with a nurse navigator?
3. Can you tell me your understanding of the nurse navigator role?
 - a. What does she do?
4. In what ways is it similar to care received from other health care providers? Different or distinct from...?
5. Why is she there? Why is she important?

Challenges

1. What are the challenges you believe nurse navigators encounter?
 - a. Personal challenges?
 - b. At the patient level?
 - c. At the organizational level?
 - d. At the health care system level? (i.e. politics, discrimination, prejudices, systemic stigma, lack of adequate services? Others?)
2. How do you believe the nurse navigator overcomes these challenges?

Strengths, Facilitators, and Supports

3. What are some of the things that support the nurse navigator role?
 - a. Organizational support? (management, physical space – Windòcage room, policies?)
 - b. Working with patients and families themselves? (resilience, their cultural practices, their positive outlooks, their spirituality)

Benefits

4. From your experiences, what are some of the benefits?
 - a. Of the nurse navigator role?
 - b. Of this population?

Wishlist

5. Moving forward, if you had a magic wand, what would you suggest to improve the role of a nurse navigator?
6. Do you have any recommendations in regard to the provision of culturally sensitive care with this population?
 - a. Clinical recommendations? Educational? Administrative? Research?
7. Do you have any questions or comments?

Appendix F
12- Month timeline

Task	Timeline
Establish thesis committee as per University of Ottawa guidelines <ul style="list-style-type: none"> Complete “<i>Nomination of Thesis Committee Members</i>” form with all required signatures and submit to the assistant director of the Nursing Graduate Programs. 	September 2018
Prepare thesis proposal in consultation with Thesis supervisor (Dr. Wendy Gifford) <ul style="list-style-type: none"> Complete and submit “<i>Thesis Proposal Approval</i>” form 	September 2018
Proposal oral proposal defense to committee members	September 2018
Submit to University of Ottawa Research Ethics Board for ethical approval	October 1st, 2018
Waiting period (to hear back from uOttawa REB) <ul style="list-style-type: none"> <i>Complication:</i> University of Ottawa requires submission OHSN Ethics first, therefore causing a delay in commencing data collection 	October 2018
Request access to Ottawa Health Sciences Network Research Ethics Board (OHSN-REB) system for ethics <ul style="list-style-type: none"> <i>Complication:</i> 6-week delay in receiving username and password for system access for OHSN-REB 	November – December 2018
Submit to Ottawa Health Sciences Network Research Ethics Board (OHSN-REB) for ethical approval	December 2018
Waiting period (to hear back from REB)	January 2019
Approval granted from OHSN-REB	January 30th 2019
Re-submit to University of Ottawa Research Ethics board for ethical approval	February 1st 2019
Waiting period (to hear back from uOttawa REB)	February 2019
Approval granted from uOttawa REB	February 2019
Recruitment of participants	February 2019
Data collection	February – March 2019
Data analysis	April – July 2019
Writing period	April – August 2019
Submit draft thesis to Thesis supervisor for feedback (as many times as required)	July 2019
Prepare and send the list of examiners one month prior to the submission of the thesis. <ul style="list-style-type: none"> Complete and submit “<i>List of examiners for the evaluation of the thesis</i>” form 	July 2019
Submit thesis for evaluation by supervisor and committee (in as many copies as required) <ul style="list-style-type: none"> Complete and submit “<i>Statement of the Thesis Supervisor</i>” form 	August 2019
Prepare for oral thesis defense	September – October 2019
Thesis oral defense	November 2019
Submit final version of thesis for approval by thesis supervisor <ul style="list-style-type: none"> <i>Must be submitted within one month of defense</i> 	November 2019
Disseminate findings <ul style="list-style-type: none"> Submit thesis electronically to the uOttawa library in uO Research 	November 2019

Appendix G
Letter of administrative approval

15/02/2019

Université d'Ottawa

Bureau d'éthique et d'intégrité de la recherche

University of Ottawa

Office of Research Ethics and Integrity

Lettre d'approbation administrative | Letter of administrative approval

Numéro de dossier / Ethics File Number	S-02-19-1150
Titre du projet / Project Title	Providing a culturally sensitive approach to support Indigenous cancer patients and their families: A nurse navigator's experience
Type de projet / Project Type	Thèse de maîtrise / Master's thesis
CÉR primaire / Primary REB	Réseau de science de la santé d'Ottawa (RSSO) / Ottawa Health Science Network (OHSN)
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	15/02/2019
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	30/01/2020

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Tara ABDUL-FATAH	École des sciences infirmières / School of Nursing	Chercheur Principal / Principal Investigator
Wendy GIFFORD	École des sciences infirmières / School of Nursing	Superviseur / Supervisor
Roanne THOMAS	École des sciences de la réadaptation / School of Rehabilitation Sciences	Autre / Other

Conditions spéciales ou commentaires / Special conditions or comments:

OHSN REB # 20180917-01H

550, rue Cumberland, pièce 154 550 Cumberland Street, Room 154
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada

613-562-5387 • 613-562-5338 • ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie | www.recherche.uottawa.ca/ethics

Appendix H
Ottawa Health Science Network Research Ethics Board (OHSN-REB) approval



The Ottawa Hospital
RESEARCH INSTITUTE | L'Hôpital d'Ottawa
INSTITUT DE RECHERCHE



*Ottawa Health Science Network Research Ethics Board (OHSN-REB) / Conseil
d'éthique de la recherche du réseau de science de la santé d'Ottawa (CÉR-RSSO)*

Date: January 30, 2019
Principal Investigator: [REDACTED] TOH/OHRI
Protocol ID: 20180917-01H
Study Title: Providing a culturally sensitive approach to support Indigenous cancer patients and their families: A nurse navigator's experience
Submission Type: Initial Application
Review Type: Delegated
Date of Approval: January 30, 2019
Approval Expiry Date: January 30, 2020

Dear Mrs Barton,

Thank you for submitting the above referenced study. The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the application and granted approval for your study. This approval is granted until the expiration date noted above. This research study is to be conducted by the investigator noted above.

The **OHSN-REB ethics approval** is applicable only for [REDACTED] University of Ottawa Heart Institute and University of Ottawa Faculty of Medicine.

An **Institutional approval (OHRI) letter is required prior to the conduct of the study** at this site. The institutional approval letter is an indication that you have satisfied ethics, contracts, departmental notifications, as applicable.

Documents Approved:

Document Name	Document Version Date
English Informed Consent Form.docx	
English Recruitment Email Script 1 (Nurse Navigator).docx	January 10, 2019
English Recruitment Email Script 2 (Others).docx	January 10, 2019
English Semi Structured Interview Guide 1 (Nurse Navigator).docx	January 10, 2019
English Semi Structured Interview Guide 2 (Director).docx	January 10, 2019

Civic Campus, Box 675, 725 Parkdale Avenue, Ottawa, Ontario, K1Y 4E9
613-798-5555 extension 16719 Fax: 613-761-4311 <http://www.ohri.ca/ohsn-reb>

[Study Protocol.docx](#)

November 12, 2018

No deviations from, or changes to, the protocol should be initiated without prior written approval of an appropriate amendment from the OHSN-REB, except when necessary to eliminate immediate hazard(s) to study participants.

REB members involved in the research project do not participate in the review, discussion or decision.

If the study is to continue beyond the expiry date noted above, a Continuing Review Form must be received by the OHSN-REB on or prior to the full board submission deadline date of the meeting scheduled to occur a minimum of 30 days prior to the study expiry date. If the study has been completed by the expiry noted above, a Study Closure Report must be received by the OHSN-REB.

The OHSN-REB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use; Integrated Addendum to ICH E6 (R1): Guideline for Good Clinical Practice E6 (R2); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. OHSN-REB is qualified through the CTO REB Qualification Program and is registered with the U.S. Department of Health and Human Services (DHHS) Office for Human Research Protection (OHRP).

Please do not hesitate to contact us if you have any questions.

Sincerely,



Francine F-A. Sarazin, Ph.D., C.Psych
Vice Chairperson
Ottawa Health Science Network Research Ethics Board

/hl

Chapter Four

“Working with Indigenous cancer patients and families to navigate health care: The role of a nurse navigator”

This chapter is written as a manuscript prepared for publication and formatted for submission to the

Canadian Oncology Nursing Journal

Authors:

Tara Abdul-Fatah, BScN, RN
University of Ottawa, Faculty of Health Sciences

Wendy Gifford, PhD, RN
University of Ottawa, Faculty of Health Sciences

Gwen Barton, MHA, RN
The Ottawa Hospital Cancer Program, Patient Experience Manager

Roanne Thomas, PhD
University of Ottawa, School of Rehabilitation Sciences

Abstract

This study aimed to describe the experiences of a nurse navigator (NN) working in a tertiary care hospital in Ontario, Canada, and how the NN practiced to support Indigenous cancer patients in a culturally safe manner. Six interviews were performed, and shadowing of a NN occurred over two weeks. Interviews were transcribed, and field notes with reflective journaling were documented during shadowing. All data were imported into NVIVO 12 qualitative software and coded thematically. Analysis revealed the NN to be an important complement to clinical care and a key resource to navigating the health care system, providing mechanisms for building trust, and raising awareness of the historical context of colonization. The NN practiced non-conventional, patient-centered approaches that included engaging with the land and arts, advocating for and interpreting healthcare for patients, and aiding patients to have autonomy over their healthcare. All participants felt the NN had a positive influence on health and wellbeing. Results inform healthcare delivery and nursing practice in helping to improve quality of care and outcomes for Indigenous cancer patients.

Background

Indigenous Peoples in Canada (First Nations, Inuit, and Métis) have long experienced lower health status compared to non-Indigenous people (Allan & Smylie, 2015; Fontaine, 2012; Tang & Browne, 2008). Over the past few decades, cancer among Indigenous Peoples has disproportionately risen compared to overall Canadian sub-populations (Canadian Partnership Against Cancer, 2011; Cancer Care Ontario, 2018; Chiefs of Ontario, 2017; Marrett & Chaudhry, 2003). For example, based on a recent Cancer Care Ontario (2018) report, between 1991 and 2010, the incidence rates for lung, colorectal, kidney and cervical cancer were all higher among First Nations People in Ontario, in comparison with non-Indigenous people. The intergenerational effects of colonialism, residential schools, and systemic racism paired with health disparities related to the social determinants of health, are the root of the health challenges faced by Indigenous Peoples (Adelson, 2005; Kurtz et al., 2008; Wilson & Young, 2008). However, the health disparities that stem from these inequities have also been exacerbated by institutions such as the Canadian health care system in that the indiscriminate application of the Western biomedical model, without critical consideration of its applicability, echoes Eurocentric views and ways of thinking, and has stifled and largely excluded Indigenous ways of knowing (Browne, Smye & Varcoe, 2005). Varying culturally, Indigenous ways of knowing describe the ways in which Indigenous Peoples perceive, understand, and interact with the world around them (Turton, 1997; Wright et al., 2019). The dominance of the Western biomedical model in Canadian health care, which does not align with Indigenous ways of knowing, in addition to lingering racism, has therefore created culturally unsafe and unwelcoming environments for Indigenous Peoples (Arnold & Bruce, 2005; Denzin & Lincoln, 2008; Howell et al., 2016; Smye & Browne, 2002; Sherwood & Edwards, 2006).

Although Indigenous Peoples have been demonstrating resilience in the face of this exclusion and marginalization, Indigenous Peoples with cancer may have difficulty optimizing their health and getting the care they need, as experienced systemic racism contributes to the high rates of non-adherence, avoidance and reluctance to seek mainstream health care services (Allan & Smylie, 2015; Browne et al., 2011; Kurtz et al., 2008; National Aboriginal Health Organization, 2014). This, in turn, reduces the opportunity for screening, early intervention and prevention of health problems, as well as leads to later-stage diagnoses, ensuing implications in terms of treatment and patient health outcomes (Allan & Smylie, 2015).

Thus, the lack of culturally appropriate programs and services, paired with the individual and system level barriers, contributes to the poor health status of Indigenous Peoples (O'Sullivan, 2013). As health care professionals, Registered Nurses are uniquely placed in the health care system, and therefore providing culturally sensitive patient care can hold promise to reducing health outcome disparities (Clifford, McCalman, Bainbridge, & Tsey, 2015; Feather et al., 2017).

Nurse Navigation to Reduce Health Inequities

Worldwide, existing strategies aimed at improving equity in Indigenous health outcomes continue to suggest use of culturally appropriate health care services, particularly cancer patient navigation, as a potential solution to reducing barriers to accessing and using services throughout the cancer continuum (Bernardes et al., 2018; Burhansstipanov et al., 2015; Dohan & Schrag, 2005; Eschiti, Burhansstipanov & Watanabe-Galloway, 2012; Fayerman, 2011; Grimes, Dankovchik, Cahn, & Warren-Mears, 2017; Krebs et al., 2013; Meiklejohn et al., 2017; Natale-Pereira et al., 2011; Warren-Mears, Dankovchik, Patil, & Fu, 2013; Wells, 2008; Whop et al., 2012). In Canada, since the 2000s, cancer patient navigation programs have existed, with new

navigator positions emerging in community and urban settings to specifically address the distinct cultural and spiritual needs of Indigenous Peoples (Cancer Care Ontario, 2015). However, the title of these navigator positions along with their role description varies by region, and therefore navigators are not always Registered Nurses (Canadian Partnership Against Cancer, 2012; Cancer Care Ontario, 2015). As such, although the amount of literature on navigation has increased during the past two decades, the role of Indigenous cancer patient navigation carried out by a Registered Nurse remains relatively new and under-explored. Thus, the purpose of this study was to achieve a deeper understanding of Indigenous cancer patient nurse navigation, through the perspectives of a Registered Nurse navigator (NN) and other related health care providers, administrators and senior management. The research question in this study was: “What are the experiences and processes of a NN working with Indigenous Peoples living with cancer, in the context of a large tertiary care hospital?”

Theoretical Framework

Madeleine Leininger's Culture Care Diversity and Universality Theory (CCDUT) underpinned this research study. Mirroring constructivism (Guba & Lincoln, 1994), the CCDUT acknowledges that individuals should be at the center of care, and ultimately seeks to understand people in terms of their “lifeways, cultural values and beliefs...and living contexts” (Leininger, 1991a, p. 55), valuing both emic (insider) and etic (outsider) insights (Leininger & McFarland, 2006). The strength of Leininger's CCDUT lies in its ability to guide exploration of people's lived realities and provides a broad scope to inductively investigate the Registered NN and the manners in which they support Indigenous Peoples living with cancer in a culturally sensitive manner. In this study, the CCDUT was used as a theoretical lens to discover specific and holistic care through the process of nurse navigation, paying specific attention to the sociopolitical

factors that influence care, wellness, health, and illness beyond the biomedical and psychological dimensions (Leininger, 2002).

