ABSTRACT

Patient navigation (PN) is a model of care that addresses the complex nature of navigating health, education, and social services. Currently, there is no consensus on when to use a lay navigator versus a professional navigator, with little research on this topic in a Canadian context. The purpose of this study is to explore the roles of patient navigators in different settings and situations for various patient populations in Canada, and to understand the rationale for implementing lay and professional models of PN in a Canadian context.

This manuscript is written in an article-based format. The first section is an introductory chapter that discusses background information on PN and situates the current project within existing academic literature. Following this is an article that describes the study, including the research design, findings, as well as a discussion and implications section. Finally, the third section is a conclusion chapter, which summarizes the research findings and provides a detailed discussion of the study’s strengths and limitations, as well as a discussion and recommendations for future research.
ACKNOWLEDGEMENTS

I would like to acknowledge the incredible contributions of my supervisors, Dr. Shelley Doucet and Dr. Alison Luke, who gave up so much of their time to help me succeed. I do not know what I would have done without their endless support and encouragement.
# Table of Contents

ABSTRACT................................................................................................................................. ii

ACKNOWLEDGEMENTS ........................................................................................................... iii

Table of Contents ....................................................................................................................... iv

List of Tables ............................................................................................................................. vi

List of Abbreviations ................................................................................................................ vii

Introduction............................................................................................................................... 1

  Background and Significance ............................................................................................. 2

Purpose and Research Questions ........................................................................................ 4

Literature Review .................................................................................................................... 4

  Lay Navigators ................................................................................................................ 5

  Professional Navigators .................................................................................................. 12

Summary ................................................................................................................................. 16

References ............................................................................................................................... 19

Research Article – Exploring the Role of Lay and Professional Patient Navigators in
Canada....................................................................................................................................... 24

Abstract ................................................................................................................................ 24

Introduction .......................................................................................................................... 25

Methods ................................................................................................................................. 27

Design .................................................................................................................................... 27

Sample .................................................................................................................................... 28
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data Collection</td>
<td>28</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>29</td>
</tr>
<tr>
<td>Results</td>
<td>29</td>
</tr>
<tr>
<td>Lay Models of PN</td>
<td>36</td>
</tr>
<tr>
<td>Professional Models of PN</td>
<td>39</td>
</tr>
<tr>
<td>Discussion and Implications</td>
<td>44</td>
</tr>
<tr>
<td>Conclusion</td>
<td>48</td>
</tr>
<tr>
<td>References</td>
<td>49</td>
</tr>
<tr>
<td>Conclusion</td>
<td>51</td>
</tr>
<tr>
<td>Summary of the Thesis Manuscript</td>
<td>51</td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td>54</td>
</tr>
<tr>
<td>Rigor in Qualitative Research</td>
<td>55</td>
</tr>
<tr>
<td>Discussion and Recommendations</td>
<td>56</td>
</tr>
<tr>
<td>Conclusion</td>
<td>59</td>
</tr>
<tr>
<td>References</td>
<td>61</td>
</tr>
<tr>
<td>Appendix I: Consent Form</td>
<td>63</td>
</tr>
<tr>
<td>Appendix II: Recruitment Letter for Potential Participants</td>
<td>64</td>
</tr>
<tr>
<td>Appendix III: Interview Guide</td>
<td>65</td>
</tr>
<tr>
<td>Appendix IIII: Demographic Form</td>
<td>68</td>
</tr>
<tr>
<td>Curriculum Vitae</td>
<td>v</td>
</tr>
</tbody>
</table>
List of Tables

Table 1: Participant Information ................................................................. 31
Table 2: Patient Navigation Program Information ...................................... 33
Table 3: Themes from Participant Interviews .............................................. 36
### List of Abbreviations

1. Patient Navigation................................................................. PN
2. Collaborative Personal Health Record.................................. C-PHR
3. Lifestyle And Values Impacting Diabetes Awareness.............. LA VIDA
4. United States........................................................................ US
5. Newfoundland & Labrador.................................................... NL & LAB
6. Prince Edward Island......................................................... PEI
7. Nova Scotia........................................................................... NS
8. New Brunswick................................................................. NB
9. Ontario................................................................................ ON
10. Manitoba............................................................................ MB
11. Alberta................................................................................ AB
12. British Columbia.............................................................. BC
Introduction

The topic of this thesis is patient navigation (PN) in Canada, specifically exploring the various types of patient navigator roles across the country. An article-based format was used as the approach for this manuscript. Following the requirements set out by the School of Graduate Studies at the University of New Brunswick, this format for a master’s degree includes a minimum of one research article, preceded by an introductory chapter and followed by a conclusion chapter. The research article that is presented in this manuscript is titled *Exploring the Role of Lay and Professional Patient Navigators in Canada*. The lead author of this article is Amy Reid, a Master of Applied Health Services Research candidate at the University of New Brunswick. As the first author, I was responsible for leading the research project under the oversight of my supervisors Dr. Shelley Doucet and Dr. Alison Luke. I identified the specific research topic and developed the design and structure for my research with guidance from my supervisors. I conducted, transcribed and analyzed the research interviews, followed by writing each section of the research article, as well as the introductory and conclusion chapters within this thesis manuscript. This was reviewed and edited multiple times by my direct supervisors. Dr. Doucet, and Dr. Luke will be co-authors on the research article that is submitted for publication. The article has been prepared in a format that will be conducive to submitting it to the “Journal of Health Services Research and Policy” once the thesis defense has been completed. This included formatting the references and in-text citations to Vancouver style, and adjusting the headings to what is common across articles in the target journal. The aim of this peer-reviewed journal is to explore ideas and policies that shape health services delivery, which fits well with the purpose of the
current project. Formatting a master’s thesis in this way will help to ensure that the research findings are able to quickly progress from writing the thesis to publication of results.

**Background and Significance**

Patient navigation (PN) is a model of patient-centred care that emerged out of a need to address the health disparities of underserved populations (Freeman, 2013). The complexities of health, education, and social service delivery across Canada and abroad have also contributed to the continued growth of PN interventions throughout the health care system (Carter et al., 2018). Dr. Harold Freeman was responsible for creating the first PN program located in Harlem, New York, in the 1990’s to support patients in their cancer journey by reducing barriers to care and providing patient education (Freeman, 2013). Although PN is still an important aspect of cancer care in the United States (US) and Canada, it is increasingly being used to assist diverse patient populations, such as those experiencing mental health and/or addiction concerns (Corrigan, Pickett, Batia, & Michaels, 2014), diabetes (Abernethy, 2018), and those with non-specific conditions who need help navigating complex health, education, and social services (Corrigan et al., 2014). PN will be defined here as “a partnership between a patient, family, or member(s) of the care team and a patient navigator, who facilitates timely access to health and/or community resources and fosters self-management and autonomy through education and emotional support” (Reid, Doucet, Luke, & Azar, In-press, p.1).

Patient navigators often come from varied personal and professional backgrounds, thus, there are different types of navigators. For example, some models of navigation employ trained lay navigators with a high school education or bachelor’s degree in social
sciences, including peers with lived experience (e.g. with cancer or mental illness) of navigating the system. Within this manuscript, lay navigators or lay PN will be used to reflect programs that do not employ professionals. When referring to navigators with lived experience, the term peer navigator will be used to provide more clarity on the specific type of lay navigator under study.

In contrast, professional navigators are trained professionals that may be registered nurses, social workers, occupational therapists, or counsellors (Anderson & Larke, 2009; Carter et al., 2018; Corrigan, Pickket, Batia & Michaels, 2014; Freeman, 2013). PN programs may be embedded within community settings or at a hospital, while engagement with patients and/or families can occur virtually using phone or e-mail, through in-person meetings, or a combination of these methods (Abernethy, 2018; Corrigan et al., 2017a; DeGroff et al., 2017). Functions of the patient navigator role include, but are not limited to, advocating on behalf of the patient; supporting care coordination and collaboration; fostering community engagement; administrative activities; providing education; psychosocial support (e.g. social and emotional support); helping to access services and resources (e.g. referrals); and reducing barriers to care (Kelly, Doucet, & Luke, In-press). PN is not yet regulated and there is no consensus on when a lay or professional navigator may be better suited for a specific patient population. On top of this, most research on patient navigation does not include a rationale behind why the program was implemented, making it more difficult to discern when one model may be appropriate versus another. Further, the Canadian literature in this area is quite limited. Research on the roles of patient navigators and rationale for implementing different models of PN in Canada is merited at this time.
Purpose and Research Questions

PN continues to evolve and expand on the types of patient populations that it serves in the US, Canada, and elsewhere. There is a need to better understand what situations, including what settings and populations, are suited for the use of lay and professional navigators in Canada. In gaining this information, there are policy, research, and practice implications for this growing field. A better understanding of the roles of patient navigators related to their intended patient population will assist current and future PN programs with their decision-making processes regarding what type of navigator is suited for a given situation. Therefore, the purpose of this study is to explore the roles of patient navigators in different settings/situations for various patient populations in Canada, and to understand the rationale for implementing lay and professional models of PN in a Canadian context. The following research questions will be addressed: (1) What setting, situations or populations are suited for lay or professional patient navigators in Canada, and (2) What is the rationale when deciding whether to implement a lay or professional model of PN in Canada?

Literature Review

This section includes a review of the literature related to the purpose of this study and includes quantitative and qualitative studies, as well as grey literature and reviews. Databases that were searched included Pubmed, CINAHL and PsycInfo. A general Google search to find other sources of information was done after the initial database search. Included information was found by using the following combination of key terms, “navigator” or “patient navigation,” and “lay” or “peer” or “professional” or “nurse” or “social worker”. Additional records were found by hand-searching the references of
relevant articles. This literature review maps existing evidence on lay and professional PN for various populations. The details and characteristics of these programs (e.g. settings, populations served) are discussed. Where possible, the provided rationale for using a lay or professional navigator is reported. This section concludes with a short summary of the literature regarding lay and professional navigators, and the relevance of the proposed research project.

