

M.Sc. Thesis – J. Feather; McMaster University - Nursing

A NARRATIVE STUDY OF A COMMUNITY-BASED SYSTEMS NAVIGATION
ROLE

NARRATIVE STUDY OF A COMMUNITY-BASED SYSTEMS NAVIGATION
ROLE IN AN URBAN PRIORITY NEIGHBOURHOOD

By

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ABSTRACT

In response to the striking health and social inequalities existing across communities within a large Southern Ontario City the McMaster University School of Nursing has partnered with the local family health team, municipal government, and other community partners to evaluate a pilot program designed to enhance health and social outcomes within a specific priority neighbourhood. The innovative pilot program is a nursing-based system navigation role, grounded concurrently in the community and a local Primary Care Practice. The role is uniquely designed as the nurse provides navigation for individuals and families while functioning as a networker to facilitate improved service integration at a systems level. This study serves as a narrative person-centered evaluation of the program, emphasizing the impact on the lives of community members. This study employed the Three-Dimensional Narrative Inquiry Space method as described by Clandinin and Connelly (2000) to explore the experience of nine community residents utilizing navigation services through the Community Nurse Navigator/Networker (CNN). Programs tell a story; therefore, the collection and analysis of participants' life stories, in conjunction with field notes, observations, and documents, created a common narrative of the experience of navigation in a community setting. A thematic analysis of participants' life stories was conducted to present a common narrative of community members' experience of navigation. The major finding of this study was the positive experience residents shared interacting with the CNN. Participants valued the development of a therapeutic relationship through social interactions, the significance of place on the impact of the CNN role, and the effect of the navigation role

to address health disparities over time. Study findings have implications for continued development of the CNN role and other community-based nurse navigation roles in priority neighbourhoods to address health inequities.

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Thank you to the participants who offered their time to share their stories with me, allowing me the privilege of entering their lives to understand their experiences. It is my hope and desire that this account honours your stories and experiences. Thank you to the Hamilton Community Foundation and the Hamilton Family Health Team for the generous financial support for the research process. Thank you to the Hamilton Family Health Team, City of Hamilton, McQuesten Planning Team, Michelle Stockwell, and Rachael Haalboom for all your contributions during the research period.

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LIST OF ABBREVIATIONS

CARNA	College & Association of Registered Nurses of Alberta
CNN	Community Nurse Navigator
CHNC	Community Health Nurses of Canada
GCM	Guided Care Model
HCF	Hamilton Community Foundation
HFHT	Hamilton Family Health Team
RN	Registered Nurse
RNAO	Registered Nurses Association of Ontario
SON	School of Nursing (McMaster University)
SPRC	Social Planning and Research Council of Hamilton

Prologue

Narrative Beginnings

In narrative research it is understood that the inquiry is beginning in the midst of stories (Clandinin & Connelly, 2000). I am not only beginning this inquiry in the midst of participants' stories as they unfold but I am also beginning in the midst of my own story of experience. As an undergraduate nursing student I had the opportunity to work locally and internationally to promote and advocate for health equity and social justice for marginalized or disadvantaged populations. These past experiences have fuelled my desire to see advances in health equity through the development of policies supporting population health. Grounded in my identity as a nurse, my research pursuits are to see an optimal utilization of the Registered Nurse role to improve health equity.

Feeling dually challenged, with a sense of responsibility to actively participate in the advocacy for health equity for marginalized populations, and privileged to have the means and opportunity to affect change I enrolled in graduate studies. As a Registered Nurse, my clinical nursing experience is an acute care background with obstetrical patients, seemingly far from primary care and community nursing. However, when I was presented with the opportunity to evaluate an innovate nursing role to improve health outcomes for a priority population in a community setting, I jumped at the prospect of researching an area outside my clinical expertise as it so closely aligned with my underlying assumptions of nursing roles and health equity.

As I had the privilege of listening to residents' stories I began to see how important the connection between acute care and community nursing is. Since I do not

live or work in the region, I have had no previous contact with any of the participants or experiences within the community outside the study period. I participated in the initial meetings concerning the evaluation of the Community Nurse Navigator/Networker (CNN) role before the successful candidate was selected, but was not directly involved in the hiring process or the design of the role. Throughout the research period I kept in contact with the CNN for purposes of gaining entrance into the community and participant recruitment. Outside of this the Hamilton Family Health Team (HFHT) was made aware of the study progress but was not actively involved in the process.

CHAPTER 1 – INTRODUCTION

The Problem

“This is a very needy community, about 75% of our kids live under the poverty line. People here are so disadvantaged, it’s just heartbreaking. There are some extra services offered in the community but people aren’t sure where to go or who to turn to for help. There are so many barriers and boundaries; they need someone to connect the dots, to support them with what they need” (Tom)

Social Inequities and Health Disparities

Health disparities or inequities are unfair and avoidable differences in health outcomes directly related to social disadvantage and inequity (Gardner, 2008; Raphael, 2011). Health disparities and social inequity marginalize and isolate populations. However, populations are not inherently marginalized but rather are adversely effected by structural inequities stemming from systemic policies and practice that create and sustain inequitable distribution of social determinants of health (Browne et al., 2012). Inequities

have tangible effects on health as they are embedded in the political and economic structure of society manifested in welfare, justice, and health care systems (Farmer, 2003). Despite increasing prioritization of addressing sources of inequalities, financial, ethnic and gender disparities in access and health outcomes persist (Natale-Pereira, Enard, Nevarez & Jones, 2011).

It is commonly understood that health disparities are rooted in broader social and economic inequalities. Dohan and Schrag (2005) argue that these disparities cause dissatisfaction and concerns with the health care system, and perpetuate or even exacerbate social inequity. Differential access to key social determinants of health is the underlying foundation of health disparities (Gardner, 2008). One crucial foundation of health disparities is poverty and the unequal distribution of income (Raphael, 2011). Persons with low income tend to experience greater healthcare needs due to reduced access to health promotion and disease prevention services and resources. The reaching effects of poverty intersect with many of the other social determinants of health, including housing, education, employment, and social exclusion (Gardner, 2008). Therefore, the most impactful forces contributing to health disparities lie far beyond the health care system, in macro social and economic policy requiring a coordinated collaborative partnership to improve health equity. Coordinated efforts are required across multiple levels of the health and social system; in this context a bottom-up approach rooted in primary care has been designed to address health disparities.

Local Health Disparities

Health disparities not only exist across populations but also within populations. Take for example the City of Hamilton, an industrial midsize Canadian city in southwestern Ontario. Hamilton is an amalgamated city of over 500,000 with more affluent suburban neighbourhoods surrounding a central urban core, divided into upper and lower areas by the Niagara Escarpment. Hamilton residents represent the full socioeconomic spectrum, with a significant proportion of individuals and families living at or beneath the poverty line (DeLuca, Buist, & Johnston, 2012). The central lower city, heavily industrialized, has been ravaged with environmental damage and poverty, which was intensified in 2006 with plant closures and layoffs. The unequal distribution of wealth within the city has magnified the longstanding health and social disparities across Hamilton communities.

In 2010 the Hamilton Spectator, a large English daily newspaper, published a series entitled “Code Red”, describing the health and social disparities existing across Hamilton communities related to the social determinants of health (DeLuca, Buist & Johnston, 2012). The series was widely accessible and was presented in an easily comprehended format for a lay audience using simple statistics, stories, interviews, and maps. This award winning series shed light on the communities in Hamilton with the highest needs, sparking a municipal response.

Responding to the “Code Red” series (Buist, 2010), the Social Planning and Research Council of Hamilton (SPRC) designated ten neighbourhoods as ‘priority action neighbourhoods’ due to the health and social indicators of the communities (Mayo,

Klassen, Bahkt, 2012). Given the unique social and environmental factors contributing to the health and social status of each neighbourhood, a pilot program in one of the priority neighbourhoods was implemented. The goal of the program was to utilize a novel navigator role as a potential solution to remedy the health inequalities perpetuated by disparities in social determinants of health.

Fragmentation

The health care system is laden with complexity and transitioning between various health and social services to meet individual needs can be potential points of fragmentation, limiting the accessibility and usefulness of services (Holsapple & Jensen, 2013; Manderson, McMurray, Piraino & Stolee, 2012). Fragmentation of the health care system has been recognized as problematic within Canada, highlighted initially in the Romanow report (2002) noting that individuals must “find their way through a maze of services and providers to get the best information and the full range of services they might need” (p. 122). In Ontario, 10% of the population consumes nearly 80% of the health resources (Ministry of Health and Long-Term Care, 2012). A lack of knowledge of services coupled with a lack of access to appropriate services can reduce utilization of supportive services. Assisting individuals and families to navigate through complex systems and access appropriate resources can increase their connectedness and utilization of community services with the intention to enhance one’s well being.

The experience of patients attempting to independently navigate a fragmented health care system is perceived as a negative experience in the literature. Doty and colleagues (2012) conducted a secondary analysis of a large international study assessing access to

health care and reported that patients who did not have access to navigation services were more likely to experience system fragmentation, poor communication, disorganized and uncoordinated care across the continuum of care, especially when transitioning from acute care discharge to the community. Similarly, patients with multiple chronic conditions expressed issues with continuity of care, fragmented health care delivery (Ravenscroft, 2010), lack of confidence in the coordination and communication among providers (The Change Foundation, 2011), lack of access to adequate information (Ravenscroft, 2010), challenging environments with duplicate testing, and overall frustration with the experience (Ravenscroft, 2010; The Change Foundation, 2011).

A Potential Solution

To put it simply, individuals and families with better education, income, and social supports enjoy a greater level of health compared to those with fewer economic and social opportunities (Public Health Agency of Canada, 2008). Therefore, a coordinated multi-level response is required to address disparities with participation from all Hamiltonians from politicians and policy makers to community residents. With supportive policies and structures in place, targeted interventions to address the inequitable distribution of wealth, education, and social supports may alleviate the persistent effects of social determinants of health and improve health outcomes.

The Registered Nurses Association of Ontario (2014), explain that the solution is clear, a greater attention to social determinants of health, addressing mental illness from a younger age, delaying chronic conditions while minimizing their complication, and an emphasis on advancing primary health care for all will help to build a seamless and

reliable health care system. Subsequently, this shift will contribute to a health care system with optimal health outcomes that is easy to navigate.

Navigation

Systems navigation, through the use of a designated professional navigator, has emerged as a potential intervention to address health and social disparities resulting from fragmentation and inequitable access to services (Natale-Pereira et al, 2011). Broadly, navigation is a person-centered approach to empower individuals and families to identify needs or concerns and establish a connection with appropriate services (Freeman & Rodriguez, 2011). Navigators address health, and often social systems navigation, to coordinate care and facilitate access along the continuum of care (CARNA, 2008; Doll et al., 2005; Freeman & Rodriguez, 2011; Manderson et al., 2012). The current body of literature provides an array of definitions and titles of professionals providing navigation services, ranging from patient navigator, nurse navigator, and case manager, to care coordinator. Generally, navigation is a health care delivery model, which is patient specific, reducing barriers and facilitating access to care by providing professional or lay support through the continuum of care (Thoms & Moore, 2012). Although navigational roles can be filled by a variety of interdisciplinary team members or even lay navigators, in the context of this pilot the navigation role is a nursing based role. In a systematic review of navigator roles Manderson et al., (2011), explains that this role has been traditionally assumed by nurses due to their involvement in advocacy for vulnerable populations, as they are “uniquely positioned” (p.124) to understand and deliver patient navigation and advocacy in clinical settings.

Navigation has evolved over the past twenty years, originating in oncology and stemming from the observed correlation between late-stage cancer diagnosis and poverty (Lindsey, 2005). However, fragmentation of health services is not exclusive to a particular setting but is a systemic challenge in various settings. With a barrier reduction focus, navigator roles work to facilitate access in various settings where the need is great and fragmentation is high. Navigator roles have been implemented in acute care, outpatient, primary care (Anderson & Larke 2009a; Doolan-Noble et al., 2013), and community settings (Fischer, Sauaia, & Kutner, 2007). The design of a navigation role is not only influenced by setting, but is also dependent upon the intended client population as the impact of fragmentation is often magnified in specific populations.

Currently, navigators work to improve health equity by providing a variety of services for various subpopulations such as geriatrics (Manderson et al., 2012), chronic disease management (Manderson et al., 2012), oncology (Carroll et al, 2010; Freeman, 2006; Wilcox & Bruce, 2010) palliative care (Fischer, Sauaia, & Kutner, 2007), maternal/child health (Holsapple & Jensen, 2013), for patients with financial restraints (Doolan-Noble et al., 2013), or in the presence of certain illnesses including HIV (Bradford, Coleman, and Cunningham, 2007) and mental health and/or addictions (Anderson & Larke 2009a; Brekke et al, 2013). Population specific navigation may also be expanded to provide to services by geographical location, rather than by illness (Shojania et al., 2007).

Navigation with vulnerable populations. As highlighted above, inequitable access to key social determinants of health leave people at a heightened risk of adverse health outcomes. Persons living in disadvantaged and vulnerable situations often

experience more difficulty navigating health and social systems and services (Brown et al., 2011; Gardner, 2008). Freund (2010) suggests that patient navigation has the potential to help bridge the health disparities gap with vulnerable populations, defined as populations with low income, education, and literacy, inadequate coverage, or an ethnic minority. Navigation programs have the ability to reduce disparities by addressing individual and system barriers to accessing appropriate services and resources (Dohan & Schrag, 2005; Holsapple & Jensen, 2013; Natale-Pereira et al., 2011).

Barriers faced in navigating the healthcare system by disadvantaged persons reflect the broader social context. Common barriers that patients experience in accessing care, most often cited in the literature include: limited education, low health literacy, poor communication, cultural issues, financial restraints, lack of affordable transportation, and childcare costs (Campbell et al., 2010). Navigator roles in local environments are designed to operate as a broker to confront system and environmental barriers disproportionately effecting vulnerable populations (Natale-Pereira et al, 2011).

Since the most vulnerable people experience the most challenges navigating the system, interventions to improve navigation for these populations will have a disproportionately greater impact on health outcomes (Browne et al., 2012; Gardner, 2008). This assertion is supported by the assumption that populations who are advantaged in terms of social determinants of health are generally more apt to navigate the system independently.

Development of a Community Nurse Navigator Role

If navigation is a feasible strategy to address health disparities and inequities with vulnerable populations, in what clinical setting should these interventions originate? Primary health care is the argument put forward by The World Health Organization (WHO, 2008), as primary health care systems play an important role in reducing health inequity and represents the most efficient way to bridge the equity gap for vulnerable and disadvantaged populations. Reforming primary health care service delivery can improve health equity for those disadvantaged by intersecting social determinants of health (Browne et al., 2012). Within primary health care, one of the most effective methods to increase health equity is through the integration of accessible and quality services with concurrent structural and policy changes to enhance equitable access to the social determinants of health.

Therefore, the Hamilton Family Health Team (HFHT), the City of Hamilton, the McQuesten Community Planning Team, and the McMaster University School of Nursing (SON) collaborated to develop an innovative solution in primary health care. The Community Nurse Navigator (CNN), also termed the Community Nurse Networker, initiative is an innovative pilot program to improve health and social outcomes of individuals and families in a priority neighbourhood in the City of Hamilton. This role was designed as a Registered Nurse role given the value and importance of understanding the linkages between social indicators and health outcomes for navigation. The pilot was funded through collaboration between the City of Hamilton, the HFHT, and the Hamilton Community Foundation (HCF).

Of the SPRC designated ‘priority action neighbourhoods’, the McQuesten community was selected as the specific setting for the CNN pilot program due to the combination of the health and social climate, the organization and culture of the community, the presence of a HFHT practice, the congruency with the McQuesten Community Planning Team’s identified goal of enhancing community health and well being and other environmental and contextual factors (McQuesten Community Planning Team, 2012). The driving force has been the commitment and readiness of the HFHT practice, key community leaders, and various stakeholders in the planning and development of the pilot program. Therefore, the study setting is the McQuesten neighbourhood as the program is only being piloted in one community at this time.

The McQuesten community (described in greater depth in Chapter 3) is home to approximately 7,000 residents, some of whom experience health and social inequities compounded by inadequate supports and resources. Compared to the City of Hamilton as a whole, this community has a younger population distribution, higher rates of poverty, and lower rates of education contributing to poorer health indicators. However, when comparing across the lower city, the McQuesten community is not the highest need neighbourhood with respect to health and social indicators. This neighbourhood has unique health and social characteristics contributing to the health inequities initially reported by the Hamilton Spectator in the Code Red series (Buist, 2010). Key decision makers and service providers need to understand the unique dynamics of the neighbourhood, coupled with a firm foundational understanding of the community strengths to implement effective interventions in the neighbourhood. To address the

health and social inequities in the community, McQuesten is in need of a strong community based initiative to address residents' holistic needs, contributing to greater health and well being within the community.

CNN role description. The innovative nature of the piloted CNN role is captured in its duality. The nurse functions as a *navigator* to assist residents and families with unaddressed needs and as a *networker* to form connections and improve service integration within the community. Within the function of navigation, the role was designed not to simply connect residents with resources to address health and social needs but to walk with residents and facilitate warm 'hand-offs' when making connections. The networking functions of the role stem from an emphasis on developing and building relationships within the community and the HFHT practice.

The role was complicated by differing expectations from the community and the HFHT practice. Within the community the CNN role was designed to foster relationships between the CNN and residents, residents and residents, residents and service providers, service providers and service providers, and the CNN and service providers. At the primary care practice level, the CNN role was to build relationships between the HFHT practice and the community, public health and the HFHT practice, service providers and the HFHT practice, and build relationships with individual patients and the community. Therefore, based out of the community HFHT practice and the local community center, the CNN partnered with healthcare professionals and community service providers to address social inequities and health disparities within the community.

With a population health orientation, the CNN met with patients and residents in the community and utilized assessment and planning skills to navigate and network based on individual needs and resources. The CNN, employed by the HFHT, allocated half her time to working in collaboration with the HFHT to provide navigation services for patients referred from the practice, assisting in the navigation of health and social systems. The remainder of the CNN's time was spent partnering with the neighbourhood planning team to identify and address system issues, reducing current gaps in services while navigating community residents. This not only helps to facilitate navigation needs for the clients of the HFHT practice, but also addresses gaps in services experienced by residents in the community without a primary care practitioner. Furthermore, the CNN has public health nursing experience and practices within the Ontario Public Health Standards and the Population Health Promotion Model (Hamilton & Bhatti, 1996), with a comprehensive knowledge of the social determinants of health and community based health promotion strategies. Not surprisingly, the CNN role was in a continual state of evolution during the course of the pilot, informed by community needs, uptake of the program, and guided by a developmental evaluation, given the complexity of the role.

Program Evaluation

Through a review of systematic reviews Shojania et al., (2007) found that most navigation programs in public and private settings were not formally evaluated. Recently program evaluation has become more common, with a variety of methodological approaches and varying degrees of rigour. To provide a comprehensive evaluation the pilot program for key stakeholders and decision makers, a number of evaluation measures

were designed by the SON and the HFHT. The HFHT collected quantitative measures of effectiveness using tools related to quality of life. In order to understand the impact the CNN role had on the HFHT practice and health providers at the systems level, a graduate student peer conducted a developmental evaluation. Finally, a narrative study was used to explore and understand the effect of navigation of individuals and families within the community, which is the focus of this thesis.

Narrative Inquiry as an Approach to Understanding the CNN Role

Programs, like communities tell a story, shaped by setting, context, and culture (Rappaport, 2000). Therefore, the use of the qualitative Three-Dimensional Narrative Inquiry Space approach as described by Clandinin and Connelly (2000) guides the evaluation of residents' experience of the piloted CNN role. Residents' stories were collected and analyzed to understand their experience of navigation through the CNN role. This narrative study aims to collect stories from residents interacting with the CNN to develop an understanding of their experiences, and to inform key decision makers and community stakeholders about the influence of the CNN role. Conducting this narrative study provided residents' perspectives of the utility of the role, and suggestions for improvements to the role to increase the CNN's capacity to provide effective navigation. Conducting the study in a priority neighbourhood enabled participants who may otherwise be silenced due to health status or social exclusion an opportunity to have an influential voice within their community (Rappaport, 2000). This research study was conducted by Janice Feather in partial fulfillment of her Masters of Science in Nursing under the supervision of her thesis committee.