Methodology

Study Design

Qualitative Case Study. This was a qualitative case study design following Merriam's (1998) approach, who defines case study research as an "an intensive, holistic description and analysis of a bounded phenomenon such as a program, an institution, a person, a process, or a social unit" (p. xiii). Focusing on its unique attributes, a case study design provides humanistic, holistic, and descriptive details about the complexities of situation and presents information from a wide variety of sources and viewpoints in a variety of ways, making it a valuable research tool (Merriam, 2015). Given that there is limited understanding regarding the social process of nurse navigation, this methodology was appropriate to examine the research question; specifically, the process by which NN support Indigenous Peoples living with cancer.

Setting and Boundaries of the Case Study. In setting a case study, Merriam (2015) concludes that "the single most defining characteristic of case study research lies in delimiting the object of the study: the case" (p. 38). In this study, the unit of analysis was the Registered NN. While 10 other navigators exist in the province of Ontario, under Cancer Care Ontario's Aboriginal Cancer Strategy III (2015-2019), not all navigators are Registered Nurses. This case was therefore selected because this Registered NN's role in supporting Indigenous Peoples was "intrinsically interesting," unique, and under-researched (Merriam, 2015, p. 38). The case, therefore, was identified to be the NN, and the health care professionals, administrators and senior management that work to support the NN. Additional boundaries included: time limitations (3 months for data collection), data collection processes (face-to face and telephone

interviews, and a maximum of 2 weeks of shadowing), and place (limited to Canada's capital region), ultimately ensuring that the study remained in scope (Crowe et al., 2011).

Ethical Approval

Approval for this study was obtained from both the University of Ottawa Research Ethics Board (uO-REB #S-02-19-1150), and the Ottawa Health Sciences Network Research Ethics Board (OHSN-REB #20180917-01H). Institutional approval from the affiliated tertiary care hospital was also obtained. The study was also conducted in compliance with the second edition of the Tri-Council Policy Statement (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2014). Informed consent was obtained from participants prior to participating in research activities.

Data Collection

Participants and Sampling. In case study research, what is classified as the “case” influences the inclusion criteria. Purposive sampling was used; specifically, a type of purposive sampling known as snowball sampling, whereby each participant referred the researcher to other participants (Merriam, 1998). The study sample consisted firstly of the NN working to support Indigenous Peoples with cancer in the context of a large tertiary care hospital, in the city of Ottawa, in the province of Ontario, Canada. Specific inclusion criteria for the NN included: a) being a Registered Nurse in the province of Ontario who works or has worked as a NN, and b) currently navigating or have navigated Indigenous Peoples living with cancer. Other participants included an oncologist, as well as people in administrative and senior management roles, who work or have worked within the context of the tertiary care hospital, and who currently have or have had supportive roles and/or direct interaction with the NN. For feasibility reasons, both the

intended and actual sample size was six. As this study focused on the perspectives of health care providers and managers, Indigenous Peoples living with cancer did not directly participate in this study.

Data Collection Procedures. All participants were asked to participate in one individual interview. Guided by a semi-structured interview guide, six individual face-to-face ($n = 4$) or telephone ($n = 2$) in-depth interviews with health care providers and managers were conducted. Each interview lasted 30-45 minutes and was audio-recorded. In addition to interviews, participant observations of the NN using a technique known as shadowing occurred over a two-week period to allow for more in-depth observational details than traditional observational methods (Ferguson, 2016; Quinlan, 2008). Shadowing provided a fuller picture of the NN's world including verbal and non-verbal behaviors, expressions and body language (Quinlan, 2008). Observations during shadowing were documented through reflective journaling and field notes in order to gain an intimate familiarity with the NN and the environment (Creswell & Poth, 2018; Phillippi & Lauderdale, 2018), as well as to situate the study within a larger societal and temporal context by explicating the process of navigation "inherent in the social organization of everyday activities" (Quinlan, 2008, p. 1483). By utilizing reflective journaling during shadowing, the researcher documented all events happening and personally reflected during and afterwards with regards to personal values and interests. Although patients were observed during shadowing, no data was collected from patients as the unit of analysis in this case study was the NN.

Data Analysis. The analysis occurred concurrently with data collection. Audio-recordings of interviews were transcribed verbatim and then imported into NVIVO 12 qualitative data analysis software. Data was then analyzed in levels, beginning with the use of coding (the

process where the researcher defined what was happening to begin to make analytical sense of data) (Miles & Huberman, 1994). An initial coding frame was developed and then used to help capture the emerging data categories (Miles & Huberman, 1994). All qualitative data from participant interviews were then deductively organized and inductively coded to allow the key themes to emerge from the data set (Merriam, 1998). Constant comparative methods were then used to determine analytic distinctions and move towards theoretical concepts (Graneheim & Lundman, 2004; Merriam, 1998). The analysis moved “back and forth between concrete bits of data and abstract concepts, between inductive and deductive reasoning, between description and interpretation” (Merriam, 2007, p. 2144). Extensive feedback was given on the preliminary coding from both the thesis committee and thesis supervisor.

Observational findings from shadowing and reflective dialogues from journaling provided rich, thick descriptive data, that included verbal and non-verbal expressions and elements of body language observed, and extensive notes on the NN's interactions. This data was incorporated into NVIVO, organized temporally (to facilitate recall of events and experiences), and incorporated into the on-going analysis of the interview data into existing themes (Quinlan, 2008). Further combining and collapsing of existing themes occurred, and no new ones were created. Shadowing data “served only to confirm emerging understanding,” from the interview data and nothing refuted or contradicted the themes, suggesting that data saturation had occurred (Suter, 2012, p. 350).

Memo-writing, where the researcher wrote down thoughts, feelings and/or questions related to the analytic process, also occurred simultaneously during the coding (Merriam, 1998). Following these steps allowed for a more holistic understanding of the case, as findings were checked against all sources of data from the interviews and shadowing observations (Suter,

2012). Through this process of data analysis, a visual depiction of the results was created to illustrate emerging themes and concepts in the data.

Results

Six participants were interviewed in this study including health care providers including a NN and physician ($n = 2$), and senior management and administrators of the Cancer Program ($n = 4$). Table 1. provides demographic characteristics of the participants.

Table 1. Participant Demographics

Demographic Variable			
Role	Years Employed in Position	Gender (Male/Female)	Frequency (n)
Health Care Providers ($n = 2$)	4 – 15 years	F	1
		M	1
Senior Management & Administrators Positions ($n = 4$)	2 – 10 years	F	1
		F	1
		F	1
		M	1
Total			6

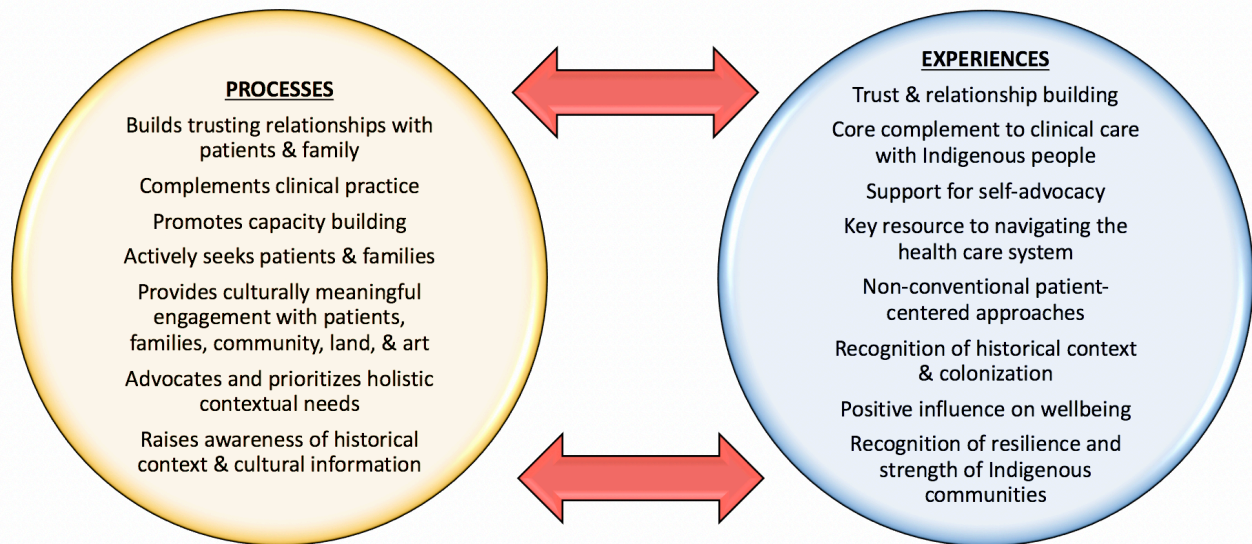
Results from this study are described and visually depicted in terms of the processes and experiences of a NN engaging with Indigenous Peoples, the challenges experienced by the NN in supporting Indigenous Peoples, facilitators and recommended supports of the NN role.

Processes and Experiences of a NN Engaging with Indigenous Peoples

Seven main themes emerged to describe the processes and experiences of the NN role. The themes are depicted in Figure 1. The processes are described as action items and the experiences expressed by participants working with the NN are described as concepts. The bidirectional arrows represent how each process corresponds to multiple experiences, and vice versa (i.e. each experience corresponds to multiple processes). We describe the processes below

with descriptions of how they are interconnected with participants' experiences of working with the NN engaging with Indigenous People.

Figure 1. Processes and experiences of a NN engaging with Indigenous Peoples.



1) Builds Trusting Relationships with Patients and Families. The process of building trusting relationships with patients and families corresponds to participants' experiences of the NN valuing trust and relationship building with Indigenous Peoples. In describing both this process and experience, participants noted the importance of patient-centered care, and the importance of building trusting relationships with Indigenous patients and families, whom historically have a justified mistrusted in the health care system.

The role of the nurse navigator is first and foremost to establish those relationships with people. If you establish individual relationships with people, you can start to open doors on the sharing of what their needs are and how to address them and navigate them and support them through their whole journey... starting from pre-diagnosis, even at screening, to suspicion and diagnosis, right through the whole treatment process... to survivorship or end-of-life care. (Participant C)

Participants further noted the methods in which the NN established relationships as being unique, involving taking action in ways that other navigators and health care providers may not:

The nurse navigator was willing to meet with them outside the organization...willing to take them to Parliament Hill or to Gatineau Park, wherever they were interested, in taking them outside of the hospital environment, to a place where they could feel comfortable and have an honest discussion and just start to develop that trusting relationship. It's an unbelievable role... And I don't know if even some of the other navigators in the other in the province work this way. (Participant F)

Participants also spoke to the importance of having the NN build these relationships, in order to then provide psychosocial support to positively influence Indigenous patients' health and wellbeing. The NN stated:

It's so much emotional and mental health. But as that trust develops, it moves into when they are hospitalized. Because unfortunately, so many of our patients are diagnosed at later stages, if not late-stage, and come here for diagnosis, find out they're palliative and so... In those situations, I really work hard to give positive experiences. Improve mental health, develop that trust, to give them a sense of some control of this terrible diagnosis that they have. And then as we get into when we're in hospital, the relationship is very very strong there... It's very emotional, and it's very touching, but from the patient perspective they know there's someone here that has their back.

Participant C added:

I think the individual cases speak for themselves, about the impact of having that role has had on their journey... it's just those little things that give them that extra boost to continue to take on this journey... the outcomes include expressed gratitude from patients for the support they've received, and it's very positive. (Participant C)

Thus, participant narratives reveal the efforts of the NN to establish a trusting relationship with Indigenous patients and families, and the unique approach the NN used to gain trust with Indigenous Peoples as the foundation of client-centered care.

2) Complements Clinical Practice. The process of complementing clinical is correspondent to participants' experiences of the NN being a core compliment to clinical care for Indigenous Peoples. Participants described the NN to be a core complement to clinical practice, however, not a "replacement" for existing clinical care services, other health care provider roles, or case-management. The NN in describing their role, explained that it is a complementary service:

I can assist, I can complement, but I don't replace any job or organization that's already in place. So just because a person is Indigenous, it doesn't come to me. I'm not going to replace... I'm not a case manager, I'm not a translator, I'm not a social worker. It's business as usual, I'm just an additional voice to complement, should the patient want.

However, and despite the NN being a complementary service, participants described the NN to be an integral part of the patient's care team.

I can't quite remember how long the NN here has been in her role, but maybe about a few years. But over that time, it has become essential to have her involvement in the care. Especially with the Inuit patients...because with the Inuit Peoples, their needs are so high that she takes on a lot there. So, what can I say? To become essential in 2-3 years is a testament to how important she is here. (Participant D)

Participants added that, though the role and navigational service takes place in a health care setting, it is not clinical in its nature.

She's not hanging chemo; she's not delivering radiation therapy from a nursing perspective... the nurse navigator role is more intensive; in that she has the time and the ability to step outside the hospital to develop those relationships with patients. (Participant C)

The NN further added:

It's definitely not a clinical role... I'm not a clinical nurse. I complement. So, I don't need to be in a hospital to take vital signs, or... So, I can review charts if that's what the patient wants. If they want to ask questions about their condition. I'll look in the chart and re-explain, re-explain blood work or things like that. But there's no equipment, other than access to their chart, that I need in hospital. So, it doesn't have to be in hospital.

Thus, though there is a "clinical" aspect to the NN role, it does not operate through clinical service delivery. However, participants explained that the NN being a Registered Nurse is important to the role, as given the complexity of cancer and the cancer care system, the role requires someone with a licensed clinical background.

I think you can imagine some of the complexities with respect to symptom management and understanding diagnoses and helping support them through this complex system, requires someone who understands someone who understands the system, and the terminology and the nature of the disease course. (Participant C)

The NN has a clinical background, she understands the physiology, she understands what the patient is going to be facing when they go through chemotherapy, she understands the care they're going to require physically, clinically, emotionally and spiritually. So, having her as a nurse, she understands everything holistically. (Participant E)

Thus, in supporting patients across the spectrum of cancer, knowing that the cancer system is complex in the way it is structured, providing navigational services as a Registered Nurse allowed for a different level of navigational support.

3) Promotes Capacity Building. The process of promoting capacity building is correspondent to participants' experiences of the NN supporting self-advocacy for Indigenous patients and families. Participants described that the NN promoted capacity building by encouraging Indigenous patients to become their own advocate, steering away from a relationship of dependence, to ultimately assist patients to have autonomy over their own health care.

The NN wants people to discover their own capacity and their own self confidence to be able to take on their own healthcare, right? Which I think is amazing, because if we create this system of like people being so dependent on program that they can't function without it, we're actually doing harm. Because if the program were to disappear, we would leave people in a worse off situation. So always creating that capacity and that autonomy to actually take on their own healthcare is something that's really important to the role. It's something that I think you can see in a lot of the patients as they kind of graduate out. So, for those who go on to survivorship, and kind of graduate the Cancer Program, it's amazing to see the growth.... and see how they've really grown to take autonomy over their own healthcare. (Participant B)

Furthermore, in supporting a culture of independence, the NN described that they did not assume management of any patient, *"I don't go in or escort. So, people think that I'm going to follow them and go to every appointment...it's all about self-advocacy. You taking control, right? So, I'll assist but I'm not replacing."*

Participants added that because the NN provided Indigenous patients with a better understanding of their illness and treatment trajectory, they were better informed to make a decision about their care.