**Lay Navigators**

Lay navigators are trained individuals who have varied educational backgrounds and are familiar with local community resources to assist a specific patient population (Meade et al., 2014). They offer the benefit of reduced costs in comparison to professional navigators and are more likely to be located within rural community locations to assist disadvantaged populations (Hedlund et al., 2014; Valverde, Calhoun, Esparza, Wells, & Risendal, 2010). As non-professionals, lay navigators are able to relate to the often-vulnerable populations that they serve to help them navigate through complex health systems. It is important to note that peer navigators are a type of lay navigator, distinguished in the literature either by the requirement of having lived experience of a health condition or being a culturally attuned community member from the region where the PN services are provided (Broeckaert, 2018; Meade, 2014; Rocque, Pisu, & Kyale, 2017). However, the evidence on lay and peer PN are frequently often presented separately within the literature (e.g. studies describe their model as lay, or as peer navigation, rather than peer as a type of lay navigation). Below, I present literature on lay PN first, followed by articles that specifically discuss peer PN.
For older individuals with complex care needs, including cancer, navigating the health care system can be difficult because of the number of settings and providers. Rocque, Pisu and Kyale (2017) sought to determine the effect of a lay PN program for adults 65 years and older with cancer on health care usage and Medicare costs using an observational cohort study design with propensity score-matched controls. This study was conducted at a community cancer center at the University of Alabama in the Birmingham Health System Cancer Community Network (Rocque, Pisu, & Kyale, 2017). The educational requirements for the navigators was a bachelor’s degree, with no requirements for a clinical degree, such as nursing or social work (Rocque, Pisu, & Kyale, 2017). They concluded that lay PN services for older adults were associated with a decrease in resource utilization and Medicare costs compared to non-navigated patients (Rocque, Pisu, & Kyale, 2017). Lay navigators held a mean caseload of 152 patients per quarter. The rationale provided for choosing a lay navigator was to save on costs. The authors noted that if lay navigators receive training and can perform well in the functions of PN, there may be no need for a professional navigator (Rocque, Pisu, & Kyale, 2017).

Because colorectal cancer is one of the leading causes of cancer-related deaths, an intervention study explored the use of two bilingual lay navigators to increase colonoscopy screening in Boston, Massachusetts (DeGroff et al., 2017). The target population was Hispanic and non-Hispanic blacks between 50 and 75 years of age who faced barriers to care, such as language, lack of understanding of the procedure, and fear or distrust of the medical system (DeGroff et al., 2017). Both lay navigators had knowledge of community resources and the ability to reduce patient barriers. One of the navigators had previous PN training and worked as a lay navigator for a different
program, while the other navigator received training and was mentored by their counterpart (DeGroff et al., 2017). Services of emotional support, assistance with scheduling appointments, and educational materials were provided primarily over the phone. In addition, the lay navigators facilitated communication with the primary care provider to ensure colonoscopy results were received (DeGroff et al., 2017). In this case, lay navigators were able to improve colonoscopy completion rates within 6 months among a low-income and disadvantaged population. DeGroff et al. (2017) noted that there is little known on what model (lay or professional) of PN is the most effective. The authors suggested that given the clinically complex nature of a colonoscopy, a registered nurse who is also culturally competent may be more effective as a navigator due to their expertise. However, their opinion was that a combination of a professional and lay navigator could be the most effective (DeGroff et al., 2017).

A peer navigator is a type of lay navigator who generally has lived experience with the same condition(s) as those who are receiving the navigation services (Broeckaert, 2018). Having lived experience is not always a requirement, and in cases where they have not had a similar health experience, peer navigators are members of the same community as the target population, speak the same language, and understand their cultural needs (Corrigan, & Michaels, 2014; McCloskey, 2009). Due to their similar life experiences and ability to create a trusting relationship, peer navigators give patients a safe space to communicate openly on health-related issues so that barriers to care can be identified and improved (Cantril, & Haylock, 2013).

Bekelman, Johnson-Koenke, Bowles, and Fischer (2018) conducted a study to examine a model of PN with both a peer and professional navigator for patients with
terminal cancer who were 18 years and older. The peer navigator in this case was a Veteran who previously received care within the Denver Veterans Affairs Medical Center in Colorado (Bekelman, Johnson-Koenke, Bowles, & Fischer, 2018). The peer navigator provided emotional support and basic palliative care education either in person or over the phone. When deemed necessary, the peer navigator referred the patient to a professional navigator (social worker) to provide more in-depth psychosocial support. This model was chosen because the complex psychosocial needs of patients in palliative care were considered to be better suited for a professional navigator to address, while the peer navigator could offer basic education and support (Bekelman, Johnson-Koenke, & Fischer, 2018). However, very few cases necessitated referral to the professional navigator within the population under study. The navigators engaged with each of the 17 individuals over the course of five planned navigation sessions. The intervention was considered complete after palliative care education was provided, and a closing session was held (Bekelman, Johnson-Koenke, Bowles, & Fischer, 2018). Seven participants completed satisfaction surveys at the end of the study, and all noted that the navigators listened to their concerns and provided emotional support. However, two participants said they were dissatisfied based on their perception of whether the navigator provided helpful or new information (Bekelman, Johnson-Koenke, Bowles, & Fischer, 2018). These results reflected perceptions of both navigators, rather than a comparison between peer and professional navigators. Recommendations made by participants and the authors suggested that PN in palliative care would be more beneficial if it was based in rural areas where the needs may be greater, and if it began as early as possible versus being
implemented at more advanced stages (Bekelman, Johnson-Koenke, Bowles, & Fischer, 2018).

A culturally targeted patient navigation (CTPN) program was implemented in Harlem, New York to increase colonoscopy screening at an urban primary care clinic for African American patients (Jandorf et al., 2013). Patients were randomized to receive either peer or professional navigation services. Participants were an average of 59 years of age between the two groups, with most being characterized as having a low socio-economic status. There were five peer navigators who had recently undergone colonoscopy screening. No educational requirements for peer navigators were discussed. Four professional navigators were hired and described as representatives of the health care system, but their specific role (e.g. nurse, social worker, counsellor) was not reported (Jandorf et al., 2013). All navigators were African American and were given information on addressing financial, structural, sociocultural, and psychological barriers to colonoscopy completion. Peer navigators shared their experience with colonoscopy screening with the patients they were assisting, while all other aspects of the PN intervention for education and support were identical between professionals and peers. Results indicated that 71% of patients in the peer group, and 80% in the professional group completed a colonoscopy. Although this shows a difference, it was not statistically significant. Patients perceived an equally satisfactory and trusting relationship when comparing peer and professional navigators (Jandorf et al., 2013). This was the first and only study identified that directly explored the differences between peer and professional PN. The authors suggest that further research should examine and compare efficacy of peer versus professional navigators, as well as characteristics such as personal experience.
and education level that may have an effect on the navigators’ abilities (Jandorf et al., 2013).

A pilot study of a peer health navigator intervention provided insights on PN for individuals with housing instability and serious mental illness (Kelly, Braslow, & Brekke, 2017). Kelly and colleagues conducted a six-month PN intervention combined with the use of a collaborative personal health record that was provided by one full-time and two part-time trained peer navigators within an existing peer health navigation program called “The Bridge” within a community mental health care centre. The navigators were individuals who had experienced living with mental illness and were already engaged in the peer health navigator role prior to the research project (Kelly, Braslow, & Brekke, 2017). Participants were individuals who were living on the street or resided in supervised homes or temporary shelters between 18 and 65 years old with diagnoses of mood disorders, schizophrenia, or post-traumatic stress disorder (Kelly, Braslow, & Brekke, 2017). Navigators offered one-on-one education sessions related to chronic disease management and prevention due to the high prevalence of comorbid physical health issues in individuals with mental illness (Kelly, Braslow, & Brekke, 2017; Walker, McGee, & Druss, 2015). In addition, assistance with planning medical visits and coordination with health care providers was provided. Navigators used the electronic C-PHR alongside each participant to demonstrate how to use the system, and collaboratively input relevant health information (e.g. diet, exercise, weight, allergy information) while building rapport with participants (Kelly, Braslow, & Brekke, 2017). After the PN intervention, participants reported an increase in visits to their primary care provider, improved satisfaction regarding their relationship with their primary care
provider, and heightened self-management related to general communication with health care providers (Kelly, Braslow, & Brekke, 2017).

Corrigan et al (2017a) conducted a randomized controlled trial to evaluate the impact of a peer PN program in Chicago that was tailored to Latinos with serious mental illness. Four individuals who were bilingual Latinos recovering from serious mental illness served as the peer navigators. This program was delivered in a face-to-face format, and participants were contacted at minimum once per week to assess and review health concerns and conduct planning to achieve identified goals (Corrigan et al., 2017a). Participants were on average 48 years old, with diagnoses of major depression, bipolar disorder, anxiety disorder, post-traumatic stress disorder, schizophrenia, schizoaffective disorder, or attention deficit hyperactivity disorder (Corrigan et al., 2017a). The requirements for the role of a peer navigator included familiarity with the cultural values of the population. The navigators were provided with a resource guide with available health services within Chicago to assist this population (Corrigan et al., 2017a). Participants’ engagement with existing health care services increased rapidly upon the implementation of the peer-led PN program compared to the control group (Corrigan et al., 2017a). Similar results were reported by Corrigan et al. (2017b), who completed a study of a peer-led PN program with African-American patients with serious mental illness. In both studies, peer navigators assisted disadvantaged populations in overcoming linguistic and cultural barriers that inhibited them from gaining access to necessary services and resources (Corrigan et al., 2017a; Corrigan et al., 2017b).

In the Hispanic-American community, there is a higher rate of type 2 diabetes than among white Americans (National Diabetes Information Clearing House, 2005). To
address this disparity, a program called LA VIDA, or Lifestyle And Values Impacting Diabetes Awareness, targets those who are at risk of, or currently have diabetes. The program, located within communities across southwest New Mexico, was delivered face-to-face by *promotores*, also known as community health workers or integrated care team coordinators (McCloskey, 2009; Rural Health Information Hub, 2018). Promotores are trained peers who understand patient needs and have knowledge of the resources and services as they are from and live in the same communities. Senior promotores who have gained the most experience and training in this role were responsible for supervising and training new promotores. McCloskey (2009) noted that promotores acted as health navigators by providing emotional support, assisting with complex financial applications, and connecting families to both health and social services. Outreach was also noted as an important part of this role, as promotores help to promote healthy communities by connecting to various community groups. In the year 2010, 17 promotores provided services to 5,700 individuals and families (McCloskey, 2009). The authors felt that trained individuals who understand the cultural values of the population are well-suited to perform in this navigation role for those with type 2 diabetes (McCloskey, 2009).