Purpose Statement and Research Questions

The purpose of this narrative study is to explore and describe residents' experience of a novel navigation pilot program led by a Registered Nurse within the context of primary care services provided by a HFHT in a priority Hamilton, Ontario neighborhood. This study explores the impact of the CNN pilot on the lives of residents and their families accessing navigation services. The objectives of the study are 1) to understand residents' experience of navigation services and the impact of this service on their lives through stories; 2) to contribute to the knowledge of how a navigation role can impact the health of individuals and families by addressing root causes of health disparities; and 3) to inform future primary care navigation initiatives in other urban priority neighbourhoods.

To meet the study objective and fulfill the study purpose, the overarching research question guiding the inquiry is: What do residents' life stories reveal about their experiences of system navigation services offered by the CNN role in a priority Hamilton neighbourhood?

The secondary study questions are as follows:

1. What do the stories of residents tell us about their interactions with and impact of the CNN role on their lives and on the neighbourhood?
2. What are residents' perceptions of the CNN role as an effective approach to meeting their individual and/or family health needs?
3. What do residents identify as areas for improvement related to the CNN role based on their experience of system navigation?

Thesis Organization

In this thesis, as in any story there is a beginning, middle, and end. In this introductory chapter the context or back-story was provided to paint a picture of the contributing conditions leading to the development and design of the CNN role. To further develop the context, a review of the literature related to navigator roles specifically within primary care and community settings is presented in Chapter 2. Presenting outcomes and examples of other navigation roles will highlight the need for research on the participants'/residents' experience of navigation. The plotline of this thesis builds in Chapter 3 as a brief overview of Three-Dimensional Narrative Inquiry Space approach, a description of the study setting and methods, strategies to ensure rigour, and ethical considerations is presented. Study findings are presented over two chapters. In Chapter 4 the main characters are introduced, as nine stories of participants' experiences with systems navigation and their interactions with the CNN is presented. In Chapter 5 we reach the climax of the study, the findings of the thematic analysis are presented, drawing comparisons and commonality between the narrative themes of participants' experiences of navigation. The resolution of the study begins in Chapter 6 with the review of the main findings linked with existing research on the experience of navigation. This thesis concludes by presenting the implications of the research as it applies to further development of the pilot program, as well as nursing practice, policy, education, and future research.

CHAPTER 2 – LITERATURE REVIEW

This literature review will build upon the overview of navigation presented in the first chapter but focuses on literature relevant to the research questions. First, a description of the search strategy is provided. Then a description of literature relevant to nurse-led navigation in primary care is provided. Finally, the focus of the literature is on patient experiences and navigation.

Literature Search Strategy

The literature search was conducted in conjunction with a scoping review of primary care navigation programs conducted by a team including the researcher. For the purposes of this study the literature review was conducted utilizing CINAHL, MEDLINE, PUBMED, and a hand search of key documents. Primary and secondary sources from 1990 to March 2014 were included in the search. The search terms used in the search reflect the heterogeneity of navigation roles and definitions. The terms used were patient navigator, nurse navigator, systems navigation, and care coordinator, with an emphasis on service delivery in primary care settings. The majority of the relevant studies originated in the United States, Canada, and the United Kingdom.

Navigation in Primary Care and Community Settings

Navigation can occur in various settings, as the experience of fragmentation is not limited to specific clinical settings or patient populations. For the purposes of this literature review, we will further explore navigation in primary care and community settings. The provision of navigation in primary care may address issues such as delays or failure to receive care, system fragmentation and reduction in the use of more expensive

acute care services (Ferrante et al, 2010). Bodenheimer et al., (2014) identified ten building blocks of a high-performing primary care setting, one of which was comprehensiveness and primary care based care coordination/navigation, arguing that improving navigation requires a team based approach with primary care practices having a designated care coordinator/navigator whose sole responsibility is navigation. Despite the variation across programs and primary care structures, Fischer, Sauaia, and Kutner (2007) argue that navigators work to establish trust in the community by providing person-centered and culturally specific empowering interventions.

Within Canada, navigation programs are being implemented as province-wide initiatives, while other provinces are implementing a variety of navigation programs at a regional or local level (Walkinshaw, 2011). For example, the province of Nova Scotia has been leading navigation innovation within Canada, as evidenced by the identification of competencies and training for nurses in navigator roles (Walkinshaw, 2011). In Alberta, nurse navigators in Primary Care Networks (PCN) have been developed and evaluation of their roles suggest over half their time was spent communicating for the purposes of sharing patient information with specialists, giving appointment reminders, and updating the electronic medical record (Besner et al., 2011). The remainder of the navigators' time was divided between administrative activities and routine clinical activities. The College and Association of Registered Nurses of Alberta (2008) recommend that navigator is a RN role requiring knowledge and analysis of individual and systems level dynamics influencing navigation processes and an understanding of the complexity of the health care system structure, system, and processes. The Registered Nurses Association of

Ontario (RNAO) (2014) has proposed the Enhancing Community Care for Ontarians (ECCO) Model as a strategy to advance primary care through care coordination/systems navigation. They propose that all Ontarians receive complete care coordination and health systems navigation from interprofessional primary care organizations through a person-centered model. The ECCO Model proposes that care coordination/system navigation be the responsibility of existing primary care RNs, optimizing scope, leveraging strengths, and empowering a greater sense of professional autonomy.

Examples of Navigation Models in Primary Care

The process of developing models for navigation in primary care continues to evolve and two tested models of navigation in primary care were found that are relevant to this thesis. The Guided Care Model (GCM) (Boyd et al., 2007; Boyd et al., 2009) was developed in congruence with the Chronic Care Model and was designed to provide coordinated and comprehensive care for older adults with chronic conditions, reduce health care costs and reduce caregiver burden. Within a primary care setting, the model leverages the scope and expertise of Registered Nurses (RNs) to facilitate patient navigation in the community. In the GCM, RNs assess, plan, monitor, coach, educate, and support clients and caregivers while coordinating transitions between settings and providers. In a randomized controlled trial, Boyd and colleagues (2009) reported participants who received the GCM intervention reported improvements in quality of care, satisfaction, care coordination, access to care, wait-times, and client activation. In other studies, GCM navigation was associated with caregiver perception of quality of care (Wolff et al., 2010), improved physician satisfaction with patient/family

communication and patient/ family level of knowledge of their chronic conditions (Marsteller et al., 2010), and high nursing job satisfaction (Boult et al., 2008). Patients' experience has been measured using tools and scales, subsequently limiting the ability to understand the patient experience (Boyd et al., 2009; Marsteller et al., 2010).

The Sooke Navigator Service Model is a Canadian model designed to introduce and implement navigators within a rural under-serviced community addressing primary mental health care and addictions (Anderson & Larke, 2009b). In collaboration with primary care physicians and service providers, the navigators (described as clinicians with a background in social work and psychiatric rehabilitation) worked to enhance communication and connections within the community for improved integration and collaboration. Navigator activities include needs-based assessment, planning, education, knowledge exchange, coordination, support, and comprehensive follow-up. The model was evaluated using a mixed methods approach, and outcomes resulted in 168 referrals from navigators to mental health and addictions services, stronger communication and connections within the community. The evaluation of the pilot program/role suggests the importance of role clarity, an understanding of the barriers to care, patients' experiences, and the need for a model to develop the role. Although the researchers acknowledge the importance of client experiences, the method of data collection did not allow for an in-depth understanding of their experience with the navigator role.

In this study, the navigation program being evaluated has not drawn from a specific navigation model, rather it has been predominately based on the Population Health Promotion Model (Hamilton & Bhatti, 1996), coupled with a foundation based on the

social determinants of health. Specifically designed as a nursing role, the navigator functions within the multidisciplinary team to provide patient navigation in the context of primary care and in a community setting.

Patient Experiences

Patient perspectives are instrumental in defining high quality care and influencing health care reform (Laberge, Pang, Walker, Wong, Hogg & Wodchis, 2014). Patient perspectives highlight the aspects of service delivery that are important to patients and their families (Wong & Haggerty, 2013). Since patients are active participants and recipients of health care delivery, they should be directly involved in decision-making and quality assessment of care. Incorporating patient experiences in practice improvements fosters a culture of patient engagement, enhancing health behaviours and agreement with treatment plans. Subsequently, patients who are engaged and validated by having an influence in their care are more likely to report higher quality of life and satisfaction with health care (Davis, Schoenbaum & Audet, 2005). Therefore, evaluating patients' experiences is essential to promote innovation and measure changes in service delivery and inequities (Wong & Haggerty, 2013).

Patient Experiences in Primary Care

In a scoping review conducted to support the creation of a patient experience questionnaire to assess quality and performance of primary health care in Canada, Wong and Haggerty (2013) identified an underutilization of patient experiences in Canadian primary health care research. Reviewing publically available instruments to measure patients' experience in primary care the most frequently measured experiences were

access, interpersonal communication, continuity and coordination, health promotion within technical quality of care, trust, and patient-reported impacts of care.

Laberge and colleagues (2014) published a Canada-wide report on primary care performance with particular attention to patient experience. This report is part of the Quality and Costs of Primary Care study, a large international study in 34 countries. Data was collected from 8,332 patients and 810 physicians in 785 primary care practices that provide comprehensive primary care services. Patient experiences were measured utilizing the Patient Experience Survey, validated as part of the larger international study. The researchers categorized the survey results from patient values into four domains; 1) continuity and coordination, 2) communication and patient-centered care, 3) patient activation, and 4) access (Laberge et al., 2014). Continuity and coordination was the most important aspect of primary care as primary care serves as a point of entrance into the healthcare system. Communication, patient-centered care, and patient activation were valued by patients and contribute to quality care and improved health outcomes. However, access to primary healthcare services was the lowest ranked patient value in the study. This reflects the major limitation of the study, the sample population did not capture the acutely ill or patients who are poorly connected with primary care services. Therefore, the value of access to primary care may be minimized, as the sample was reflective of patients in good health with the means to readily access primary care services. With the use of a large sample and validated survey instruments, this study contributes to the understanding of the aspects patients' value in primary care.

Patient Experiences with Navigation

Patient satisfaction is the most commonly reported measure used in the literature to evaluate the patient experience with navigation. Many studies evaluating patients' experiences of navigation reported improved satisfaction (Boyd et al., 2009; Campbell, et al., 2010; Carroll, et al., 2010; Ferrante, et al., 2010; Hook et al., 2012; Marsteller et al., 2010). However, patient satisfaction is often poorly defined and varies due to the numerous instruments used to measure satisfaction. Jenkinson and colleagues (2002) explored patient satisfaction as an indicator of patient experience, concluding that patient satisfaction scores provide a limited and optimistic picture of the patient experience. The authors noted that more meaningful evaluation of patient experience is gained when patients report on specific aspects of their care. Therefore, since navigation models and programs are based on the philosophy of advocating for overcoming barriers and reducing health disparities evaluation should involve patient-centered measures that do not minimize the importance of patient experiences and perspectives for informing continued development of navigator roles (Palos & Hare, 2011).

Navigator roles vary upon scope, setting, and target population, which presents challenges for evaluating and comparing patient experiences of navigation programs. To address the heterogeneity of patient outcome measures of navigation there was a movement to standardize the measurement of outcomes that are meaningful and valued by patients in oncology settings. The aim was to develop criteria for program evaluation across navigation programs (Fiscella et al., 2011). Suggested outcome measures include treatment adherence, satisfaction with navigation, working alliance with navigator,

perceived knowledge/self-efficacy, cultural competence of navigator, and quality of life. However, Fiscella et al., (2011) criteria fails to capture the essence of the patient experience of navigation and the potential to reduce health disparities.

Carroll et al., (2010) conducted a randomized controlled trial with oncology patients in primary care, hospital, and community settings, comparing usual care to patient navigation services. In follow-up interviews, patients reported feeling emotionally supported, valuing the navigators' presence, consistency, availability, and accessibility. Similarly in a Canadian qualitative study of patients' experience with a nurse navigator in a hospital based cancer setting, Gotlib Conn and colleagues (2014) also reported the experience of receiving emotional support from the navigator. Patients highly valued the person-centered, holistic, and individualized care from the navigator that focused on patient strengths as a resource in their cancer journey. The authors described that patients' specifically valued the accessibility of the navigator and the capacity to advocate within the hospital system. In this study patients considered navigation to be effective when they experienced a trusting and empathetic relationship between the patient, their family, and the navigator.

Pieters, Heilmann, Grant, and Maly (2011) explored the experience of older women navigating barriers for breast cancer care from pre-diagnosis to completed treatments. The qualitative descriptive study guided by grounded theory included a sample of 18 women, 7 of whom had worked with a nurse navigator. Five participants reported benefiting from working with the navigator as it facilitated their care transitions. Participants who accessed the navigator valued the nurse being 'present' and helpful,

invaluable to help navigate beyond knowledge deficits, pre-existing comorbidities, and multiple appointments. The authors concluded that nurse navigation enhanced the ease of transitions and maneuvering barriers to care compare to the experience of participants without access to a nurse navigator.

The available literature exploring patient experience of navigation was limited, studies reporting on the patient experience of navigation did not present a comprehensive understanding of the experience of navigation, with the exception of Carroll et al., (2010) utilizing a mixed methods approach to explore patients' experiences with navigation in cancer care. It is unclear if patient experiences with navigation are dependent upon the design of the navigation program, the setting where navigation occurs, and/or the patient population. Therefore, we will examine the literature of patients' experiences with navigation in primary care and community settings with various patient populations.

Patient Experiences with Navigation in Primary Care

There are limited studies exploring patients' experience of navigation, particularly in primary care and community settings. Hook et al., (2012) conducted a descriptive study to explore patient satisfaction with registered nurse-led navigation for breast cancer in a rural community multispecialty physician clinic. Utilizing a likert-type survey, 97% of patients reported gaining new knowledge, 83% felt emotionally supported, 87% valued follow-up calls from navigator and 80% of participants reported that the nurse navigator improved their cancer experience. The authors concluded that overall participants were highly satisfied with navigation in the community. This study further substantiates the experience of emotional support and increasing patient knowledge but it minimized the

patient experience of navigation to a measure of satisfaction rather than presenting a comprehensive understanding of the patient experience. The study was limited by the lack of established reliability of the researcher-developed survey instrument.

Ferrante et al., (2010) evaluated the pilot of a navigator with a background in social work working with primary healthcare practice in a suburban New Jersey community. The goal of the navigator role was to reduce clinician burden of complex social issues while assisting patients to better utilize the health care system. The evaluation of the role was a qualitative cross-case comparative analysis with data collected through interviews with physicians, patients, and family members. Patients expressed a sense of gratefulness for the opportunity to work with the navigator, valuing the information, support, and guidance they received. Their experience with the navigator also elevated their perception of the primary care office and enhanced the quality of care of the whole practice. Most patients reported having supportive social networks before navigation but believed the benefit of the navigator role would be magnified for patients with minimal social supports. However, the patients' experience of the navigator program was minimized by the emphasis on the physicians' experiences in this study.

Boult and colleagues (2008) conducted a cluster-randomized controlled trial on the effect on the quality of care for multimorbid older adults with nurse navigation based on the Guided Care Model in eight primary care practices. Patients' perceptions were measured utilizing a validated survey instrument assessing qualities of chronic illness care. Compared with the control group ($n = 415$) at six months, patients receiving navigation ($N = 485$) experienced improvements in goal setting, care coordination, and

decision support aided by health information provided by navigators to inform patient behaviours. The findings from the study suggest that navigation based on the Guided Care Model did not appear to improve patient activation, a valued dimension of primary health care performance (Laberge et al., 2014). This study highlight the aspects of chronic care positively affected by nurse navigation in primary care settings compared to a control group receiving routine care. However, what this study fails to describe is the patient experience of navigation, completely ignoring the emotional, psychosocial, and relational aspects of chronic care service delivery.

Of the available literature of patient experiences with navigation in primary care and community settings, there is a general lack of rich description of the patient experience. This is a gap in the literature that this study was designed to address.

Measuring Patient Experiences

The measures utilized to explore patient experiences of navigation are in itself reflective of the variation of navigation programs. Many studies evaluated patient experiences using validated surveys (Boult et al., 2008; Boyd et al., 2009; Campbell, et al., 2010) or researcher-developed surveys (Anderson & Larke, 2009a; Hook et al., 2012). The majority of the surveys addressed indicators of patient satisfaction, quality of life, communication, and care coordination. The use of survey instruments allowed for larger sample sizes and ease of data collection but did not allow patients the opportunity to describe their experiences with navigation. Some studies explored patient experiences through qualitative interviews in oncology (Carroll et al., 2010, Gotlib Conn et al., 2014; Pieters et al., 2011) and community settings (Ferrante et al., 2010; Ravenscroft, 2010).

These studies provided a more comprehensive understanding of patients' experiences with navigation, highlighting the importance of emotional support, accessibility, consistency, and person-centered care.

Some of the literature exclusively reported on the patient experience (Carroll et al., 2010, Gotlib Conn et al., 2014; Hook et al., 2012; Pieters et al., 2011), whereas other studies presented the patient experience to complement the experience of physicians and other healthcare providers (Anderson & Larke 2009a; Boult et al., 2008; Ferrante et al., 2010). In the studies where the patient experience was not the central focus of the evaluation of the navigation program, patients' voices were often overshadowed by the perspectives of physicians and other health care providers. Yosha and colleagues (2011) conducted a paired qualitative analysis of patient and lay navigators' perspectives of cancer care navigation. The rationale provided for a paired approach to exploring patients' experiences of navigation was that relying solely on patients' perspectives risked presenting a limited view of the navigation relationship and experience as patient may not be aware of the scope and tasks of navigators. Yosha and colleagues (2011) advocate for a multi-perspective analysis to understand navigation process and provide context for patient experiences.

Summary

Navigation is operationalized broadly in the literature, due to the variation in definition, role/function, setting, target population, model, and program design. However, a recurrent theme in the literature indicates that navigation is employing a person-centered approach to assist individuals and families to improve health outcomes by

increasing access to services by bridging gaps and reducing barriers. Navigation can occur in a variety of settings, as the experience of health care system fragmentation is a persistent systemic challenge. Navigation in primary care can be a potentially beneficial strategy to address system fragmentation and is congruent with primary health care reforms. With an increased interest in systems navigation, it is important to conduct rigorous research and contribute to what is known about navigator roles in primary care.

Navigation roles have been evaluated utilizing diverse methods, reporting various outcomes. Many of the evaluations of existing navigation programs are largely concerned with quantitative outcomes and economic evaluations, missing the humanizing perspective of the patients' experiences. There are limited studies exploring patient experience. The majority of studies exploring the patient experience of navigation were conducted in with cancer patients in hospital and community settings (Carroll et al., 2010; Gotlib Conn et al., 2014). However, there is a lack of studies exploring the general patient experience of navigation in primary care in a priority population. Therefore, there is a need for rigorous qualitative research exploring the patient experiences of nurse-led navigation in primary care to develop a more comprehensive understanding of experiences with services and learn about strategies to improve the role.

The findings of this research will contribute to our understanding of a nurse navigation role in primary care to address health disparities and social inequalities. Conducting this narrative study will provide residents' perspectives of the utility of the role, and suggestions for improvements to the role to increase the CNN's capacity to provide effective navigation and inform continued development of primary care

navigation role. This evaluation of the novel CNN role may provide an avenue of future inquiry into effectiveness measures of navigation roles and assist health researchers to continue to make advances in systems navigation. Furthermore, evaluating this pilot program may contribute to the evidence required to establish a province-wide primary care navigation program, currently absent in Ontario.