Some might decide that they come down and hear everything of what's going to be required, and they might decide that 'you know what, I don't want treatment.' And that's their choice, but at least I have a sense that they would have a better understanding of what that care trajectory would look like and what it would entail because the NN would have taken the time, either within the hospital setting or outside of the hospital setting where they were more comfortable, to explain that. So, they would have, they would be more engaged in their decision making and they would be making more informed decisions about their care than they were in the past. (Participant F)

Thus, the NN role promoted capacity building and re-enforced the idea of independence by encouraging patients and families to be more autonomous in taking on their own health care.

4) Actively Seeks Patients and Families. The process of actively seeking patients and families is correspondent to both participants' experiences of the NN being a key resource to navigating the health care system, and experiences of the NN positively influencing the well-being of Indigenous patients and families.

Participants described the NN to be a point-of-care and a key resource for navigating the health care system by actively seeking to bridge the gap between the Western health care system, the interdisciplinary health care team, and Indigenous cancer patients and families. For example, Participant B explained:

Having the NN there is incredible. I think she is really needed to help walk people through that system. Especially because of the fear. Like people don't know and are just paralyzed by just coming into the Cancer Centre that they don't even know what to do. And It's so overwhelming to them sometimes that they're not able to, I mean for some folks, they're not even able to put one foot in front of the other. Like it's just they need somebody to come and help them walk that journey. And I think that we're not meant to walk these journeys alone, especially Indigenous People where community is so important. It's like, they need somebody... a nurse that's dedicated specifically to Indigenous folks... So, from a patient-centered perspective, she really puts the patient at the centre of their care. She doesn't have patients come in and say "This is what I can do for you." She says "what's going on in your life? what's going on with you?" and over

time, when they develop a relationship, she will ask “what happened in your life? what have you experienced? and what are your experiences?” and then she’ll ask “what can we do together to help better support you in your cancer journey. So that’s very patient-centered of her, putting the patient at the center of their own care and saying, “what do you need?” And not “this is what I can give you.” Which is amazing.

The NN further explained how they actively sought patients in walls of the Cancer Centre to provide positive experiences.

Okay, so here, I do it a lot and I call it going on a tour. And walk around the hospital a lot, especially in the cancer center. And I see the van that comes from a boarding home for the people from Nunavut who have to come here for care. And so, they’re obviously from Nunavut, often even wearing traditional clothing, and I just go up and start a conversation and being the chatty person that I am, you know, so I’ll ask what community are you from? And then as they kind of get to know me, and it takes 5 minutes, and they just open up and talk about... And I say, you know, part of my role... and I say I realize that it’s hard to be away from your community. I know time can be long here. I’m a different kind of nurse, or I try to do things a little different to give you a positive experience.... So, once I get their name, I can go in the system and see where they are. And then I can do a little pop-in. And usually by the second time they see me, they’re coming to my office to see me.

Participants explained that the NN did not wait in the office for referrals from other health care providers before seeking Indigenous patients.

Her role is so expansive that I think if she sees there’s something that she can fulfill to improve their experience she just does it, she doesn’t even think twice about it. For example, I have a patient with an inherited tumor predisposition syndrome, so many people in this person’s family are affected too. So, the NN sees all of them, even if they haven’t all been referred...by contacting them directly. Even if they are children, at the children’s hospital. (Participant D)

Thus, participants described the ways in which the NN reached out to contact Indigenous Peoples, often irrespective of their diagnosis, in order to connect and let patients and family members know that the NN is there to support them. In shadowing the NN, the researcher also observed the NN physically seek patients and families by leaving the confines of the office and by introducing herself, providing a card and pamphlet with hospital resources, and by directly

providing her telephone number to each patient. In this manner, the NN served as a key resource within the context of the tertiary care hospital for Indigenous patients and families admitted.

5) Provides Culturally Meaningful Engagement. The process of providing culturally meaningful engagement is correspondent to participants' experiences of the NN providing non-conventional patient-centered approaches in supporting Indigenous patients and families.

Through discussions with participants, many highlighted the unique approach taken by the NN to provide culturally meaningful experiences with patients, families, the community, land and arts outside of the hospital setting.

The NN role specifically, is very patient focused, and she does a lot of community engagement, and outreach, and things like that. From a land-based perspective... you want to get people out onto the land. It's even like... because we're not Elders, we don't do land-based teachings, but what we do is we get people out onto the land. So, the NN will take people out and get them even into just the Gatineau park. Which is the most urban land-based thing you could do, right? But it's still amazing. People will really respond to that. Just being near water, and on the land... I mean I think everyone responds to that. But for Indigenous patients, because they've grown up with that relationship with the land, and their life and their teachings are based in the land... Being able to actually get back to the land is so important to our Indigenous patients. So really, it's amazing the things that will come out and the experiences that people will share that really often people will disclose a lot of trauma to the NN when they're like on the land. That kind of thing is really incredible. (Participant B)

Participants described that the NN strived to put the patient at the centre of care, and therefore worked from a patient-centered land-based culturally appropriate lens.

From a cultural perspective, just trying to get people into environments and situations that really support them in their own cultures. The NN really tries to get people out of the hospital, and that's a really important thing to do because this environment just doesn't support the Indigenous people. It's just not a natural environment for them, and often it can invoke feelings of fear or mistrust or like unease. And it's not on the part of the individual health care practitioner, but it's just the system, right? So the NN really tries to get people out of the hospital, and in places that are comfortable for them, and tries to support them in a way that they need, so whether that's emotional support, or whether that's helping to explain a diagnoses, or sit with them, I know she has become an integral part of patient's care teams where they don't want to hear news unless she's in the room with them. (Participant E)

Furthermore, in shadowing the NN, the researcher witnessed the NN take Indigenous patients and families, including Elders, to a horse-carriage ride in the winter, several hockey games, as well as trips to Cabela's Hunting and Fishing store. The NN, in describing culturally meaningful approaches in the provision of care, spoke to the importance of these experiences:

I try to give experiences that's special and meaningful and they wouldn't really have the opportunity to do if they weren't here. If they were just here on their own. I mean there's so much... Well, look at it. If you and I were to go to Nunavut, and they put you and I in the middle of a trap line in Nunavut, no help. Now you get from A to B, with no assistance. How would you feel? Lost, right? So, I kind of tap into that. So there's lots of pretty things to do here in Ottawa, and they don't drive, and the bus is hard to navigate so... I just use an approach with every patient like let's get out to Gatineau Park, let's go for a ride, let's do whatever you want... I just saw it as like I knew in my heart it was the right thing, just having the interaction with the patient.

Thus, the NN was described to use non-conventional, patient-centered approaches to provide opportunity for engagement with the land, and arts, to ensure that the health care Indigenous patients are receiving is safe, comfortable, and culturally welcoming.

6) Advocates and Prioritizes Holistic Contextual Needs. The process of advocating and prioritizing holistic contextual needs is correspondent to participants' experiences of the NN's recognizing the historical context of colonization on Indigenous patients when providing care. Participants' experiences revealed the importance of the NN advocating for and prioritizing Indigenous patients and families' holistic needs within their historical and cultural context in order to better provide health services.

Because she's made sure the team understands the sensitivity and the cultural issues and how they're important and that if somebody wants to have a Smudging exercise then we need to do that. And the alternative therapies that are so important to them, we really wouldn't have understood that unless the NN was advocating and telling the teams, you know what, you got to question yourself, it's not just about chemotherapy, if this alternative or complimentary therapy is important to them, this is what they believe in, we need to support it. So, from a patient and a person-centred perspective, this role has been vital... I think the patients felt that if there was any way that the NN could help, they knew that she would, and she would help facilitate whatever they needed to make sure that it happened. (Participant F)

Participants further explained that the NN role is distinct in that they have the time to understand the context of people.

Nobody else has the time in day to be able to do the things that she's doing. It wouldn't happen otherwise. Even though we've educated staff and physicians and everybody else on the team, nobody would understand it because they've not done what she's done to understand the impact that the role has had. (Participant F)

During shadowing, the researcher also observed the NN schedule activities with patients after-hours (i.e. post day-time hours) including weekends, thereby making themselves available to support patients and families whenever required. The NN added, that the role is more than a job in their perspective and is advocacy focused.

They're here with cancer. And they're removed. And they're mistreated. And there's racism. And there's all these obstacles, and they're in addition to this. All these other things they have to face. So of course, you need a nurse navigator to come in with the knowledge and do something. And by doing something, it's not just sitting here... like, you've got to walk the walk. We do all these things, and we cry, and there's no shame in tears. They know we care, right? There's just a lot of work to be done... I take it to heart. It's not just a job. It's really advocacy.

These findings suggest the importance of the NN role in dually advocating for and providing holistic care that is responsive to the needs of Indigenous Peoples.

7) Raises Awareness of Historical Context and Cultural Information. The process of raising awareness of historical context and cultural information is correspondent to participants' experiences of the NN speaking to the resilience and strength of Indigenous communities.

Participants described that the NN raised awareness of the historical and cultural context of Indigenous Peoples in Canada, and the resilience demonstrated by this population through the provision of education both individually (i.e. one-on-one) and organizationally (i.e. group activities).

Another component of the whole program, including the NN role, is providing cultural awareness information whether it's one-on-one, participating in a [KAIROS] Blanket

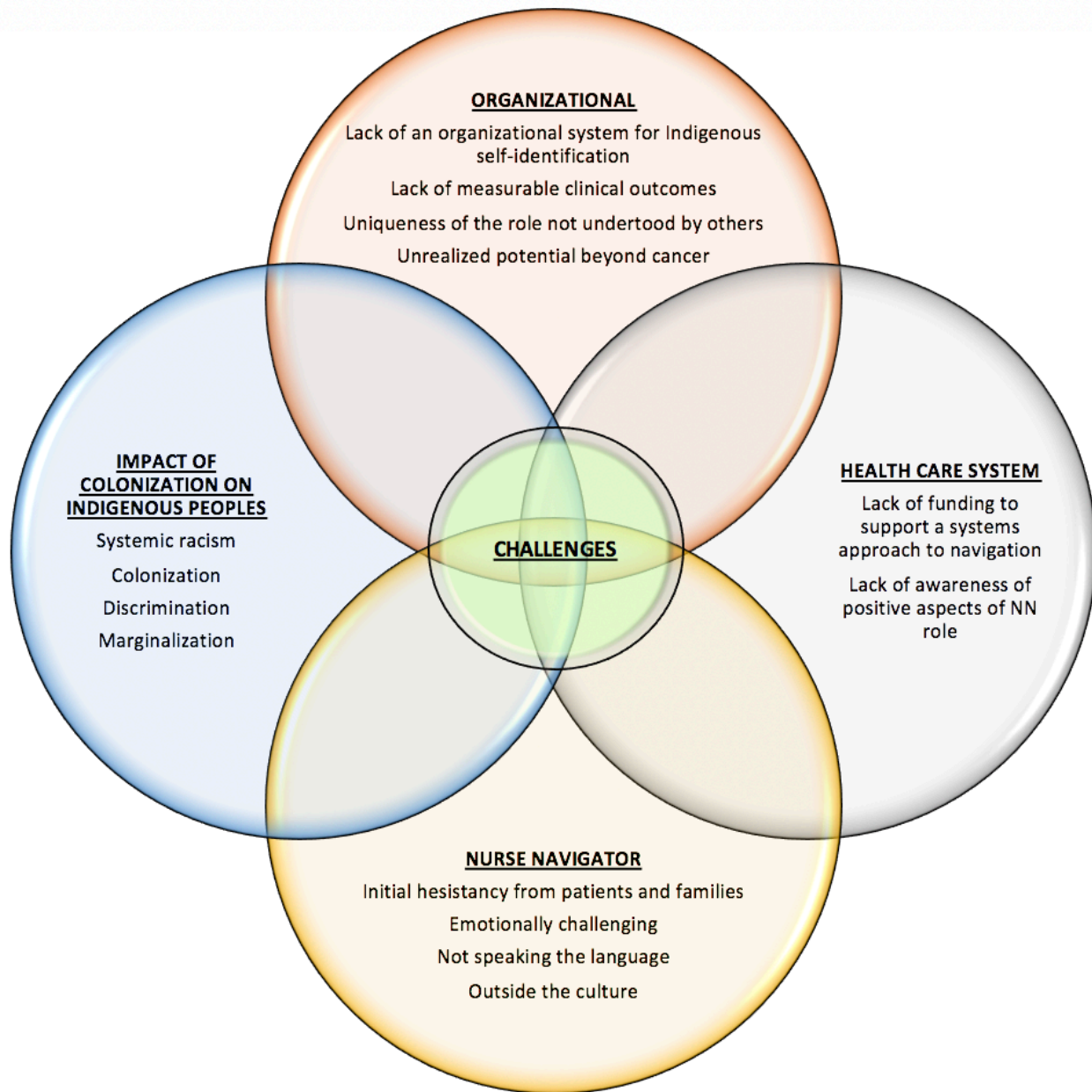
Exercise, or a formal presentation. And so, when you hear people who participate in the Blanket Exercises say “Oh my gosh, I never knew that” – you realize the impact the navigator, and really the entire program is having on changing the relationships between Indigenous Canadians and other Canadians. It’s breaking down some of those walls and those silos to build those relationships, and not to erase the history because you don’t want to ever forget, but to move forward with it, and begin to address some of those calls those Truth and Reconciliation Calls to Action, and this is our way of doing that.

(Participant C)

The NN further highlighted that although Indigenous Peoples have demonstrated resilience in the face of marginalization and discrimination, “*we still have a lot of things that need to be fixed, and there are things that need to be addressed*” suggesting starting with education. These findings revealed the efforts of the NN in trying to create a more culturally safe and welcoming environment by increasing staff awareness of Indigenous culture and history through education.

Challenges and Supports

Challenges. Four categories of challenges emerged to describe the challenges of the NN role in supporting Indigenous Peoples receiving cancer care. Three categories describe the level in which the challenges were related, being the levels of the: 1) nurse navigator, 2) organization, and 3) health care system. A fourth category also emerged of challenges that influenced each of the levels: the impact of colonization on Indigenous Peoples. The challenges are depicted below in Figure 2.

Figure 2. Challenges experienced by the NN in supporting Indigenous Peoples

1) Nurse navigator level. The NN experienced several challenges at the individual level when supporting Indigenous patients and families: specifically, initial hesitancy from patients and families, emotional challenges, not speaking the language, and being outside of the culture.

Initial hesitancy from patients and families. All participants alluded to the challenge of trying to create meaningful connections and establish trust and a relationship with Indigenous Peoples who have a justified mistrust with the health care system.

I think there's almost a disbelief that there's this person out there that's really dedicated to helping you through the cancer system, or through any health care experience, when in the past you haven't really had that. So, there's a bit of surprise- and it's a pleasant surprise – but there's a bit of hesitance. Do I trust this person? When can I begin to trust this person? How can I trust this person? So, there's a bit of relationship building, and that requires a certain personality...and our NN has that. So I think that those barriers start to come down quickly, and then there's word of mouth among the patient population that spreads and says “when you go there, talk to so and so” and so that starts to build referrals, and a volume of patients that she follows. So from a patient's perspective, it may be that disbelief and possible unwillingness to self-disclose, because of that history of “well, do I really want to tell my story to another person? What can they do for me?” – so really a bit of mistrust. (Participant D)

Emotionally challenging. The NN also explained that on a personal level, the role is emotionally challenging, sometimes requiring time off to cope.