**Professional Navigators**

Implementing professional PN programs typically requires the most resources of any PN model. However, due to their clinical expertise, professional navigators can provide a high level of service and support for patients (Gilbert et al., 2011). Although many professionals are capable of coordinating care at various levels, professional navigators are situated within a role where care coordination is of high importance versus only being a small function of their role (Conway, O’Donnell, & Yates, 2017).
Registered nurses, social workers, and other professionals, such as counsellors, may deliver PN services. Described here are PN interventions delivered by nurses and social workers, as they are the most commonly presented professionals performing in the role of a patient navigator in the literature.

**Nurse Navigators.** Many nurses are being employed in dedicated PN and care coordinator positions to improve the integration and continuity of care (Conway, O’Donnell, & Yates, 2017). One systematic review examined the effectiveness of care coordinator roles, including patient navigator roles, performed by either advanced practice nurses (e.g. nurse practitioners) or registered nurses (Conway, O’Donnell, & Yates, 2017). Most studies (78%) that were included were conducted in the US (Conway, O’Donnell, & Yates, 2017). Included were several studies that discussed case management, but their roles aligned with our definition of PN. It is relevant to note that among all articles reviewed, better outcomes were more likely to occur when navigators offered frequent and in-person meetings, including follow-up contacts to ensure goals were achieved for populations at high-risk or who have complex care needs (e.g. diabetes, mental health concerns, and various chronic conditions) (Conway, O’Donnell, & Yates, 2017). On the other hand, there were mixed results regarding hospitalization rates. Several studies reported reductions in hospitalization after implementing a PN intervention, but the majority were not statistically significant, with one study reporting that hospitalization rates after two years showed no change (Conway, O’Donnell, & Yates, 2017).

To address the complexities and potential barriers that arise with a diagnosis of diabetes, a PN program can be beneficial (Abernethy, 2018). Acquiring a diagnosis of
neonatal diabetes is rare and maintaining communication between providers and families is essential to achieving positive health outcomes and successfully caring for the child in a home environment (Abernethy, 2018). Having one contact person—a navigator—can help to coordinate multiple appointments, facilitate transitions in care, and offer education to help weed through unfamiliar medical jargon. Abernethy (2018) described the role of a nurse navigator in neonatal diabetes, but no evaluation or outcomes were measured. The navigator’s role was to meet with families in person to create an individualized needs-based plan for diabetes education (e.g. applying for a pump that qualifies under their insurance coverage). In addition, the navigator helped prepare the family for the transition from hospital to home with emergency contacts and coordinated future follow-up appointments for the child with health care providers, such as endocrinologists, pharmacists, pump trainers, direct care nurses, and primary care providers (Abernethy, 2018). A nurse with specialized knowledge on diabetes care was chosen in this case, but there was no rationale provided for this decision.

Oncology nurse navigators have expertise and clinical experience within the cancer care system and can promote continuity of care by acting as a link between patients and their health care team (Pautasso, Zelmanowicz, Flores, & Caregnato, 2018). Pautasso and colleagues conducted a review of 17 published articles on the topic of oncology nurse navigators. They found that oncology nurse navigators are well-suited to assist in the screening and diagnostic stages of at-risk patients with the aim of gaining an earlier diagnosis and improving wait times for treatment or surgery (Pautasso, Zelmanowicz, Flores, & Caregnato, 2018). The selected studies in this review primarily represented the US (53%) and Canada (23%). The evidence suggested that implementing
a nurse navigator program early in the cancer journey helps to achieve improved care processes throughout the continuum (Pautasso, Zelmanowicz, Flores, & Caregnato, 2018). Results noted that patients felt supported and more engaged with their treatment due to a trusting relationship and had improved experiences of care during their treatment with PN services (Pautasso, Zelmanowicz, Flores, & Caregnato, 2018). Two review articles noted that although lay persons can be successful navigators who assist patients in overcoming certain barriers of oncology care, oncology nurse navigators possess the required clinical reasoning skills that are particularly suited for navigating through complex diagnostic stages (McMullen, 2013; Gilbert, et al., 2011).

**Social Worker Navigators.** Compared to nurses, social workers are less frequently discussed as navigators in the PN literature but are well-positioned to help navigate complex situations, particularly regarding the social determinants of health for individuals and families (Browne, Darnell, Savage, & Brown, 2015). As mentioned above, Bekelman, Johnson-Koenke, Bowles, and Fischer, (2018) discussed a stepped navigator model where a peer navigator would support palliative care patients until deemed that there was a greater need for support from a professional navigator. Based on the patient’s identified needs, the social worker would offer educational modules and information about advance care planning, the importance of social support, and relaxation techniques (Bekelman, Johnson-Koenke, Bowles, & Fischer, 2018). Taking the role of the professional navigator, a social worker was well-suited to help with addressing barriers to advance care planning for palliative care and complex psychosocial needs.
Patient satisfaction outcomes for this study were discussed previously under the heading peer navigators.

Luke, Doucet, and Azar’s (2018) environmental scan of pediatric navigation services in Canada noted that several programs used a social worker in the position of a patient navigator. One program identified was for youth aged 13 to 18 years old with type 1 diabetes. The program was delivered by the navigator (social worker) via phone or email across the province of Nova Scotia (Luke, Doucet, & Azar, 2018). Another intervention was delivered by phone with some face to face interaction and tailored to individuals 17 years and younger with complex care needs in British Columbia. The navigators in this program were both social workers and registered nurses (Luke, Doucet, & Azar, 2018). In addition, a PN program that employed navigators with a master’s degree in either social work or psychology, as well as peer navigators, was found in the Greater Toronto Area. This program was offered over the phone or through email for youth aged 13 to 26 with a mental health condition (Luke, Doucet, & Azar, 2018). This environmental scan provided insight on various PN programs within Canada, but was unable to report on patient outcomes or each program’s rationale for choosing a professional model of PN over a lay model of PN.

Summary

Lay, including peer, and professional navigators can all perform well in the functions of PN (Hedlund et al, 2014). However, the specific personal and professional background of a navigator could affect their ability to perform well within a given situation (i.e. setting and population). Populations served by lay navigators within this literature review included patients in cancer screening, treatment, and palliative care,
individuals with serious mental illness and housing instability, and diabetes (Bekelman, Johnson-Koenke, Bowles, & Fischer, 2018; Corrigan et al., 2017a; Kelly, Braslow, & Brekke, 2017; McCloskey, 2009; Rocque, Pisu, & Kyale, 2017). Professional navigators cared for patient populations that included those in cancer care and palliative cancer care, as well as those with mental health concerns, diabetes, chronic conditions, and various complex care needs (Abernethy, 2018; Conway, O’Donnell, & Yates, 2017; Luke, Doucet, & Azar, 2018; Pautasso, Zelmaniwicz, Flores, & Caregnato, 2018). Although rationale was provided for the implementation of certain PN programs, the reasoning behind the choice to implement one model over the other (e.g. lay versus professional) was not discussed in most studies. However, some research studies did suggest that a combination of lay and professional navigators may be effective (Bekelman, Johnson-Koenke, Bowles, & Fischer, 2018; DeGroff et al., 2017). Only one study by Jandorf et al. (2013) completed a comparative analysis between peer and professional PN. They found small differences in their ability to help patients complete colonoscopy screening, while there were no differences in level of trust and satisfaction with peer and professional navigators (Jandorf et al., 2013).

A number of reasons for selecting lay or professional navigation models were discussed. Common themes for choosing lay navigators will be presented here first, followed by professional navigators. Cost-savings (Roque, Pisu, & Kyle 2017; Hedlund et al., 2014), knowledge of community resources, the ability to relate to the program’s target population, and the ability to understand the same language (Cantril, & Haylock, 2013; Kelly, Braslow, Brekke, 2017; McCloskey, 2009) were prominent reasons for employing lay and peer navigators. Unique to peer navigators was their lived experience
of navigating through the health care system with a particular diagnosis and shared cultural values with the target population (Corrigan et al., 2017a; Corrigan et al., 2017b; McCloskey, 2009). One concern that was identified was that a lay navigator may not have enough training to provide patient education on complex medical issues or high-levels of psychosocial support (Bekelman, Johnson-Koenke, & Fischer, 2018). Within the literature, the rationale for choosing a professional navigator included their knowledge of medical jargon (Abernethy, 2018; Meade et al., 2014) and clinical expertise to navigate complex situations and provide patient education (Bekelman, Johnson-Koenke, Bowles, & Fischer, 2018; Gilbert, et al., 2011; McMullen, 2013; Pautasso, Zelmanowicz, Flores, & Caregnato, 2018).

The current study draws on the findings of previous research that has been presented above. The research article presented in the following section of this manuscript will add to the literature by discussing the rationale for implementing one model of PN over another, while exploring which type of navigator is best suited for various settings, situations, and populations in Canada.
References


https://doi.org/10.1177/0163278717734610


https://doi.org/10.1176/appi.ps.201700241

https://doi.org/10.1016/j.amepre.2017.05.010


Research Article – Exploring the Role of Lay and Professional Patient Navigators in Canada

Abstract

Patient navigation (PN) is a model of care that employs lay and/or professional navigators who help individuals and their families navigate a complex maze of services and programs across sectors. Currently, there is no consensus on when employ a lay navigator versus a professional navigator in this model of care, with little research on this topic in a Canadian context. It is important to gain an understanding of what model of PN is best suited for different contexts to ensure that resources are being allocated efficiently and to ensure the optimal delivery of PN services. The purpose of this qualitative descriptive study is to explore the roles of patient navigators in different settings and situations for various patient populations in Canada, and to understand the rationale for implementing lay and professional models of PN in a Canadian context. Participants were purposefully recruited based on the results of an environmental scan of PN programs across Canada. Data was collected through individual semi-structured interviews with patient navigators from eight Canadian provinces who serve various patient populations across diverse settings. Braun and Clarke’s six phases of thematic analysis were used to guide the analysis of interview transcripts. Findings indicate that a navigator’s personality and experience (personal and work-related) may be more important than their specific designation (i.e. lay or professional). This study has the potential to inform future research, policy, as well as the delivery of existing and future PN programs, particularly those in Canada.
Introduction

Patient navigation (PN) has been described as a relationship between a patient, family, or care provider(s) and a patient navigator, who facilitates access to various health-related services and resources by providing education and emotional support.¹ Common functions of the patient navigator role include supporting care coordination and collaboration; fostering community engagement; reducing barriers to care; providing psychosocial support; helping navigate services and resources; and offering patient education.² ³ This model of care began in the 1990’s through the work of Dr. Harold Freeman, who initiated a PN program to address health disparities among low-income African-American women with breast cancer.⁴ Since this time, navigation programs have expanded across North America and beyond for various patient populations, including those outside of the cancer system. The current study adds to the scarce Canadian literature on PN by contributing a better understanding of the roles of patient navigators in different settings and situations for various patient populations in Canada, as well as producing a description of the rationale for implementing lay and professional models of PN in a Canadian context.