CHAPTER 3 - METHODS

This chapter will provide a brief introduction to the Three-Dimensional Narrative Inquiry space approach and its applicability for the study (Clandinin & Connelly, 2000). A detailed description of the study setting is provided, as it builds on the context of the study and the place where participants' stories are unfolding. Subsequently, a description of the participants in the study, the sampling/recruitment strategies, data collection, and data analysis is provided. The chapter concludes with the study design elements to enhance rigour and ethical considerations.

Narrative Inquiry

Storytelling is a basic method used to create and share meanings, conveying the character of human experience (Bowman, 2006). Stories can be functional, strategic, and purposeful. Narrative research, with the foundational assumption is that storytelling creates meaning from life experiences, allows for the systematic study of personal experience and meaning (Riessman, 2000). In this study, I sought to understand the impact of interactions with the CNN on the lives of participants, assuming that their stories would reflect the meaning of their experience of navigation.

This narrative study represents a case-centered approach to qualitative research, guided by the Three-Dimensional Narrative Inquiry Space approach, as described by Clandinin and Connelly (2000). A methodology founded in Dewey's theory of experience, narrative inquiry is commonly used in the field of education yet is highly applicable in nursing research (Clandinin & Huber, 2010; Overcash, 2004; Sandelowski, 1991). The Three-Dimensional Narrative Inquiry Space approach is comprised of three

interrelated dimensions or commonplaces, Temporality, Sociality, and Place, creating a lens to guide data collection and analysis (Clandinin & Huber, 2010). Narrative inquiry is defined by the temporal dimensions addressing temporal matters which focus on an appropriate balance of personal and social conditions as they occur in specific places (Lai, 2010). By attending to all three dimensions, the researcher is able to study the complexity of experiences.

Temporality

The stories we tell and the meaning we ascribe to life events are not fixed; rather they are in a state of constant evolution influenced by subsequent life events (Riessman, 2000). Storytelling is making sense of past experiences in relation to our current selves. Therefore, stories are dependent upon temporality, which is placing the experience in the context of ones' past, present, and future (Clandinin & Huber, 2010). The past is remembered experiences, feelings, and stories from an earlier time (Ollerenshaw & Creswell, 2002). The present is current experiences, feelings, and stories relating to current events. The future is a forward look at possible experiences and implied plot lines. Grounded in Dewey's notion of continuity, Clandinin and Connelly (2000) conceptualize experience as continuous, since people, stories, and events are in a constant process of revision. Consequently, narratives are often presented in a temporal order, organizing the plot by locating the experience in particular times and places. However, narratives may also be organized episodically or thematically (Riessman, 2008). It is therefore the responsibility of the researcher to acknowledge the ongoing temporality of participants' experiences, which guides data collection and analysis (Clandinin & Huber

2010). While attending to the temporal nature of experience it is understood that who we are is also shaped through personal and social interactions over time.

Sociality

The dimension of sociality originates from Dewey's theory of experience, as experiences are conceptualized as personal or internal conditions and social or external conditions (Murphy, Ross, & Huber, 2012; Ollerenshaw & Creswell, 2002). Therefore, when attending to the dimension of sociality the researcher attends to both personal and social dynamics simultaneously (Clandinin & Connelly, 2000). The central relationship in this study is the relationship each participant or narrator has with the CNN. The personal characteristics narrators bring to the relationship and the unique interpersonal dynamics with the CNN form a major component of the inquiry space.

Storytelling can be a vehicle for individuals to construct their personal identity (Riessman, 2008). Narratives can highlight how one perceives the process of being, becoming, and belonging. This can illuminate one's personal feelings, hopes, desires, moral dispositions, and aesthetic reactions (Clandinin & Connelly, 2000). The emphasis on the narrator and the meaning they ascribe to events provides listeners with the opportunity to gain an understanding into the person behind the story.

Storytelling is a relational activity; therefore our stories are framed by the social conditions in which one experiences the unfolding of life events (Clandinin & Huber 2010). This is a shift from the participant outward to the conditions in the environment with others and their purposes, intentions, assumptions, and points of view (Ollerenshaw & Creswell, 2002). Since stories are deeply rooted in evolving social context as

situational, relational, cultural, historical, and societal contexts shape how stories are told and understood (Murphy, Ross & Huber, 2012). Since storytelling is a relational process, the relationship between the narrator and the listener influence the story being told. The participant and the researcher engage in an active process of co-creation, as narrative inquirers cannot readily remove themselves from the relationship or become a passive note taker (Clandinin & Huber, 2010; Riessman, 2008). Therefore, the researcher is actively engaged in analyzing the participant/CNN relationship as it temporality unfolds in significant places within the Three-dimensional Narrative Inquiry Space.

Place

Along the third dimension is a place or a series of places, as Clandinin & Huber (2010) describe it, the concrete physical space binding the place or places where the experience unfolds. Stories of experience are not created in a vacuum, but rather are innately bound by the place where the experience exists. Places hold meaning and significance in narratives, as all stories are set in real places influencing our experiences (Murphy, Ross & Huber, 2012). Places can be opportunistic or can create barriers with respect to individual experience (Kirkpatrick, 2008). Therefore, it is the intention of the researcher to examine the dimension of place as it applies to participants' stories and interactions with the CNN.

The community and places within the community are the settings where interactions between participants and the CNN occur. However, the places of temporal importance in participants' lives are also significant as they shape how narrators

experience their interactions with the CNN. Therefore, attention is given to the influence of the community on the relationship between participants and the CNN.

Narrative Inquiry and Program Evaluation

Stories have been recognized as a valuable tool in evaluation research, to capture the individual experiences in their own words, illuminating complexity anchored in the context of the experience (Hunter, 2010; Polkinghorne, 2007). McClintock (2003) highlights advantages of stories as a form of evaluation, which include the focus on interventions while reflecting on contextual factors influencing outcomes, and the process of participatory change as persons make meaning of their experiences. Narrative inquiry can integrate evaluation with ongoing program development to enhance and inform the pilot program. Stories can prove to be valuable to key stakeholders and policy makers, providing a humanizing complement to quantitative data.

This methodology is appropriate for potential study participants since narrative, opposed to other modes of inquiry, acknowledges the voices and stories of marginalized or silenced persons (Bowman, 2006; Rappaport, 2000). The holistic and person-centered nature of narrative inquiry addresses the level of complexity required to analyse the impact on one's health and social status (Hunter, 2010). Participants' stories will be utilized as the main data source to inform our understanding of the influence of system navigation through CNN services in the lives of residents of the community.

Study Setting

The Hamilton Spectator's Code Red series (Buist, 2010) first shed light on the marked health and social inequities in a number of neighbourhoods within the City of

Hamilton in 2010. These significant and persistent differences in health are influenced by income, education, employment, gender, ethnicity, and other social and economic factors. The Social Planning and Research Council of Hamilton (SPRC) designated the setting of the CNN pilot program, the McQuesten neighbourhood, as a priority neighbourhood due to the health and social indicators of the community. The following is a demographic description of the study setting, painting a picture of the community's past, evolving with time through social and environmental influences.

The SPRC composed a comprehensive analysis of the McQuesten neighbourhood, serving as the source of the demographic data (Mayo 2012; Mayo, Klassen, & Bahkt, 2012). The lower east end Hamilton community is comprised of 7000 residents, as reported in the 2011 census. The age distribution of the community reveals that 31% of residents are younger than twenty years of age, 18% are between the ages of 20 – 34, 39% are between the ages of 35 – 64, and 12% are 65 years and older, compared to the distribution for the City of Hamilton 25%, 19%, 41%, and 15% respectively. From these findings, children comprise a large portion of the McQuesten community, compared to the smaller proportion of seniors, differing from the average age distribution of Hamilton. Approximately 40% of families with children in the community are female lone parents while married or common-law couples comprise 51% of families. This compares to 23%, and 73% respectively in the City of Hamilton. The variation between the community and city, with respect to female lone parents is significant. It is one of several factors contributing to the community child poverty rate, which is as high as 75% - almost triple the rate of the City of Hamilton. Poverty is not only a critical issue for the children in the

community, but for the community as a whole since the total poverty rate is 44%, compared to the city average of 18%.

Populations who are economically disadvantaged can be further disadvantaged with education and employment opportunities. The high school non-completion rate in the McQuesten community is nearly double the rate for the City of Hamilton, 31% and 16% respectfully (Mayo, Klassen, & Bahkt, 2012). Subsequently, only 6% of residents have completed a university degree, compared to 24% in the City of Hamilton. With respect to employment, in 2006 at the time of the census the unemployment rate in the community was 11% compared to 7% for the City (Mayo, 2012). However, since there is a lack of more recent census data it is unclear as to the current comparative unemployment rates. In addition to unemployment, there is also a 43% non-participation rate for all persons over the age of 15 in the community compared to the City average of 35%.

Given the established relationship between social determinants of health and health outcomes residents in this community are at an increased risk for adverse health outcomes, specifically isolating poverty, education, and employment as major determinants within the community (Raphael, 2009). This creates conditions for poorer health outcomes and inequitable access to services and resources. For example, per 1,000 residents in the community there are 300 additional emergency room visits per year compared to the city average. Furthermore, the rate of emergency psychiatric visits in the community is 21 per 1,000 residents, which is more than 40% higher than the average for the city (Mayo, 2012). The comparatively high utilization of emergency room services is

a major indicator of unaddressed or unmet health needs within the community. The lack of access and utilization of appropriate health and social services is not an acute issue within the community, the chronic nature of the problem is exemplified by the average age of death in the McQuesten community, 72.8 years, which is less than the City of Hamilton average of 75.2 years (Mayo, Klassen, & Bahkt, 2012).

This community's story cannot simply be told from these statistics alone. Residents' personal life stories, shaped through negotiation with the context of the community, provide a glimpse of life in the community (Rappaport, 2000). Residents hold common or shared stories contributing to a community narrative influenced by culture and context. In McQuesten, despite the serious health and social inequities, the community has numerous strengths and assets contributing to its identity as a community. One major asset is the presence of a resident led Community Planning Team with a vision and action plan in place to improve the quality of life for McQuesten residents (McQuesten Community Planning Team, 2012). McQuesten is home to a group of residents who are passionate about their community and are committed to actively improving the neighbourhood. There is a level of openness in the community to new programs and services with the focus on inclusion and partnerships.

Study Participants

It was the intention that the sample for this study would reflect the composition of the CNN's primary caseload. As the pilot program evolved there were subpopulations identified within the community that the CNN was servicing. These identified groups were residents in the community utilizing the food bank and clothing exchange in the

community center, patients of the HFHT who were referred to the CNN by members of the interprofessional team, youth within the community, and parents with young children through the elementary school in the neighbourhood.

The inclusion criteria guiding participant sampling is as follows:

1. Resident of the McQuesten Community
2. Clients having a minimum of two interactions with the CNN
3. English speaking adults

Additionally, the CNN was asked to participate in an interview after the finalization of study themes to incorporate her perspective on the interactions with residents in the community. This perspective provided additional insight into the interactions with residents and enhances our understanding of the piloted role.

Sampling and Recruitment

Narrative inquiry is not appropriate for studies with large samples of nameless and faceless participants (Riessman, 2000). The methodology requires a slow approach, subtlety giving attention to contexts, relationships, language, and the structure of the story. Given the depth and nature of the inquiry the projected sample size was 8-10 participants, acknowledging the importance of sensitivity to the quality of data and variation within the sample.

Sampling Strategies

As the purpose of the narrative study was to understand the meaning and experience of navigation through the eyes of community residents, it was only logical to sample persons who have interacted with the CNN on a more frequent basis. This is

based on the assumption that residents who had had multiple interactions with the CNN are more likely to have a rich, meaningful experience while sharing their story.

Therefore, purposive sampling strategies were employed during data collection to obtain a heterogeneous sample based on criterion sampling. The primary sampling strategy was intensity sampling, as described by Patton (2002) to understand the experience of information rich residents with at least two interactions with the CNN. Convenience sampling was also utilized due to the low rate of uptake and integration of the CNN within the community.

Recruitment

To actively recruit study participants, the CNN provided a letter of invitation (Appendix A) to all of her clients. Passive recruitment strategies included an advertisement in the community center and the HFHT waiting area (Appendix B) and word of mouth at the community centre. Interested residents were invited to seek clarity at any time about the study from the primary researcher, research team, or HIREB if there were any concerns. Potential participants were assured that confidentiality would be expressly maintained and any information shared about their experience of utilizing the CNN services would not affect their future relationship with the CNN, the HFHT, or other service providers. Many of the potential participants did not have computers or cell phones to facilitate follow-up regarding study participation. Therefore, the researcher was physically present at the community center and the HFHT practice to connect with potential participants and to begin to develop trust with potential participants given the request to share their life story with the researcher.

A twenty-dollar gift card for a local grocery store was given to every participant as an incentive and an expression of gratitude for study participation. Participants were compensated for any transportation, and child or elder care costs associated with participating in the interview. The local grocery store was within walking distance or a short bus ride away from the community centre. The selection of the specific grocery store was based on the advice of community residents.

Challenges faced during the recruitment process. Due to the nature of a pilot program the uptake and integration of the CNN was not as rapid as originally planned, leading to a longer time spent in the field collecting data to accumulate quality data. There was a lag time between initial interactions with residents and the time to develop an intense experience with the CNN, having at least two interactions minimum. As the CNN role was expanding and evolving new subgroups of residents developed based on the connections and networks that were forming. After a lack of success with recruitment, an amendment was proposed and approved by ethics, which more readily facilitated data collection. Some revisions included the language used on the poster, the change in the inclusion criteria to include residents who were not part of the HFHT practice.

Data Collection

A story can be told from multiple perspectives and presented in a variety of forms (Clandinin & Connelly, 2000). Vehicles used for storytelling include traditional methods of oral and written stories, but also include pictures, observations, and reflections. Therefore, narrative inquiries have multiple methods of collecting stories at their disposal. In the Three-dimensional Narrative Inquiry Space approach stories are collected

through the composition of field texts. Field texts, in the form of field notes, interview transcripts, observations, documents, or pictures, are constructed representations of experience and serve as data in narrative inquiry as ‘data’ carries connotations of objective representation of the research (Clandinin & Connelly, 2000). Regardless of the types of field texts included in the study, it is essential to situate the field texts within the temporal, sociality, and place dimensions (Clandinin, 2006). To examine the lived experience of community residents interacting with the CNN the following field texts were collected and analyzed:

1. Individual narrative interviews
2. Field notes
3. CNN documentation

The process of data collection commenced with being in the field, starting with telling the story. The researcher was present in the community eight months before data collection began to settle into the community by attending monthly community meetings and volunteering to gain entrance and insight into the place and context influencing the temporal unfolding of residents’ lives. While gaining a deeper understanding of the community centre where interactions between residents and the CNN frequently occurred, the researcher was also able to observe interactions with the residents and the CNN. These observations included how the CNN approached interactions with residents and their response or reception to her approach. Since the process of sharing one’s life story can be an intimate process for some, the researcher’s presence in the community allowed for interactions between participants and the researcher prior to the interview.

Narrative Interviews

Interviews, being the most common form of collecting narrative data, allow for the collection of narratives of experience through oral storytelling (Clandinin & Connelly 2000; Riessman 2008). Narrative interviews differ from other qualitative interviews in structure and the role of the researcher (Riessman, 2008). Narrative interviews aim to generate a detailed account of ones' experience by encouraging participants to guide the interview as they narrate (Reissman, 2008). Rather than brief questions and answers, open-ended questions are posed to participants to allow them to construct responses in meaningful ways using their own language. This approach to interviewing allows for a less dominating and more relational interview, respecting how narrators organize meaning to life events and bridging the gap between dehumanizing data collection methods and naturally occurring conversations (Riessman, 2000).

This mode of data collection allowed residents to share their story during a face-to-face individual interview. Semi-structured interviews enabled each narrator to tell their story with limited redirection or interruption from the interviewer/researcher. The role of the interviewer in narrative interviews is to actively listen, provide supportive comments and appropriate questions to encourage and shape the storytelling process (Hsu & McCormack, 2011; Reissman, 2008). Therefore, the researcher jointly participates with the narrator to construct the narrative. For this reason, the primary researcher conducted all of the interviews.

Approach to narrative interviewing. The narrative interviews were conducted in a manner informed by the four-phase method developed by Jovchelovitch and Bauer

(2000). In phase one, initiation, the focus was on explaining the broad context of the experience of living in the McQuesten neighbourhood. Participants were encouraged to engage in storytelling while providing a temporal context to their story. For example, the length of time lived in the community and a description of life in the community before the CNN pilot. In phase two, main narration, the focus was on the participant sharing their experience with the CNN with the researcher taking a passive role listening, allowing the participant to narrate the story as they see it unfolding. Open-ended questions like ‘What is your experience with the CNN?’ were employed to facilitate this phase of the interview process. In phase three, questioning, the focus is on building upon the heard narrative by asking specific questions to fill in gaps or seek clarity. With the conclusion of all three phases the audio recording was stopped and transcribed later with consent from each narrator.

In phase four, concluding talk, general conversation or ‘small talk’ was conducted with the narrator to further understand the narrators’ view of self and the social context in which their story exists. For some participants, this final phase of the interview gave them permission to relax and speak more freely with the auto recording off, while others provided a summary of their experience bring in new details and themes. The data gleaned from the ‘small talk’ were incorporated into the researcher’s field notes, as it was not part of the transcription. This fourth phase is important to the interview as it provided an opportunity for some participants to make further meaning of their experiences and draw conclusions. The content of the interviews was informed by the questions on the ethics approved interview guide (Appendix C). However, due to the iterative nature of

qualitative research the interview guide evolved as emergent themes became apparent through concurrent data collection and analysis.

Conducting the interviews. It was estimated that the interviews would range from 30 to 90 minutes in duration, dependent upon the participant. When possible the letter of invitation/consent (Appendix A) was given to each participant prior to the day of the interview. If this was not possible participants were given the letter of invitation/consent on the day of the interview to review. For every participant the letter of consent was read aloud by the researcher and participants were encouraged to ask questions or seek clarity before consenting to study participation.

Documents

Documents can also tell a story and help to contextualize the experience. Clandinin and Connelly (2000) note that due to the emphasis on experience in narrative inquiry researchers frequently ignore the existence of relevant documents. In the case of this pilot program, the CNN was utilizing a tracking tool, capturing interactions with residents from the CNN's perspective and a description of the interventions, services, and resources provided. This is a relevant component of field texts, adding value and richness to the study by enhancing our understanding of what needs were identified during resident interactions and the navigation interventions employed to assist residents to meet their needs.

Consent to obtain CNN documentation was requested on an individual basis for every participant before the onset of the interview. All participants consented to the access of the CNN documentation but each participant was informed that they would not

be excluded from study participation if this consent was not provided. Consent was also obtained from the CNN and HFHT to access the documentation. This process was in keeping with the Personal Health Information Protection Act (2004) and approved by the Hamilton Integrated Research Ethics Board.

The number and types of interactions participants had with the CNN determined the richness of the documentation. The documentation was structured to include the participants' issue or concern, the intervention, and follow up when available. The documentation was problem based and only included interactions with residents where interventions were performed. Interventions varied depending upon the nature of the problem and the available resources.

Field Notes

Field notes are ongoing notes full of details of our inquiry in the field of study and are the basis from which we can tell our story of experience (Clandinin & Connelly, 2000). Field notes are an important type of field text as it allows the researcher to balance involvement in the field and distant observation. At the conclusion of each interview the researcher took time to compose field notes, which included descriptive and reflective components. Field notes were written with reference to temporality, place, and sociality dimensions utilizing the template seen in Appendix D. The field notes provided a complement to the interviews, as audio recording and transcription do not include non-verbal communication or reflections from the researcher. Research questions, impressions, interpretations, and decisions were also recorded during the analysis of the research texts. Clandinin and Connelly (2000) stress the importance of the composition

and continued reference of field notes as they assist researcher to maintain their location in time as their experience in the field changes with time.