And so that's challenging for me on a personal level, because obviously I'm very passionate about what I do, and what I believe in. It's not just a job for me. It's sad when patients pass away... or, you know it's really hard because you get so involved. Sometimes you take that step back. I had a teen where... I just needed some time. You know, it might be a day or some time... so it's challenging and it's emotional. You have to take care of yourself in terms of healthy choices.

Not speaking the language. Participants also explained that the NN encounters a challenge of not speaking the language. Participant D stated “*the NN still has the challenge of not speaking the language,*” and Participant E added:

I think the other challenge is trying to create meaningful connections... especially with our First Nations, Inuit and Métis cultures, language, being able to create that connection and to establish that trust and that relationship with different groups and having credibility within those different groups can be a challenge.

Outside the culture. At the level of the NN, in supporting the FNIM population within their own culture and context, being outside of Indigenous cultures was described as a challenge.

If a problem is that these people coming down from the North and are dealing with White Southerners telling them what to do, well then, the NN is just another White Southerner. I mean I think she establishes a different orientation with these people pretty quickly, but I mean at least initially there's probably – people have no intrinsic reason to trust any more than anybody else. So that's a challenge. (Participant D)

I think that the biggest challenge for the patient is, first of all, here is somebody who is perceived as an outsider... and trying to develop that trusted relationship. So, for the patient, it's 'okay and who are who?' she's reaching out wanting to develop that relationship... So, from a patient and family perspective, that doesn't happen in one meeting. She has to be willing to put herself out there but also at their convenience not hers. So, she's got to be willing to be extremely flexible and open-minded... So, from a patient's perspective, you don't want them to think, here's somebody else I have to tell my story to, who's a total stranger, whereas when they know and they meet the NN and understand what she can help to provide to them then they become extremely grateful. But it's got to be tough to start to try and develop that relationship with total strangers. Because she is a stranger. (Participant F)

Thus, the findings suggest the importance of establishing trusting relationships in order to overcome these challenges.

2) Organizational level. Participants described organizational level challenges experienced by the NN in supporting NN challenges, mainly: a lack of an Indigenous self-identification system, a lack of measurable clinical outcomes, the uniqueness of the role not being understood by others, and the unrealized potential of the NN role beyond cancer.

Lack of an Indigenous self-identification system. The NN explained that there is no self-identification system in place at the hospital to provide Indigenous Peoples the opportunity to self-identify, presenting a barrier to providing navigational services.

There's no self-identification at the hospital to self-identify if you're First Nations, Inuit or Métis. So that's a big barrier. Other hospitals have it, but we don't. So that's a hospital wide question that we're working on because again, I'm just cancer. Officially. But this is gone beyond cancer. But even just coming into the Cancer Centre, there's no self-identification.

In describing this challenge, the NN explained that the lack of a self-identification system is a reason why they physically leave their office, and actively and physically seek Indigenous

patients and families. To change, the NN suggested that the organization partner with other institutions provincially and across Canada who have already implemented a self-identification system to learn from their experience.

Lack of measurable clinical outcomes. Participants explained that since the role does not operate through a clinical service delivery model, it does not produce measurable clinical outcomes, ultimately posing a risk to the existing NN position in the organization.

It's very difficult to put a measurement around it. So, I would think that people would say, "Oh this is not a need-to-have role, but a nice-to-have role" where I would differ and say this is a need-to-have role because honestly I know the care that is being provided to those patients now is better than it ever was. Because she's made sure the team understands the sensitivity and the cultural issues and how they're important... I would cut something else before cutting that role. (Participant F)

I suspect the challenge that people in her position would have at the organizational level, would be that the deliverables for her job are hard to quantify. At some point, the hospital is being constantly crunched for money, and so they'll say: "what are we getting for what we're paying here?" and it'll be hard to graph or chart. So that would be a challenge at the organizational level, I mean A) Retain the positions we have, or B) if we try to expand them or get more... the challenge would be that the outcomes... I think there are people in the hospital who have no choice but to pay attention to the dollars and cents all the time, and so I think it'll be hard to show the ability of that position in those terms. (Participant D)

Participant E suggested that more studies focused on measuring the impact of the NN role could help demonstrate the value of the role.

I think clinically more studies would be really helpful in an evidence-informed sort of environment that we're in that actually does measure the impact of a NN's involvement on health outcomes in some way. Having robust data that way I think would be really helpful... That would provide support for health systems in our organizations to demonstrate the value of roles like these. I think that would be really helpful.

Thus, through these narratives, participants suggested that because of the lack measurable, quantifiable, clinical outcomes, it essential to advocate for more research, as well as to both horizontally (i.e. among staff) and vertically (i.e. to those in senior management) spread information about the beneficial aspects resulting from the role, starting with leadership.

Uniqueness of the role not understood by others. Another challenge faced by the NN is that the uniqueness of the role is often not understood by others organizationally, thereby discrediting the NN role and devaluing the positive aspects associated.

From an organizational perspective, without the cultural awareness and the history and the background on why this program exists, there could be this “Oh my goodness, she has a cushy job! She gets to take patients out to the park!” So, there’s that old school... sort of putting your values on a role that’s not well understood without learning more about it. And you can sometimes understand that when some nurses have 8 patients on a busy unit, and you don’t have time to go to the bathroom, let alone provide all the nice bits of care that you would love to provide. So, there could be a bit of “Gee... well I’d love that job.” So, without the history or the understanding of the background of FNIM, there could be a lack of understanding and sort of discrediting of the role. (Participant C)

Participants therefore suggested that the reason for the role not being understood stems from a lack of understanding and awareness related to the historical and cultural injustices experienced by Indigenous People and allude to the idea that racism, even if unintentional, continues pervade and persist in health care domains. Findings thereby suggest a need for cultural change in health care.

Unrealized potential beyond cancer. Through discussions with participants, several mentioned the unrealized potential of the NN role beyond the Cancer Program, explaining that there are many Indigenous Peoples all over the health care system that could benefit from nurse navigational services.

There are needs outside of cancer and it’s kind of rich here in that we have the dedicated team to support patients and family members. There are Indigenous patients in all aspects of our hospital, and in this whole region that surely could benefit from the same support and attention... one person could not do all that. The navigator has been called upon to help with other cases, whether its cardiology or orthopedics, but we are funded by the Cancer Care Ontario. So, we do help, and we do whatever we can, but fundamentally our target is cancer. (Participant C)

The NN added that there is a specific need to address the patients coming from the eastern sector of Nunavut as the hospitals in Ottawa, the Capital region of Canada, serve as the main catchment

centre for this population. The NN stated, *“we need a Nunavut program. We have these patients coming in from Nunavut for all aspects of their care, all of it. And they're all passing away here...we need a much broader Nunavut program.”*

Thus, in response to the distress experienced by Indigenous Peoples when engaging with the healthcare system, though the NN role is technically targeted towards Cancer patients, the NN goes beyond the walls of the Cancer Program when needed. These findings highlight that despite efforts, current health policies and the current navigational system is inadequate in its approach to create conditions for equitable access to health services, especially for patients coming from the North.

3) Health care system level. At the health care system level, participants described two main challenges: a lack of funding to support a systems approach to navigation, and a lack of awareness of the positive aspects of the NN role.

Lack of funding to support a systems approach to navigation. Participants described that because of a lack of funding on a systems level, the NN is limited in the provision of navigational services.

So not providing adequate funding to be able to do the services that she needs to do, so like everything that we do with our program and even like the amazing things that the NN's been able to do have been on a very limited budget. And that's not coming from our direct supervisor, or manager, or VP, that's not coming from them – it's systems level. And it's huge. That's like a funding level kind of thing. Like she's not able to have access to a lot of funding to be able to do services. And that comes from like a place of.... well why would we do this specifically for Indigenous People and not for like other people? Right? So yeah there's a bit of discrimination and a bit of prejudice. A bit of misunderstanding of why we would provide these services specifically for Indigenous People. (Participant B)

Thus, participants described that the current health systems approach does not recognize and prioritize the needs of Indigenous Peoples in Canada, thereby limiting the navigational support available. These findings suggest the need for cultural reform in health care, as on a

societal level, there must be commitment on a political level, to address systemic racism and create change to improve access to health care for Indigenous Peoples.

Lack of awareness of positive aspects of the NN role. On a societal level, the lack of awareness of the positive aspects of the NN role also presented as a challenge.

If you're not providing that direct care such as hanging chemo, or delivering the radiation, I suppose there's a risk that those who are not understanding what we're doing, can say "well that's an easy program to cut," from a budget perspective. So, there may be always a need to share what we're doing, and why and the benefits of it. So, in the back of my mind, when we're out at our director's office, we're speaking of the benefits of it, and the positive aspects, so that we know that others are aware of it. (Participant C)

These findings highlight the need for a shift in the entire system's perspectives regarding the NN role, starting with a reorientation of public attitudes and perspectives to one that values the NN role and the positive aspects associated.

4) Impact of colonization on Indigenous Peoples. Participants described that an underlying theme to all experienced challenges is the presence of systemic racism that has persisted at all levels of the health care system, which serves to further perpetuate Indigenous Peoples' lower health outcomes.

Some people may be challenged as to why we would provide such dedicated resource-intensive support to some populations and so that might come up from time to time. So, that could be challenging in certain scenarios. Especially if that person's a leader or has some sort of influence. If you're having to explain why certain populations face this specific burden and why we need to provide a different level of support to care for them in an equal way. That is a challenge. (Participant E)

Participants also added that some individuals are under the illusion that in health care everyone is treated equally, so there is no need for the provision of culturally specific care in supporting the Indigenous population. Other participants explained that some individuals believe racism to be an issue of the past. Participant B stated "*some [people] think, well in health care, everyone is*

treated equally... or supposed to be, but, you know, so why treat Indigenous patients any differently?"

Participant D explained:

Systematic racism against our Indigenous population, unlike what some may believe, is not something of the past. It's still a daily thing. And that's the kind of awareness that perhaps, coupled with awareness of what the NN does, could be a template for others to copy or emulate.

The NN further added:

The biggest challenge I found is starting...from my first days, it's been discrimination. "Why do you have that job? Why do they get their own navigator? We are a multicultural hospital. Shouldn't every culture or people have their own navigator? Why do the First Nations, Inuit and Métis have it? Well, of course they have it!" ... And the history, the true FNIM history is not taught in school. We're only beginning to teach those truths in school. So, it's quite overwhelming... it was really... it's dispelling the myths. That's the huge challenge, and that's the challenge that will carry on for another hundred years. Dispelling the myths.

Thus, given the pervasive nature of systemic racism in Canada's educational system, similar systemic issues must be recognized in the health care system. The findings suggest that starting with leadership, education on the colonial history of Indigenous Peoples could firstly, serve to dispel myths, stereotypes, and prejudices associated with Indigenous Peoples, and secondly, help to ensure that racism is not being further (intentionally or unintentionally) perpetuated in health care, thereby instilling cultural change.

Lastly, in addressing systemic racism and the damage wrought on by a colonial past, and in moving towards more equitable health care, participants described the need to specifically include the voices of Indigenous Peoples to inform and implement a culturally safe model of care.

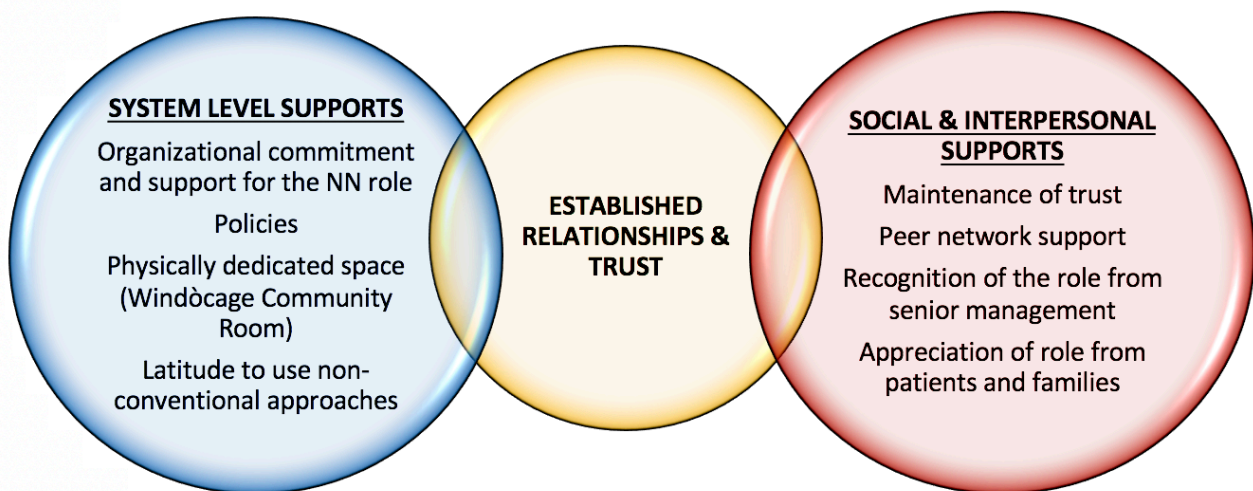
I think that the more solutions are codesigned and the more we listen, the more that trust is established... I think it's our actions in planning together and in creating those networks together that will truly be the next step. I think acknowledgement is one thing, I

think trying to do better is another. And then kind of the next iteration will actually be a true desire to codesign a system and model for care together. (Participant E)

Thus, in acknowledging the impact of colonization on Indigenous Peoples, participants agreed that Western knowledge and the biomedical perspective deeply rooted in Canada's health care system does not incorporate Indigenous holistic ways of knowing, and thereby call for the integration of Indigenous perspectives in research to co-develop an "Indigenized" model of care.

Supports. There were two main themes that emerged when discussing the supports experienced of the NN role: 1) the system level supports, and 2) the social and interpersonal supports. A third sub-theme was also found to influence both mentioned supports: the established of relationships and trust with Indigenous Peoples. All facilitators and supports are depicted in Figure 3.

Figure 3. Facilitators and supports of the NN role



Established relationships and trust. Participants explained that the NN's role builds upon established relationships and trust with patients and families, and community. Thus, the most crucial support is described as trust coming from Indigenous patients, families, and communities.

We're trying to increase screening rates through our program... and through those relationships we're building hopefully we'll save lives if you have more people being screened and getting cancers caught earlier in the trajectory, then we can hopefully see overall improvements in the health and longevity of our Indigenous patients and family members. (Participant C)

Participant narratives suggest that without trust, the NN would not be able to provide the navigational service, and thereby would not be able to address the inequities and inequalities experienced by Indigenous Peoples in accessing health care.

System-level supports. Four main system level supports were described: the organizational commitment and support for the NN role, current in-place policies, physically dedicated space, and the latitude to use non-conventional approaches in the NN role.