PN programs employ lay and professional patient navigators. Lay navigators are individuals who have varied educational backgrounds and have an in-depth understanding of local community resources to assist a specific patient population.⁵ They often practice in the community to assist disadvantaged or underserved populations.⁶ ⁷ As non-professionals, lay navigators draw on individual traits, such as respect and empathy, to connect with the often-vulnerable populations that they serve.⁸ ⁹ Peer navigators are a type of lay navigator, distinguished most often by the requirement of having lived
experience of a health condition, or being a culturally attuned community member living in the region where the PN services are provided. The term lay PN will be used to reflect programs that do not employ professionals. When referring to navigators with lived experience, the term peer navigator will be used to provide more clarity on the specific type of lay navigator under study. Due to their similar life experiences and ability to create a trusting relationship, peer navigators give patients a safe space to communicate openly on health-related issues so that barriers to care can be identified and improved.

PN programs may alternatively employ professional navigators. Because professional PN programs hire registered professionals who earn higher wages than lay persons, they typically require the most resources of any PN model. However, due to their clinical expertise, professional navigators can provide a high level of service and support for patients. Although many professionals are capable of coordinating care at various levels, professional navigators are situated to roles where care coordination and navigation is of central importance rather than only being a small function. Registered nurses, social workers, and other professionals (e.g. counsellors) may provide professional PN services.

Most literature on PN comes from the United States (US) and focuses predominantly on its’ application within cancer care. With the continually growing number of publications in this area, information regarding patient navigator roles and their impact on patient satisfaction and health outcomes is expanding. Limited Canadian publications, along with differences in the delivery of health care between Canada and the US make it difficult to compare the delivery of PN models, even in PN
programs focused on similar populations or settings. Moreover, although the characteristics, functions, and impact of PN is becoming well-studied, Jandorf et al suggest that exploring the differences among lay and professional navigators across characteristics, such as education level and personal experience, may assist in determining a navigators’ ability to provide PN. In addition, Wells and Nuhaily conducted a review of the literature on models of navigation within cancer care, and concluded that there is still “a lot that is not known about which type of patient navigation model is best suited for a particular situation.”

As is clear, there is currently no consensus on when to choose a lay or professional navigator when implementing PN programs in Canada. Thus, it is unclear whether lay navigators are suited for specific settings, situations (e.g. face-to-face or virtual navigation), or populations over professional navigators. It is important to gain an understanding of what model of PN is best suited for different contexts to ensure that resources are being allocated efficiently and to encourage the optimal delivery of PN services. To address these gaps, the current study sought to explore the following research questions: (1) What setting, situations or populations are best suited for lay or professional patient navigators in Canada, and (2) What is the rationale when deciding whether to implement a lay or professional model of PN in Canada?

Methods

Design

The current study used a qualitative description design, as it allows for a comprehensive description of the research findings. The philosophical underpinnings of qualitative description are derived from naturalistic inquiry. Naturalistic inquiry
promotes the study of something within its’ natural state without holding a commitment to a specific theoretical view prior to conducting the research. Because of its descriptive nature, this approach leads to high levels of agreement among researchers, participants, and knowledge users. As such, qualitative description is a valuable methodological approach for health services research.

**Sample**

Maximum variation sampling was used to examine both the unique and common characteristics across lay and professional PN models of care. Potential participants were selected to provide varied perspectives on PN programs for a range of patient populations and types of navigators (lay and professional) across various Canadian provinces. Initial participants were identified based on the results of an environmental scan of PN programs within Canada. Additional participants were identified through an internet search using keywords including “patient navigation” and “Canada,” or the name of each province and territory. Recruitment occurred over the phone or through e-mail correspondence using a standard invitation letter to explain the study and participant expectations. Individuals who qualified as participants had to be either a patient navigator, a program manager, or a program director of a patient navigation program in Canada with knowledge of the patient navigation role.

**Data Collection**

Data collection occurred through semi-structured individual interviews. Given that the participants were geographically located across Canada, interviews were conducted over the phone or using the Zoom platform. A flexible interview guide with open-ended questions allowed those being interviewed to freely elaborate on their
experiences, and in turn, produce participant driven data. The dependability of the current study was enhanced by using a consistent approach to each individual interview. Participants gave consent to have their interviews audio-recorded and later transcribed. Interviews varied in length depending on each individual’s conversational style, but were on average 40 minutes long. Participants also completed a short demographic questionnaire to collect information related to their educational background and the setting of the PN program. By including this demographic information, readers will be able to decide whether the results are transferable to other contexts. All information collected was stored on a secured network, password protected, and only accessible to the primary investigator and two direct supervisors.

Data Analysis

Interview transcripts were analyzed using Braun and Clarke’s six phases of qualitative thematic analysis. This includes (1) familiarizing self with data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) providing the report.

Results

A total of 10 patient navigators volunteered to take part in this study, of which 2 patient navigators were in dual roles as both patient navigators with additional responsibilities as interim program manager (n=1) and program coordinator (n=1). Of the 10 participants, three had a nursing background, two had a social work education, one was trained in counseling psychology, one in child life and psychosocial care, one with a bachelor of fine arts with an in-progress master’s in art-therapy, one who was a registered dietician, and one occupational therapist. Three of the navigators had previous experience
in PN prior to their current role in their respective programs. Lay programs required a bachelor’s degree in a relevant field plus familiarity with the patient population and their community. One peer program required college-level education in health services and lived experience. For lay PN programs, some navigators held higher levels education—this was considered to be an asset to the program. Four of the professional models incorporated close partnerships with community peer support or advocacy groups, while one of these specifically had a parent advocate with lived experience as a paid member of their staff in addition to the 10 professional navigators. Please see Table 1 for an overview of the demographic background of the participants.

The PN programs the participants currently worked in targeted various patient population groups, including general health and wellness (n=2); transgender, two-spirited, or gender-diverse (n=1); mental health and addictions (n=3); cancer (n=3); and diabetes (n=1). Programs were located across eight provinces in Canada—Newfoundland and Labrador (NL & LAB), Prince Edward Island (PEI), Nova Scotia (NS), New Brunswick (NB), Ontario (ON), Manitoba (MB), Alberta (AB), and British Columbia (BC). Among the included PN programs, the majority were professional models (70%), while the remainder were lay or peer (30%). Most programs (70%) were established within the community, while the remaining 30% were hospital-based with the option to provide support within the community (e.g. schools, primary care practices, or connecting virtually). Please see Table 2 for an overview of the included PN programs.

The number of patients/families and care providers that navigators have assisted was dependent on the number of navigators in the program, how long the program has existed, and the method of patient contact. Having more navigators within the program
created more capacity for that program to help more patients. Only one PN program was established less than two years ago. Navigators who have been in this role since their respective programs were established noted that it took time to gain clientele within the first year of implementation. Reported caseloads indicate that after approximately 2 years, greater uptake occurs. In combination with the previous factors, providing services virtually enabled navigators to accommodate more requests, while providing PN face-to-face required more time and interaction with the individuals or families that the navigators cared for. Table 2 provides an overview of the patient navigator’s caseload.