Data Analysis

The objective of narrative analysis is the study of the story itself, allowing for the systematic study of personal meaning and experience (Riessman, 2000). Narrative analysis is a case based approach where the story in its entirety is greater than the sum of its parts. It attends to the sequence of the story in temporal, social, and spacial context as narrated by the participant. Narrative analysis refers to a group of methods used to interpret texts in a storied form (Riessman, 2008). In narrative analysis attention is given either to the content or the form of the story, focusing on what is being said versus how it is being said (Lieblich et al., 1998). In this study a thematic approach to narrative analysis was conducted. In contrast to a structural or performance analysis, thematic analysis focuses exclusively on the content of the story rather than the language and how the story is delivered. Thematic Narrative Analysis is the most common mode of narrative analysis in applied settings, utilized by nursing researchers and other health occupations to uncover and categorize the themes of patient experiences (Riessman, 2008). In the following section I will describe my inductive journey of data analysis beginning with transcribed interviews to the development of the final research texts and thematic analysis.

Analysis of Narrative Interviews

Since the emphasis is on the story that is being told, the spoken language, which can be incomplete and complex, is transformed from the verbatim transcription to make it

easily readable (Riessman, 2008). In this case, the audio-recorded interviews were transcribed verbatim and cleaned to remove personal identifiers, acknowledging that we are still often identifiable by the stories we tell. The first initial interviews were transcribed by the researcher to provide an opportunity to become immersed in participants' stories and to step away from the field to further develop the interview guide in an iterative manner. Digital recording was transcribed verbatim. All interview transcripts were checked and cleaned by the researcher to establish a close relationship with all participants' narratives.

The approach to analysis of the field texts was guided by the Three-Dimensional Narrative Space approach. Analysis began with the composition of field texts by removing simple affirmative utterances by the researcher that did not contribute to the co-creation of the narrative. The sequencing of the words was preserved and the text remained in blocks unless there was a significant pause or there was a change in topic. Field texts from each participant were re-storied by analyzing them based on the setting, temporality, and sociality of their experience. The researcher read and re-read each transcript, spending time immersed in each narrative. The re-storying process was guided by the holistic content analysis steps outlined by Lieblich et al., (1998), creating storied accounts of participants' experiences.

Interim field texts in the form of narrative summaries were composed using narrators' own language and arranged chronologically and/or thematically. Participants were presented their narrative summaries once and given the opportunity to make revisions. Assistance from the researcher was given for participants with limited literacy.

The main question posed to narrators was “Can you see yourself in this story?” This was important in the co-creation of the narrative, as collaboration and negotiating relationships minimize the potential gap between the story presented by the participant and the story reported by the researcher (Clandinin & Connelly, 2000).

Composition and Analysis of Research Texts

The narrative summaries for each participant were combined with the CNN documentation and the field notes to contextualize the narrative from the researcher’s perspective while incorporating the narrative of the CNN’s experience with each participant. The contextualized narratives, termed research texts (Clandinin & Connelly, 2000), were analyzed using a two stage thematic analytic approach. A holistic content analysis, as described by Lieblich et al., (1998), was conducted concurrently while composing the research texts. Through the multiple readings of each individual transcripts and research texts global impressions, themes, and foci were identified. After discussion with the thesis supervisor, the emergent themes were used to guide the subsequent thematic narrative analysis.

Thematic Narrative Analysis

Thematic analysis is common among many qualitative methodologies; however, there is a distinct method of coding specific to narrative analysis. Narrative researchers strive to keep the story intact, by viewing each story as a case and preserving it as an analytical unit rather than fragmenting the story into small coding units or categories as in Grounded Theory (Riessman, 2008). The narrative approach to coding can preserve individual agency and context in the inductive thematic coding process with close

attention to analysis of individual cases (Riessman, 2008). Stories are rarely bound clearly, but involve negotiation between the narrator and the listener to determine relevance and story placement. Therefore, researchers must determine a unit of analysis to guide the analysis and interpretation of the narrative, dependent upon the theoretical assumptions, purpose of the study, and research questions (Riessman, 2000). For the purposes of this study, the unit of analysis was the discrete story of interactions with the CNN, opposed to one's life story in its entirety. Thematic analysis was conducted employing the categorical content analysis approach (Lieblich et al., 1998) using NVivo 10 software to assist with analysis.

Strategies to Ensure Rigour

The trustworthiness or rigour of narrative research cannot be evaluated utilizing traditional measures of validity (Riessman, 2000). A widely accepted standard upon which to judge the rigour of narrative inquiry does not exist due to the interpretive nature of the research approach. Polkinghorne (2007) presents potential threats to validity in narrative research as the participants' language stories may leave out or obscure details important to the meaning of the experience of utilizing CNN services. Furthermore, validity issues arise as to how well the composed field texts express the actual meaning of the participants' experiences. To address these and other potential threats to validity Kirkpatrick (2005) proposed six strategies to enhance rigour in narrative research, which have been incorporated in the study design.

Adequate Planning

To develop a comprehensive understanding of narrative methods the researcher spent time immersed in narrative literature. With guidance from the member of my committee specializing in narrative research I began to develop a greater understanding of Clandinin & Connelly (2000) Three-Dimensional Narrative Inquiry Space approach, which was ultimately selected as the methodology guiding this inquiry. At the onset of the study the purpose and research questions were firmly established to guide the research process.

Defined Criteria for Participants

Defined criteria for participants were accomplished by adhering to the established inclusion criteria, providing participants the opportunity to share their stories during the interview. Defined sampling strategies were used, but the inclusion criteria were altered slightly during participant recruitment due to lack of success. The criteria were changed to include residents of the community who did not access the CNN through the HFHT practice. This change also reflects the evolution of the pilot program as the initial inclusion criteria were created before the CNN was interacting with clients. The ethics amendment was approved for the change and the sampling criteria for participants remained consistent for the duration of the recruitment period.

Prolonged Engagement

Prolonged engagement in the field occurred both intentionally and unintentionally due to lengthy recruitment process. The researcher had prolonged engagement with the community, eight months prior to data collection and a five-month data collection period.

The prolonged engagement with the community fostered an enhanced understanding of the context and place, the physical setting, organizational structure, culture, and shared community narratives.

Process of Checking and Confirming

The process of checking and confirming through peer review is a strategy Kirkpatrick (2005) has identified as a component of rigour. Therefore, regular research team meetings were conducted with an experienced research team to guide data collection and analysis. Since the primary researcher is a novice researcher, two committee members reviewed all the narrative summaries and discussed emergent themes. Thematic coding was checked by the thesis supervisor to develop intercoder reliability. Study themes were presented to two members of the thesis committee for review and finalization. After the themes had been finalized, an individual interview was conducted with the CNN to gain her perspectives on the study themes and to understand her approach to interacting with residents in the community. This provided further clarity and understanding of the CNN role. The interview was used as a method of checking and confirming the study findings. The interview guide can be found in Appendix E.

Member Checking

The strategy of member checking was expressly incorporated into the study design. McCormack (2004) suggests that the re-storied stories are returned to participants to be checked. Participants were given their transcribed interview and re-storied stories and were encouraged to make changes at they saw fit. Only one narrator was not available for follow up due to lack of reliable method of contact. Each participant was

asked if they saw themselves in the story and if how the narrative read resonated with their experiences.

Broadening the Feedback

The final component of rigour is broadening the feedback to prompt further reflection. Purposeful knowledge translation will occur with all invested parties, in addition to other navigators or navigation programs, and other priority neighbourhoods. Ensuring confidentiality is maintained; the researcher will present the thematic study findings to the HFHT and to community members, guiding further reflection and potential changes to the program.

Additionally, the criteria for rigour established by Lincoln and Guba (1985) was used to further enhance rigour. Member checking, prolonged engagement, and review of coding was incorporated to increase credibility into the study design. Transferability will be achieved by providing a thick description of themes. To achieve auditability the research developed an audit trail, and engaged in debriefing with the research team when appropriate. Lastly, confirmability was achieved by the use of reflexivity, triangulation with other literature, and approaching the CNN and members of the FHT with the study results.

Ethical Considerations

Due to the narrative nature of the research design, there are innate issues of anonymity and confidentiality as research texts make visible the complexity of participants' lives (Clandinin & Huber, 2010). Therefore, there is an increased attentiveness to ethics incorporated into the study design. During the recruitment process,

every resident who met the inclusion criteria was provided with a letter of invitation (Appendix A). Therefore, the CNN was not aware of who participated in the study to ensure study participation will not influence participants' future relationship with the CNN. Experienced researchers supervising the novice researcher read interim research texts to ensure that interpretations were void of any individually identifiable information. As there are numerous stakeholders and invested parties in the CNN pilot, a thematic analysis was conducted to present common themes in the narratives. In this way, service providers, key community members, and others will be provided with themes, which are true to participants' experience while maintaining confidentiality.

Ethics approval was obtained from the Hamilton Integrated Ethics Review Board (HIREB) prior to conducting the study. At any time participants were able to withdraw from the study or decide to only consent to part of the research process. After initial interview transcription, transcripts were cleaned to remove personal identifiers and the field texts collected will be given unique identification numbers. All data was stored securely on a password protected external hard drive kept in a locked office. Only members of the research team who have signed confidentiality agreements have access to the data. After completion of the research data will be kept for five years and destroyed.

CHAPTER 4 – FINDINGS

STORIES FROM THE FIELD

Description of Participants

There were nine participants in this study, eight community residents and one community partner working in the neighbourhood. The CNN's primary caseload was comprised of four main groups; 1) residents accessing the community centre; 2) patients of the HFHT practice referred to the CNN; 3) selected youth/ young adults in the community; and 4) parents with young children in the neighbourhood schools. Of these identified groups, residents accessing the CNN through the community centre were most interested in sharing their story. Families with young children at the school and a patient of the HFHT practice also participated in the study but were recruited at the community centre. Seven of the participants were female and two were male, ranging in ages from 25 to 60 years old with a mean age of 38 years. Only one participant was currently employed, one was retired, and the remaining seven were on social assistance (Ontario Works or Ontario Disability Support Program). All participants had children ranging in ages from 4 months to 28 years of age, and five were female single parents. One participant was a government-protected refugee, and another resident self identified as aboriginal.

The participants varied on their level of education, length of time in the community, and length of time interacting with the CNN. Three participants did not complete high school, four completed high school, and two completed post secondary education. The length of time lived in the community varied greatly, from as little as four

months to over fifty years. Only one participant had been in the community less than a year, three had lived in the community between one to four years, two participants between five and ten years, and three participants over twenty years.

The participants also varied on the length of time interacting with the CNN and the number of discrete interactions. The CNN was in place in the community for nine months. Two of the participants had interacted with the CNN for two to three months, three participants for four to five months, and three participants for over eight months. All participants met the study criteria and had a minimum of three interactions with the CNN. Five participants had over five interactions and three had over ten interactions. The length of time in the community, length of time spent with the CNN, and number of interactions with the CNN are only loosely related because the pilot was only implemented for ten months, and the visits were on a drop-in basis. A few participants had numerous interactions with her in the short period of time. Finally, five of the participants had a primary care health provider and four did not. However, during the course of interacting with the CNN, she connected an unattached participant and her family to the HFHT practice. Four participants reported they felt connected with services before interacting with the CNN.

Interviews varied in duration from 15 to 75 minutes in duration, with the majority lasting 45 to 60 minutes. The variation was dependent upon individual storytelling style, richness of experience with CNN, interview setting, and external time constraints. Interviews were set in a variety of locations including offices, the community centre, and participants' homes. The researcher took great care to ensure that the interviews were set

in places that maintained privacy and confidentiality. On a few specific instances interviews were conducted with young children present due to lack of childcare, which was not ideal as there were distractions and interruptions during the interview, shortening the interview duration.

Description of Setting

Before presenting the stories of participants, it is important to first set the scene and describe the significance of place within the study. All initial and many subsequent interactions between participants and the CNN occurred at the community centre. The community centre, an old school, is located centrally within the community. It is only a minute walk from low-income housing and a handful of apartment buildings, which is convenient because most residents walk to the community centre due to transportation issues. Additionally, it is only a short walk away from one of the elementary schools in the community and from the HFHT practice. The outside of the building is in good repair, surrounded by houses and an adjacent park. When entering the community centre, it is apparent that the structural design of the school remains intact. There are numerous classrooms, which have been re-purposed for various programs, including after school children's activities, seniors day programs, a community meeting space, and a food bank.

When entering the centre on a weekday, you would likely be greeted by a few residents in conversation or one of the service providers organizing programming. While walking down the hallway, often there are volunteers from the community planning team working to greet and engage residents at the centre. On days the food bank is open the centre comes alive. There are residents with carts of groceries and others waiting in line

for their turn to access the food bank. There are mothers with young children in strollers, middle aged, and older adults. As residents wait in the halls there are poster boards with a variety of community resources with contact information.

At the end of the hall, beside the classroom housing the food bank there is a smaller room likely used as a small office or closet - when the school was open. The room has no natural light and is often cold in the winter and warm in the spring. Shelving and tables line the walls of the room filled with piles of used clothes and shoes. This is the community clothing closet and the CNN's office. The CNN does not have a desk or a private area to meet with residents in the clothing closet. Since space is limited within the centre the CNN does not have a designated office space so she located herself in an area of the centre frequently accessed by residents. Equipped with only a small portable laptop, she has lined the walls of the small room with information advertising health and social services and programs. There are no chairs in the room but there is a small area with toys and books where young children can play when parents sort through clothes. Parents are encouraged to participate in play with their child and not leave their child when waiting in line for the food bank.

Some residents enter the room and immediately began sifting through clothes; some cautiously enter the room looking around, while others purposefully enter the room to interact with the CNN. With the contents and layout of the room, it comfortably fits five to seven people, along with a grocery buggy or stroller. When the CNN is not in the room she can be found speaking with people waiting in line for the food bank or in one of the open classrooms with volunteers. Residents can stop by the clothing closet without

speaking with the CNN, however she always attempts to greet and interact with everyone when available.

The centre conveys a sense of community, as you would be hard pressed to visit the centre without speaking to at least a few residents or volunteers. The centre is not only a setting for centralizing some of the services and programs within the community but is often also a social outlet for residents. The centre opens in the morning and stays open in the evening to host various meetings, events, and programming. The food bank and community closet are only open in the mornings on specific days. Residents in the community are often aware of the schedule at the centre but are not always aware of other activities or services available. It is here, in the community centre that we see the unfolding of the initial and subsequent interactions between the CNN and the participants, acknowledging that the centre functions within the greater community to create the setting of the following stories.

Stories of Participants

In this section nine stories are presented. These brief narratives interweave interviews, field notes, and CNN documentation to produce a story of experience of living in the community and interacting with the CNN. The first eight stories are residents in the community who frequent the community centre and the last story is of a community service provider. Each story is presented with a pseudonym, which was chosen by each participant. For the purposes of storytelling, the CNN will be referred to as Sandra, a pseudonym to personify the CNN role.

Sylvia

I first met Sylvia, a tall slender woman in her thirties, at the community centre. She was well spoken and educated, enthusiastic about sharing her stories of experience with Sandra. She is a single mother who has been living in the community for ten years. She enjoys living in the community and being “busy with volunteering”. It took Sylvia a few years to become comfortable and engaged in the community, although she expressed embarrassment in living in low-income housing. Despite having a post-secondary education, she has struggled to find employment, holding part-time cleaning jobs for short periods of time. At the time of the interview, she was unemployed and on social assistance, which was an additional stressor further complicated by her anxiety and self-reported mental health issues. Sylvia has a strong sense of agency and desires to achieve success in all that she does, determined to break free from the cycle of poverty and have financial freedom.

She interacted with Sandra on multiple occasions since the onset of the pilot through the events at the community centre. She described her most recent interaction with Sandra this way:

It was just recent, very recent like a few weeks that my life has been feeling like it's falling apart with relationships and finances. And for me at that time she says to me “How can I help you, how can I assist you?”. I didn't ask her to do this but I really appreciated it because just the effort. I mean I didn't ask her to do it, I was at the point when you are just paralyzed, you know. The stress is so intense that you crawl into bed crying. I went into the center that week and I just broke down

because I really appreciated her effort. She went *above and beyond* for me. The questions that I had she just, as if she wanted to carry the burden for me. I mean it's a *great* quality to have as a nurse.

Sylvia described how meaningful her interactions with Sandra were to her personally and to others in the community. She believed the CNN role had a meaningful impact on her life by assisting with navigating complex social systems by calling organizations on her behalf and being with her to ease the transitions between services and programs. Sandra collaborated with Sylvia to set obtainable goals, connecting her to others who can assist in her skills development. Sandra provided emotional support and encouragement to support Sylvia's journey of building greater capacity and learning to advocate for her own needs. Sylvia explained that Sandra connected her with service providers and through warm hand-offs, by attending appointments together, helped Sylvia build beneficial networks and relationships.

The importance of the CNN as a nursing role was clearly emphasized in the narrative as she considered it as an important component of the role, given the caring qualities of a nurse. Sylvia also broadened her view by looking at the impact of the role in the community; she observed that Sandra "is always talking to someone". Moving forward she believes that "if the CNN continues more people will be able to be helped, be navigated".

Rose

On a cold winter morning, I had the privilege of speaking with Rose, a woman in her mid twenties who frequently accessed the community centre clothing closet and food

bank. She appeared worn and tired, chasing her busy two year old around the building. Rose, who identified herself as a recovering drug addict, is determined to give her two children a better life. She has lived in the community for almost two years, “in the beginning I kind of just stuck to myself enjoying my house. This is the first time I’ve had a house”, as she has experienced periods of homelessness and living in shelters. However, as time passed she began to volunteer in the community as a result of her interactions with a community development worker. In addition to volunteering, Rose is a stay-at-home mother on social assistance. At the time of the interview she was trying to finish her high school education.

She was a newly single mother after she and her common-law partner recently ended their relationship. She suffers from mental health issues and the stress of her relationship falling apart has exacerbated her illness, further complicated by a recent change in medication. Before the onset of the pilot, she believed she was well connected with services and resources and has had positive experiences with public health nurses in the past. Given her previous positive experiences, she readily pursued a therapeutic relationship with Sandra.

She interacted with Sandra at the community centre on numerous occasions over the past five months when she accessed the food bank and community closet. Sandra supported Rose during a family crisis, provided health teaching for healthy childhood development and parenting, and navigated social services by connecting her with a CAS worker and assisting her to find relief care for her children. Sandra worked to empower Rose in the care of her young family with stress reduction strategies and building her

confidence and capacity as a single parent. Sandra also enhanced Rose's connectedness with the community and participation in volunteer opportunities to build relationship and skills. Rose summed up her experience with Sandra this way:

I've had a couple of issues and I go to her. I find her good and really helpful. She just looks solid to me and approachable too, definitely. I even approached her one time I got really mad at the kids. She helped calm me down and decide what to do. She's very close to everybody. She is in a good location here. I just think [Sandra] needs to be here because I'm not at that point right now but I just know what it was like not being able to deal with things without crying. I think it's a necessity having a health nurse around.

Sandra provided emotional, social, and health promotion support for Rose and her young family. This support helped Rose fight the urge to return to a life of addictions and street life and to continue on her journey of moving forward. The importance of the CNN as a nurse is highlighted in Rose's narrative. Rose expressed not only the positive impact of the CNN role on her own life but also the capacity of the role to be beneficial for other mothers and community residents. She described Sandra as "not just an asset to the community. She is one of the main ones I think. That's just what I think and I really appreciate that actually from my past experience I guess".

Dale

On a warm spring afternoon, I had the privilege of speaking with Dale (mid 20s) and listening to her life experiences. I was invited to her two-bedroom apartment for the interview, as she had no one to watch her toddler because her regular babysitter was busy.