Organizational commitment and support for the NN role. Participants explained that the role of the NN, in the way that she works to support patients, would not be possible without the organizational commitment, trust, and support from administration and senior management.

I think the support administratively of the centre, to say that "this is a priority, and this is something we will continue to do, and your work is important to us, and were going to continue to do it" is there. (Participant D)

The Administration, they had to trust that she was doing it for all the right reasons and think that 'okay this is not the typical way that you would think that we would be having staff spending their day but we did it for the right reasons'. (Participant F)

Participants also described the manners in which the NN was provided specific opportunities from administration that permitted the NN to directly reach out to management in order to support Indigenous communities in a non-conventional way.

I think the other thing we have is an ongoing Steering meeting, where we have leadership for ourselves at the hospital and others in our regional Cancer Program present. Where our navigator shares a patient's story that roots us in the importance of the work and the navigator is able to participate and bring up a systemic issue that she has concerns with or that she sees. Or perhaps ethical issues that have arisen. So, that forum exists to escalate things. (Participant E)

Policies. Policies implemented organizationally, such as the Smudge policy, allowed for the NN to support Indigenous patients and families in a culturally sensitive manner, by acknowledging the importance of this spiritual practice.

The smudge policy we just passed in January, the most recent version of it, and it's another strength, because it supports the patients because they're able to practice that spiritual practice in the hospital. And it really legitimizes and allows patients to feel pride in their culture in that it's something that's allowed. So a lot of what the NN does is promoting this to patients and saying things like this is available to you, and if you want to do this let me know and we'll set it up. And that's when the NN will get in touch with me, and we'll do all the organizational stuff behind it. And it really makes a difference. Patients say that it's just incredible and they'll say you know, "this is just what they needed to take on my treatment" or like "I feel like my care is complete now." Things like that where you're like this is amazing... and it really drives home the holistic piece.

Physically dedicated space. Physically dedicated space, such as the Windòcage Community Room in the hospital, developed in consultation with Indigenous communities, is further described to support the NN in creating a welcoming space for Indigenous patients and families.

We have the Windòcage room... and it's our Indigenous community room. And it was developed 4 years ago I believe, maybe even 5, in consultation with Elders from all three groups, so Métis, First Nations and Inuit. And it's a community room for people to go and rest and relax between treatments. So often we'll have patients who go there to eat their lunch between treatment, or they'll rest before or after treatment. A family member will wait for a patient, or if somebody... like if a patient is in the ICU, for example, so it's not a cancer patient, then their family members might be here all night, so they might come and take a nap in the Windòcage room. They'll just close the door. And so, it's really a very multipurpose room and we also do our smudging in there, and it's just a very welcoming space for Indigenous folks. (Participant B)

As such, having a dedicated multipurpose room is described to be distinctly welcoming for Indigenous Peoples, especially when recognizing the difficulty in finding a space in a busy hospital environment.

Latitude to use non-conventional approaches. The NN was further supported by the flexibility and latitude from leadership and management that allowed her, in her evolving role, to use non-conventional approaches in practice.

Anything that she's felt that she needed to do in that role, she's had the opportunity to do it... And there's still that flexibility and trust in the individual. Part of it is the individual. So, that that role can still be as creative and innovative as it needs to be. Because that will be important. If you change the Leadership team and people come in and say, 'what the heck are you doing that for? That's not necessary, that's overboard'. That role could be confined. This role is not confined in any way shape or form. It's metastasized into whatever it needed to be. It has just morphed into anything that it needed to. And I think that's important... That the leadership can continue to support the evolving role and trust the individual that's in it, whether it's her or somebody else. (Participant F)

Social and interpersonal supports. Participants noted four main social and interpersonal supports: the maintenance of trust from management, peer network support, recognition of the role from senior management, and appreciation of the role from patients and families.

Maintenance of trust. The commitment of the NN to maintain trust from Indigenous patients, families, staff, and senior management further allowed the role to develop to the extent that it has.

To have that commitment to purpose is essential because without that passion, seeing through some of those barriers on both sides, to be honest, and creating that connection with the community, to be able to build that trust to see through and to get through all of the people, the patients, the community members that might be sceptical as to why you want to do this, of why you want to create that connection with a culture that might be different than yours, et cetera, et cetera... I think a person needs to be passionate, they need to be positive and they need to be relentlessly committed to improving and to reducing that disparity. (Participant E)

Peer network support. A strength of the NN role and program was described in the way the role received support from both the team and staff within the Cancer Program, as well as provincially amongst other navigators. Participant B stated, "*the strength I think of the program here, and the way the roles have developed in the Champlain Region, is that we work really closely together.*" Participant E added:

CCO through those roles also has annual face to face type events where the Navigators in each of the regions can connect and to plug in to what innovative initiatives people might be involved with in other regions, what sorts of ideas they're using, what strategies they're using to connect with. So, there's that kind of peer support network that exists."

Accordingly, the NN explained that "*support from your team for your mental health*" further optimized the functioning of her role.

Recognition of the role from senior management. In describing the positive strengths of the role, the NN referred to the recognition and appreciation received from administration and senior management. The NN stated:

I didn't come in looking for any of this... but the recognition from my team, from my directors, from the CEO. Like it's just so much appreciation.. And it just kept building and building and building, and the recognition just kept coming in. And it was like, this is great! So, people way above me saw the value in it, and they saw it in ways where I didn't.

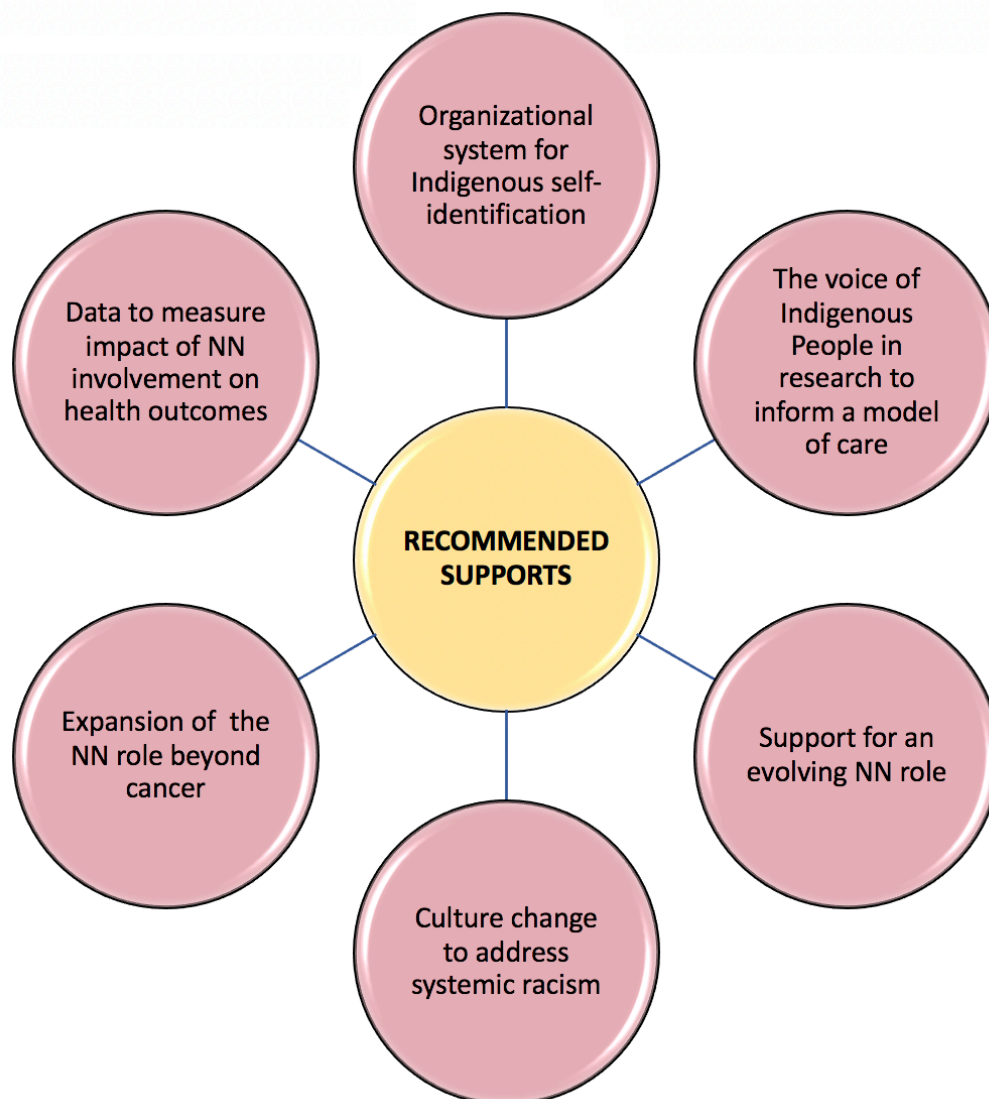
Appreciation of the role from patients and families. In working closely with the Indigenous community, receiving words of gratitude and thanks from patients and families were described as important supports in the NN role. The NN explained, "*the relationship with the patient. I've never felt so appreciated, and respected, and valued... ever. It's unbelievable. It's like the gifts, and just so much appreciation.*" Participant E added:

I think if you ask [the nurse navigator], I think she'd say that the support she gets, in particular with the Inuit community is their connection with the people and the connections she makes with patients and families are really at the essence of what she does and the support that she needs.

In essence, the support and appreciation for the NN's holistic and culturally sensitive approach in her provision of care further demonstrates the significant positive impact that the role has had on Indigenous patients and families.

Recommended supports. In moving forward participants discussed six main recommendations to further support the NN role: 1) an organizational system for Indigenous self-identification, 2) the voice of Indigenous Peoples in research to inform a model of care, 3) support for an evolving NN role, 4) culture change to address systemic racism, 5) expansion of the NN role beyond cancer, and 6) data to measure the impact of NN involvement on health outcomes. These supports are depicted below in Figure 4.

Figure 4. Recommendations to further support the NN role



Discussion

Our study is the first study that we have been able to locate that uses both interviews and shadowing as data-collection methods to document the activities and interactions of a Registered NN supporting Indigenous Peoples living with cancer. Findings have highlighted three areas for consideration: 1) the uniqueness of the NN role working with Indigenous Peoples; 2) systemic racism in health care; and 3) cultural change in health care.

The Uniqueness of the NN Role Working with Indigenous Peoples

Our study demonstrates the uniqueness of the NN role working with Indigenous patients and families, in that participants described the role of the NN to be different than other navigation roles with non-Indigenous populations. Participants described that the NN working with Indigenous patients used non-conventional, non-standardized, non-Western health care approaches to build trust and connect with Indigenous Peoples when supporting them to navigate the health care system. These patient-centered, holistic approaches included engaging patients and families with the land and arts to create culturally meaningful experiences during their cancer journey. Shadowing allowed the researcher to see first-hand how the NN actively sought out patients and families, advocated for and interpreted health care pathways and information, ultimately supporting and assisting patients to build capacity to have autonomy over their health and healthcare. The NN was described as a “*gateway to engagement with the health care system,*” (Participant E), first, by helping Indigenous patients access and receive care. Second, by being embedded in the Cancer health care system, the NN served to bridge the gap between the Western interdisciplinary health care team, and Indigenous patients and families. In a literature review concerning navigation as an intervention to eliminate disparities in American Indian communities, Krebs et al. (2013) similarity iterated “collaborating with patient navigators who

are embedded within and trusted by their communities helps to bridge the gap between patients and providers, increases adherence to care recommendations, and improves quality of life and survival” (p. 1-2). While findings in the Krebs et al (2013) study are compatible, navigators in this study were not Registered Nurses; thus, our study offers a unique perspective of the role of the Registered Nurses as navigators for Indigenous cancer patients and families.

Our study findings additionally highlight that, in response to the inequitable health outcomes experienced by Indigenous Peoples in Canada, patients would benefit from the NN role expanding beyond cancer care. Participants explained that “on-paper” but not officially, the NN role is for the Cancer Program, but can go beyond the walls of the Cancer Program when needed. Given the demand for more culturally safe services (Cancer Care Ontario, 2015; Leung, 2018), and improved access to coordination of care and system navigational services (Feather, Carter, Valaitis, & Kirkpatrick, 2017), participants in our study highlighted the need for nurse navigation to be offered to all Indigenous patients admitted to tertiary care settings.

Systemic Racism in Health Care

Participants in our study identified systemic racism as an underlying challenge that has persisted throughout all levels of the Western health care system, and whether indirectly or directly, intentionally or unintentionally, has resulted in a culturally unsafe and unwelcoming environment for Indigenous Peoples when accessing and receiving healthcare. Similarly, previous research has shown that the dominance of the Western biomedical model in Canadian health care has created culturally unsafe and unwelcoming environments for Indigenous Peoples (Arnold & Bruce, 2005; Howell et al., 2016; Smye & Browne, 2002). Thus, the literature confirms what emerged from participant narratives in this study; specifically, the need for culturally appropriate services in Western health care (Adelson, 2005; O’Sullivan, 2013).

Participants felt that having the NN in the tertiary care setting well versed in the context of Indigenous Peoples, having previously worked with Indigenous communities and having an acute lens of the social impacts of colonization, is an important and necessary step in supporting Indigenous Peoples within their own culture. In effort to intensify approaches to reduce health inequities for Indigenous Peoples, our study shows that the NN used a patient-centered, land-based culturally appropriate approach to build trust with Indigenous Peoples living with cancer, essentially serving as a key resource to navigating and receiving culturally safe health care. Given the high demand among Indigenous Peoples for more culturally safe services that firstly, incorporate Indigenous ways of knowing, and secondly, acknowledge the social and historical determinants of health that shape their experiences (Reading, 2014; Truth and Reconciliation Commission of Canada, 2015), our study findings demonstrated how the NN ultimately helps to address the unique challenges and barriers faced in accessing cancer-related care.

Cultural Change in Health Care

Although our study showed that the NN experiences support for the role at the provincial level (i.e. Cancer Care Ontario), as well as organizationally from peers, administration, and management, participants described pressures, micro-aggression (consciously or unconsciously perpetrated), and hostility towards the role, that stem from on-going systemic racism, echoing the need for culture change. There is therefore a need for cultural change in health care, specifically, at the individual level, the organizational level, and the health systems level.

Individual Level. Our study reiterates what is found in Canadian reports including the Truth and Reconciliation Commission (Niezen, 2017; Reading, 2014; Truth and Reconciliation Commission of Canada, 2015). Participants described the ways in which systemic racism has been able to pervade and persist in health care domains, since many individuals have not been

taught the true history of Indigenous Peoples in Canada and do not know the resistance experienced and multifaceted and immeasurable struggles faced by First Nations, Inuit and Métis people in accessing and receiving health services. As a result, participants emphasized that many health care providers are unaware of their (largely) unacknowledged racist attitudes, beliefs, and behaviours when interacting with Indigenous Peoples. However and in addition, participants added that most people are under the illusion that “*in health care everyone is treated equally, so there is no need for culturally specific care*” (Participant B), a finding that is similar to findings in Johnstone & Kanitsaki’s (2008) study that iterates that “racism is an issue of the past” (p.137). This Eurocentric Western-focused ideology fails to account for the socio-historic roots of the health inequities experienced by Indigenous Peoples, and as described by Cauchie (2019), this kind of perspective “thereby ignores or denies the existence of race-based injustice” (p.1). Furthermore, this perspective suggests and assumes that “good care” is what is considered to be “good” by the Western biomedical world, which largely ignores Indigenous cultures and ways of knowing and values, and therefore “perpetuates ethnocentrism and ‘cultural imposition’” (Johnstone & Kanitsaki, 2008, p. 137; Leininger, 1991).