<table>
<thead>
<tr>
<th>Program</th>
<th>Description</th>
<th>Type of navigator(s)</th>
<th>Educational background</th>
<th>PN-specific training prior to role?</th>
<th>Duration of experience as a navigator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Navigation Program</td>
<td>Professional</td>
<td>Bachelor of Science, Registered Dietician</td>
<td>No, specific PN training after being hired</td>
<td>2 years 3 months</td>
<td></td>
</tr>
<tr>
<td>Wellness Navigators (within Community Health Teams)</td>
<td>Professional</td>
<td>Bachelor of Science, Occupational Therapist</td>
<td>No</td>
<td>4 years in program; 8 years 6 months total in PN</td>
<td></td>
</tr>
<tr>
<td>TransCare Health Navigation Program</td>
<td>Lay</td>
<td>Bachelor of Social Work</td>
<td>No</td>
<td>1 year 4 months in program; 6 years total in PN</td>
<td></td>
</tr>
<tr>
<td>Family Navigation Project</td>
<td>Professional + parent with lived experience</td>
<td>Master of Child Life and Pediatric Psychosocial Care, Certified Child Life Specialist</td>
<td>No</td>
<td>5 years 3 months; 10 years total in PN</td>
<td></td>
</tr>
<tr>
<td>Mental Health and Addictions Systems Navigator</td>
<td>Professional</td>
<td>Master of Social Work</td>
<td>No</td>
<td>2 years 6 months</td>
<td></td>
</tr>
<tr>
<td>Peer Navigation Program</td>
<td>Peer</td>
<td>Master of Counselling Psychology</td>
<td>No, on-the-job shadowing</td>
<td>1 year</td>
<td></td>
</tr>
<tr>
<td>The Maestro Project</td>
<td>Lay</td>
<td>Bachelor of Fine Arts (completed), Master of Art</td>
<td>No</td>
<td>17 years</td>
<td></td>
</tr>
<tr>
<td>Program</td>
<td>Level</td>
<td>Education</td>
<td>Required</td>
<td>Years</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>-------</td>
<td>----------------------------------</td>
<td>----------</td>
<td>-------------------------</td>
<td></td>
</tr>
<tr>
<td>Pediatric Cancer Patient Navigation Program</td>
<td>Professional</td>
<td>Bachelor of Science, Registered Nurse</td>
<td>No</td>
<td>8 years</td>
<td></td>
</tr>
<tr>
<td>Indigenous Cancer Patient Navigation Program</td>
<td>Professional</td>
<td>Bachelor of Science, Registered Nurse</td>
<td>No</td>
<td>4 years 9 months</td>
<td></td>
</tr>
<tr>
<td>Adolescent and Young Adult Cancer Patient</td>
<td>Professional</td>
<td>Bachelor of Science, Registered Nurse</td>
<td>Yes, through provincial PN program</td>
<td>1 year 11 months</td>
<td></td>
</tr>
<tr>
<td>Program</td>
<td>Description</td>
<td>Patient Population</td>
<td># of navigators in PN program</td>
<td>Navigator-Reported caseload</td>
<td>Setting</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>--------------------</td>
<td>--------------------------------</td>
<td>-----------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Health Navigation Program</td>
<td>All ages; anyone interacting with health care system</td>
<td>1</td>
<td>Unable to share numbers</td>
<td>Community</td>
<td>Phone and some e-mail</td>
</tr>
<tr>
<td>Wellness Navigators</td>
<td>All ages; any health concern</td>
<td>2 for children (0-18), 9 for adults</td>
<td>15-25 new patients or families per month per program</td>
<td>Community</td>
<td>Face-to-face, some phone</td>
</tr>
<tr>
<td>TransCare Health Navigation Program</td>
<td>All ages; transgender, gender-diverse, or two-spirited individuals</td>
<td>2.5 (+ 3.5 regional network coordinators)</td>
<td>Approx. 130 interactions per navigator per month (1/4 are pre-existing clients)</td>
<td>Community</td>
<td>Phone or e-mail, rarely face-to-face</td>
</tr>
<tr>
<td>Family Navigation Project</td>
<td>Youth 13-26 years with mental health &amp; addictions</td>
<td>10 (+ 1 parent advocate)</td>
<td>30-35 patients per navigator at a time</td>
<td>Community</td>
<td>Phone or e-mail</td>
</tr>
<tr>
<td>Mental Health and Addictions Systems Navigator</td>
<td>All ages; mental health &amp; addictions</td>
<td>1</td>
<td>3-15 patient contacts per day (some pre-existing)</td>
<td>Community</td>
<td>Phone and some e-mail</td>
</tr>
<tr>
<td>Peer Navigation Program</td>
<td>17 years and up with mental health &amp; addictions</td>
<td>7</td>
<td>20-25 patients per navigator at a time</td>
<td>Community</td>
<td>Initially phone or e-mail, then face-to-face</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------------------------------------------------</td>
<td>---</td>
<td>----------------------------------------</td>
<td>-----------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>The Maestro Project</td>
<td>Youth 16-25 years with Type 1 or Type 2 diabetes</td>
<td>1</td>
<td>170 transitions from pediatric to adult care per year, 10-12 active patients per week</td>
<td>Community</td>
<td>Initially face-to-face, then phone, e-mail, or Facebook</td>
</tr>
<tr>
<td>Pediatric Cancer Patient Navigation Program</td>
<td>Children 0-18 years with any type of cancer diagnosis</td>
<td>2</td>
<td>20-25 new diagnosis per year, divided to each navigator by health authority</td>
<td>Hospital + Community</td>
<td>Initially by phone, then face-to-face and phone or e-mail</td>
</tr>
<tr>
<td>Indigenous Cancer Patient Navigation Program</td>
<td>All ages; Indigenous persons with any type or stage of cancer</td>
<td>1</td>
<td>Up to 80 in-person meetings and phone consults per month</td>
<td>Hospital + Community</td>
<td>Phone and face-to-face where possible</td>
</tr>
<tr>
<td>Adolescent and Young Adult Cancer Patient Navigation Program</td>
<td>17-29 years with any cancer diagnosis</td>
<td>1</td>
<td>12-15 active patients per week</td>
<td>Hospital + Community</td>
<td>Phone and e-mail, face-to-face where possible</td>
</tr>
</tbody>
</table>
Half of the PN programs had two or more navigators within their program, while the other half were delivered by one navigator alone. One peer and one lay PN program embodied a team approach, while three of the professional programs functioned in this way. This meant that the navigators worked collaboratively to support one another in their role of supporting patients. The partnership between navigators allowed them to assist one another when complex situations occurred. Many programs employed individuals from different disciplinary backgrounds, encouraging navigators to draw on knowledge from a range of health-related disciplines. One lay PN program and four professional PN programs were delivered by only one navigator. In these cases, it was essential that the navigators were able to work independently, as there were no similar counterparts to collaborate with. These navigators would instead rely on their various connections with care providers and community organizations in their region.

Across different settings, situations and populations, the navigator’s main functions remained consistent regardless of their role as a lay or professional navigator, and included the following: advocacy; care coordination and/or collaboration (with the family and/or care team); community engagement (e.g. partnerships with organizations and outreach presentations); administrative activities; education (for patients and the care team); psychosocial support (e.g. social and emotional); facilitating access to services and resources (e.g. referrals to programs); and reducing barriers to care (e.g. facilitating medical transportation, or assisting with complex applications). Although the main functions were consistent across PN programs, there was variation in the amount of time that each function was performed across models of PN. Lay navigators often focused on the functions of support and education for the patient and their care team.
(including family members), while professional navigators more frequently discussed coordinating services in collaboration with care providers and organizations across sectors in addition to providing informational support to patients.

Through individual semi-structured interviews, participants provided valuable insights on factors that were unique to the role of lay navigators compared to the role of professional navigators, as well as factors that were common across all models of PN. Thus, themes are organized below into three areas of focus: (1) lay models of PN, (2) professional models of PN, and (3) commonalities across lay and professional models of PN. Table 3 provides an overview of the themes under each area of focus.

<table>
<thead>
<tr>
<th>Area of Focus</th>
<th>Themes</th>
</tr>
</thead>
</table>
| Lay models of PN | 1. Non-threatening personal connections  
2. Learning curve  
3. Stigma toward lay navigators |
| Professional models of PN | 1. Navigation and clinical expertise  
1.1 System knowledge  
1.2 Understanding patient needs  
2. Professionals as another obstacle |
| Commonalities across lay and professional models of PN | 1. Opportunity for patient and family-centred care  
2. Meeting patients where they are  
3. Embedded within the system  
4. Personality and experience |

**Lay Models of PN**

When exploring lay PN models, the following three themes emerged: (1) non-threatening patient connections, (2) learning to navigate, and (3) stigma.
Non-threatening personal connections

The primary rationale for choosing a lay model of PN was to have navigators who were “non-threatening” (P01). Lay navigators (including peers) can approach their patient/families as equals, which is supported by the following statement from a lay navigator: “when they find out that I am also [a peer] it makes them a lot more comfortable, and a lot more inclined to access care,” (P09) versus having to manage the natural hierarchy that occurs within a professional/patient relationship. Across multiple patient populations (e.g. youth in the general population and of Indigenous decent with diabetes; individuals seeking gender-affirming care; and those with mental health and/or addictions), lay navigators were able to connect on a personal level with their patients/families, eliminating any fear that may be associated with receiving care from a professional. One participant stated, “it’s nice that they know that they have a personal connection to me [the navigator]. And it saves them from feeling that they have been lost in the system” (P08). Sharing similar personal experiences with patients or families assists navigators in gaining trust through common ground.

“We’re able to disclose a little bit more about ourselves than we would if we were in a professional role, a nurse or a counselor or somebody else. And so we’re able to build empathy. I mean, I’m building rapport through that and um, yeah, that can be a really valuable thing for when people have had really hard experiences. We can help bridge them back into, um, receiving the care that they need.” – P04

An interesting finding was that although having a personal connection with the navigator was seen as a strength, this was also seen as a weakness or a challenge within lay PN programs.

“The youth got very connected to me, as the patient navigator. And really, their connection should be to their educators, and the [other members of the] care
Learning curve

Many participants expressed their admiration for lay navigators but were hesitant in endorsing their ability to provide PN services. This was due to the notion that lay navigators, peers specifically, may not come in to this role knowing everything about how to navigate difficult situations within the context of the broader system.

“So, I think that peer advocates are great, but a lot of times we assume that they come knowing everything they need to, to help people navigate complex systems, and so we need to support them in multiple ways. Including how do you be a peer advocate? How do you stay impartial and unbiased? – P06

Participants perceived that being able to build rapport and empathy comes naturally to lay navigators given their personal experiences of an illness or health condition, but understanding the health, social, or education systems and being able to provide individuals with navigational services was not seen as intuitive.

Stigma toward lay navigators

Peers with lived experience (e.g. an individual who has experienced mental illness or addiction, or gender-affirming care) are sometimes subject to adverse attitudes from care providers, professionals, and even other patients. This stigma was described as a weakness of peer PN, because it was perceived to prevent some professionals or care providers from supporting the role. One participant mentioned that the stigma surrounding the role of lay navigators, specifically peers, was related to a lack of understanding on what peers can contribute as navigators. As one professional navigator stated,
“my hesitancy with peer-led navigation would be that, I worry about what influence would the peer have on navigating the system. Would they be able to identify... when people are falling through the cracks. You know, they [the peer] might... call that office for you, and help you to get your questions answered, but would the receiver of the call on the other end recognize the importance of ensuring that we are meeting their needs? I think if it is someone [professional] from the system, then I could speak to a director of a program and say that this is not meeting their needs so we need to try and make sure that it is. Whereas if it is a peer-led navigator, I don’t know that there would be that same opportunity. (P03)

That said, one participant noted that perhaps more wide-spread education on what peer PN programs can offer would be helpful in reducing this stigma. A participant stated that it was important to be “an example of the fact that you can struggle [with mental health] and also be... able to support other people.” (P04)

Professional Models of PN

When exploring professional patient navigation models, the following two themes emerged: (1) navigation and clinical expertise [subthemes include (1.1) system knowledge and (1.2) understanding patient needs], and (2) professionals as another obstacle.

Navigation and clinical expertise

Participants reported that the main reason behind choosing a professional as the type of navigator when implementing their PN program was for their clinical and navigation expertise. This can be broken own into two sub-themes: system knowledge and understanding patient needs.

System knowledge. Knowledge of both community and hospital-based services and resources available to support their patient populations was a main factor in choosing a professional model of PN. Professional navigators understand the system and
have existing connections with programs and relationships with providers. As stated by one professional navigator: “we’re registered health professionals starting out, [and] we kind of come with a skill set” (P06) that enables them to navigate complex situations and coordinate with care providers. For example, in professional PN programs, “sometimes you are dealing with situations that nobody else knows how to deal with, or has the time to deal with... It’s to be a support that those patients wouldn’t otherwise have.” (P08) This was especially true for general health and wellness PN programs, where professional navigators often encountered unique situations across varied patient groups.