There was a history of violence and criminal activity in the building, which was considered a ‘rough’ area within the community. Dale is a single unemployed mother, who continues on her journey of recovery from her past life choices. At 16 years of age Dale dropped out of high school and through a series of events became addicted to crack cocaine, living between shelters and the streets. She considered the birth of her daughter as the turning point in her story, motivating her to seek help with addictions and distancing herself from that lifestyle.

In the process of moving on, she moved out of city to downtown Hamilton. She experienced issues with safe housing so subsequently moved into the McQuesten community a year ago. “I don’t mind it here. I find the rent is cheap and the people are friendly”. Dale still considers herself new to the city of Hamilton. She is strong willed and determined to provide a good life for her daughter. However, she shared her feelings of ‘being alone’ and feeling isolated from family and friends who still live in her hometown. Her daughter’s father visits every other weekend but Dale maintains a cautious distance, as he is still heavily involved with drugs which is a negative influence in her life. Her family, who were previously supportive, are now sceptical of Dale’s new lifestyle and believe she continues to use drugs. Her family cut her off financially, which seriously hurt their relationship almost as much as her disappointment in their lack of belief in her ability to change. Despite feeling isolated, she accesses multiple community resources with her involvement with supportive programs including the food bank and clothing closet where she met Sandra.

Dale, having only interacted with Sandra three times, was beginning the process of establishing trust with her. Dale explained that she prefers to keep to herself and focus on “being a good mother” and finishing her high school education. Her desire to keep to herself influenced her relationship with Sandra. Dale explained that she stops by the clothing closet when waiting for the food bank. She brought her daughter by to interact with Sandra as she learned parenting tips while entertaining her daughter. She described her experiences this way:

When I go to the center I go visit [Sandra]. When I walk in there she is always giving me clothes. She is right in there and makes people comfortable. What she does here is pretty helpful, I like it. She makes you feel welcome. Every time I go in there she’s approachable, so you’re not left out, she doesn’t make anybody feel left out. If somebody has a question she always tries to answer it. She always interacts with everyone. I think her role is pretty good so far, I know that the location is pretty good. She’s in the middle of where the people are who need help. If she comes up with more stuff then great, but otherwise she is doing what I think she should be doing.

Dale’s interactions with Sandra revolved around her daughter and this was echoed in her story that the “Sandra’s room is the toy room for my daughter”. Sandra’s interventions for Dale at this time were providing health teaching and supporting her as a single parent. The experience of interacting and trusting Sandra with parenting or childhood development issues opens up an opportunity to address other issues in the future. Dale, relatively new to Hamilton, has experienced the CNN working to promote social

inclusion within the community given her current feelings of isolation from family and friends. Dale intends to continue her relationship with Sandra in the future, hopefully moving from observing Sandra to actively participating in the development of a therapeutic relationship.

Frank

On a busy spring morning at the community center, I had the privilege of speaking with Frank and hearing his story. He was waiting in line for the food bank with his youngest daughter when he approached me about participating in the study. He is a quiet and friendly man in his fifties he “grew up here” and has “lived in the community all my life”. Frank described that “a lot has changed” but does not plan on moving out of the community in the foreseeable future. He and his wife provided for their family of five on a tight budget provided by Ontario Disability Support Program. Frank explained his struggle to provide for his family on a limited income.

Finding safe housing and dental services were his main priorities at the time of the interview. Frank was employed at a manufacturing job before being injured at work. He completed his high school education and has a family doctor who he saw regularly for health promotion and disease prevention interventions. Frank took pride in his ability to provide for his family but was not averse to seeking assistance when necessary.

He has interacted with Sandra over five instances in the past five months at the community centre. Sandra assisted Frank by directing him to the dental bus, helping with school issues for his daughter, and assistance with the community closet for his family. Sandra primarily navigated Frank to services and resources by providing him with the

information he needed. In Frank's case, he did not need assistance accessing the resources due to his personal sense of agency; instead he needed information presented in a clear and simple format. "For my family [Sandra] has been helpful. She's got a lot of information if you need it, you just need to ask". Frank's narrative did not touch upon the CNN as a nursing role, as the majority of his interactions with Sandra were based on social issues. He summed up his experience of interacting with Sandra this way:

She is accessible and she is always willing to talk to you, always. Even just going by I come in and say hi. She makes it easy to talk to her. She is always talking to somebody. She helps everybody you know. If I need something she would probably know where it is. She is pretty informative.

Dianne

On a warm spring morning I had the privilege of listening to Dianne's story. Sitting in front of me was an obese woman in her late 50's, well put together with an infectious smile. Dianne had just met with Sandra and had picked up groceries from the food bank. She "loved" living in the community with her family for over twenty years. She is a mother, an adoptive mother, and a grandmother. Family was of upmost importance to her but she also takes time to take care of herself, as she is diabetic, with gastrointestinal and joint issues. She was very interested in gaining knowledge about available services as an addition to support from her family physician, to improve her and her family's wellbeing. Dianne faces financial constraints since she is retired and still provides for her family. She appreciatively welcomed Sandra's assistance to access supportive services while pragmatically trying to make do with what she has. Dianne

holds to the perspective that the ‘glass is half full’ and makes every effort to maintain a positive outlook when confronted with a challenge or barrier.

Sandra directed Dianne to the dental bus and the cancer screening coach by providing her with the information to access the services. Sandra connected her to supportive services by making phone calls to arrange physiotherapy and diabetic foot care appointments, which Dianne can access with her vehicle. Sandra has given her health teaching with regards to diabetic care, nutrition, lifestyle choices, and wellness. With the warm hand-offs and valuable connections made by Sandra, Dianne explained that:

The CNN was right there to make the phone call, she was very helpful. I really enjoyed speaking with her (...) very easy language to understand. I had a few diabetic questions she was right there on a dime. Knew everything. She is really knowledgeable. And even when she wasn't dealing with me I could see she was going up to people.

Dianne interacted with Sandra over five times in the past three months. She spoke about potentially continuing to feel stuck in her health issues if the CNN had not helped her to navigate the services she needed. Dianne was able to set priorities for herself and her family but needed help to know where to turn to get assistance. Her partnership with Sandra opened up opportunities for health promotion, health maintenance, and disease prevention for herself and her family. Sandra's friendly approach helped Dianne build a trusting relationship with her over a few short interactions. She summed up her experience with Sandra this way:

I really think this nurse idea is really great because she is so hands on and she is right there to help people. And you know what, it's really good that she is so educated and she is really geared to this type of people down here.

Jane

I had the opportunity to speak with Jane and learn about her experiences on a warm June morning. She was volunteering with the clothing closet at the community centre when she approached me concerning study participation. She was a very slender and energetic woman approaching her forties but appeared older than her stated age. She has lived in the community for over twenty years as a single mother raising three almost adult children. Jane volunteers in the community and often frequents the community centre not only to access the food bank but also as a social outlet. She explained, "I enjoy living in the community. I don't drive so I walk all the time". Jane is able to access all the resources she requires for her health and wellbeing including her family physician, pharmacy, and dentist. She has a high school education and worked for many years for a large department store in the area. However, she is now on social assistance and struggling to get disability support with the assistance of her Ontario Works worker.

Jane was interacting with Sandra since the beginning of the pilot program after watching her friend have positive interactions with Sandra. She was excited to have new programming within the community. Since Jane is well connected with multiple social and health services Sandra has been working with Jane to promote health, in relation to smoking cessation and increasing physical activity by organizing a reduced cost recreation pass. Other than her current illnesses, which are being evaluated further by her

family doctor, Jane does not consider herself to be in high need compared to others within the community. Jane described her experiences this way:

If I needed help I could talk to [Sandra], say if I wasn't getting the help from my family doctor or something. She is pretty good to talk to; she is always here. She works as a nurse and a social worker, she is both I think. She is very friendly and very nice. She's really good. They never used to have a nurse here.

Elaine

I had the privilege of speaking with Elaine on a hot morning in June. She was accessing the food bank and the clothing closet at the community centre when she inquired about study participation. Elaine, an aboriginal woman in her mid-thirties struggling with obesity sat bouncing her new baby on her lap. She began the interview slightly reserved as she had negative experiences in the past with developing and maintaining trusting relationships. She had to relocate her family on multiple occasions to escape problematic interpersonal situations. Elaine explained that she misses aspects of her life on the reserve but is glad to have distance from her emotionally abusive father. She lived briefly with family when first moving to Hamilton until she was forced out on the street in the middle of the winter. She proceeded to live in a shelter before moving to the McQuesten neighbourhood. Elaine, her common law partner, and their two young children have been living in a rented apartment in the community for just under three years. Elaine utilizes the community centre but does not actively engage in the community compared to other participants.

Elaine does not have a family physician and indicated her desire to “find one in the area”. She is a stay-at-home mother on social assistance with a high school education and aspirations of going to college when her children get older. She first began interacting with Sandra after observing other residents positive experiences. She had five interactions with Sandra, but explained that she is hesitant to trust people and “does not like asking for help”. The CNN assisted Elaine with healthy childhood development and parenting issues, financial barriers to accessing community services through the provision of a recreation pass, and provided health teaching and empowerment. Sandra also strived to build stronger connections with the community by inviting Elaine to participate in community events and volunteer opportunities. She described her experience with Sandra this way:

She helps me when I've had questions about my kids. [Sandra} has been encouraging my friends and I to help with the clothing closet and do some planting in the community garden. She's been pretty good. I think she's better as a social worker than a nurse because she talks to people and she interacts with them and this and that. She tries, you can talk to her about your problems and she'll listen. I usually don't talk to her about health problems, just social stuff. She's helping me out with the \$150.00 whatever thing, so she's helping me out with that and the recreation pass. I keep basically to myself now after all the rumours where I lived before. So I don't really open up to her unless I need to. I think she is here every time we have been here, so it's been good.

Marcia

Marcia was the last resident I had the opportunity to meet with and hear her story. She was at the community centre accessing the clothing closet, the food bank, and meeting with Sandra. She is a single mother in her 40s, with a friendly smile. She has two teenage/young adult children and two school-aged children. She was a government-protected refugee who lived in the community for five years. After first immigrating to Canada she found herself in an abusive relationship, from which she was able to break free from for her own and her family's wellbeing. During the interview she spoke broken English and struggled with very limited English literacy. Language was an ongoing barrier to accessing community supports and services, as she was unable to complete paperwork without assistance. She had a family physician in the area but was eager to gain knowledge about accessing resources to help her family of five. She was unemployed on social assistance but did not consider finances a major stressor, utilizing the food bank to provide for her family. However, she did describe challenges with her immigration status due to the complexity of the paperwork.

Marcia had numerous rich experiences with Sandra, interacting with her at the community centre since the onset of the pilot and described them this way:

I met [Sandra] almost one year ago I think through the clothing closet. She was very, very important to help me find a women's immigration centre where I can go and do my paperwork. Any health problems I go to her first. She helped me with advice for the kids. Every time I come here it's for 9:00 to 12:00 when my kids are in school. I can ask her everything for my kids she helps me with that too.

She is very good to talk to with your problems. I see so many people she does that with. She will help and talk about everything with you; for your kids, for your health, how you can stop smoking, immigration, and other things. She tries so much, she try everywhere. When she is here she does everything. She goes to meetings where housing happen, and every community meeting. She is nice with people, with all people with old people, with young people, it doesn't matter you know. Really, if I need something I can go ask her, she is available for you every time, that's good. Very friendly, very nice, and easy to talk to.

Sandra worked with Marcia to reduce barriers and facilitate access to the services and programs she required to address her health and social needs. Marcia frequently approached Sandra with health-related questions for her and her boys despite having a family physician, as Sandra is highly approachable and accessible to her at the community centre. Sandra worked with Marcia by providing health teaching and advising her to follow-up with her physician when appropriate.

Through partnership with Marcia, Sandra worked to promote her social wellbeing and connected with service providers and the community. She assisted Marcia with filling out forms, calling to arrange appointments, and seeking information about immigration procedures to ease her transition. Marcia was transitioning between multiple supportive services and potential points of fragmentation. Sandra was physically present with her to transfer trust and support warm hand-offs when making connections. Marcia described the actions Sandra took to promote her inclusion within the community by encouraging her to attend community planning meetings and have a more influential voice within the

community. Sandra provided Marcia with information regarding parenting and youth engagement opportunities for her children of varying ages. In Sandra's interactions with Marcia she worked to build her capacity, reduce language barriers, promote health and well being, and provide support and empowerment.

Tom

I had the opportunity to meet with Tom, a community partner working as an educator in one of the neighbourhood schools. The interview with Tom added variation within the sample to understand the CNN role in the community. He was relatively new to the community, working here for just over four months. Despite his short time in the community he had rich experiences with Sandra interacting with her on numerous occasions. Tom's comparatively short time in the community and past experiences in other communities provided a unique perspective on the community and the role. An educated and professional man in his late thirties, Tom shared his experience of being in the community and building a working relationship with Sandra to improve the health and wellbeing of community residents. Tom described his experiences with Sandra this way:

[Sandra] has been fantastic in the short time I've been here. Right off the bat we connected. She has been supporting families, just trying to connect them with community services, family care. She has been helpful with a number of families, connecting with a family physician. A number of families have been identified with not having a health care provider; she has connected them with a doctor she is working with through the HFHT. She is definitely needed, especially in this

neighbourhood. We have some really needy families. She's been really, really instrumental at connecting people, which is what they need. Because you know, sadly for many of our families they don't know how to advocate so they are not sure where to go to or who to turn to. She is just one more support.

Tom's experience of the CNN's role in forming connections for families within the school and other community residents was resounding. He described working with Sandra to prioritize families at need, to develop programming to support families, linking families with other community resources including the HFHT practice. Sandra's work of networking and making connections was not only directing people to services or physically going with residents to ensure connections were made but also working to increase awareness of community resources. Sandra was able to recruit volunteers to help support new and existing school programming. She supported Tom by connecting him with additional supports and fostered a greater connection between the school and the community. In his experience, Sandra has partnered with families in crisis, helping them to navigate CAS and other services while supporting crisis resolution. Tom ended the interview by expressing his desire for an on going relationship and partnership with Sandra, highlighting the need for a liaison between the community, the school, and public health.

CHAPTER 5 – FINDINGS

THEMES ACROSS STORIES

Following the introduction to the participants, this second findings chapter is dedicated to presenting the themes across participants' stories of their experiences with the CNN role. All participants considered their interactions with Sandra as positive and many commented on the impact of the role in their lives. However, to gain a deeper understanding of the experience of participants interacting with the CNN common themes among narratives are presented. There were four main themes that emerged during the concurrent collection and analysis of residents' narratives.

Stories can be told from multiple perspectives, which often contribute to a greater understanding of the event or experience (Clandinin & Connelly, 2000). Therefore, after study themes were finalized an interview was conducted with Sandra, posing the question "Can you see yourself in these themes?". The point of this inquiry was to validate if these themes were congruent with her experiences of interacting with residents. This was a purposeful process to protect the identity of participants. This process was also used to understand the findings in relation to the role of the nurse as part of the requirements of this thesis. The inclusion of Sandra's perspective was designed to enhance the understanding of the experience and to increase rigour by broadening the feedback to complement and confirm the study themes. This story provided a contextual commentary on the thematic findings but did not influence the creation of the themes or how participants perceived their interactions with Sandra.

The themes are purposefully presented in a temporal order to guide the audience through participants' journeys of interacting with Sandra. The voices of participants, through quotations, are included wherever possible to ensure that the participants' perspectives are presented and their experiences are preserved throughout the research process. The voice of the CNN will also be presented as a commentary when examining study themes. Each theme was composed of sub-themes, presented with supportive quotations (Table 1). The main themes were (a) *Opening the Door*; (b) *More than just a Conversation*; (c) *Making Connections*; and (d) *Changing and Shaping the Future*.

Table 1 – Themes across Narratives

'Opening the door' through:

Always talking to someone

Approachability

Accessibility

'More than just a conversation'

Why a Nurse?

Assessments

'Making Connections' by:

Knowledge of resources

Going above and beyond to help

'Changing/Shaping the future' by:

Supporting 'Moving on'

Acting as 'an asset in the community'

Opening the Door

The theme of *opening the door* was the most predominant theme of participants' experiences with Sandra and is synonymous with establishing a therapeutic relationship. The term *opening the door* is meaningful as the participants connected with Sandra at the community centre, where the door to the clothing closet she operates out of is always open when she is there. When analyzing all the narratives it was apparent that participants were in different stages of developing a therapeutic relationship with Sandra. Although, it is not known what the process of building a therapeutic relationship with the CNN was, there were common experiences shared in the narratives. These common experiences were the sub-themes of: always talking to someone, approachability, and accessibility. The sub-themes were viewed as ways in which Sandra attempted to 'open the door' to residents to assist them to navigate health and social systems by first establishing trust and building a therapeutic relationship.

Always Talking to Someone

Early in the interviewing process and in the analysis of field texts, the experience that Sandra was *always talking to someone* was a resounding theme. Whether participants observed other residents' interactions with Sandra before they began engaging with her or if it was a concurrent experience is unclear. It was difficult to select the most supportive quotations, as all participants shared this experience. From Sylvia's perspective Sandra is "always talking to somebody, always connecting with people. I can see her talking to people in the hallways and engaging the people that come by". Dianne had a similar experience, "even when she wasn't dealing with me I could see she was going up to

people and she was saying ‘I’m the nurse from the area, is there anything I can help you with?’”. Frank stated in a very matter of fact way that Sandra “is always talking to somebody, she helps everybody you know”. Marcia also echoed her experience through her observations, “I see so many people talk with her about their problems”.

Despite participants’ observations that Sandra was always talking to someone, no one mentioned that she was too busy to speak with them if they had questions or concerns. In response to this theme, Sandra explained that residents within the community may often face social exclusion based on their health or social status, therefore developing a sense of inclusion was highly important. She purposefully engaged residents and took an active approach to building therapeutic relationships. The notion of the CNN as ‘always talking to someone’ may have positively influenced participants’ perception of her approachability.

Approachability

The sub theme of *approachability* was a major recurrent theme in most narratives. Participants explained that Sandra was approachable due to her friendly and open manner of interaction with community residents. Dale shared that “She makes you feel welcome. Every time I go in there she’s approachable... She always says hi to the parent and child so you’re not left out. She doesn’t make anybody feel left out”. This experience was echoed by Marcia as she explained that Sandra is “nice with all people, with old people, with young people, it doesn’t matter you know. She’s a very nice lady”. This sense of inclusion and *approachability* helped to create conditions for participants to begin

interacting with Sandra in meaningful ways as exemplified by Dale as she described that Sandra is “right in there and makes people comfortable”.

Once participants did not perceive her as a threat but as an approachable person in the community centre they began to interact with Sandra more purposefully. Rose explained that Sandra is “probably like my favourite person here for approachability. I’ve had a couple issues and I go to her. I find her good”. Other participants also shared this experience. In Marcia’s experience Sandra was “very good to talk to for your problems” and Elaine stated “you can talk to the CNN about you’re problems and she’ll listen”.

Some participants noted that the *approachability* of the CNN was enhanced by her relatability and the ease of communication. Dianne shared that she “really enjoyed speaking with [Sandra]. She was very clear and very easy language to understand, it wasn’t great big words. She was very good”. She went on to further explain that Sandra is relatable and “is really geared to this type of people down here”. The ease of communication with Sandra reduced access barriers of health literacy for Dianne and other participants.

Frank, Sylvia, Dale, Dianne, and Elaine all indicated that they would go to the community centre specifically to say hello or speak with Sandra even if they were not using other services at the community centre that day. To sum up the experience of the CNN as approachable, Jane stated, “If I needed help I could talk to [Sandra]. She is pretty good to talk to. Like even if we don’t come here for the food bank I will still go in and chat with her. She is very friendly and nice”.

When speaking with Sandra about the theme of *approachability*, she credited her previous nursing experiences through her career as she developed therapeutic communication skills that open up opportunities and “make it easier to connection with clients”. Her non-threatening approach assisted her to begin to build trust with residents. Having experiences with people from different walks of life in a nursing role and having developed skills to interact professionally have enhanced her ability to easily relate to community residents. Sandra explained that her approach to interactions with residents is “always meaningful or purposeful”.

Accessibility

In addition to being approachable, Sandra was also considered accessible. The perceived degree of *accessibility* of the CNN at the community centre contributed to *opening the door* to build trust and develop relationships with residents. In Frank’s experience Sandra “is accessible and is always willing to talk to you, always”. Most participants spoke to their positive experience of the accessibility of the CNN role with the current design of the initiative. Dale, Dianne, Sylvia, Tom, and Rose commented on her location within the community centre. There was a shared impression that the community centre “is a good location. She’s very close to everyone who needs help” (Rose).

With respect to the amount of time Sandra spent at the community centre, there were variety of opinions and experiences. Dianne, Marcia, and Sylvia shared the feeling that if Sandra “stays on a consistent basis it’s going to be very fruitful. I think if she continues more people will be able to be helped, be navigated” (Sylvia). Furthermore,

Marcia suggested “it would be good if she were here more often”. However, in Jane and Elaine’s experiences “she is here enough” (Jane), “She is here every time I have been here, so it’s been good” (Elaine).

During the interview Sandra identified that her *accessibility* and regular presence at the community centre was an aspect of her role for continued improvements moving forward with the pilot program. She suggested making a concentrated effort to inform community members about her schedule at the community centre.

Participants’ narratives and Sandra’s story highlight the need for consistent *accessibility*. For Sandra to establish trust within the community she must be professional, accountable and consistent. Dianne, Elaine, Jane, and Frank perceived the CNN role as consistent in the community, whereas Sylvia and Marcia in particular believed Sandra should develop a more consistent presence at the community centre. The balance of a consistent presence in the community centre may be influenced by Sandra’s schedule and her concurrent commitments at the HFHT practice.

More Than Just a Conversation

The theme of *more than just a conversation* is connected to the theme of *opening the door*, as it reflects the progression of the process of building a therapeutic relationship with the CNN. Since Sandra’s activity within the community centre is on an informal drop-in basis, interactions with residents are often framed as conversations rather than appointments or meetings, as to not negatively impact her *approachability* and *accessibility*. Some participants explained above that Sandra is “good to talk to” (Dale), but did not view their interactions as anything more than a social conversation. However,

there were some participants who viewed their interactions with Sandra as *more than just a conversation*. Tom, Dianne, Rose, and Sylvia described their experiences with Sandra as meaningful interactions, with the intention to assist residents to make the connections they need for greater health and well-being. How residents understood the nature of their interactions with Sandra, whether simply a social conversation or *more than just a conversation*, was reflective of each persons' view of the CNN and the nursing role.

For example, in Dale's narrative she explained "I think the [Sandra] is better as a social worker than a nurse because she talks with people and interacts with them". This interesting statement reflected her understanding of the interactions with Sandra as exclusively social, void of any meaningful therapeutic purpose. Whereas, Jane believed Sandra "works as a nurse and a social worker, I think she is both". Tom, Sylvia, Rose, Dianne, Frank, and Marcia commented on congruence of the CNN role with nursing. Although Rose was already well connected with multiple supportive services she shared "I think it's a necessity having a health nurse around. She is a necessity for accessing programs". Many of the participants who supported the CNN as a nursing role had positive past experiences with nurses and are connected to primary care practices, highlighting the dimension of temporality.

Tom had unique insight into the role, which not only emphasized the CNN as a nursing role but suggested that the CNN reflects the normalizing experience of nursing to promote health and well-being compared to the perhaps negative connotations associated with involvement with a social worker. He explained that:

She's has been very beneficial. I think it's good she is a nurse; she's not a social worker, which sometimes is a scary option for people who are in a vulnerable sector. So her having a nursing background and coming from an education teaching role and a facilitation role is beneficial.

In conversation with Sandra, she described all interactions as purposeful; she performed assessments, provided support, empowerment, and health teaching. When interacting with residents she performed physical and mental health assessments while listening to collect information relating to priority issues, social or financial situations, available supports, and potential connections. She assessed barriers to access and formulated action plans and interventions to assist residents to address their needs.

Acknowledging her unavoidable inclination to advocate for a nurse in the CNN role, given her nursing background, she highlighted the focus on health. Sandra explained there is “some overlap in what I do and what a social worker can do, especially those in mental health and counselling roles”, but the difference is health assessments. “That's the key difference and that is why a nurse needs to be doing this role” because the overarching aim of the CNN role is to “increase or enhance health within a high priority neighbourhood” supported by building relationships and connections. She went on to further assert that an understanding of population health is a key asset to identifying gaps and “moving forward to have an impact and inform policy development or resource allocation”. The theme of *more than just a conversation* speaks to the value of a nurse in the CNN role and the importance of the underlying nursing processes and approaches to navigation and helping make connections for residents in the community.

Making Connections

The third main theme, *making connections*, encompasses the experience of Sandra connecting people to the services and resources they require for health promotion, health maintenance, disease prevention, and/or well-being. This theme reflects the importance of the networking function of the CNN role to create and facilitate connections with residents to community services. Tom's narrative was rich with the theme of *making connections*, as he spoke of initially connecting with Sandra and subsequently being connected to other resources and service providers as a result of his interactions with her. From his perspective the CNN role is "a nurse who can try to connect some dots for people". Tom described his experience with Sandra; "She has been really, really instrumental at connecting people with what they need. Sadly, many of the families in the community don't know how to advocate or where to turn to. She has been helpful with a number of families, connecting them with a family physician". This quote highlights the two sub-themes described below; Sandra's *knowledge of resources* to connect or direct residents to, and her efforts to *go above and beyond to help* make connections.

Knowledge of Resources

Most participants described Sandra as a source of knowledge or information regarding available resources and community supports. From Dale's experience "if somebody has a question [Sandra] always tries to answer it". Marcia was eager to learn about community resources and explained, "If I needed something I can go ask [Sandra] she wants to give you so much information". Frank also had a similar experience that "If

I need something she would probably know where it is... She's got a lot of information if you need it, you just need to ask”.

Some participants perceived the CNN role as only a resource for social issues, whereas other participants perceived her as a source of knowledge for health and social resources. Although Jane was connected to multiple health services she explained “if I need information about this or that or say I'm not getting it from my doctor I can ask the CNN too. Or certain things, organizations that she knows too I could ask her if I needed to”.

Sandra's knowledge and education was considered a valuable asset to her role. Dianne credited Sandra's knowledge of resources within and outside of the community to her nursing education. She explained that “any information I get from the CNN I use. She has guided me to a number of services for my health. I even had a few diabetic questions. She was right there on a dime and knew everything. She is really knowledgeable”.

Sandra noted that her knowledge of community resources was related to her previous public health experience in the area and was a result of her networking with other service providers to offer comprehensive and organized services and programs to community members. She stressed that knowledge of resources is essential to her role but the “transferring of trust” and “warm hand-offs” are instrumental to forming meaningful connections to help residents address health and social issues.

Going Above and Beyond to Help

The sub-theme of *going above and beyond to help* is borrowed language from Sylvia's experiences with Sandra, “I really appreciated her effort. She went above and

beyond for me”. In Sylvia’s experience the CNN was “really engaged, always putting her best foot forward and always there to help people”. Assisting or helping participants to make connections, which they view as valuable or beneficial, is a common experience shared across narratives. While the specific needs of participants varied, their experience of being helped and supported did not. Whether Sandra was connecting them to health promotion services such as the dental bus or cancer screening bus, calling to make appointments with social services, assisting with parenting and healthy childhood development, or even providing information on available community resources, participants reported feeling helped and supported. After Dianne was directed to health promotion services she stated, “[Sandra] was right there to make the phone call, she was very helpful. I really think this nurse idea is really great because she is so hands on and right there to help people”. Frank, a father of three, explained, “For my family [Sandra] has been helpful. She directed us to the dental bus when we needed help”.

A resounding theme in Marcia’s narrative was her appreciation for the help and information Sandra provided her. “She helped me with the kids, with my health, and with immigration. She really helped, I can ask her anything”. Elaine and Dale both having similar interactions with Sandra reported “She helps me when I have questions.” (Elaine) and “What the CNN does there is pretty helpful, I like it.” (Dale). The degree to which participants felt helped and supported may reflect their satisfaction in the connections Sandra facilitated for them.

The experience of Sandra *going above and beyond to help* and the support given to residents is of some immediate value for short-term needs but the focus of the role is

“doing with, not doing for” (Sandra). Given the temporal nature of the pilot, Sandra worked to build capacity and enabled residents to become empowered to continue to move forward and address unmet health and social needs to enhance health, rather than creating a dependence on the CNN role to access resources and supportive services.

Changing and Shaping the Future

The final main theme in the narratives was *changing and shaping the future*. Many narratives had stories of *changing and shaping the future*. This theme is multidimensional as there was a focus on the lives of individual residents and the future of the community as a whole. Due to the nature of the pilot program it was difficult to capture long-term changes in the health and well being of participants and other residents within the community. The two supportive sub-themes are *moving on* and the CNN as *an asset within the community*.

Moving On

Rose, Dale, Elaine, and Marcia narratives tell the story of *moving on*, with the motivation of providing their children with a better life. Rose and Dale, recovering addicts, have beautiful stories of *moving on* from prostitution and homelessness as a result of becoming a mother. Elaine and Marcia have stories of troubled past relationships and environments that they needed to flee from for the safety and well being of their children. Their journeys of *moving on* are of temporal importance because these stories began unfolding well before the conception of the CNN pilot program. Each of these women has varying degrees of connectedness with supportive community services due to their past experiences. Sandra supported and helped to empower these women on their

journey of *moving on*. After a family crisis Rose explained, “[Sandra] helped and supported me so much when I was going through crisis. She helped calm me down when I was in tears. I was starting new depression medication and trying to take care of the kids all by myself. It was hard to not let the stress get the best of me and just pick up a crack pipe again. Now, I am so glad that I didn’t.”

All participants spoke about their relationship with Sandra as an ongoing one, often sharing the questions they were going to ask her during the next encounter. The CNN role is impactful on the lives of participants as each person expressed the intention of continuing their relationship with Sandra and continuing to receive assistance navigating their unique health and social needs. Tom explained from his perspective that this community tells a story of *moving on* as families new to the community often come from city subsidized housing or are newcomers to Hamilton or Canada. The CNN has an important role in the community to assist residents in their journeys of *moving on*, providing support and connecting them with resources to change or shape their future.

In conversation with Sandra, she resonated with the sub-theme moving on. She explained that the CNN role is “not just for crisis intervention or short term but there is an opportunity for long standing relationships at both the individual and community level”. However, she specified that ongoing or future relationships may not necessarily be with the CNN. When the time comes to end the therapeutic relationship either precipitated by residents’ personal circumstances or a decision to discontinue the role, Sandra explained that the emphasis is placed on “warm hand offs and transferring trust”. This can promote the continuation of the journey to greater health and well being.

An Asset within the Community

Some participants broadened their lens beyond the individual level and shared their perspective of the CNN role as *an asset within the community* at a population level to evoke change and shape the future of the community. In many of the narratives there was a focus on the continued involvement of the CNN within the community. Dale shared, “I think her role is pretty good so far. She’s in the middle of where the people are who need help the most”. Sylvia, having multiple interactions with Sandra, analyzed the CNN role in the community by explaining with conviction, “If you were to ask me if I see a community without [Sandra], yes I do. But I think we would lose a great gem. We couldn’t run this community without [Sandra] and other service providers”. Tom also spoke about Sandra as an asset and that the role is “just one more support” in the community to help residents and their families navigate health and social systems to meet their needs. Sandra supported and empowered Marcia to take a more active role in the community through volunteering and Marcia spoke about Sandra’s engagement in the community through meetings and organizing events for residents.

Rose expressed her full support of Sandra’s work to bridge gaps and reduce barriers by implementing a grocery bus for enhanced food security and advocating for other resources to be brought to the community as opposed to residents having to find means of transportation to access services. She summarized her perspective of the CNN role this way “[Sandra], she’s not just an asset to the community; she is one of the main ones I think. I really appreciate her from my past experience I guess” (Rose). The understanding that Sandra was not only supporting individuals but was also supporting

the community to enhance health and well-being is a valuable as it reflects the initial design of the pilot program.

When discussing the temporal nature of the piloted role with Sandra, she explained that “this position might not be in the community long term” but her focus was “the relationships I can build long term or sustainable changes I can create so that the individuals, the HFHT practice, and communities can continue to benefit from any positive outcomes” as a result of the role. The CNN partnered with the McQuesten Community Planning Team to support the further development of the community by identifying and addressing needs within the community while advocating for change. By networking and promoting greater connectivity within in the community and connecting the community to other organization or service providers, Sandra worked to develop capacity and empower community members to foster enhanced community participation and engagement.

CHAPTER 6 – DISCUSSION

Introduction

This study provides an important contribution to the understanding of the experience of interacting with and receiving navigation services from a CNN in a community setting. The major finding of the current study is the importance of *opening the door* to facilitate the development of therapeutic relationships, which are essential to assist residents by *making connections* to address unmet health and social needs and build capacity to *change/shape their future* for enhanced health and well-being. This journey of interacting with the CNN occurred across the temporality, sociality, and place dimensions of experience described by Clandinin and Connelly (2000). This chapter explores congruence of the study findings with related literature and presents a discussion of the how these findings inform the research questions, highlighting study implications, limitations, and final conclusions.

Discussion of Findings

As was originally conceived, upon a secondary review of the literature, it became apparent that participants' experiences of navigation might not be unique to the specific design of the navigator role or the setting. The study findings align with the validated Professional Navigation Framework conceptualized by Fillion et al., (2012) for cancer navigation in hospital and community settings in Canada. The framework acknowledges the bi-dimensional nature of the navigator role, concurrently organizationally and clinically oriented. Within the first dimension in the framework of health systems orientation, navigation facilitates continuity of care through informational, relational, and

management continuity. Participants valued the CNN's knowledge of resources or informational continuity and the accessibility and consistency of the CNN-resident therapeutic relationship or relational continuity. Some participants considered the CNN an asset to the community, as she demonstrated management continuity she functioned as a liaison between the community and other service providers and identified a lack of resources or gaps finding temporary solutions.

In relation to the second dimension, patient-centered clinical functions, navigators promote patient and family empowerment through active coping, self-management, and supportive care. Especially in Sylvia, Rose, Maria, and Dianne's experiences, the CNN worked to promote active coping to alleviate or circumvent stressors originating from personal crises or frustration with fragmented services. The encouraged self-management and capacity building by empowering participants to regain control over their health and well-being by making connections and providing resources to address unmet needs. In their interactions with the CNN, most participants experienced emotional support when facing health, financial, or personal challenges. Therefore, since the Fillion et al. (2012) Professional Navigation Framework is congruent with the stories and experiences of residents interacting with the CNN the following discussion includes literature from other relevant studies on patients' experiences of navigation outside the context of priority populations in primary care and community settings.

Participants' Experiences of Navigation with CNN

The study findings help to inform the research questions by enhancing our comprehension of the interactions with the CNN and the impact on individuals, families,

and the community. Oriented to Clandinin and Connelly's (2000) Three Dimensional Narrative Inquiry Space, we explore participants' social interactions with the CNN, personal experiences of the impact of the CNN role, significance of place and impact on the community, and addressing health disparities over time.

Social Interactions with the CNN

Systems navigation is a social function in that it necessitates social interaction and relationship building between two engaged parties, the CNN and individual residents. The social conditions of each participant influenced the interactions with the CNN, the strength of the therapeutic relationship, and the subsequent outcomes of navigation interventions. From the narratives it is evident which participants were open to social interactions and those who were not. For example, Marcia, Dianne, Rose, Tom, and Sylvia benefited significantly from their interactions with the CNN due to their readiness to engage in a therapeutic relationship, whereas, Elaine and Dale did not take full advantage of the CNN role due to their hesitancy to interact and build social relationships. Participants' openness to social interactions with the CNN was mediated by past social experiences. Most participants who readily interacted with the CNN had positive relationships or experiences with other health care providers. Conversely, participants with negative past experiences limited their social interactions with the CNN.

In a study of primary health care indicators in two Canadian Health Centres, Wong and colleagues (2011) found that engagement in 'small talk' was important to patients who face social isolation. Social conversations and ways of communicating had a positive impact on healthcare access. The overall experience of interacting with the CNN

was positive as described by all participants. However, despite the importance of positive experiences with health professionals and continued health seeking behaviours, we sought to present an in-depth understanding of residents' experiences and the impact on their lives. The temporal and sociality or relational dimensions of participants interactions with the CNN is explored in their social experience of establishing a therapeutic relationship, accessibility, consistency, and trust.

Establishing a therapeutic relationship. Palos and Hare (2011) assert that establishing a therapeutic partnership between the patient, family, and navigator can strengthen delivery of navigation services. The inclusion of a patient's social network or family in the navigation process can not only enhance connectedness but may also allow navigators to devote resources and time to patients without supportive social networks. In the current study, establishing a therapeutic relationship with the CNN was a function of sociality and temporality within Clandinin and Connelly's (2000) Narrative Inquiry Space. Unlike other qualitative studies exploring patients' experiences of navigation in particularly oncology settings, the narrative dimension of temporality presented an opportunity to understand participants' temporal journeys of establishing a relationship with the CNN. This journey may not represent the exact experiences of all participants or is in anyway a suggested process. It represents a shared narrative and provides readers with a window into the lives of participants.

Parallels of this journey can be drawn with the Hildegard Peplau's Theory of Interpersonal Relations (1997). Therapeutic nurse-client relationships regardless of duration are non linear and have a beginning, middle, and end (Arnold & Underman

Boggs, 2011). Peplau (1997) described three phases in building a therapeutic nurse-client relationship orientation, working, and termination. The theme of *opening the door* and *more than a conversation* has similarities to the orientation phase and represents the outset of the relationship. The theme of *making connections* mirrors the working phase, as the CNN was providing nursing interventions. Finally, the theme of *changing/shaping the future* overlaps the transition between the working phase and the termination phase. Given the short period of time participants have been interacting with the CNN the termination phase was not captured in its totality in the narratives.

The process of building a therapeutic nurse-client relationship is essential, as this relationship is the fundamental basis for the provision of safe, competent, compassionate, and ethical care (Registered Nurses Association of Ontario 2006). Building a strong therapeutic relationship can positively impact client satisfaction and outcomes (Curtis & Wiseman, 2008) and help to enhance the CNN's ability to address unmet health and social needs of residents. To begin building therapeutic relationships navigators must play an active role in creating the conditions for *opening the door* at the outset of the relationship. Through *always talking to someone*, being *approachable*, *accessible*, and consistent the CNN created environmental conditions to facilitate social interaction and provided participants with an open door to enter into a therapeutic relationship to meet their individual and family needs.

The most notable obstacle was establishing a therapeutic relationship with the CNN, as evidenced by Elaine and Dale's narratives was a lack of understanding of the CNN role. Whereas, Sylvia, Rose, Dianne, Tom, and Marcia established strong

therapeutic relationships with the CNN as they had a greater understanding of the role. A similar finding was reported in Gotlib Conn et al., (2014). Participants who did not fully understand the extent of the navigation role did not take full advantage of the program.

Accessibility. The perceived degree of ‘accessibility’ of the CNN was a recurrent sub-theme in the narratives and contributed to social interactions and the experience of *opening the door*. The CNN had drop-in hours twice a week and was easily accessible in the community centre. To enhance her accessibility the CNN was frequently found walking around the community centre engaging residents as opposed to staying in a specific place and waiting for residents to come interact. In the experience of patients with cancer in the Gotlib Conn et al., (2014) study, navigators made themselves available to patients and spent time explaining the structures and processes of care. These were essential navigation techniques.

The significance of the accessibility of the CNN role is twofold; it is instrumental in the development of trust and accountability in the community, and it also symbolizes the focus on barrier reduction for residents overwhelmed by gaps in services and complexities. Most participants considered the accessibility of the CNN an asset to the role and residents with a family physician would often approach the CNN before making an appointment with their physician. This experience of accessibility aligns with the findings of Gotlib Conn and colleagues (2014), in which patients valued the accessibility of the navigator, especially compared to their physicians in the hospital setting.

Consistency. Participants spoke to the importance of the CNN having a consistent presence within the community. Participants enjoyed stopping by to interact with the

CNN even if they did not have specific issues they wanted to address. Her consistent presence in the community supported and encouraged social interactions important to building trust and accountability. This finding is echoed by Carroll et al., (2010), who compared the experience of oncology patients with and without navigators and found that being present and consistent was not only important to building a trusting relationship but was also a buffer against isolation.

Trust. The issue of trust is a vital component to building a therapeutic relationship (Arnold & Underman Boggs, 2011). In this study, trust was a social assumption of participants based on the experience of interacting with a nurse, the understanding of confidentiality, and the assumption that the CNN's intentions were to help residents in the community. However, a few participants expressed difficulties trusting others in the community with regard to personal or intimate details in their lives due to their past challenging experiences. This community, due to health and social inequities, is often a setting for interventions or programs to support residents. The majority of the programs involve non-residents in the community, creating issues of trust for some residents. The journey participants underwent in the development of a trusting relationship with the CNN was unclear. However, most participants expressed a high level of trust with the CNN, which may be due to the caring nature of the nursing role. The importance of establishing a trusting relationship with the navigator coincides with other literature on patients' experience of navigation. In the Gotlib Conn et al. (2014) study the experience of effective navigation was founded in a trusting and empathetic relationship with the individual, their family, and the navigator.

Through social interactions with the CNN participants began to develop trust in the CNN role, participating in meaningful therapeutic relationships *opening the door* to discussing their health and social needs with the CNN. This disclosure was a natural progression in the relationship for some participants, whereas, others were reluctant to let down their guard and gain the full benefit of the therapeutic relationship. In Peplau's (1997) Theory of Interpersonal Relationships, the transition between the orientation and working phase of the relationship is marked by the development of a person-centered therapeutic partnership to collaboratively establish priorities and begin taking action to positively impact the health and well being of the individual or family. In this study, the social interactions with the CNN presented an opportunity for her to assess residents personal resources, partnering to empower them to address the health and social needs they perceive as significant, impacting their health and wellbeing.

Personal Experience with Navigation and Impact of the CNN on Participants' Lives

In attempts to navigate complex and fragmented systems one's sense of individualism can be lost or reduced to the feeling of being just a number. Ravenscroft (2010) explored the experience of people with complex health needs in the community who attempted to navigate the health care system independently without the assistance of a navigator. They reported feelings of frustration, fragmentation, and challenges with a lack of access to adequate information. These findings echo the experience of participants in this study. Frank in particular described frustration with a lack of knowledge about available support resources, which he contributed to a failure in how knowledge was disseminated prior to the CNN pilot. Other participants similarly shared past experiences

of fragmentation and frustration when attempting to access resources. In keeping with the dimension of temporality, previous experiences of fragmentation shaped how participants view their experience of being connected as a result of interactions with the CNN.

Therefore, participants frustrated with independently navigating health and social systems may be more inclined to report a positive experience of navigation with the CNN.

The personal experience of systems navigation with the CNN role is contextualized on a temporal plot line. Participants' personal feelings, hopes, and values carried forward in their initial and subsequent interactions with the CNN. Each participant had past experiences in the community with navigation, barriers, and relationships with health care professionals and other services providers. Likewise, each participant had expectations of the CNN role, as many residents described their hopes of gaining useful information regarding resources and services from the CNN. All participants had families and in most of the narratives they placed emphasis on the value of providing for their families, increasing not only their personal health and wellbeing but their families' as well. The most significant personal experiences of systems navigation with the CNN role and the impact of the CNN were the feelings of emotional support, reducing system complexity through navigation, and a greater connectivity to supports and resources.

Emotional support. The experience of feeling emotionally supported as the CNN was *going above and beyond to help* was a commonly shared experience in the narratives. In the experience of the participants, if you found yourself in a time of crisis, or overwhelmed by with finances, family, or health concerns, the CNN was a consistent and

approachable support person for your health and social needs easily accessible at the community centre with an open door policy and a warm smile. The CNN's informal and non-threatening approach with residents helped to reduce anxiety and support self-management and capacity building. For participants who previously felt the effects of social exclusion and isolation, the level of support and the caring qualities of a nurse were a highly valued experience.

The level of emotional support participants reported from their interactions with the CNN is a common experience for persons working with navigators. The experience of emotional support from the navigator is a recurrent theme particularly with oncology patients. For example, Carroll et al., (2010) reported that cancer patients with navigators valued the emotional support, as they were often overwhelmed with care complexities. In the Gotlib Conn et al. (2014) study patients valued the individualized support to address emotional needs and anxieties related to their cancer care. Of the non-oncology navigation literature in primary care and community settings patients reported feeling 'supported' but emotional and psychosocial support was not specifically identified as a study finding (Boult et al., 2008; Ferrante et al., 2010). This variation across the literature may be due to the perceived vulnerability of cancer patients or the lack of description in the Boult et al., (2008) and the Ferrante et al., (2010) publications. However, this study substantiates the oncology navigation literature that patients experience emotional support from the navigation role.

The CNN emotionally supported residents as she acknowledged each participant as the central focus of the relationship and validated them with a person-centered

approach. The experience of personalizing navigation was highly valued by participants in the Carroll et al., (2010) study as the person-centered approach offered more flexibility to adapt to individual needs. Gotlib Conn et al., (2014) explained that navigation with a person-centered and holistic approach made patients feel that they were more than just their cancer diagnosis as navigators focused on patients' personal strengths as a resource in their care journey.

Reducing system complexities through navigation. All participants actively working with the CNN either reported experiencing a reduction in barriers or complexities, or considered the CNN as a potential solution for navigating fragmented systems. Comparing participants' personal hopes and expectations of the piloted role with the actual outcomes of their interactions, the CNN met or surpassed residents expectations. The CNN was perceived as a resource when residents did not know where to turn or were overwhelmed with the disfluencies of health and social services. Participants valued the CNN's knowledge of resources to address their unmet health and social needs. For participants' frustrated or overwhelmed with fragmentation and complexities, the CNN functioned to clarify these complexities and bridge the gap between unmet needs and supportive services. This experience is congruent with Carroll et al., (2010) finding that the navigator is an insider to linkages in the health care system, having expert knowledge of the system. Furthermore, in the Gotlib Conn et al., (2014) study, cancer patients' experienced navigation as a means of demystifying complex systems.

Greater connectivity to supports and resources. Since participants were recruited from the community centre, they were connected to supports in some capacity within the neighbourhood, most commonly the food bank. However, many participants expressed a desire and longing for a greater connectivity to supports and resources within the community. For these participants the CNN facilitated a greater connectivity with the HFHT, health promotion and disease prevention services, and/or social services. Their feelings of being supported and the CNN's dedication to *going above and beyond to help* were impactful, especially for those facing social exclusion and isolation. The CNN made connections based on acute and chronic issues to address unmet needs. In this study, we evaluated participants' experiences of interacting with the CNN and the short-term impact of the role in their life. In Rose, Dianne, and Maria's narratives they explained the instrumental importance of the connections to resources and supports resulting from their interactions with the CNN. Dianne described the feelings of "being stuck" in her health and social challenges without the assistance from the CNN. All participants who utilized the resources provided by the CNN expressed satisfaction with their experience. Personal or patient satisfaction with services provided by navigators is a common outcome in related literature (Campbell, et al., 2010; Carroll, et al., 2010; Ferrante, et al., 2010; Gotlib Conn et al., 2014).

The personal experience of greater connectivity, illustrates how Clandinin and Connelly's (2000) narrative dimensions are interrelated. The CNN facilitated increased social interaction by connecting participants to other residents, service providers and resources while concurrently addressing the challenge of place by problem solving

transportation barriers and increased geographical accessibility of resources. In most instances, the CNN also encouraged and empowered residents to become more engaged in the community, taking an active role in the community planning team and volunteering. Sylvia, Rose, and Dale shared stories of “just existing” (Sylvia) in the community but not thriving or experiencing connection in the community until they accessed the community centre and became connected to service providers and other residents. The significance of the community centre as a physical place for connections and accessibility will be explored further. The innovative nature of the CNN role is exemplified by the fluidity of transitioning between focusing on individual residents and the community as a whole.

Significance of Place and Impact of the CNN on the Community

The McQuesten neighbourhood has an identity as a community facing economic and social challenges, trying to recover through a resident-led community planning team promoting greater social inclusion and resident engagement. Some participants described the negative connotations of living in particular areas of the community, whereas others told stories of McQuesten as a place of *moving on* from past experiences and lifestyles. As a whole, participants valued their experience in the community and incorporated it into their personal experiences. Participants’ narratives tell the story of living in the community (Rappaport, 2000), therefore, place is not only significant in shaping personal narratives, but also to the story and experience of the CNN role.

Situated in the McQuesten community centre, the CNN is geographically and physically located in an area with individuals and families requiring assistance navigating

health and social systems. The physical location of the CNN innately enhances accessibility, as she is “right where the neediest people are” (Dale). The CNN’s room/clothing closet is directly beside the room functioning as a food bank, a feature of the CNN role valued by residents experiencing difficulty with access and fragmented systems. Within the community centre, the CNN can readily connect with other service providers, the community planning teams, and residents. The significance of the community centre is not only its physical location but also what it represents; connectivity and a place to go when in need of assistance. Participants described going to the community centre primarily to interact with the CNN, whether they had a concern or not. From the narratives the CNN role was not perceived as separate from the community centre, as the centre was where the initial and subsequent interactions with the CNN occurred. With the exclusion of Tom, participants were not fully aware of the extent of her work and partnership with the HFHT, the schools, and other organizations in the community.

Sylvia shared her perception of how the CNN successfully gained entrance and established trust in the community with the planning team and key residents in the neighbourhood from the onset of the pilot. Fischer, Sauaia, and Kutner (2007) argue that despite the variation across programs and primary care structures, navigators must work to establish trust in the community by providing person-centered and culturally specific empowering interventions. This was evident in many narratives, whether it was arranging safe housing for domestically abused women, giving health teaching information, welcoming new immigrants, or lending a listening ear to a person in crisis, many

participants expressed their observations of the CNN helping other residents in the community. All participants shared the understanding that the CNN role was designed to help residents in need in the community, partnering to improve the health and well being of participants and their families, and the community as a whole.

With the design of the study and the short duration of time of the pilot, it is difficult to fully explore the impact of the CNN role on the community as a whole; however, most participants considered the CNN role *an asset to the community*, facilitating a greater accessibility of supportive services and programs. Participants' experience of the CNN's impact in the community is reflective of a barrier-focused, rather than service-focused, description of this navigation role (Dohan & Schrag, 2005) with an emphasis on identifying and minimizing barriers by working with the community planning team, service providers, HFHT, and other organizations to change organizational practices and build partnerships to facilitate access.

The CNN Role as an Effective Approach to Address Health Disparities Over Time

Navigator roles in various settings have improved health outcomes, particularly related to increased cancer screening in vulnerable and disadvantaged populations (Dohan & Schrag, 2005; Freund, 2010; Natale-Pereira et al., 2011). However, the vast majority of navigation programs are designed to alleviate the burden or reduce the impact of social or contextual factors adversely influencing health outcomes not addressing foundational causes of inequity. In chapter one, we discussed how health disparities stem from persistent social inequities permeating well beyond the reaches of the health care system (Gardner, 2008).

In this study the CNN role was considered to have a positive impact on the lives of individuals and the community as a whole. However, is the CNN role an effective approach to addressing health disparities? To address this question we explore the narrative dimension of time by discussing addressing health disparities as a function of time, addressing past barriers, finding present solutions, and influencing future health and wellbeing.

Addressing health disparities as a function of time. In this study, we explored participants' experiences with the CNN role and the impact on their health and wellbeing. The effect of the CNN role on health and social equity is difficult to assess in a short period of time as the conditions contributing to inequity have unfolded over many years. Therefore, a distinction between short-term and long-term outcomes is essential in the evaluation of the role. The CNN made connections based on new or emergent and long-term challenges addressing acute and persistent unmet needs. These connections were not intended to solely be a quick fix; rather they were designed to concurrently address immediate concerns and underlying social determinants of health such as housing supports, food security, education, poverty, and social exclusion.

Therefore, we explored participants' experiences of interacting with the CNN and the short-term impact of the role in their life. Most participants reported a greater sense of connectivity, knowledge of resources, emotional support, and barrier reduction as a result of interacting with the CNN. The process of working towards resolution of persistent unmet or under addressed health and social needs have lasting impacts in the future. Longitudinal research could be helpful to assess this impact. The CNN role was not

designed to simply address current issues, but to empower and equip residents with the knowledge, self-management skills, and capacity to navigate health and social systems in the continued quest to enhance health and wellbeing, by addressing acute and persistent challenges.

Addressing past barriers. People shape their lives as they interpret their past (Connelly & Clandinin, 2006), the past informs the present but it does not predict the future. Participants past experiences of barriers is diverse. Some participants shared stories of “feeling stuck” with their health challenges where others told stories of moving on by overcoming obstacles and past situations. Barriers can be individual or systemic challenges, as participants shared their stories and experiences in the community it became apparent that some barriers were systemic, related to environmental, social, and cultural factors influencing many residents in the community.

In Chapter One and Chapter Three we paint a picture of the McQuesten community from the SPRC (Mayo 2012; Mayo, Klassen, & Bahkt, 2012), a picture of a community burdened by poverty, low education, a high workforce non-participation rate and subsequent health outcomes. However, these characteristics were a call to action and not a fixed prediction of the future.

The process of addressing such persistent social inequities and health disparities is a daunting undertaking. The first step to address health disparities is to identify individual and systems barriers in the community and establish connections, networks, and collaborative partnerships to minimize or remove barriers. The identification and prioritization of barriers was grounded on a firm understanding of the social determinants

of health, utilizing the knowledge, skills, and scope of a Registered Nurse to bridge gaps and barriers within the community to find present solutions.

Finding present solutions. For participants the present is their interactions with the CNN and their experiences of her assistance navigating complex systems and *making connections* with the resources and services. The role of the navigator to identify barriers and service gaps can be instrumental to inform policy development and the creation of coordinated health and social systems (Dohan & Schrag, 2005; Fillion et al., 2012; Freund, 2010). In this study the CNN not only identified individual and systemic barriers but also utilized strengths and assets to reduce or circumvent barriers when possible. From participants' narratives the CNN most frequently addressed barriers affecting accessibility.

The setting of the McQuesten community highlights the geographical importance of resource location as the majority of resident depend on public transportation. The environmental context impacted how the CNN functioned and the resources and services she could connect participants with. The CNN reduced accessibility barriers by mediating language/literacy barriers, financial barriers, and advocating for resources to be brought to the community as opposed to residents having to find means of transportation to access services. The CNN promoted accessibility by acting as a liaison between organizations, service providers, and residents. She promoted increased utilization of services and resources by disseminating information in meaningful ways to overcome barriers of health literacy and education. Participants described the CNN's approach to

disseminating information of available resources and supports as impactful, facilitating greater connectivity and resource utilization.

The CNN was responsive to changing needs during the pilot and functioned with a health system orientation, described in the Professional Navigation Framework (Fillion et al., 2012). Exemplifying management continuity, the CNN identified lacking resources, found temporary solutions, facilitated coordination, and reported systems gaps to the HFHT and community planning team.

Influencing future health and wellbeing. This piloted role was not designed to exist in the community indefinitely. Every participant intended to continue interacting with the CNN in the future and expressed a desire for an extension of the pilot with the ongoing presence of the CNN in the community. With the knowledge of an inevitable finite end of the role the CNN worked to empower individual participants, building capacity to independently navigate complex systems by equipping them with the knowledge, skills, resources required to overcome emergent and persistent barriers. For some participants the CNN played a precipitating role for individuals to take action and push past a static state of frustration with fragmented systems to find solutions to improve their health and wellbeing. For others the CNN was a support on individuals' ongoing journeys of moving on and overcoming past challenges. One of the ways to promote continued connectivity to resources and supports was through transferring trust from the CNN/resident relationship to residents and other service providers. This transfer of trust is a social function of interaction and due to the temporal nature of this study only began to happen in a few participants' stories.

The CNN functioned on a systems level to create sustainable change within the community, by addressing systemic barriers and forming connections for the community planning team with the HFHT, the local schools, other service providers, and organizations. The CNN worked to develop capacity and empower community members to foster enhanced community participation and engagement, supporting self-governance of the community. The present work of the CNN helped to shape and influence the future of individual residents and the community as a whole, setting them on a new trajectory to achieve enhanced health and well-being.

Implications for Practice, Policy, Education and Research

A major finding of the study was the importance of establishing a strong therapeutic relationship to effectively partner with residents by building capacity and connecting them with the appropriate supports and resources to address their health and social needs. These findings have a number of implications for practice, policy, education, and research. The findings and implications of the study must be presented to policy makers and key decision makers. These stories should not fall on deaf ears and should honour the experiences of participants who gave their time to share their story to further our knowledge of the experience of navigation/networking through the CNN role.

Practice

The practice implications of understanding residents' experiences can be used to inform continued development of the role. One of the major implications of this study is that the CNN role should remain a nursing position given the necessity to understand social determinants of health, population health, and the "normalizing experience of

working with a nurse” (Tom) compared to the more stigmatizing experience of working with a social worker. The concurrent focus on the individual and the community, and the dual function of navigation and networking, contributes to the impact of the role. The role can be enhanced by further role clarity for residents, and service providers.

The Professional Navigation Framework (Fillion et al., 2012) and the Community Health Nursing Standards (CHNC, 2011) can be used to guide the further development and implementation of the CNN role. The flexible nature of the role in the community center was highly valued as it contributed to the accessibility and approachability of the CNN. The CNN should be highly visible and accessible within the community by participating in community events and working to engage a wide variety of residents in the community. The physical environment should be conducive to privacy when residents wish to discuss private matters. The current lay out of the community center did not have a designated space for the CNN, which made it challenging to maintain privacy when the community center was busy. A consistent and regular presence of the CNN at the community center with posted hours would enhance the accountability of the CNN to the community and help to develop trust. To reach a greater number of community residents evening or weekend hours would also be beneficial for those who cannot access the community center during usual business hours, for example the working poor.

The knowledge and skills of the CNN is a major contributor to the success of the role thus far. Effective communication and being present and personable with residents allow for the establishment of trust and the initiation of a working relationship. When working with a population who has been marginalized or excluded due to health or social status a

non-judgmental and open approach to active listening allows for the opportunity to build strong therapeutic relationships. Allowances should be made for the CNN to participate in continuing education with time specifically designated for networking and finding new resources.

On an organizational level, supports should be in place for the CNN to be able to problem solve and debrief. The CNN functions well in an autonomous role but organizational support of the role was important to ongoing success and professional development. Finally, when selecting the successful candidate for the CNN role a nurse with experience in the community, knowledge of resources, and an understanding of population health were essential. Congruency between the populations needs and past nursing experience was also of value as the CNN's experience with women and children was very applicable to the residents at the community center.

Policy

Lessons learned in the design and implementation of the CNN role has implications for future policy development in priority neighbourhoods. For example, any program design that creates barriers to access, such as a referral-based system to access the CNN, is counterproductive given the aims of barrier reduction and facilitating access. In this study the CNN was functioning within an optimal scope of practice as a Registered Nurse. Policy should support the optimal scope of nurses in primary care and community settings to promote health and well being. Community members should be given a voice in policy development and the opportunity to participate in decisions

affecting their community. If community members have a sense of ownership and inclusion new programs or services will be adopted faster and embraced more readily.

Addressing the root causes of health and social inequities is not in the exclusive domain of primary care, public health, or acute care, nor is it the responsibility of any one organization or profession or sector. A collaborative approach with buy-in from a variety of stakeholders creates optimal conditions for the most comprehensive approach to addressing these persistent issues. Collaboration and networking between services and programs in the same region should not merely be encouraged but mandated to reduce redundancies and service the community more effectively. This can be facilitated through the utilization of a navigator/networker with an understanding of the community needs and resources.

With respect to the transferability to other priority neighbourhoods, this study presents the stories of residents' experiences with the CNN and the beneficial impact of the role on individuals, families, and the community. Other relevant literature aligns with the current study findings and presents the possibility that the experience of navigation likely extends beyond program design or setting. Therefore, the experience of a nurse navigator/networker in other urban priority neighbourhoods may also have a beneficial impact for disadvantaged residents experiencing challenges navigating complex and fragmented health and social systems.

The value of the CNN as a nursing role in systems navigation. In the literature navigator roles can be filled by social workers, laypersons, family members, or interprofessional teams (Wells et al., 2008). This raises an interesting question; is the

nurse the most appropriate person for the role of assisting residents to navigate complex health and social systems? Participants offered various perspectives on the value of a nurse in the CNN role. Most participants supported the ongoing involvement of a nurse but one participant believed the role is better suited for a social worker. In a study of a navigator role in primary care, Ferrante et al., (2010) retrospectively recommended the use of nurses in navigation after piloting the role with a social worker. However, there is a lack of reliable literature comparing the outcomes of professionals in navigation roles.

In this pilot, the CNN has a comprehensive understanding of the social determinants of health, which enabled her to work concurrently on the individual and community level to reduce barriers and promote greater health and wellbeing. This additional dimension of the role, along with the networking aspect of the role requires the knowledge and skills of a nurse with an understanding of population health. Policy should support the optimal scope of nurses in primary care and community settings to promote health and wellbeing.

The RNAO (2014), in a politically charged ECCO model asserted that care coordination/systems navigation should be a function of a primary care RN as they are “well situated with the educational preparation, clinical knowledge/experience, public trust, awareness of the system and comprehensive understanding of the social determinants of health, to support and coordinate the broad preventative and responsive care needs of Ontarians” (p.18).

If not a Registered Nurse, where does the CNN role belong in the organizational structure of health care delivery in Ontario? In this current study, participants expressed

the value of having the CNN located in the community fulfilling the functions of a Community Health Nurse (CHN). Currently, some navigation functions are the responsibility of nurses working with patients in transitions from acute to community care with the CCAC and under the umbrella of care coordination. However, the RNAO (2014) argues that patients need a single point of contact with the health care system, enabling overall navigation. Given the structure and flow of the health system, the RNAO is advocating for structural reforms for designated Registered Nurse navigators in primary care to function as the single point of contact, so that all care and transitions will be facilitated through primary care. So where does the role of a Public Health Nurse (PHN) fit and what role do they play in system navigation? The answer is unclear, however, what is clear is the need for an organized and collaborative approach to systems navigation with role clarity and minimization of duplication and overlapping roles.

Education

There are a number of implications for education as a result of study findings. These implications largely highlight the key knowledge required to function within a navigator/networker role. Nurses should have a comprehensive understanding of population health, Community Health Nursing Standards, and the social determinants of health to design and execute interventions aimed at barrier reduction and addressing key social determinants of health. Nurses should be educated to assess barriers and develop creative strategies to overcome barriers that cannot be removed or minimized.

Additionally, nurses must learn the value of collaboration, the importance of networking,

and the skills for effective communication. Nurses entering community settings should develop the capacity to practice with creativity, adaptability, and flexibility.

A number of organizations are attempting to compose competencies and educational programs for navigators, especially in oncology settings. Developing competencies for navigators/networkers in community settings with priority populations would not only help to define the role but to create a standard to educate others to service other priority neighbourhoods. An understanding of the Community Health Nursing Standards of Practice (CHNC, 2011) would be beneficial for the development of education programs to create a framework for delivering services within the community. Finally, when implementing a new CNN program there should be educational opportunities for members of the community, health professionals, and other service providers to understand the aims and scope of the role to allow for increased role clarity leading to increased utilization and collaboration.

Research

There are numerous implications for areas of future research as a result of this study. Stories are a powerful and meaningful method of understanding individuals' experience of a program or initiative. These stories bring to life what is often lost in surveys or in collecting data with prescribed and restrictive instruments. In future program evaluations, a mixed method approach with a narrative complement would be beneficial to capturing the measurable outcomes in addition understanding the human experience of the program. Evaluations of other navigation programs with a specific

focus on the client experience is an important area for future research to determine if there are common themes in the experience of navigation.

Long-term evaluation of the pilot program assessing residents' experiences and the organization and structure of the community would be valuable. The addition of a tool to measure residents' perception of their degree of connectedness before and after their interactions with the CNN would have been a meaningful way to quantify the change in connection with services. A social network analysis of new connections made by the CNN for the community and/or residents would be a very informative addition to the evaluation to evaluate the influence of the role on a systems level. If the CNN role is implemented in other priority neighbourhoods across the city it would be interesting to compare the evolution of the role in different settings based on the unique needs of the populations they are servicing.

As a result of conducting the study there were implications and lessons learned from the sampling and recruitment of participants with limited resources. How the study is advertised and the inclusion of a relevant incentive for participation is essential. When attempting to recruit participants with limited resources it is important to find reliable methods to follow up as telephone or email may not always be available options. Giving the people the opportunity to share their story and be heard is an empowering and therapeutic process, allowing them the ability to influence programs within their community.

Limitations

There were several limitations in this study. Given the narrative nature of the interviews the sample size was small due to the in-depth inquiry into the experience of participants. Due to the nature of narrative research, the study findings may not be readily transferable given the importance of individual and situational context of the findings. Since the role is being piloted the population to which the CNN is providing services is dynamic. Despite every intention to recruit a sample representative of the CNN's caseload it is unclear if we were successful. Variation with the sample was intentional with respect to the number and nature of interactions with the CNN. However, despite attempts to recruit a variety of residents there were a number of mothers with young children who expressed interest in sharing their story, as they were accessing the CNN through the clothing closet and food bank. This may have lead to an under representation of men utilizing the CNN services in the community.

The element of timing was a major limitation in this study. There was a relatively short period of time from the onset and duration of interactions with the CNN and the collection of participants' stories of experience with the role. This may have lead to a underreporting of the impact of the CNN role as complex health and social needs often require time to experience improvements.

With the design of the pilot program and the daytime drop-in hours at the community center the sample was mostly comprised of residents who were unemployed and/or on social assistance. This is not necessarily representative of the McQuesten

community as a whole, but does comprise a large proportion of the CNN caseload, neglecting the working poor, as there are no evening or weekend hours at this time.

Given the informal nature of the drop-in format there was a lack of consistency of CNN documentation across study participants. While the documentation added context and perspective to narratives, some participants were not captured in the CNN documentation. Most participants with numerous interactions with the CNN were represented in documentation but interactions with the majority of participants with fewer interactions or less complex needs were not.

Conclusion

The major finding of this study is the relational importance of the CNN role as perceived by participants, to facilitate a greater connectivity to supports and services impacting the temporal unfolding of their lives and setting them on a new trajectory to achieve enhanced health and well-being. The orientation to Clandinin and Connelly's (2000) narrative dimensions of temporality, sociality, and place illuminated the temporal, relational, and contextual elements of working with a nurse navigator/networker to address foundational unmet health and social needs of residents in a priority neighbourhood disadvantaged by a complex interplay of social determinants of health, situational, and environmental factors. This study further validates the experience of persons interacting with professional navigators and offers a unique perspective of the temporal experience of building a therapeutic relationship with the CNN and the impact of the role in the lives of study participants.

Epilogue

As I draw final conclusions from the study findings, I am also compelled to reflect on my own conclusions as a result of conducting this inquiry. This study has not only challenged my ability to think narratively but has also helped me to gain a deeper understanding of social conditions contributing to health inequities. As a result of this study I was provided the privilege to enter the lives of residents in the McQuesten community. The resilience of many of the participants brought the stories to life, which I hope I was able to convey in this thesis.

The study themes also apply to my journey as a novice researcher conducting my first study. This study served as a my experience of *opening the door* to a world of curiosity and inquiry into optimization of Registered Nursing role, advocacy for health equity, and the use of narrative in community based research. The interviews I facilitated and the discussions with my thesis committee members were *more than just a conversation*, these interactions helped to frame my perspective during data collection and analysis. Through this experience I was able to *make connections* with other researchers, healthcare professionals, service providers, policy makers, and community members. These connections will help to inform my continued involvement in community-based research and development. Finally, not solely in the completion of this thesis, but in my personal and professional journey of conducting this inquiry I gained skills, experiences, and perspectives that will help to *change and shape my future* in nursing research.

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Appendix A

Letter of Invitation / Consent

Narrative Inquiry of a Community-based System Navigation Role in an Urban Priority Neighbourhood

Investigators:

Local Principal Investigator:

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Student Investigator:

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You are invited to take part in this study to evaluate your experience with the Community Nurse Networker. You have been selected because you are:

- A resident of the McQuesten neighbourhood,
- You have worked with the Community Nurse Networker,
- You may be interested in finding ways to make your community better by sharing your experiences with us

Why is this study being done?

The Community Nurse Networker role was designed to address unmet health and social needs by helping residents to navigate and access appropriate programs and services in a timely manner. We value your input and experience with the Community Nurse Networker. We wish to find ways to improve the program to better meet your personal, family, and community needs.

What is the purpose of the study?

The purpose of the study is to enhance our understanding of how people experience navigation services through stories. It is our hope that we learn how a networker or navigation role can impact individual and family health by addressing social issues. What we learn from this study may be used to help other family health teams and communities within the City of Hamilton.

What will happen in the study?

If you volunteer for this study you will be asked to:

- Take part in a one-on-one interview with the researcher to share your story. The interview may last 45 – 90 minutes, depending upon how much you would like to share with us about your experience. With your permission, the interview will be audio taped.

- The types of questions we may ask you are to tell us about yourself and your experience with the Community Nurse Networker.
- We want to make sure that we understood everything you told us. You may be asked for a short secondary interview to check that I correctly understand your story. This may be up to a few months after your initial interview.
- With your permission, we will access the Nurse Networker's file or documentation of your meetings to better understand your experience.

Are there any risks or discomforts to doing the study?

It is not likely that there will be any harms or discomforts from taking part in the study. Taking time for the one-on-one interview might interrupt your day. You may feel uncomfortable with sharing certain feelings or experiences that you have had with the Community Nurse Networker or the Family Health Team. It is up to you what you want to share with us. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable.

Are there any benefits to doing this study?

We cannot promise that you will get any direct benefit from taking part in this study. By participating in this study you will be able to share your story and may help to make changes within your community. Any feedback you provide may be used to improve the Community Nurse Networker program and similar programs in other Hamilton neighbourhoods.

What If I choose not to take part in the study?

It is important for you to know that you can choose not to take part in the study. If you choose not to take part, it will in no way affect your relationship with your health care providers or the Community Nurse Networker.

Payment or Reimbursement

You will receive a \$20 grocery card to thank you for taking part in the study. You will also be reimbursed for parking, riding the bus, or childcare costs during the interview.

Confidentiality

Every effort will be made to protect your confidentiality and privacy. I will not use your name or any information that would allow you to be identified. Since we are often identifiable through the stories we tell, your story will be analyzed for main themes and not reported word for word. Personal information (name, phone number or email address) will be taken, but we will replace this with a unique identification number instead. A list that tells us whose information belongs to which number will be created and kept on a password protected computer in a locked office. The only people who will have access to the information you choose to provide will be members of the research team, who have signed confidentiality agreements. Once the study is finished the data will be destroyed and an archive of the data, without identifying information, will be deposited for five years.

If the study results are published, your name or any personal identifiers will not be used. No information that can give away who you are will be shared or published without you telling us that it is okay to share it.

Legally Required Disclosure

The information you tell us will not be shared with anyone, unless you permit it, or if it is required by law.

What if I change my mind about being in the study?

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you; it will not affect your relationship with your health care providers, the Community Nurse Networker, or myself. If you decide to withdraw from the study information provided up to that point will be kept unless you request that it be removed. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

How do I find out what was learned in this study?

I expect to have this study completed by approximately June 2014. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at: feathjmr@mcmaster.ca or (905) 807-9886.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HIREB at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Janice Feather of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a signed copy of this form. I agree to participate in the study.

- | | |
|---|-----|
| 1. I agree that the interview can be audio recorded. | Yes |
| No | |
| 2. I agree that the researcher may access the Nurse Networker's file on me. | Yes |
| No | |
| 3. I would like to receive a summary of the study's results. | Yes |
| No | |

If yes, where would you like the results sent:

Email: _____

Mailing address: _____

- | | | |
|--|-----|----|
| 4. I agree to be contacted about future research and I understand that I can always decline the request. | Yes | No |
|--|-----|----|

Please contact me at: _____

_____	_____	_____
Name of Participant (Printed)	Signature	Date

Consent form explained in person by:

_____	_____	_____
Name and Role (Printed)	Signature	Date

Appendix B

Recruitment Poster

Version #_4__ - Version Date: _Mar 16/14__

Have you met with the Community Nurse Networker, Rachael?

We are doing a study to learn about your experience of the Community Nurse Networker Program. We would like to hear your stories.

We are looking for people who:

- Live in the neighbourhood
- Have met with the Community Nurse Networker at least twice
- Can meet with us for an hour to share your experience

A \$20 grocery card will be provided to thank you for sharing your story with us.

**FOR MORE INFORMATION,
PLEASE CALL
JANICE AT
905-807-9886**



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Appendix C

Participant Interview Guide

1. Tell me about your life? (*Temporality*)

Prompt:

- a. Experience living in the community (*Place*)
 - b. Family history
 - c. Health and social factors
2. Tell me about what has changed in your life that has led you to work with the Nurse Networker/Community Nurse Navigator? (*Temporality*)

Prompt:

- a. Perceived health and well-being
 - b. Accessibility of services/fragmentation
3. What did you hope to get out of the experience of working with the Nurse Networker/CNN? (*Personal dimension - Sociality*)

Prompt:

- a. Needs/priorities identified
4. What was your experience while working with the Nurse Networker/CNN? What was this relationship like? (*Relational dimension - Sociality*)
 5. What if any changes have you experienced in your life since you began working with the Nurse Networker/CNN?

Prompts:

- a. Individual, family, and community?
 - b. Health, wellness, achievement of personal wellness goals?
 - c. Access to appropriate services and programs? Comprehensiveness of services?
6. Based on your experiences do you feel as though there has been an improvement in your health or well being? Why or why not?
 - a. Comprehensiveness of health and social services
 - b. Accessibility to services

7. From your experience, how could the Nurse Networker/CNN role be improved?
8. Do you have anything else you would like to share with me?

Appendix D

Field Notes Template

Interview #

Interview Date:

Time:

Focus	Descriptive Notes	Reflexive Notes
Setting (place)		
Sociality dimensions:		
Personal (Hopes, feelings, desires, moral dispositions, aesthetic reactions)		
Social (interpersonal interactions, Communication pattern, use of language, relationship with researcher)		
Temporality (past, present, future)	<p>Past</p> <p>Present</p> <p>Future</p>	
Other Comments	Risk factors/SDOH:	

Appendix E

CNN Letter of Invitation / Consent

Narrative Inquiry of a Community-based System Navigation Role in an Urban Priority Neighbourhood

Investigators:

Local Principal Investigator:

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Student Investigator:

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You are invited to take part in this study to contribute to an enhanced understanding of the impact of the Community Nurse Navigator/Networker (CNN) role on the lives of residents in the McQuesten community.

Why is this study being done?

The CNN role was designed to address unmet health and social needs by helping residents to navigate and access appropriate programs and services in a timely manner. We value your input and experience with the role. We wish to understand the experience of systems navigation and find ways to improve the program to better meet individual family, and community needs.

What is the purpose of the study?

The purpose of the study is to enhance our understanding of how people experience navigation services through stories. It is our hope that we learn how a networker or navigation role can impact individual and family health by addressing social issues. What we learn from this study may be used to help other family health teams and communities within the City of Hamilton.

What will happen in the study?

If you volunteer for this study you will be asked to:

- Take part in a one-on-one interview with the researcher to share your story. The interview may last 30 – 45 minutes, depending upon how much you would like to share with us about your experience. With your permission, the interview will be audio taped.

- The types of questions we may ask you are to tell us about yourself and your experience in the CNN role.
- You will be asked to share your perspectives on study themes to present a more holistic story of the experiences of residents interacting with the CNN.
- We want to make sure that we understood everything you told us. You may be asked for a short secondary interview to check that I correctly understand your story. This may be up to a few months after your initial interview.

Are there any risks or discomforts to doing the study?

It is not likely that there will be any harms or discomforts from taking part in the study. Taking time for the one-on-one interview might interrupt your day. You may feel uncomfortable with sharing certain feelings or experiences. It is up to you what you want to share with us. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable.

Are there any benefits to doing this study?

We cannot promise that you will get any direct benefit from taking part in this study. By participating in this study you will be able to share your story and may help to make changes within the community. Any feedback you provide may be used to improve the CNN program and similar programs in other Hamilton neighbourhoods.

What If I choose not to take part in the study?

It is important for you to know that you can choose not to take part in the study. If you choose not to take part, it will in no way affect your relationship with the research team.

Payment or Reimbursement

You will receive a \$10 gift card to thank you for taking part in the study.

Confidentiality

Every effort will be made to protect your confidentiality and privacy. I will not use your name but due to the nature of the pilot program you may be identified given your current role in the project. However, participation in the study will not enhance the extent to which you are identifiable. The only people who will have access to the information you choose to provide will be members of the research team, who have signed confidentiality agreements. Once the study is finished the data will be destroyed and an archive of the data, without identifying information, will be deposited for five years.

If the study results are published, your name or any personal identifiers will not be used. No information that can give away who you are will be shared or published without you telling us that it is okay to share it.

Legally Required Disclosure

The information you tell us will not be shared with anyone, unless you permit it, or if it is required by law.

What if I change my mind about being in the study?

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you; it will not affect your relationship with your health care providers, the Nurse Networker, or myself. If you decide to withdraw from the study information provided up to that point will be kept unless you request that it be removed. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

How do I find out what was learned in this study?

I expect to have this study completed by approximately May 2014. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at: feathjmr@mcmaster.ca or (905) 807-9886.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HIREB at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Janice Feather of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a signed copy of this form. I agree to participate in the study.

- 4. *I agree that the interview can be audio recorded.* Yes
No
- 5. *I would like to receive a summary of the study's results.* Yes
No

If yes, where would you like the results sent:

Email: _____

Mailing address: _____

- 4. *I agree to be contacted about future research and I understand that I can always decline the request.* Yes No

Please contact me at: _____



Name of Participant (Printed) Signature Date

Consent form explained in person by:

Name and Role (Printed) Signature Date

Appendix F

CNN Interview Guide

- 1) How would you describe the CNN role?
- 2) What past experiences (both nursing and personal) have helped you to prepare for the CNN role?
- 3) Why do you see the CNN role as a nursing role compared to a social worker or other professional?
- 4) What is your approach when meeting a resident in the community for the first time?
- 5) When you are interacting with residents it is often framed as a ‘conversation’. What underlying assessments and nursing actions are you performing, if any?
- 6) From the thematic analysis of participants’ stories, they experienced you “opening the door” to a therapeutic relationship. Was this intentional? What steps did you take to make this possible?
 - a. Prompts: approachability and accessibility
- 7) Do you see the therapeutic relationship with residents as on going or is there a finite end when they have resolved health/social issues?
- 8) Moving forward, are there any improvements to the role that you would like to see in the continuation of the pilot program?