Findings from this study make visible the degree to which systemic racism plays a role in influencing health care on an individual level, and the need to instigate change. Reflecting, recognizing, and redressing prejudicial, ethnocentric and racist attitudes can help foster humility, empathy and respect when providing patient care, “fostering good patient outcomes” (Johnstone & Kanitsaki, 2008, p. 137). Moving forward, acknowledging that racism in health care is a problem that is invisibly promoted within the organizational culture and practices, and not simply one of individual behaviour, is essential to reveal the organizational factors that foster health care disparities before focusing on individual-level change (Griffith et al., 2007).

Organizational Level. On an organizational level, our findings confirm what is in the literature in that Canadian health service organizations often fail to create “culturally safe environments” in which Indigenous Peoples can access and receive care (Fontaine & Health Council of Canada, 2012; O’Sullivan, 2013; Shah & Reeves, 2012; Truth and Reconciliation Commission of Canada, 2015; Niezen, 2017). Accordingly, as described by participants and noted by McGibbon (2018), discrimination and racism have been a part of the “fabric and tradition of Canadian society” (p. 29), and have therefore adversely affected marginalized Indigenous Peoples, health care providers, health institutions, and the entire health care system.

On a local level, findings show that specifically, there is a need for organizational culture change to foster a culturally safe, inclusive, and welcoming environment for Indigenous Peoples who have been historically marginalized, as well as a need to emphasize the importance of working with this underserved population to improve health outcomes. Building upon the individual level challenge of a lack of understanding and knowledge regarding the impact of colonization on Indigenous Peoples and the importance of the NN role in specifically serving this population, on an organizational level, participants explain that racism must be eradicated by taking steps to correct the organizational processes, beliefs, and ultimately culture that allow it to occur (Truth and Reconciliation Commission of Canada, 2015; Niezen, 2017). Will et al. (2016) add that while there may be an impetus to transform and change, sustained change needs to involve more than just the CEO – it requires top-down and bottom-up leadership to create urgency, set directions, reinforce expectations, and provide resources (Lukas et al., 2007). In essence, to create culture change regarding the eradication of systemic racism and the promotion of cultural awareness and safety, a comprehensive, organization-wide multi-level approach is required, fundamentally linked to organizational strategy (Luxford, Safran & Delbanco, 2011).

Moving forward, as a health care priority, interventions and policies to improve Indigenous health and address inequalities must consider the effects of racism. Ultimately, increasing organizational capacity to improve Indigenous health equity involves making it a priority, embedding it into the organization's mission, and continuously building it into all high-level decision making (Richardson, 2018; Truth and Reconciliation Commission of Canada, 2015).

Health Systems Level. The findings in this study highlight what has been largely discussed in the literature, in that the history of racism in health care is a problem that is rooted fundamentally in organizational, institutional, and systems level structures and practices (Allan & Smylie, 2015; Griffith et al., 2007; McGibbon, 2018; Niezen, 2017; Walker et al., 2009). Given how embedded racism is at all levels of health care, participants describe that a significant shift in the entire system's policies and practices at the provincial and federal levels are required to address societal racism and create change to reduce health care disparities. To do this, as noted by McGibbon (2018), "first this means recognizing that societal structures are built, one log or brick over time, to produce a cohesive overall structure of power and privilege. In health care, the bricks include all of the events and processes, large and small, that exclude Indigenous healing practices, and make Canadian health care what it is today—Eurocentric, biomedical, individualistic models of care, and repetition of the cycle of oppression in policy-making, clinical practice, research, and legislation. The structure of health care rests on these bricks." (McGibbon, 2018, p. 46).

As explained by our study participants, current health policy fails to recognize and prioritize the health needs of Indigenous Peoples in Canada, and despite efforts, fails to create adequate approaches and conditions for equitable access to health services, especially for those

in Northern regions. As such, participants add that recognizing the need for reform in health care must start with societal commitment to “culture change” and must be created and must be sustained through distinct political will to improve access to health care for Indigenous Peoples. This means that, focusing on upstream policy change, cultural reform in health care needs to be addressed across all domains of the health care system, and not just front-line or within service delivery (Allan & Smylie, 2015; Richardson, 2018). Transformative societal culture change will require a “significant shift in philosophy, a reorientation of public attitudes” and “a commitment by the federal government in acknowledging the rights of Indigenous Canadians” (Richmond & Cook, 2016, p. 11), specifically, one that prioritizes the health and well-being of all the inhabitants of Canada including Indigenous Peoples.

Limitations

This study was limited in terms of setting, time, and participant sampling. At the time this study was conducted, Cancer Care Ontario's patient navigation program consisted of 10 navigators in Ontario; however, not all navigators were Registered Nurses (Cancer Care Ontario, 2015). This study focused on the role of a Registered NN, in an organization in Ontario that had one position for a NN, and therefore the results may not be transferable to other navigators in other settings.

Additionally, the sample size was small and did not involve Indigenous patients and families directly due to feasibility issues and resource constraints. A major limitation of this study is that Indigenous Peoples living with cancer were not interviewed, as per the selection criteria, which did not include patients or family members, and solely focused on the perspectives of health care providers and senior management. The intended sample size was however reached, providing diverse perspectives from different health care providers including the NN.

Lastly, shadowing took place over a 2-week period providing a variety of NN activities to be observed; however, the two weeks were non-consecutive to accommodate the logistics of the NN's schedule, specifically, attending management-related meetings. When possible, management related meeting minutes were provided, and therefore the lack of physical observation in this aspect did not impact the understanding of the unique processes and experiences of the NN role.

Conclusion

This study explored the experiences of a NN and the processes by which they support Indigenous cancer patients and families in a culturally sensitive manner, in the context of a tertiary care hospital. Results highlight the importance of reaching Indigenous Peoples through multiple strategies. Despite identified challenges, participants felt that collaborating with a NN who is well-versed in Indigenous health and already embedded within the healthcare system, is a step in the right direction in responding to the culturally diverse health needs of Indigenous Peoples. Results from this study will help inform healthcare delivery and nursing practice, helping to close the current gap in health status between Indigenous and non-Indigenous Peoples, and address the health-related Calls to Action of the Truth and Reconciliation Commission of Canada (2015).

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Chapter Five

Integrated Discussion

Introduction

Although research has shown strong benefits of navigation roles and programs in the field of oncology over the past two decades (Abbott et al., 2017; Braun et al., 2015; Cavanagh, et al., 2016; Dohan & Schrag, 2005; Fiscella, et al., 2012; Guadagnolo et al., 2011; Hohl et al., 2016), little research has been conducted on how Registered NNs go about their role to guide and support Indigenous patients and families throughout their cancer journey. More clarity is needed regarding how Registered NNs enact their role to address the distinct needs of Indigenous Peoples specifically in Canada. The purpose of the current study was to describe the experiences of a NN working with Indigenous Peoples living with cancer, in the context of a large tertiary care hospital. In this chapter, I first summarize the findings of the current study and discuss them within the broader research literature. Next, I discuss recommendations for practice, research, and policy. Lastly, I discuss study limitations, and provide concluding remarks.

Summary of Findings

Firstly, this study showed that the NN practiced using a non-conventional, patient-centered, holistic approach that included engaging with the land and arts, advocating for and interpreting health care for patients and families, essentially assisting patients to have autonomy over their health care. This role was described to be unique, as all participants described the NN to be a complement to clinical care and a key resource for Indigenous patients and families to navigate the health care system.

Secondly, this study described the challenges experienced by the NN in supporting Indigenous Peoples, at the NN level, organizational level, and health care system-level. These included experiencing hesitancy from patients and families, challenges faced by being outside of the culture and not speaking the language, a lack of measurable clinical outcomes in relation to

the NN role, the uniqueness of the role not being understood by others organizationally, as well as a lack of systems level understanding and awareness of the role and its positive aspects. In addition, the impact of colonization on Indigenous Peoples was discussed, specifically focusing on the deep-rooted discrimination, marginalization, and systemic racism as a result of colonization that has perpetuated the health inequities and challenges that Indigenous Peoples experience in accessing and receiving health care.

Lastly, facilitators and supports of the NN role were described in detail. Social and interpersonal supports included peer network support, trust from the Indigenous community, and recognition and appreciation of the NN role from management, staff, patients and families. System-level supports included organizational commitment and support for the NN role, policies, physically dedicated space, and the latitude and flexibility in the role to use non-conventional, non-Western health care approaches to support Indigenous patients in a culturally sensitive manner.

In summary, from the perspectives of health care professionals, this research has demonstrated that the NN had a positive influence on Indigenous Peoples' health and wellbeing. Results inform healthcare delivery and nursing practice to help improve the quality of care and outcomes for Indigenous cancer patients.

Integrated Discussion

Findings from this study have highlighted three areas that I will discuss: 1) the uniqueness of the NN role working with Indigenous Peoples to navigate the health care system; 2) systemic racism in the health care system and the context of colonization affecting Indigenous Health; 3) the need for cultural change within the health care system.

The Uniqueness of the NN Role Working with Indigenous Peoples

The NN role uniquely serves a key resource for Indigenous Peoples to navigate the health care system. Our study is the first study that we have been able to locate that uses both interviews and shadowing as data-collection methods with a NN, aiming to document the activities and interactions of a registered NN to support Indigenous Peoples living with cancer. While patient navigation research conducted to date shows that NN's have the ability to reduce health disparities by employing a patient-centered approach (Burhansstipanov et al., 2015; Clifford, McCalman, Bainbridge, & Tsey, 2015; Dohan & Schrag, 2005; Fayerman, 2011; Natale-Pereira et al., 2011; Warren-Mears, Dankovchik, Patil, & Fu, 2013; Wells, 2008; Whop et al., 2012), these studies do not describe the activities and processes the NN engages in or explicitly what the role entails. Thus, our study provides insights into this innovative role, such as the provision of culturally meaningful engagement with land and art, and specifically describes the ways in which the NN uniquely serves as a resource for Indigenous Peoples to navigate the health care system and access cancer care in a tertiary care setting.

Findings from this study are consistent with the research on the role of NNs conducted to date showing that NNs have the ability to help individuals navigate their way through the their cancer journey and the health care system by assisting them to overcome individual and system level barriers in access to and continuity of health care (Burhansstipanov et al., 2015; Clifford, McCalman, Bainbridge, & Tsey, 2015; Dohan & Schrag, 2005; Fayerman, 2011; Natale-Pereira et al., 2011; Warren-Mears, Dankovchik, Patil, & Fu, 2013; Wells, 2008; Whop et al., 2012). However, this study further demonstrates the uniqueness of the NN role working with Indigenous patients, in that participants described the NN role to be different than other navigation roles with non-Indigenous populations. Accordingly, participants described the NN

working with Indigenous patients used non-conventional, non-standardized, non-Western health care approaches to build trust and connect with Indigenous Peoples to help them navigate the health care system. Through interviews, participants provided in-depth details, describing the NN's use of non-conventional, patient-centred, holistic approaches that included engaging patients and families with the land and arts to create culturally meaningful experiences during their cancer journey. Shadowing allowed the researcher to see first-hand how the NN actively sought out patients and families, and how the NN advocated for and interpreted health care for patients and families living with cancer, assisting patients to have autonomy over their healthcare. The NN was described as a "*gateway to engagement with the health care system*" (Participant E), first by helping Indigenous patients access and receive care. Second, by being embedded in the cancer system, the NN thereby served to bridge the gap between the Western interdisciplinary health care team, and Indigenous patients and families. In a literature review concerning navigation as an intervention to eliminate disparities in American Indian communities, Krebs et al. (2013) similarly iterated "collaborating with patient navigators who are embedded within and trusted by their communities helps to bridge the gap between patients and providers, increases adherence to care recommendations, and improves quality of life and survival" (p. 1-2).

Our study findings additionally highlight that, in response to the inequitable health outcomes experienced by Indigenous Peoples in Canada, patients would benefit from the NN role expanding beyond cancer care. Participants explained that "on-paper" but not officially, the NN role is limited to the Cancer Program, going beyond the walls of the Cancer Program when needed. Examples included the NN providing navigational services to patients admitted to the hospital, irrespective of diagnosis (i.e. non-cancer related), and even to patients staying at the

Children's Eastern Hospital of Ontario, located in Ottawa. There is therefore a limitation to the NN Role, in that keeping it cancer specific feeds into the inequities experienced by Indigenous Peoples. This is because by keeping the NN role cancer specific, the program further places limitations on who can access the navigational service. Thus, as discussed by participants in our study, society, specifically health care professionals, must examine the social inequities in health care and the specific organizational policies and amend them to ensure equitable access to health care for all.

Ultimately, our study showed that the NN holds a crucial culturally sensitive innovative role, designed to help address systemic barriers to care with the goal of enhancing personal empowerment to promote more effective service delivery for Indigenous Peoples in Western health care. However, given the high demand for more culturally safe services (Cancer Care Ontario, 2015b; Leung, 2018), access to coordination of care and system navigational services (Feather, Carter, Valaitis, & Kirkpatrick, 2017), participants in our study highlighted the need for nurse navigation to be offered to all Indigenous patients admitted, to facilitate their journey through the health care system.

Systemic Racism and the Context of Colonization

Participants in our study identified systemic racism as an underlying context in navigating and receiving health care within the Western healthcare system. More specifically, health care providers described systemic racism through racialized stereotypes, stigma, and prejudices that continue to unjustly serve as barrier for Indigenous Peoples to receiving cancer care and contributing to the societal disadvantages and poor health status of Indigenous Peoples. Numerous studies reiterate that the intergenerational effects of colonialism, residential schools, and systemic racism paired with the health disparities related to the social determinants of health,

are the root of the health challenges faced by the Indigenous population (Adelson, 2005; Kurtz et al., 2008; Wilson & Young, 2008). As explained by Adelson (2005), “a history of colonialist and paternalistic wardship, including the creation of the reserve system; forced relocation of communities to new and unfamiliar lands; the forced removal and subsequent placement of children into institutions or far away from their families and communities; inadequate services to those living on reserves; inherently racist attitudes towards Aboriginal peoples; and a continued lack of vision in terms of the effects of these tortured relations – all of these factors underlie so many of the ills faced by Aboriginal peoples today” (p. S46).