“If it is a child with medical needs, then they might be supported by the education system and family and human services, and then a number of different divisions within health. Like physiotherapists and occupational therapists, speech-language-pathologists, so it is really coordinating a number of professionals. So, in those instances, it might be one case, but I might have a multitude of interactions with a family to help them navigate” – P03

Understanding patient needs. Another common sub-theme that arose in choosing a professional PN model was to ensure that patient needs were being met, making it essential that reputable education was delivered by the navigator to both patients and care providers. Understanding patient needs (e.g. for cancer PN programs, navigators often have experience in the oncology setting) improves their ability to support and educate both patients and care providers. One cancer patient navigator for adolescents and young adults said, “...in a population that is undeserved, a significant part of my role is bringing that awareness to the care team and other providers of the unique needs and challenges of the population.” (P10) Coming from a professional perspective, understanding patient needs is different from having lived experience. A professional
can provides an outside or system-level perspective of the given condition(s) versus an insider’s perspective of an illness experience as provided by lay navigators.

*Professionals as another obstacle*

Professional patient navigators recognized that patients may be hesitant to engage with their PN program because health professionals are sometimes conceptualized as being impersonal or “cold” (P02). Because of this perception, professional navigators were concerned that adding another professional to the care team could be a perceived barrier to patients who have had a negative experience with the system. Thus, even a professional navigator may be viewed by patients as “another obstacle” (P09), whereas PN services from lay navigators are not necessarily subject to this challenge. Professional navigators noted that this challenge can be mitigated as they assist in helping their patients to understand that impersonal behaviour from professionals within the system is not intended to be taken personally. One navigator noted that they prepare patients to meet new providers by discussing their personalities ahead of time.

“But if you can understand that this is the person [the provider] and this is how I'll be treated, but it’s not me, then you’re more likely to stay with it because you don't internalize it. So, I like to tell people who they're meeting, and what their personality is like.” – P02

*Commonalities Across Lay and Professional PN*

Common themes where there was overlap between lay and professional patient navigators emerged regarding the PN programs, including: (1) opportunity for patient and family-centred care, (2) meeting patients where they are, (3) embedded within the system, and (4) navigators’ personality and experience.
Opportunity for patient and family-centred care

Participants noted that both nationally and globally, “there has been a shift to focusing on family and patient centred care within health care,” (P03) leading most provinces to find innovative ways to improve the patient experience and integration of care. Implementing PN programs “was a way to really focus,” (P03) on such system improvements. Navigators felt strongly that PN services ought to be patient or family-centred, and community-based, regardless of the method of patient contact or whether the model was lay or professional.

Meeting patients where they are

A common characteristic of multiple PN programs was to deliver services through a blend of modalities, including virtually over the phone, email or Facebook, or in-person at a location chosen by the patient, such as a local coffee shop. Some of the patient navigators (one lay, one peer, four professional) felt that their ability to connect with patients in a way that was the best for them was a notable strength. This approach to care enabled all types of navigators to easily integrate as part of the care team, or “circle of care.” (P01) One navigator for a provincial cancer PN program said,

“...it is a service that is offered to all families no matter where they live [in the province] or what their background is or the diagnosis... I think that is a huge strength of our program that we can literally be where the family is and meet them where they’re at.” (P07)

When it was identified that a face-to-face interaction was the best method of contact for a specific patient or patient population, being able to meet them where they were facilitated a connection between the navigator and the patient regardless of whether they were lay or professional. One lay navigator noted that, “the more often that I get to
meet with patients, the more opportunities there are to grow that relationship. I like doing that. That is the life-blood of how I meet and connect with the youth.” – P01

Embedded within the system

Six of the included PN programs were delivered province-wide. Being provincially mandated increased the ability to access to PN services for individuals seeking gender-affirming care (n=1); general health and wellness (n=1); mental health and addictions (n=1); and cancer (n=3) across the province. Being embedded within the health care system through their respective health authorities was a great strength of each of the models, allowing them to quickly advocate for patients’ needs because they can “see the larger picture,” and know “how things are connected.” (P02) As one participant stated:

“having patient navigation embedded within the health care system, there is a different relationship. We can call providers and sometimes work with them to do education and resource provision and I think that there is some level of trust there with providers. So, it is able to create more buy-in from providers.” – P09

Navigators’ personality and experience

Participants from lay and professional models of PN felt that considering the individuals’ personality in addition to relevant experience was an important factor in determining who was best-suited for the role. It was noted that because, “people come to this work in so many different paths,” (P04) it is essential to consider the navigators’ personal and/or professional (i.e. work-related) alignment with the target population group and purpose of the program.

“I think for a navigator position like this one, it is really a personality you hire, not a skill-set, although that is helpful too…. People don’t connect with a person’s designation. They connect with the personality.” (P01)
For example, a peer navigator with lived experience of mental health and addictions (personal connection and empathy through having this experience) coupled with relevant work experience in this area is well-suited for a navigator role for this population. However, the same individual may not be the best-suited candidate for a province-wide PN program for general health and wellness concerns, as their expertise lies in that one area of mental health and addictions. Instead, an individual who is personable and has experience either within or in partnership with various sectors (e.g. health, social services, and/or education) would be best-suited for that role, as they would come with an understanding of available resources and how to access them. The specific level of education (e.g. college, undergraduate, or graduate-level) was perceived to be less important than the relevant experience of the individual. One participant stated, “I think sometimes the [education] requirement could be a barrier for people who are really good at the job. So, I think it shouldn't be a formal requirement, but...a good amount of experience is, uh, [should be] a requirement.” – P04

Discussion and Implications

In the US, PN services for a variety of health conditions are often focused on addressing health disparities faced by racial and ethnic minority groups. However, PN programs in Canada are frequently tailored to diverse patient population groups that have complex care needs and require additional support beyond what is needed in the general population. Whether the lay or professional PN program is for patients and families who are experiencing various health, social or educational concerns or who have condition-specific challenges, Canadian PN programs assist in streamlining often-fragmented systems of care.
Common across lay and professional PN programs within this study was the importance of offering PN in community-based settings combined with the ability to meet patients where they are (either face-to-face or virtually as determined by patients’ needs) and tailoring care to the patient population. For example, if a patient is seeking help to understand how to access a program or resource, communicating through the phone and/or e-mail would be enough to meet this patients’ needs. However, if patients or families with more complex needs require various referrals and higher levels of support, they would benefit from face-to-face interaction to effectively meet their needs. Virtual methods of communication are useful for province-wide PN programs; however, creating connections and building rapport with patients and families was best done through face-to-face meetings.

It is a complex task to determine what type of navigator is best-suited for a given setting, situation, or population. This study suggests that there is no clear-cut answer, but findings suggest that this decision can be made easier when considering some key factors. Choosing the type of navigator that is best suited for the target population was a matter of aligning the purpose of the program (e.g. to transition youth from pediatric to adult care) with population needs, and navigator experience (i.e. personal and professional).

Lay programs were often centred around providing a specific patient population with support and the necessary education to make informed decisions about their care. Professional programs were more often involved in coordination of services and collaboration with providers and organizations across sectors for either specific populations, or for general health and wellness concerns; in addition to supporting
patients with relevant information. For PN programs that are not specific to one patient group, professionals (regardless of which discipline) may be best suited for the role due to their ability to work through unique and unexpected situations. In contrast, lay navigators may be best suited for specific patient populations that are aligned with their personal experiences, rather than for PN programs that serve diverse patient populations.

Based on these findings, the specific type of navigator (lay or professional) is not as important as the individual’s personality and experience that leads to their own unique ability to provide PN. Thus, it seems that the best-suited individual to provide PN services is not tied to one type of navigator or discipline. This creates implications for practice, policy, and research. Because lay navigators have extensive knowledge through their personal experiences with the system, their expertise in the practice of navigation may be best to be implemented in PN programs that are specific to a given population, while PN programs that are not tailored to a specific program (e.g. province-wide program for health navigation) may benefit from professional navigators, who have a wider breadth of knowledge related to systems of care. There is a need to consider revisiting existing policies and/or decisions around the type of patient navigator employed in various PN models within PN programs in Canada. For example, during the hiring processes for PN programs, special consideration should be taken to decide whether the requirement for a specific level of education (e.g. Master of Social Work) is necessary. Rigid educational requirements for the role may limit the given organizations’ capacity to hire the best individual for the role if they are solely focused on professional experience, rather than personal traits that are essential to this role, such as respect and empathy.
Through exploring each of the navigators’ caseloads, findings demonstrated that there is still a clear need for PN services in Canada. Although exploring caseloads was not the purpose of this study, it is important to note there is a high demand for both lay and professional PN programs. Implications for future research in this area include the need to directly compare the impact of lay and professional PN on various health outcomes, including patient reported outcomes (e.g. quality of life), and to determine the cost-effectiveness of PN in Canada. In addition, it would be informative to gain more information on this topic by exploring patient and family experiences with lay and professional navigators, as well as perspectives from stakeholders such as government decision-makers and policy-makers within provincial departments of health, social services and/or education.

Limitations

Participants were included from eight of the ten Canadian provinces, and none of the three territories. But, the Indigenous PN Program in Alberta also provided navigational services to individuals from the Northwest Territories and Nunavut who were receiving care in the province. Thus, this sample was diverse but did not have representation from the entire country. Most participants were professional navigators, while only three were lay navigators. This may have limited the perspective gained from this model of PN. However, the educational and personal backgrounds of lay and professional navigators varied, adding variation to the data. Because this study sought insight from navigators who deliver PN services in Canada, the data presented may be biased due to participants being unable to speak objectively about their role. Finally, as a qualitative study with a small sample size, the results are not easily generalizable, but
may be transferable to similar situations provided the reader accounts for all relevant contextual information that has been provided.

**Conclusion**

This qualitative descriptive study contributes to a better understanding of what model of PN may be suited for different settings and situations for various patient populations. Navigator roles were consistent with what has been previously reported within the literature; however, the current study adds a more in-depth description of the rationale for implementing lay and professional PN programs in Canada. Results indicate that a navigator’s understanding of the health system and ability to connect with the patient or family is more important than their specific designation (i.e. lay or professional). In addition, the findings of this qualitative descriptive study suggest that both lay and professional navigators are well-suited to provide navigational services across populations. The rationale for implementing lay programs was to ensure that the navigators were non-threatening, and able to foster patient connections, while professional navigators were chosen for their clinical expertise, including system-level knowledge. This study has the potential to inform future research, policy, as well as the delivery of existing and future PN programs, particularly those in Canada.
References


Conclusion

This section includes a summary of the thesis manuscript, followed by a detailed overview of how ethical considerations were addressed and rigor in the qualitative research was achieved. Finally, this chapter concludes with a discussion of the strengths and limitations of the research, followed by recommendations for future research.