Similar to findings from our study, previous research has shown that the dominance of the Western biomedical model in Canadian health care has created culturally unsafe and unwelcoming environments for Indigenous Peoples (Arnold & Bruce, 2005; Denzin & Lincoln, 2008; Howell et al., 2016; Smye & Browne, 2002; Sherwood & Edwards, 2006). Accordingly, as highlighted both by participants in our study and in the literature, navigating through Canada's complex health care system for cancer care can be arduous, and these difficulties are exacerbated for Indigenous Peoples, who may not always utilize or understand the Western biomedical system (Canadian Medical Association, 2017; Cancer Care Ontario, 2015a; Walkinshaw, 2011). Recent literature reiterates that cultural differences and the inability of health care providers to appropriately address these differences have resulted in lingering racism which in turn, contributes to the high rates of non-adherence, avoidance and reluctance to seek mainstream health care services when ill (Kurtz et al., 2008; Browne et al., 2011; National Aboriginal Health Organization, 2014). This, in turn, reduces the opportunity for early intervention and prevention of health problems, as well as leads to later-stage diagnoses, ensuing implications in terms of treatment and patient health outcomes (Allan & Smylie, 2015). Thus, the receiving of differential

treatment in the health care system ultimately perpetuates and underlies many of the inequities faced by Indigenous Peoples today.

Accordingly, Adelson (2005) states that “cultural differences in how we come to understand what health means...must be addressed in concert with public health priorities and initiatives if we are to understand and effectively take on the formidable task in reducing health disparities and promoting equity in Aboriginal Canadian populations ” (p. S46). Thus, the literature confirms what emerged from participant narratives in this study, specifically, the need for culturally appropriate services in Western health care (Adelson, 2005; Feather, Carter, Valaitis, & Kirkpatrick, 2017; O’Sullivan, 2013). Participants felt that having the NN in the tertiary care setting, as someone who is well versed in the context of Indigenous Peoples, who has previously worked with Indigenous communities and has an acute lens of the social impacts of colonization, is a step in the right direction in supporting Indigenous Peoples to receive culturally safe care. In effort to intensify approaches to reduce health inequities for the Indigenous population, our study shows that the NN role uses a patient-centered, land-based culturally relevant approach to build trust with Indigenous Peoples living with cancer, essentially serving as a key resource to navigating and receiving culturally safe health care. Given the high need among Indigenous Peoples for more culturally safe services that firstly, incorporate Indigenous ways of knowing, and secondly, acknowledge the social and historical determinants of health that shape their experiences of cancer, our study findings demonstrated how the NN ultimately helps to address the unique challenges and barriers faced in accessing cancer-related care.

Cultural Change in Health Care

Although our study showed that the NN experiences support for her role at the provincial level (i.e. Cancer Care Ontario), as well as organizationally from peers, and hospital administration, and management, participants remained to describe that stemming from on-going systemic racism, the NN still faces pressures, micro-aggression (consciously or unconsciously perpetrated), and hostility towards the role, echoing the need for culture change. The next section therefore describes the need for culture change at multiple levels in health care; specifically, at the individual level, the organizational level, and the health systems level.

Individual Level

Our study reiterates what is found in Canadian reports, in that Canadians are often unaware of the historical effects of colonialism on the Indigenous Peoples of Canada (Niezen, 2017; Reading, 2014; Truth and Reconciliation Commission of Canada, 2015). As described by participants and as reiterated by Reading (2014), the basis for this ignorance can be stemmed back to the system of education in Canada, which has not included a “critical examination of our colonial history or its damaging consequences to the health and wellbeing of Aboriginal peoples. In reality, the historical ‘facts’ presented about Aboriginal peoples are at times inaccurate and/or degrading, while the issue of systemic racism is diminished or entirely ignored” (p. 4). Accordingly, participants described the ways in which systemic racism has been able to pervade and persist in health care domains, as they explain that since many individuals have not been taught the true history of Indigenous Peoples in Canada, they do not know the resistance experienced and the many multifaceted and immeasurable struggles faced by First Nations, Inuit and Métis people in accessing and receiving health services. As a result, they are unaware of their (largely) unacknowledged racist attitudes, beliefs, and behaviours when interacting with

Indigenous Peoples. However, in addition, participants also add that other individuals are under the illusion that “*in health care everyone is treated equally, so there is no need for culturally specific care*” (Participant B), or that, similar to findings in Johnstone & Kanitsaki’s (2008) study, “*racism is an issue of the past*” (p.137). This Eurocentric Western-focused ideology completely disregards and fails to account for the socio-historic roots of the health inequities experienced by Indigenous Peoples, and this kind of perspective “thereby ignores or denies the existence of race-based injustice” (Cauchie, 2019, p. 1). Furthermore, this ideology suggests and assumes that “good care” is what is considered to be “good” by the Western biomedical world, which largely ignores Indigenous cultures and ways of knowing, and therefore “perpetuates ethnocentrism and ‘cultural imposition’” (Johnstone & Kanitsaki, 2008, p. 137; Leininger, 1991a). As such, “left unaddressed, these attitudes may stand as a significant contributing factor in professional-client relationships being compromised and, *ipso facto*, wrong diagnoses being made, wrong cares and treatments being prescribed, and, related to all of these errors, poor health and safety outcomes for patients” (Johnstone & Kanitsaki, 2008, p. 137). Consequently, “such exclusion, abrogation of responsibility for poor communication and disregard of Indigenous cultural meanings associated with health practice is disrespectful and constitutes a form of institutional and interpersonal racism” (Durey, & Thompson, 2012, p. 6). An ethnocentric attitude therefore limits the comfort in accessing health services for Indigenous Peoples, as a lack of culturally sensitive care is “the outcome at the nexus of the patient-provider interaction” (Griffith et al., 2007, p. 382; Fontaine & Health Council of Canada, 2012; Shah & Reeves, 2012). Consequently, as noted by Teo & Febbraro (2003) individuals who “are not willing to inquire about alternative constructions in other cultures or sub-cultures must either admit from

the beginning that their knowledge is particular, Western-focused, and Eurocentric or they must accept the assessment that they are part of the hidden euro-centrism in their society” (p. 683).

Ultimately, participants described that on an individual level, even though not always intentional or visible, racism still exists, and its effects are debilitating to Indigenous Peoples (Durey & Thompson, 2012). Thus, the findings make visible the degree to which systemic racism plays a role in influencing health care on an individual level, and the need to instigate change. Reflecting, recognizing, and redressing prejudicial, ethnocentric and racist attitudes can help foster humility, empathy and respect when providing patient care, “fostering good patient outcomes” (Johnstone & Kanitsaki, 2008, p. 137). Emphasizing the importance of focusing on attitudes in cultural sensitivity and awareness education, and, as explained by Leininger (1991b) recognition of ethnocentric and racist attitudes is essential in the provision of culturally appropriate care. It is therefore essential to provide health care individuals with cultural awareness information to encourage individuals to explore and challenge stereotypes within society, in order to provide culturally safe care. However, acknowledging that racism in health care is a problem promoted by organizational culture and practice, and therefore not simply of individual behaviour, it is essential to “uncover the intraorganizational factors that may contribute to or reinforce healthcare disparities before focusing on individual-level change” (Griffith et al., 2007, p. 389).

Organizational Level

On an organizational level, our findings are consistent with what is in the literature in that Canadian health service organizations often fail to create “culturally safe environments” in which Indigenous Peoples can access and receive care (Fontaine & Health Council of Canada, 2012; O’Sullivan, 2013; Shah & Reeves, 2012; Truth and Reconciliation Commission of Canada,

2015; Niezen, 2017). Accordingly, as described by participants and noted by McGibbon (2018), discrimination and racism have been a part of the “fabric and tradition of Canadian society” (p. 29), and have therefore adversely affected marginalized Indigenous Peoples, health care providers, health institutions, and the entire health care system. On a local level, our study shows that specifically, there is a need for organizational culture change to foster a culturally safe, inclusive, and welcoming environment for Indigenous Peoples who have been historically marginalized, as well as a need to emphasize the importance of working with this underserved population to improve health outcomes. Participants explain that building upon the individual-level challenge of a lack of understanding and knowledge regarding the impact of colonization on Indigenous Peoples, and the importance of the NN role in specifically serving this population, on an organizational level, racism must be eradicated by taking steps to correct the organizational processes, beliefs, and ultimately culture that allow it to occur (Truth and Reconciliation Commission of Canada, 2015; Niezen, 2017).

In effort to produce change, the Truth and Reconciliation Commission of Canada (2015) final report explains that as a foundation for cultural safety, individuals are gaining a better understanding of the terms and concepts related to anti-racism education and policy. Cultural safety highlights the power dynamics in health care and seeks to address inequities through the promotion of culturally competent practices (Indigenous Physician's Association of Canada, 2008). It is further defined as “[a]n outcome that is based on respectful engagement which recognizes and strives to address power imbalances inherent in the health and social services system. It results in an environment free of racism and discrimination where people feel safe receiving health care” (Richardson, 2018, p. 9). Accordingly, participants describe that while health care providers may seek to enhance cultural safety and quality in the institutions where

they work, influencing change at the organizational level involves affecting the culture within that organization. This is because the culture of healthcare is distinctive, as it “represents the shared ways of thinking, feeling, and behaving in health care organizations” (Mannion & Davies, 2018, p.1). Thus, participants add that while health organizations are at different places in the journey to create culturally safe care, a key factor in implementing organizational culture change is the support of high-level leadership. This idea is further confirmed in the literature, as organizational culture change is known to start with genuine and passionate senior leadership (Will et al., 2016; Lukas et al., 2017). However, Will et al. (2016) further explain that while there may be an impetus to transform and change, sustained change needs to involve more than just the CEO – it requires top-down and bottom-up leadership to create urgency, set directions, reinforce expectations, and provide resources (Lukas et al., 2007). In essence, to create culture change regarding the eradication of systemic racism and the promotion of cultural awareness and safety, a comprehensive, organization-wide multi-level approach fundamentally linked to organizational strategy, is required (Luxford, Safran & Delbanco, 2011).

To add to this, while many organizations, including the participating organization in this study, have increased cultural competence and cultural safety of their staff through educational means, many participants highlighted the need for cultural awareness and safety activities mandatory, instead of optional. Participants further acknowledge that racism and the politics of resistance are unlikely to be completely eradicated in a health care context, but as discussed in the literature, they suggest that culture awareness is the first step in achieving cultural safety (Cauchie, 2019). The Métis Centre of the National Aboriginal Health Organization (n.d.) writes that cultural awareness “can be built by observing activities and how people participate in them and involves being able and willing to recognize or acknowledge and accept difference within a

population” (p. 2). While this practice does not involve asking health care practitioners to change their practices, nor does the practice advocate for organizational activities to change, cultural awareness is nonetheless important for all members of an organization to firstly understand the social, historical, and political aspects that have affected Indigenous Peoples (Métis Centre of the National Aboriginal Health Organization, n.d.). Examples of cultural awareness practices include eliminating the idea that there is one pan-Indigenous population and being aware that the term Indigenous actually encompasses distinct nations constitutionally recognized by the Government of Canada, such as, but not limited to, First Nations, Inuit and Métis, and that values, beliefs, and cultures can vary across each sub-group. The idea is that by providing more cultural awareness information and deepening the understanding of Indigenous health inequity, individuals might understand the importance of the NN role in distinctly serving this population, and therefore might embark on the journey towards the second step of attaining cultural sensitivity, and later, cultural safety with Indigenous Peoples (Niezen, 2017; Truth and Reconciliation Commission of Canada, 2015). As described by Walker, Cromarty, Kelly, and St Pierre-Hansen (2009), serving as a form of decolonization, the Indigenous “cross-cultural client safety zone” is a continuum scale of understanding that moves from a “them” ideology, to a “them and us” , to an “us” (p. 14), with a final goal of Indigenous cultural integration. Essentially, Muise (2019) adds that “cultural safety is about a heightened self-awareness of health professionals, about their inherent professional cultural bias and power imbalances” (p. 28).

Accordingly, as noted by Richardson (2018) in report on bringing reconciliation to health care, with the expectation that there is zero tolerance for racism, training should be offered to all health care providers and staff, starting with health leaders and board members. There is therefore a need to make sure that organizationally, leadership is committed to understanding

how everyone is implicated in the ongoing injustices committed toward Indigenous Peoples, and that there is a need to explicitly address a harmful organizational culture. This process can serve to “decolonize” the health care system, and involves addressing the effects of colonialism as evidenced in the national and international indices that continue to suggest that transformative change is required for health care (First Nations Information Governance Centre, First Nations Regional Health Survey, Ottawa, 2018). Moving forward, as a health priority, interventions and policies to improve Indigenous health and address inequalities must consider the effects of racism. Ultimately, increasing organizational capacity to improve Indigenous health equity involves making it a critical priority, embedding it into the organization’s mission, and continuously building it into all high-level decision making (Richardson, 2018; Truth and Reconciliation Commission of Canada, 2015).

Health Systems Level

The findings in this study highlight what has been largely discussed in the literature, in that the history of racism in medicine and health care is a problem that is rooted fundamentally in organizational, institutional, and systems level structures and practices (Allan & Smylie, 2015; Griffith et al., 2007; McGibbon, 2018; Niezen, 2017; Walker et al., 2009). Accordingly, “the political, economic and social structures of society, and the culture that informs them (e.g. law, policing, religion, health care, government)” are the root causes of racism, and “they lead to the suffering, and sometimes death, associated with widespread inequities” of Indigenous Peoples (McGibbon, 2018, p. 26). Therefore, given how embedded racism is at all levels of health care, participants describe that a significant shift in the entire system’s policies and practices at the provincial and federal levels are required to address societal racism, and create change to reduce health care disparities. as noted by McGibbon (2018), To do this, “first this means

recognizing that societal structures are built, one log or brick over time, to produce a cohesive overall structure of power and privilege. In health care, the bricks include all of the events and processes, large and small, that exclude Indigenous healing practices, and make Canadian health care what it is today—Eurocentric, biomedical, individualistic models of care, and repetition of the cycle of oppression in policy-making, clinical practice, research, and legislation. The structure of health care rests on these bricks.” (McGibbon, 2018, p. 46). Accordingly, as described by participants, current health policy fails to recognize and prioritize the health needs of Indigenous Peoples in Canada, and despite efforts, fails to create adequate approaches and conditions for equitable access to health services, especially for those in Northern regions. As such, participants explain that recognizing the need for reform in health care must start with societal commitment to “culture change” and must be created and must be sustained through distinct political will to improve access to health care for Indigenous Peoples. This means that, focusing on upstream policy change, cultural reform in health care needs to be addressed across all domains of the health care system, and not just front-line or within service delivery (Allan & Smylie, 2015; Richardson, 2018).

Consequently, health leaders must “create conditions for equitable access” for the Indigenous population, and “particular attention must be paid to their unique cultural contexts and histories” (Richmond & Cook (2016), p. 8). Thus, with the understanding that health care is a complex, highly interconnected, adaptable system (Lindstorm, 2012), and that a change in one part of the system affects other parts (Senge, 2006), dismantling racism must be treated as a “systematic intervention process” (Griffith et al., 2007) and must begin “by privileging the voices of those on the ground level” (Richmond & cook, 2016, p. 10). By firstly acknowledging the past and accepting the truth (i.e. the existing racism, discrimination, and continuous

marginalization of Indigenous Peoples), Canadian health leaders must build relationships with Indigenous Partners (i.e. Indigenous healers, Elders, advisors, advisory councils, agencies, governments, and wellness councils at provincial, regional and organizational levels) to then work collaboratively to create “an Indigenous health system that is safe, meets quality standards, and is patient-, family-, and community-centered” (Richardson, 2018, p. 15; Truth and Reconciliation Commission of Canada, 2015). Accordingly, the Canadian health system can better make health equity a reality for all by recognizing that lasting transformative change involves integrating and planning cultural awareness information and training across every part of the health system, such as “policy and program design, front line service delivery, staff development and competence, research and knowledge capacity, and traditional methods” (Richardson, 2018, p. 10; Truth and Reconciliation Commission of Canada, 2015; Niezen, 2017).

Ultimately, “there is no shortage of examples that demonstrate the impact racism has on the safety of Indigenous patients” (Richmond & Cook, 2016, p.9). Transformative societal culture change will require a “significant shift in philosophy, a reorientation of public attitudes” and “a commitment by the federal government in acknowledging the rights of Indigenous Canadians” (Richmond & Cook, 2016, p. 11), specifically, one that prioritizes the health and well-being of all the inhabitants of Canada.

Limitations

While a strength of case study research is its flexibility, its scope is bounded and therefore the findings can rarely be generalized (Merriam, 2015). This study was limited in terms of setting, time, and participant sample. At the time this study was conducted, Cancer Care Ontario's patient navigation program consisted of 10 patient navigators in Ontario; however, not all the navigators were Registered Nurses (Cancer Care Ontario, 2015b). This study focused on

the role of a Registered NN, whom may enact their role differently than non-Registered Nurses, and therefore the results may not be transferable to other navigators in other settings.

Time also presented a limitation in this study. As a master's level study to be completed over one year, time constrains limited the feasibility of directly involving Indigenous patients and families. Therefore, a limitation of this study is that Indigenous Peoples living with cancer were not interviewed, as per the selection criteria, which did not include patients or family members, and solely focused on the perspectives of health care providers and senior management.

Lastly, shadowing took place over a 2-week period; however, the two weeks were non-consecutive to accommodate the NN's schedule. This in turn, limited the activities of observation, specifically, attending management meetings; however, when possible, meeting minutes were provided, and therefore the lack of physical observation in this aspect did not impact the understanding of the role.

Researcher Reflections

While publications in nursing have emphasized the potential to understand multiple realities through the collection of multiple sources of evidence in case study research, it is important to note that my own experiences and my subjectivity may have influenced this research (Iacano & Holtham, 2009; Jones & Lyons, 2004; Luck, Jackson & Usher, 2006). Merriam (1998) identifies that “qualitative case studies are limited, too, by the sensitivity and integrity of the investigator. The researcher is the primary instrument of data collection and analysis” (p. 582-583). Thus, below, I explore and reflect on my experiences and how they may have influenced this research.

This research was conducted by a non-Indigenous person, and all members of the thesis committee were also non-Indigenous. Though Arab in origin, I was born and raised in Ottawa, Ontario, in an urban neighborhood surrounded by Western European people. My understanding of Indigenous Peoples was mainly informed during my time in nursing school, where, as a Registered Nurse in-training, I was exposed to the unfortunate reality of systemic racism, and “othering” experienced by Indigenous Peoples in the health care system. It was through working as Registered Nurse, both clinically and in research, that I became increasingly aware of the political struggles of Indigenous Peoples, and their exclusion from Western society. I started to recognize the undeniable and deep-rooted effect of colonization, and the resulting health inequities that Indigenous Peoples experience. Housing, education, employment, poverty, and food security were among the determinants of health that greatly affected the health of the Indigenous patients I cared for. The more research I read, the more profound respect I found myself having for Indigenous Peoples, for their strength and resilience throughout many years experiencing racism, discrimination, and marginalization, and for enduring intergenerational trauma. Thus, when I began my graduate studies, I had a strong desire to pursue research that would benefit this population, specifically in helping Indigenous Peoples access and receive equitable health care.

I believe that this reflective process helps in “unpeeling the layers that make up a person” (Yeager & Bauer-Wu, 2013, p. 253), and helps in better providing an understanding of how this research was conducted based on how I position myself in relation to the research. Given my experiences, as a researcher, I locate my work within a constructivist paradigm (Guba & Lincoln, 1994). I understand that, shaped by experiences, there are multiple realities through which one

can make sense of the world, and this world view is embedded in the qualitative research approach that I have undertaken.

Recommendations for Nursing

A number of recommendations arise from this study.

Education

Findings from this research juxtaposed with the literature, particularly the Truth and Reconciliation Calls to Action report (2015), which strongly suggests that education in undergraduate curriculums should include information on Indigenous culture, historical trauma, and on-going health disparities. This education is explained as necessary so that entry-level nurses are prepared to deliver equitable trauma-informed health care (Francis-Cracknell et al., 2019). Many post-secondary institutions across Canada have already begun the Indigenization of their curriculums, by not only specifically including First Nations, Inuit, and Métis content into undergraduate health professional programs, but also by incorporating Indigenous learning throughout all curriculums (Courchene, 2019). However, Sasakamoose & Pete (2015), from the University of Regina, Saskatchewan, argue that “Indigenization” extends beyond the incorporation of cultural information into curriculums, and is more a learning “process that attempts to re-centre Indigenous epistemologies and ontologies, not only for learners but for those of us who serve as faculty and staff” (p.1). Thus, incorporating Indigenous learning at University institutions should occur through the establishment of Indigenous spaces, symbols, resources, academic programs, as well as through the creation of research chairs and projects, thereby incorporating Indigenous ways of knowing in academia (Courchene, 2019; MacDonald, 2016).

Professionally, nurses have the opportunity to educate fellow nurses regarding the NN role through the dissemination of knowledge related to the beneficial impacts and positive aspects of the NN role. By increasing awareness of and conceptualizing the unique non-traditional and non-conventional approach used in the NN role, this can help promote role clarity and understanding, thereby dispelling any myths that had spread organizationally about the role. In addition, this could serve to help prevent the tendency to “discredit” or “devalue” the role based on how many referrals are made, how many patients are seen, how tasks performed, or time used. Thus, this ongoing professional education could work to reduce stigma regarding the role, helping to foster a better work environment, in turn allowing the NN to continue in the provision of care to the Indigenous population in an appropriate, respectful, and non-judgmental manner.

Furthermore, organizationally, nurses and clinical staff should participate in mandatory cultural awareness and safety training, specifically through interactive educational workshops and story-telling activities, such as the KAIROS Blanket Exercise implemented at the Ottawa Hospital, which was created to teach cultural awareness (Baldasaro, Maldonado, & Baltes, 2014; “Blanket Exercise,” 2019). These exercises allow nurses and other staff to engage in critical reflection, and through this process, encourage clinicians and staff to reflect on their own, potentially unacknowledged, racist worldviews, attitudes, and beliefs (Reading, 2014). As explained by McGibbon (2016), “enacting cultural safety provides a very real focus on the ways that historic and current intergenerational tragedies play themselves out in every health care encounter, and in every institutional decision” (p. 46). It is through cultural awareness and safety training that interpersonal transformation can be achieved, which can then help foster cultural sensitivity at both individual and institutional levels, and ultimately help to limit and ideally,

eradicate, future incidents of racism towards Indigenous Peoples (Reading, 2014; Griffith et al., 2007; Johnstone & Kanitsaki, 2008; Richardson, 2018).

Practice

As clinical health care professionals, nurses are well-positioned to improve cancer experiences for Indigenous patients and families, by ensuring the use of consistent, comprehensive, and evidence-based practices that include culturally sensitive and safe care (CNO, 2009; RNAO, 2007). However, the history of colonization on Indigenous health suggests an imperative for trauma-informed care that is welcoming and sensitive to the needs of Indigenous Peoples (Browne et al., 2016). Moving forward, health care professionals should integrate trauma-informed care as a systematic approach to ensure that all patients receive care that is sensitive to the impact of trauma (Browne et al., 2012; Browne et al., 2016). By using a non-conventional model of care, NNs and other interdisciplinary health care staff can better support Indigenous Peoples with cancer to navigate the health care system and receive high quality and effective care.

Leadership

Nurses in all fields and at all levels can assume leadership roles that include elements of role modelling, advocacy (individually and in group settings), and support (CNO, 2009). Nurse leaders are well positioned to ensure that organizational priorities and mandates support the creation and implementation of policies and protocols that hold anti-racist values and are committed to health equity (McGibbon, 2016). Nurse can therefore help create a culture “where decisions about the allocation and use of money and resources consider the implications for

social equity,” thereby helping foster an organizational norm and culture that considers racial equity in decision-making (Griffith et al., 2007, p. 387).

Furthermore, nurses can advocate vertically for the importance of the NN role in supporting Indigenous Peoples across the institution, and through leadership engagement, can help ensure that the role of the NN remains an organizational priority (i.e. by setting the agenda for change, aligning incentives, communication methods, leveraging social networks, commitment of resources), essentially supporting a culturally safe environment (Dauvrin & Lorant, 2015). Leadership engagement is crucial, as emerging evidence supports culturally safe care as evidence-based practice, and that leaders are key facilitators of implementing evidence into health care practices (Gifford et al., 2007).

In addition, informal spread of knowledge from this study and/or personal experience with the NN could be horizontally shared amongst nurses and clinicians in the local regional health district (i.e. lunch and learns, electronic newsletters, emails), as well as formally disseminated through conferences, evidence-based practice bulletins, and organizational websites. By informing other clinicians and institutions, this could potentially allow for horizontal dissemination of the innovative role of NN.

Research

Further research is needed to gain the perspective of Indigenous Peoples regarding the role of NN and how the NN can effectively support Indigenous patients living with cancer. Building on the current study, research with the OCAP (ownership, control, access, possession) framework at its core, is needed that engages Indigenous communities as full partners and collaborators, to increase cultural congruency and authenticity of health care professionals in supporting Indigenous patients and families living with cancer (Schnarch, 2004; Yeager &

Bauer-Wu, 2013). Local context is pivotal to efficacy, as the success of the NN role depends on ensuring that it reflects and serves the diverse cultural perspectives and health needs of the many Indigenous urban, rural and remote communities. Thus, we must explore decolonizing methodologies that bring together best practice ideas and models for improving the health of Indigenous Peoples by incorporating Indigenous traditional perspectives and practices of health and wellness (Yeager & Bauer-Wu, 2013). However, while partnerships in research are important, in steering away from tokenizing participation (Inuit Tapiriit Kanatami, 2018), there is a need for a capacity building approach that encourages Indigenous to conduct research and facilitate solutions themselves, ultimately ensuring that Indigenous communities truly benefit from the conduction of research and its findings (Chilisa, 2012; Healey & Tagak Sr, 2014; Yeager & Bauer-Wu, 2013).

To further identify the state of knowledge regarding nurse navigation to support Indigenous Peoples in the field of oncology in Canada, a systematic review should be conducted and designed with the assistance of a Health Sciences Librarian, who has the expertise in Indigenous studies, thereby strengthening the comprehensiveness of the search (Medical Library Association, 2005). This research should also be conducted in collaboration with Indigenous community research partners from proposal writing to dissemination of results, to ensure that Indigenous traditional perspectives and ways of knowing are appreciated, thereby helping to guide all research processes (Inuit Tapiriit Kanatami, 2018). In addition, in this conducting this systematic review, by using SPIDER (sample, phenomenon of interest, design, evaluation, research type), with an expanded inclusion criterion, this may also identify more literature for review (Cooke, Smith & Booth, 2012). Thus, this insight may better inform future nurse navigation programs by reviewing the literature with a wider lens.

Lastly, we need to conduct more studies to understand the impact of the NN role on Indigenous patients and families' health and wellbeing, including their ability to navigate and engage with the health care system to receive and access services. For example, as suggested by participants in this study, experimental designs to evaluate the impact of the NN role on Indigenous health outcomes, could produce robust data, which could help measure the impact of and benefits related to NN involvement on Indigenous health outcomes.

Policy

At the organizational level, all health care organizations should include policies that aim to support and improve health care outcomes for Indigenous Peoples. Engagement and support from Elders and traditional Indigenous knowledge keepers must be required in the development of policies, practices, and guidelines that “foster cultural safety” (Muisse, 2019). There should be an “increased effort to integrate traditional healing practices within health care delivery; a requirement of meeting TRC recommendation #22” in order to bring traditional and Western healing approaches together (Richardson, 2018, p.15). Examples of such policies include the creation of Smudge policies, such as the one created at The Ottawa Hospital, that support and respect and facilitates the inclusion of this traditional practice into the current Western health care system (McGihon, 2019). This Smudge policy helps in respecting and honouring Indigenous ways of knowing, as for many First Nations and Métis cultures, this ceremony is a holistic practice “used for prayer, offerings, cleansing, and healing of mind, body, emotion, and spirit” (Brown, 2013, p. 573; Iseke, 2010).

Furthermore, creating safe spaces “within our existing system to acknowledge and support these services, including access to traditional medicine, ceremony, and food” should be an organisational priority for all health institutions (Richardson, 2018, p. 15). For example, TOH

among other organizations, have, in collaboration with Indigenous Elders, created a physical space in the hospital known as the “Windöcage Community Room” filled with Indigenous art, as a safe space for Indigenous patients and families to use to eat, rest, and relax during their stay at the hospital (McGihon, 2019). Furthermore, organizations should continue in their efforts to recruit Indigenous health care providers, such as nurses and physicians, as more Indigenous integration should exist across healthcare facilities in Canada (Niezen, 2017).

At the municipal, provincial and federal level, a health care priority should be to standardize charting in all health institutions to include fields that contain Indigenous self-identification, to allow Indigenous Peoples the opportunity to self-identify, thereby allowing health care providers to not only recognize and respect cultural specificity in the provision of care, but also offer services that are specifically serving this population.

Lastly, at the health systems level, “a stronger legislative framework to provide structure is required” as “much of the current thinking is based on colonialism” (Richardson, 2018, p.15). Health leaders must interrogate current policies and practices at local, regional, and provincial levels, and advocate for substantive investments in Indigenous partnerships, as the “answer lies in respectful relationships with Indigenous Peoples and communities” (Richardson, 2018, p. 16).

Conclusion

This thesis explored the experiences and processes of an NN supporting Indigenous cancer patients and families in a culturally sensitive manner. The results from this study will help inform healthcare delivery and nursing practice to improve quality of care and outcomes for Indigenous cancer patients, families and communities. Despite identified challenges, all participants felt that the NN had a positive impact on Indigenous Peoples' health and wellbeing and ability to navigate the health care system. Findings indicate that an NN in tertiary care

settings who is well versed in the context of Indigenous Health is critical in supporting Indigenous Peoples within their own culture. Future research is required to assess and evaluate the impact of NN role on Indigenous health outcomes, as the success of the NN role depends on ensuring that it reflects and serves the diverse cultural perspectives and health needs of the many Indigenous Peoples and communities in Canada.

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