Summary of the Thesis Manuscript

This research project has been completed in partial fulfilment for the degree of Master of Applied Health Services Research at the University of New Brunswick (UNB). The completed study is original work that I (Amy Reid) have completed, under the direct supervision of Dr. Shelley Doucet and Dr. Alison Luke. This project was approved by the Research Ethics board at UNB in November 2018, prior to beginning the research study. This work is presented in an article-based format to encourage prompt preparation of the findings for publication after completing the defense. One publishable article is included in this master’s thesis, titled *Exploring the Role of Lay and Professional Patient Navigators in Canada*. Prior to completing the current research study, the literature was reviewed to understand existing research in this area. After an extensive review, it was discovered that no original research studies were identified that explored the differences between using a lay and professional navigation models in a Canadian context. Within the literature, however, there were three studies that stood out in relation to the purpose of the current study. Bekelman, Johnson-Koenke, Bowles, and Fischer (2018) described a PN program for patients with terminal cancer that was delivered by one peer and one professional navigator and noted that the professional navigator’s additional support was not often necessary. In addition, Jandorf
et al (2013) found that no significant differences were reported between peer and professional navigators in relation to colonoscopy completion or patient satisfaction. Finally, one literature review sought to determine what model of PN was best suited for various situations and stated that based on existing research within the cancer care continuum, any model of PN is effective in improving cancer screening rates and related outcomes (Wells & Nuhaily, 2018).

The current research sought to better understand the following question: “What is the rationale when deciding whether to implement a lay or professional model of PN in Canada?” The research was conducted using a qualitative descriptive design (Sandelowski, 2000) with individual interviews with patient navigators from 10 PN programs for diverse patient populations, representing eight Canadian provinces to capture various perspectives on the role of patient navigators in Canada.

Three over-arching areas of focus encompassed the main themes that emerged from the data. The first area of focus was on lay PNs and encompassed three themes: non-threatening personal connections, learning curve, and stigma toward lay navigators. Next, the next area of focus was on professional PN, and included two themes: navigation and clinical expertise (subthemes included system knowledge and understanding patients’ needs) and professionals as another obstacle. The final area of focus was on the commonalities with both lay and professional models of navigation and included four themes: opportunity for patient and family-centered care, meeting patient where they are, embedded within the system, and personality and experience. Interviews with patient navigators across Canada provided valuable insights related to the research questions for this study.
In summary, the rationale for implementing lay models was the navigator’s ability to be non-threatening and build trust to foster patient connections. Being on an equal level with the patient or family through sharing common experiences was an essential and unique strength of lay PN programs that led to choosing this model over professional PN models. In contrast, the rationale for selecting professional navigators was for their clinical and navigational expertise, including system knowledge and understanding the patient population based on their prior experience working in the health system and/or in partnership with health/social and education systems. Professional navigators were preferred in these models because they came with an existing skill set related to their specific profession and general system-level knowledge to navigate complex situations and provide reputable information and education.

One peer PN program for individuals with mental health and addictions decided on a peer model to ensure that the navigator was able to disclose personal experiences and foster empathy, rather than solely drawing on system-level knowledge or professional work experience to navigate. Psychosocial support was held at high importance for this model of navigation. One lay PN program for youth with diabetes was chosen, as its’ main purpose was to facilitate transitions in care, rather than diabetes management or education—which would require higher levels of expertise. The navigator in this program helped to ease transitions from one care provider to another. Adding another professional was not the aim of the program, rather, the navigator helped to build connections for the youth with their new providers. In considering the choice for a PN program, professional models where chosen over lay models for their existing expertise on the population, rather than having lived experience of a specific condition.
Professional PN programs often provided higher-level system navigation, and although psychosocial support was part of the role, the latter was of high importance.

**Ethical Considerations**

Informed consent forms (see appendix I) were provided to participants upon recruitment and read and signed prior to the interview. All interviews were conducted over the phone or using the Zoom platform. Thus, in cases where the participant was unable to sign the consent form prior to the interview, verbal consent was given and recorded prior to data collection. The audio recordings of interviews were deleted once interviews were transcribed, and names removed from written transcripts. Participant consent forms have been kept in a separate file from collected data to ensure that they are not associated with one another. The semi-structured interview guide did not include questions that were likely to produce high levels of participant stress; however, participants were made aware that their participation was completely voluntary, and they were able to choose not to answer any question and stop the interview at any time if necessary. One participant was unable to share information regarding how many patients they care for, but aside from this, all other aspects of the interviews were completed by all participants. None of the included participants decided to withdraw from the research. The interview transcripts will be held on UNB’s secure server for 10 years after the completion of the project and will then be destroyed.

This study included individuals who work as patient navigators (n=10), two of which were in dual roles where they also worked as the interim program manager (n=1) or program coordinator (n=1) for 10 PN programs across Canada. The province where each program is located was reported on to allow readers to consider contextual factors.
However, no identifying data was included other than the general condition(s) that the PN programs were intended for. Narrative excerpts and quotes from the interview transcripts have been presented anonymously by assigning each a study code (e.g. P01).

**Rigor in Qualitative Research**

To encourage rigor in the research project, I followed the principles of trustworthiness in qualitative research that have been outlined by Lincoln and Guba (1985). This includes credibility, dependability, confirmability, and transferability. Credibility refers to the ability of the reader to view the research findings as believable (Lincoln, & Guba, 1985). By adhering to Braun and Clarke’s (2006) six steps of thematic analysis and presenting a description of the findings that remains close to the data, my study has generated findings about PN programs that are credible. In addition, my supervisory team has extensive qualitative research experience, helping to ensure the study’s credibility through their mentorship throughout the research process.

The dependability of a qualitative study refers to whether the findings are reliable and would allow a future investigator to gain similar findings should they repeat the study (Lincoln & Guba, 1985). A strategy to foster dependability is remaining consistent throughout the research processes (Colorafi, & Evans, 2016). I began by inviting individuals to take part in the study with the same recruitment invitation each time (see appendix II). In addition, I used the same interview guide (see appendix III) and demographic form (see appendix IIII) for each participant interview. Working closely with my two supervisors led to a consistent approach while analysing the data and will aid in any future replication. As the primary investigator, I have carefully
documented each aspect of the study as it is recommended to keep an audit trail to track methodological decisions made over time (Colorafi, & Evans, 2016).

Confirmability ensures that the findings reflect participants’ experiences rather than researcher opinions or biases (Colorafi, & Evans, 2016; Polit, & Beck, 2012). Participant narratives have been used in the reporting of study findings to enrich the study’s confirmability. In addition, an audit trail (e.g. field notes during interviews, transcripts, coding records) also provides transparency and justification for decision-making, allowing the reader to view the results as trustworthy (Fossey, Harvey, Mcdermoot, & Davidson, 2002).

Demonstrating the transferability of the proposed research means to have provided sufficient detail concerning the characteristics of the context under study (Polit, & Beck, 2012). The current study includes demographic information provided by participants. In addition, the settings (e.g. community-based or hospital), age range, and diagnosis or condition(s) of each PN program’s target population were reported to increase rigor. These details have been presented in two separate tables, one describing information related to each of the navigators, and one describing PN program information. Readers will be able to decide whether the results may be applied to another situation based contextual similarities (Colorafi & Evans, 2016; Polit, & Beck, 2012).

**Discussion and Recommendations**

In conducting this qualitative descriptive study, themes emerged that demonstrated both unique and common characteristics of different PN models. Patient navigators caring for clients across settings, situations, and populations come to this role
through various paths, with numerous levels and combinations of education and personal experience. Despite the variation in backgrounds, all types of navigators had backgrounds that were well-aligned to provide PN within their respective programs.

**Strengths of the Research**

This research project was conducted under the supervision of Dr. Shelley Doucet and Dr. Alison Luke, who together have extensive experience in qualitative methods and conducting and evaluating research projects. This allowed me, as a novice researcher, to draw on their knowledge. Within the study, participants represented eight different provinces. There was also good variation across the target populations of the PN programs (e.g. mental health, diabetes, cancer, transgender/gender-diverse/two-spirited, and any general health and wellness concern), in addition to the different personal and professional backgrounds of each navigator. All potential participants who responded to the phone or e-mail recruitment invitation completed the entire research process and their data was included in the article presented in this manuscript. Finally, this is original research. No other study with the same purpose (to the author’s knowledge) exists in this relatively new field of study.

**Limitations of the Research**

This project was conducted as partial fulfilment of degree requirements for the Master of Applied Health Services Research program. Thus, this was a student-led research project, meaning the primary investigator has had limited experience in conducting qualitative research. In addition, this was a time-sensitive study as it was conducted within the constraints of a two-year academic program. Due to this project being undertaken with a short time-line, the participants included in the study may not
be entirely comprehensive. Given a more extended timeline, this study could have included more participants from different PN programs and included results from each Canadian province. Although participants were included from only eight of the ten Canadian provinces, and none of the three territories, the Indigenous PN Program in Alberta also provided navigational services to individuals from the Northwest Territories and Nunavut who were receiving care in the province. Thus, while this sample was diverse, it did not have representation from the entire country. Because this study sought insight from the patient navigators who are actively engaged in delivering PN services in Canada, it is possible that the data that was shared during the interviews may be biased. Given their positions as either a lay or professional navigator, participants may have been unable to speak completely objectively about their role. Finally, as this research was designed using qualitative methodology, the results are not easily generalizable, but may be transferable to similar situations provided the reader accounts for all relevant contextual information that has been provided (e.g. country, province, target population of PN program).

**Recommendations**

Although this research adds to existing literature on PN, there remains room for additional research in this area. As stated previously, there has only been one study identified within the literature that has compared the impact of lay and professional PN, and this was within cancer care. It would be beneficial for future research to focus on PN programs outside of the oncology setting. There is potential for future research on this topic to occur with patient populations such as diabetes or those struggling with mental health and/or additions, as these PN programs are becoming more common within
Canada. Future research is also needed in this area to contribute more diverse perspectives, including including patients and family members who have received care from lay and professional navigators, as well as government decision-makers and policy makers who have an influence on the delivery and funding of PN programs. Additional perspectives from stakeholders across Canada would facilitate a more complete picture of lay and professional PN programs, and may better inform the delivery of existing and future PN programs.

**Conclusion**

PN in Canada is delivered by navigators with a range of backgrounds across diverse populations, with programs tailored to specific diagnosis or conditions (cancer, mental health and addictions, diabetes), age groups (youth with diabetes, children and/or adolescents with cancer), or for any health and wellness concern of any individuals not limited by age or demographic variables. In the US, this model of care was intended to be delivered on a spectrum from lay to professional navigators as described by Freeman (2011). In reviewing relevant literature on this topic, it appeared that any type of navigator may be well-suited to provide navigational services throughout the continuum of care. The purpose of the current study was to explore the roles of patient navigators in different settings and situations for various patient populations in Canada, and to understand the rationale for implementing a lay or professional model of PN in a Canadian context. Interviews with patient navigators across Canada revealed that lay programs were implemented when the program sought to foster non-threatening and trusting relationships with patients that does not necessarily occur with professionals. Professional programs were implemented with the intent to draw on existing clinical
experience and system knowledge. These professionals had skills that have developed through relevant professional disciplines that lay navigators may not have.

There were no clear answers provided regarding what type of navigator is best-suited for a given situation. However, to support the decision-making processes of programs that are determining who should navigate for a given situation or population, it is important to consider the specific individuals’ personality and relevant experiences (i.e. personal and work-related) rather than solely focusing on the level of education attained (e.g. college, undergraduate or graduate) that may be associated with a specific profession (e.g. nursing or social work). The findings of this study have implications for policy, research, and practice for this growing field, particularly for the Canadian context.
References


http://dx.doi.org.proxy.hil.unb.ca/10.1046/j.1440-1614.2002.01100.x


https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G
Appendix I: Consent Form

I am inviting you to participate in a study on the role of lay, peer, and professional patient navigators in Canada. This study is a requirement for my Master’s degree research. The purpose of this study is (1) to understand the situations or populations that are best suited for lay, peer, or professional patient navigators and (2) to describe the rationale for choosing a lay or peer navigator versus a professional navigator. I am interviewing individuals (e.g. patient navigators, program managers or coordinators, or researchers) who are involved in patient navigation programs for any condition or diagnosis across Canada.

With your consent, participating in this study involves 1) one face-to-face, telephone, or Zoom interview, where you will share general information about the patient navigation program where you are affiliated (navigator roles, what population you serve, rationale for using a lay/peer/professional navigator), and 2) completing a short demographic questionnaire.

There may be no direct benefits to you from this study. However, the data collected may help inform the implementation of future programs or improve existing programs in Canada by creating a better understanding of when to use a lay, peer, or professional model of patient navigation.

There are minimal risks of participating in this study. The biggest inconvenience is the time it takes to complete the interview. Your participation is completely voluntary. You may withdraw from this study at any time without penalty. If any of the questions asked make you uncomfortable, you may choose not to answer them without repercussions.

With your permission, the interview will be audio-recorded and transcribed. The audio files will be deleted immediately after transcription and any identifying information from these transcripts will be removed before data analysis. All participants will be assigned a study code, with the names relating to the study code kept in a separate document. Only the members of the research team will have access to these documents.

There is a possibility of using quotations gathered during the interview to add emphasis in the reporting of the findings. If something that you have said is included, we will make sure that your name is not connected to the quote. All quotes will be anonymous and any identifying information will be removed.

By signing (or verbally agreeing to) this consent form, you are indicating that you fully understand the above information and agree to participate in this study.

Participant's signature: ___________________ Date: ______________
Researcher's signature: ___________________ Date: ______________

63
Appendix II: Recruitment Letter for Potential Participants

Hi __________.

My name is Amy Reid and I am a master’s student in the Applied Health Services Research program at the University of New Brunswick (UNB). I am contacting you in the hopes that you may be interested in participating in a research study on the topic of patient navigation in Canada.

The overall goal of this study is to explore the situations or populations that are best suited for lay, peer, or professional patient navigators. In addition, I am interested in understanding the rationale for deciding whether to implement a lay, peer, or professional patient navigation model in a Canadian context.

You have been identified as a potential participant in this study because you are either a patient navigator, patient navigation program coordinator, manager, or researcher, or are involved in a patient navigation program in another capacity.

If interested, you will be asked to participate in a one-on-one interview, either in person, by phone or Zoom (video chat) that will last approximately 30 – 60 minutes. You will have the option to withdraw from the study at any time, until the publication of results. I have attached a consent form that gives you the full details of the study.

This research study has been reviewed by the Research Ethics Boards at UNB Saint John. If you have any concerns or questions about your participation or about the conduction of this study you may contact Lisa Best, Chair of UNB Saint John Research Ethics Board by phone [(506) 648-5908] or by email [REB@unb.ca]. In addition, if your institution or agency has a research ethics office, you may contact them if you have any questions about your participation in this study.

I would like to thank you in advance for your time and consideration. After one week I will send you a follow up e-mail reminder. Should you agree to participate, we will schedule a convenient time for you to participate.

Amy Reid
Graduate Student, UNB
areid2@unb.ca
Appendix III: Interview Guide

Questions will be semi-structured and will include questions about the patient navigation program you are involved with, including the role of the navigator(s), as well as the rationale for choosing a lay or peer navigator versus a professional navigator.

Introduction

Hello, my name is Amy. I am the lead researcher who is conducting the study called “Exploring the Role of Lay, Peer, and Professional Patient Navigators in Canada.” I would like to thank you for agreeing to participate in this interview. Before we start, I would like to review the consent form with you. If you have any questions, please do not hesitate to ask. (Go through the form, address questions. If this is a phone or Zoom interview, turn on recording device prior to obtaining consent).

If you have no remaining questions, then we will begin, and I will turn on the recording device.

Patient Navigation Program and Navigator Characteristics

1) Can you tell me about your patient navigation program?

Prompt: Who is the population that you serve?
What types of diagnosis or conditions do you/your navigator(s) see?
What is the age range of your population? What type of model of navigation does your program use? (Lay/Peer/Professional?)
Prompt: What are the needs of (insert population) that are addressed by your patient navigation program?

2) Describe the roles of the navigator in your PN program (if interviewing the navigator directly: Can you describe your role as the navigator?)

Prompt: What does a typical day for you/your navigator(s) look like?
Prompt: Are there any educational requirements for you/your navigator(s)? Is there a job description available to read?
Did you/your navigator have any prior experience with patient navigation/another program?
What brought you to the field of patient navigation?
Prompt: How many patient navigators are employed through your program? Is this a paid or volunteer position?
3) How is the patient navigation program delivered?

Prompt: By phone or email? In person? What is the setting (hospital or community-based, rural or urban) where navigation services are delivered?

Prompt: Can you discuss how many individuals or families that your program serves/has served?

Prompt: What is the typical caseload of your navigator(s)? How many patients would your navigator(s) each attend to at a time? (If program has been delivered for several years) Per year?

4) Can you tell me about when this program was implemented?

Prompt: How long has this program been delivered?

Prompt: Is there a research component for your program? Have you or will you (your team) (or an outside consultant) be evaluating your patient navigation program? Through what methods (quantitative or qualitative)?

5) If program is being evaluated currently or has been in the past...

Have you/your program’s team seen any (positive or negative) impact for the population that you serve?

Prompt: Are the findings publicly accessible?

Rationale (for Lay/Peer/Professional)

1) How was the decision made when you/your team chose to implement a (Lay/Peer/Professional) model of patient navigation? (If the answer is unclear, ask: Can you speculate why your (Lay/Peer/Professional) model was implemented?)

Prompt: What is it about the given circumstances that led you/your team to implement a (Lay/Peer/Professional) navigation program?

Prompt: Can you explain more about the context that led you/your team to choose a (Lay/Peer/Professional) navigator?

Prompt: Did population needs influence the decision regarding whether to use a (Lay/Peer/Professional) navigator? (Example if needed: Barriers such as language, culture, income, or education may influence population needs).
2) What are the strengths and weaknesses (if any) of the (Lay/Peer/Professional) model of patient navigation that your program uses?

Prompt: Are you able to address how a different model (Lay/Peer/Professional) may have been beneficial (or insufficient) compared to your chosen model?

3) Thinking beyond your program, what do you perceive to be the strengths and weaknesses (if any) of (Lay/Peer/Professional) patient navigation in other settings and contexts?

Prompt: Would (Lay/Peer/Professional) navigation be beneficial in for a different population? In a different setting? Would there be a weakness of this model in a different context?

General/ Concluding Question

1) Do you have any suggestions for groups that may be considering the use of a (Lay/Peer/Professional) patient navigator?

2) Is there anything else you would like to add regarding your experiences of implementing or delivering your (Lay/Peer/Professional) patient navigation program?

Conclusion

This concludes the interview. The results of the study will be available upon request by email once the project has been completed. In addition, the results of this study are intended to be prepared for publication in an academic journal. Once again, I would like to thank you for your time and participation in this study.
Appendix IIII: Demographic Form

Study ID # __________________ Date: __________________

1. Gender: □ Male □ Female □ Other __________________

2. What language(s) do you speak?
   □ English
   □ French
   □ Other, please specify: ________________________________

3. What is the highest level of education you have completed?
   □ Grade School (Grade): ___________ □ High School (Grade): ___________
   □ Some College/University: ________(Years in)________________________ (Degree)
   □ College/University Degree: __________________________________________ (Certificate achieved or name of degree)

4. What province/territory is the patient navigation program you are involved with located? *Please include all locations if you are involved with multiple sites or programs.
   a) ___________________________ (Province/Territory)
   b) ___________________________ (Province/Territory)
   c) ___________________________ (Province/Territory)
   d) ___________________________ (Province/Territory)

5. Is the patient navigation program in a rural or urban setting?
   □ Rural □ Urban □ Both (e.g. multiple sites or province-wide)

6. What is your role at the patient navigation program?
   □ Patient Navigator
      Please circle one: Lay / Peer / Professional: Nurse, Social Worker, other:______________________________
   □ Program Coordinator or Manager
   □ Researcher
   □ Other, please specify: ________________________________

7. How long have you been in this role?
   Please specify: __________________________ / __________________________
      (Years) (Months)
8. Including your current role and any past experiences, how long have you been involved in patient navigation?
   Please specify: __________________ / __________________
   (Years) (Months)
Curriculum Vitae

Candidate’s full name: Amy Ellen Reid

Universities attended (with dates and degrees obtained):

- University of New Brunswick, MASHR, In-progress (2017-2019)
- St. Thomas University, BA in Psychology, 2017.

Publications:


Conference Presentations:

