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Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and Health Care Provider Perspectives

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Abstract

With current rapid expansions to medical knowledge and technology and rising chronicity of diseases, health care providers are increasingly called upon to work together within interprofessional teams to provide the most comprehensive care to their patients.

Interprofessional teams have been depicted as enhancing patient health outcomes and increasing patient satisfaction with care, while decreasing health care spending and wait times for receiving care. However, there is little evidence on how to collaboratively include patients in these teams.

The study's purpose was to construct a framework on the conditions and processes required for patients to assume active participant roles in their care within primary care interprofessional teams. Charmaz's Constructivist Grounded Theory approach was used. Ten patients and 10

health care providers from two Family Health Teams in Southwestern Ontario, Canada

participated in individual semi-structured interviews to learn about their perspectives on patient roles in teams. Data collection and analysis including memoing, coding and constant

comparative analysis were used to generate theoretical concepts of the framework. Member-checking interviews occurred to provide final feedback on the framework. The framework

entitled: "Patients on Interprofessional Teams in Primary Care: A Framework for Teamwork"

presents three main concepts: (1) *patient roles*; (2) *processes*; and (3) *conditions*. The *patient*

roles concept comprises three sub-concepts with each having two categories/descriptors: (1)

expert of own health – expressive and advisor; (2) *(co)decision-maker* – active voice and

trusting; and (3) *self-manager* – advocate and evaluator of care. The *processes* concept presents

five sub-concepts: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*. The

conditions concept outlines four sub-concepts: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4)

readiness. This study presents a comprehensive framework for patient-health care provider

interactions within primary care interprofessional teams, including dimensions of and more clarity about three types of roles patients can assume within these teams. This study also offers an understanding of the conditions and processes health care providers adopt in practice towards patient inclusion on these teams. Further research should utilize this framework to continue to build knowledge of patient roles on interprofessional teams within a multitude of health care settings and populations.

Keywords

patient-centred care

patient roles

primary health care

Family Health Teams

interprofessional care

interprofessional teams

semi-structured interviews

member-checking interviews

constant comparative analysis

Constructivist Grounded Theory

Summary for Lay Audience

When health care providers and patients work together as part of interprofessional teams, both groups experience benefits during care delivery. However, we do not have enough information on how patients can be effectively integrated into these teams. The term interprofessional team means a team that is comprised of two or more *different* health care providers who interact and work together with each other and the patient for more enhanced health outcomes to occur. An example of an interprofessional team is when a nurse, a dietitian, and a physiotherapist work together with and involve the patient in the planning and implementing of patient care. The study purpose was to learn about patients' and health care providers' perspectives of roles patients can hold within interprofessional teams in primary care settings, such as a Family Health Team (a clinic in a community setting that includes a team of different health care provider professions who work together to provide care to patients). In addition, the study explored what was needed to be in place for the team for patients to be able to enact such roles. Ten patients and 10 health care providers, from two primary care Family Health Teams in Southwestern Ontario, Canada underwent individual interviews with the study researcher. Additionally, some of these participants took part in a follow-up interview group where they were asked to review the first interview findings to see if they accurately captured participants' perspectives. This process resulted in construction of a framework on patient roles in teams. Three patient roles were identified: (1) *expert of own health*; (2) *(co)decision-maker*; and (3) *self-manager*. Five processes (steps) were presented that needed to be taken for patients to enact any of these roles: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*. Lastly, four conditions (items) were outlined as needing to be in place for these roles to be enacted: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4) *readiness*. This study has provided an

understanding of potential patient roles on interprofessional teams and what is needed to change current practice settings towards patients' inclusion in their care on such teams.

Co-Authorship Statement

I, Kateryna Metersky, acknowledge that this thesis includes three integrated manuscripts that evolved as a result of collaboration with my thesis supervisor and committee members. For each of the manuscripts, the primary contributions were made by the first author in terms of conducting the literature review, formulating the study design and methodology, preparing and submitting the ethics application, performing the recruitment of participants, collecting data through conducting interviews and participant member-checking interviews, transcribing, coding and analyzing data, and writing the manuscripts. The thesis supervisor (CO) and the supervisory committee (CHC, TA) provided multiple critical reviews of intellectual content of each article. Each co-author critiqued, supervised, guided, edited, and advanced sections of the articles related to their area of expertise. These include research design (CO, CHC), interprofessional knowledge (CO, CHC, TA) and patient – team interactions (CO, CHC, TA). All authors provided approval of each article prior to submission for publication.

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Dedication

I would like to dedicate this thesis to my children (Theodore, Benjamin, and Zachary) and my husband (Anton) who allowed me to take time from family activities so I could focus on my studies. I would also like to dedicate this thesis to my parents (Oleg and Larysa) who were both physicians back in Ukraine, but had to give up their professions to ensure my sister Sophia and I would have a better future. I hope I have been able to make you proud with all of my accomplishments to date. I want you both to know that I will be forever grateful for what you have done for me. Lastly, I want to dedicate this thesis to my grandparents (Bohdan, Stephania, Roman, and Bronislava) and to my great-grandmother (babusia Kasia), whose name I bare.

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List of Abbreviations

HCP	Health Care Providers
IPT	Interprofessional Teams
IPCC	Interprofessional Patient-Centred Collaborative
IPC	Interprofessional Collaboration
WHO	World Health Organization
PCC	Patient-Centred Care
ICT	Intergroup Contact Theory
CGT	Constructivist Grounded Theory
FHT	Family Health Team
NPLC	Nurse Practitioner – Led Clinic
CIHI	Canadian Institute for Health Information

CHAPTER 1:
INTRODUCTION

Introduction

We have created a health care system on the premises of those offering their services. Now we are facing a new era - a health care system on the premises of the patient. This implies changing behaviour and systems.

Enehaug, 2000, p. 181

With frequent changes occurring to the health care system, health care providers (HCP) are finding that working uni- or multi-professionally is challenging, necessitating expertise to be combined across needed interprofessional teams (IPT) (van Dongen et al., 2016). The care being offered to patients is also transitioning, with heavier reliance placed on patients becoming more active participants in their care. In Canada, an emphasis has been placed on creation of IPTs within both primary and acute care settings. The work of these IPTs has been reported to result in lowered health care spending (Mitchell, Parker, & Giles, 2011), decreased length of hospital stay (Mitchell et al., 2011; Shah, Forsythe, & Murray, 2018), enhanced patient health outcomes (Adams & Feudale, 2018; Chesluk et al., 2015; Dunn, Cragg, Graham, Medves, & Gaboury, 2018; Sidani et al., 2018; Szafran, Kennett, Bell, & Green, 2018), reduced service delivery, duplication and fragmentation (Mitchell et al., 2011), and achievement of better quality of care (Hepp et al., 2015). However, these same IPTs are less likely to include patients as either team members or active participants in planning, delivering, and evaluating of their own care (Bombard et al., 2018; Cutler, Morecroft, Crey, & Kennedy, 2019). In 2015, Accreditation Canada revised all of its accreditation standards to include the need for services and care to be delivered in partnership with patients (Accreditation Canada, 2015). However, how patient engagement is defined and applied when aiming to improve quality and care safety is not always ideal (Pomey et al., 2018). In addition, a literature review by Bombard et al. (2018) found that

methods used to engage patients at the policy, organizational, or practice level of the health care system have not always been optimal.

The limited studies published from patients' perspectives about IPTs found that some patients felt care was fragmented, role confusion occurred, and at times there was an expressed preference for single provider care over interprofessional care (Blickem & Priyadharshini, 2007; Metersky & Schwind, 2015; Shaw, 2008). Martin and Finn (2011), in an evaluative study of UK teamwork sought to explore patient (service user) involvement in IPTs and found that patients lacked understanding of the importance in being provided with clearly identified roles in teams. These findings are vital in that if patients are to become team members, they need to have an understanding the roles they can play within these IPTs. The importance of patients having distinct roles in IPTs is also a key requirement if the goals of interprofessional patient-centred collaborative (IPCC) teamwork are to be realized.

IPCC teamwork occurs when a partnership is formed between the patient and two or more HCPs resulting in development of a shared plan of care (Orchard, Curran, & Kabene, 2005). Such a shift in IPT practice is needed to alter HCPs' existing assumptions of patients as passive agents who need to be motivated, invited, or persuaded to take part in their care. These beliefs cause HCPs to persist in determining the best care for patients. In addition, this ongoing paternalistic approach results in HCPs dictating a patient's level of involvement in IPTs with limited input from the patient (Pomey, Ghadiri, Karazivan, Fernandez, & Clavel, 2015). Thus, the aim of this study was *to generate a theoretical understanding of patient roles in IPCC teams from the collective perspective of patients and HCPs.*

Background and Significance

The concept of health teams has been around for over a century, with the first articles published in medical journals as early as 1909 (Cooter, 2004). These traditional teams revolved around the doctor being the “captain” of his vessel (Frank, 2007). All other players, mainly nurses and nursing aids, were “his” subordinates and assistants (Henderson, 2006). Although this type of relationship was labeled as working in a team, it was mainly the doctor working unipersonally and the other team members carrying out “his” instructions without any input or questioning of decisions made. Patients had neither active participation in the team nor in the planning of their care.

The ongoing creation of new HCP roles, such as physiotherapists, occupational therapists, dietitians, speech language pathologists and social workers, to name a few, started to challenge traditional teams on decision-making. In addition, a divergence of HCPs’ communication patterns and approaches to viewing care needs of patients created difficulties in team functioning (Weisz, 2005). In early 2010, position statements on improving patients’ health outcomes through IPTs were published by Health Canada (2010), the Canadian Nurses Association and the Canadian Medical Association (2010). These directives put forth three notions: (1) IPTs will be able to increase patients’ involvement in their own care; (2) all HCPs will work to their full scope of practice; and (3) relationships will strengthen between HCPs and patients (Campbell, Stowe, & Ozanne, 2011). While these directives were provided for teamwork, they were absent in addressing patients’ roles in their care let alone as members of IPTs (Orchard, 2010). This notion is interesting in that one of the outcomes of IPTs has been to include increased patient involvement in their own care (Campbell et al., 2011).

Exclusion of patients from participation in their care is evident in the published literature on collaborative teamwork. One of the most commonly cited definitions of interprofessional collaboration (IPC), by D'Amour and Oandasan (2005), describes it as caregiving that occurs when two or more different HCP professions come together to combine their expertise for the enhancement of patient health outcomes. Although this definition implies that caregiving occurs around the patient, it does not describe the patient as: participating in the planning, implementing or evaluating of their own care; involving them as a member of their caregiving team; or sharing their lived experience expertise related to their unique health issues.

The most common definition of team is one by Cohen and Bailey (1997), which is:

a collection of individuals who are interdependent in their tasks, who share responsibility for outcomes, who see themselves and who are seen by others as an intact social entity embedded in one or more larger social systems, and who manage their relationships across organizational boundaries (p. 241).

Thus, all team members need to be interdependent in their task and share the responsibility for outcomes. Team members are expected to manage their relationships across boundaries.

According to Saltman et al. (2007), an interprofessional group is a collection of individuals who maintain their individual roles and work towards their individual efforts by coordinating their work within a shared location or space. The voice and inclusion of patients as team members is absent within both a team and an interprofessional group according to both Cohen and Bailey's (1997) and Saltman et al.'s (2007) perspectives of teams and their work. In IPTs, members are often assigned specific roles to reach commonly agreed upon goals, such as maintenance of health status. In Saltman et al.'s (2007) perspective interprofessional members must maintain their own roles. Thus, the inclusion of the patient with unique roles within interprofessional groups might be perceived by HCPs as an intrusion into the team and a challenge to their professional identity. If patients become more involved in their care and collaboration with

HCPs, it is proposed that the most appropriate label to represent this is IPTs and not interprofessional groups. As well, it could be argued that using the stem *interprofessional* further ignores the importance of patients as team members. This name projects the impression that these teams are only comprised of professionals coming together to share expertise, without any mention of patients' roles in the IPT. Alternatively, it could be argued that patients bring their lived experience into the team which represents their 'professional expertise'. Clearly there is no perfect title for IPTs. For the time being the field uses *interprofessional*; perhaps in time this may shift as teams embrace the patient as a member.

Teamwork models seem to continue to further reinforce profession-specific foci that lead to ignoring the value patient participation can provide to enhance care delivery. Effective teamwork is impacted by profession specific communication patterns and ethical codes, and varying approaches to patient encounters (Orchard, 2015). Thus, professional practice roles are developed outside of patients' input, continuing to sustain the notion of HCPs as experts, and contributing to creating further power differentials between patients and HCPs (Orchard, 2015).

The World Health Organization (WHO) reported that one-third of the world's population suffered from a type of chronic disease and, prior to the pandemic caused by the coronavirus disease, 82% of worldwide mortality rates could be attributed to non-communicable chronic diseases such as cancer, cardiovascular disease, chronic respiratory disease and diabetes (2014). Seeing as it is only the patients themselves who understand how these chronic diseases impact their lives, how can they not be considered members of IPTs?

In 2017, the national health care expenditure by Canadian territorial and provincial governments was \$6,082 per person (Canadian Institute for Health Information [CIHI], 2018). Health care costs continue to rise with limited improvements in health outcomes. The

Conference Board of Canada and the Commonwealth Fund rated Canada's national health system as poor in relation to its value for cost and efficiency (Scheider, Sarnack, Squires, Shah, & Doty, 2017). Leaving out the voices of patients, particularly those with chronic diseases, is not likely to curb the rising health care costs and limited improvements in health outcomes. It is theorized that changes in the roles patients enact in their health care is critical for sustainability of the health system in Canada and likely worldwide.

The capacity of health care systems to meet growing needs for care is also being challenged by a worldwide health human resource shortage. Governments have begun to address the growing costs of health care by introducing policies that are transferring responsibility for care from HCPs and the health care system to patients (Pomey et al., 2015). Patients are expected to manage and be responsible for their self-care. However, public preparation to assume this role has been limited. IPTs need to be charged with introducing programs to monitor how well these patients are managing their self-care (Orchard, 2015). As well, the roles patients assume in their self-care management are rarely discussed or studied in the published literature. Traditionally, patients are directed to participate in a standardized set of treatment protocols, whether these are needed or not, and left to attend to managing their own care (Orchard, 2015).

Patients with chronic diseases are required to manage their own care on a 24 hour 7 days per week basis and HCPs only interact with these patients at episodic intervals of time. In reality patients really are the ones who are 'in charge' of their ongoing care. The expertise patients gain is an important aspect that IPTs need to understand and build onto patients' overall plans of care. Therefore, patients need to become active in their own care and assume the role of being their 'own drivers of care' (Orchard, 2015). Moreover, if patients are to have full roles as equal participants with their HCPs in the planning, implementing, and evaluating of their care then

HCPs need to address how to strengthen IPCC care for those with chronic diseases (WHO, 2014). HCPs need to include patients in care delivery to better prepare them to manage their own care. Thus, interprofessional teamwork models and frameworks are needed to create opportunities for patients as team members taking on meaningful roles in their care.

The Canadian Interprofessional Health Collaborative's *National Interprofessional Competency Framework* recognizes the main goal of IPCC care and describes it as HCPs incorporating, seeking out and placing importance on the engagement and integration of patient input in the planning, implementing, evaluating of care/services (Bainbridge, Nasmith, Orchard, & Wood, 2010). This definition acknowledges that IPCC care is a partnership between HCPs and patients. Perhaps 'patients' needs to be relabeled to 'persons' in order to establish a more equalized relationship. However, in this study, the term 'patient' was still being used to reflect the predominant norm of how individuals are referred to within primary care teams (Herrick, 2005).

Szafran et al. (2018) in a cross-sectional survey of 565 patients addressing their access to team-based care, perceived benefits, and preferred HCP and team member roles in five family medicine academic teaching clinics in Edmonton, Alberta found only 44.1% of the participants felt that they had an active role on the team and could make decisions together with their HCPs about their care. However, the researchers did not provide a complete definition of what an active role was or entailed. As well, only 20.4% of participants felt that their role on the team should be following the treatment plan without any input into it. Next, Metersky and Schwind (2015), in a Narrative Inquiry qualitative study of three patients' experiences with interprofessional care within an Ontario, Canada acute care hospital unit, found patients wanted to be knowledgeable about their conditions and involved in monitoring and evaluating their

progress. Thus, present day patients seem to rely less on doctors to instruct them on how to act in relation to their disease(s) or health care (Metersky & Schwind, 2015). These trends provide some indication of patients being desirous of having active roles on teams. Advantages for patient involvement in their care have been cited by a number of authors who found when patients are able to assess their care progress and are more involved in their own decision-making, they experience an improved quality of life (Karazivan et al., 2015) and health outcomes (Goldman et al., 2015; Gucciardi, Espin, Morganti, & Dorado, 2016; Karazivan et al., 2015; Szafran et al., 2018) while HCPs experience increased satisfaction with the more personalized care they are able to deliver to their patients (Gucciardi et al., 2016).

While research on HCPs' perspectives and practices addressing teamwork within interprofessional care is thriving, the patients' perspective on teams is rarely conveyed with the exception of a few reported studies (Adams, Orchard, Houghton, & Ogrin, 2014; Ferguson, Ward, Card, Sheppard, & McMurtry, 2013; Metersky & Schwind, 2015; Pomey et al., 2015; Szafran et al., 2018). Even when authors focus on patient participation in their care, rarely are patient roles, and their collaboration with HCPs, mentioned. More often the emphasis is related to the patients' effectiveness in meeting the HCPs' prescribed treatment plan. There are only a few studies to date that have explored the roles of patients in IPTs (Bilodeau, Dubois, & Pepin, 2015; Ferguson et al., 2013; Martin, 2014; Martin & Finn, 2011; Phillips et al., 2014; Pomey et al., 2015; Szafran et al., 2018). Unfortunately, even within majority of these studies, minimal details, if reported, on the key requirements for successful integration of patient roles into teams were provided. As an example, in the Martin and Finn study (2011), the authors outlined four key elements required by patients to become active team members: a clear conceptualization of patient roles, required identity and skill set, feeling of being embedded in the social field of the

organization, and development of trust between HCPs and patients. However, the authors did not go into detail as to how these elements can materialize or be put into place. Overall, there is a gap in the literature reporting on patients' participatory involvement in their care within their IPTs, and the processes and conditions required to be in place for such involvement to take shape.

In summary, it is not enough to simply invite patients into IPTs (Pomey et al., 2015). Patients need to become team members in a meaningful way and be able to enact roles that will not only benefit their HCPs, but themselves. A greater understanding of the processes and conditions under which patients will feel comfortable assuming roles within IPCC care teams is critical to move forward in their care. First, to guide in a further understanding of IPCC care, definitions of its key concepts are needed. IPCC care and its related concepts require clear, specific and well-developed definitions for effective application in research and practice (Mikkelsen & Frederiksen, 2011). Upon this, an overview of this study and dissertation will be provided.

Definitions of Key Concepts

IPCC care is comprised of two separate, although highly complementary concepts – *IPC* and *patient-centred care (PCC)*. To begin, *IPC* is often variously identified through authors utilizing a myriad of terms (multiprofessional/disciplinary collaboration, transprofessional/disciplinary collaboration, and interdisciplinary collaboration). These terms are repeatedly used synonymously with one another; however, each represents varying degrees of collaboration. Thus, it is difficult to understand what authors define, describe, measure or evaluate. Leathard (1994) refers to this as a 'terminological quagmire' and requires clarity of term meanings.

Terms Related to Interprofessional Collaboration

Multiprofessional or multidisciplinary collaboration. Multiprofessional or multidisciplinary collaboration implies a number of HCPs representing a variety of disciplines who work independently on the same activity or patient case, but engage minimal, if any collaboration, communication or interaction with one another (Atwal & Caldwell, 2006; D'Amour, Ferrada-Videla, Rodriguez, & Beaulieu, 2005). In this type of collaboration, there is a hierarchical leadership structure among HCPs from a number of different professions who exhibit high levels of autonomy when working in parallel to one another; each HCP has their own objectives, tasks, and roles (Griffin, 1996).

Transdisciplinary or transprofessional collaboration. Transdisciplinary or transprofessional collaboration implies some boundary or disciplinal overlap occurring such as when an HCP takes over a role of another HCP on the team who is absent or not available (Choi & Pak, 2006). This overlap is generally of a short duration and does not occur to such an extent as within interdisciplinary collaboration (for example a meeting or a single consultation).

Interdisciplinary collaboration. Interdisciplinary collaboration occurs at the disciplinary level when a number of different HCPs come together to share in their skills, knowledge, and expertise equating to a blurring of boundaries (D'Amour et al., 2005; Mu & Royeen, 2004). Thus, the level of collaboration occurring is suggested to be in less depth than the level of collaboration within IPTs (Choi & Pak, 2006).

Interprofessional collaboration. The definitions of IPC vary and pose further impact on clarifying the distinction between IPC and the terms discussed above. These definitions often discuss IPC as being a group of HCPs coming together to deliver care to the patient, not in

collaboration with the patient. As an example, one of the more commonly cited definitions of IPC is that by Health Canada (2010, para. 3) as:

Working together with one or more members of the health care team where each make a unique contribution to achieving a common goal, enhancing the benefits for patients. Each individual contributes from within the limits of their scope of practice. It is a process for communication and decision-making that enables the separate and shared knowledge and skills of different care providers to synergistically influence the care provided through changed attitudes and behaviours, all the while emphasizing patient-centred goals and values.

However, as the aim of this study is to explore patient roles in IPTs, it would be more appropriate to select a definition of IPC that considers the patient and HCPs in some type of partnership with one another. Thus, whenever the term IPC is used in this study it connotes “a partnership between a team of HCPs and a client in a participatory, collaborative, and coordinated approach to shared decision-making around health and social issues,” (Orchard et al., 2005, p. 1).

Terms Related to and Definitions of Patient-centred Care

PCC has been described in the literature as a paradigm, a philosophy, a model of care, an approach to care, or as a practice-theory (Registered Nurses’ Association of Ontario [RNAO], 2015). The lack of uniformity around this concept and its associated dimensions has created a challenge for bridging the research-practice gap (RNAO, 2015). PCC is frequently cited as the main outcome of IPCC care with patients appearing at the ‘centre’ of care delivery and having distinct roles within their team (Bainbridge et al., 2010; D’ Amour et al., 2005; Moore, 2008). The term assigned to the entity with whom HCPs develop a therapeutic relationship with and partnership for health-related purposes varies across health and social care professions: person, consumer, client, resident, service user, and individual (RNAO, 2015). In addition, this term is

often coupled with variations used to describe the attributes of care delivery: -centred care, -focused care, -driven care, -oriented care, and -directed care (RNAO, 2015).

Although there are no broadly accepted definitions of PCC or agreements on its attributes, the Institute for Patient and Family-Centred Care (2012) identified the core concepts of PCC as being: respect and dignity, participation, information sharing and collaboration. In addition, Kitson, Marshall, Bassett, and Zeitz (2013) synthesized 60 articles across a number of health professions using a narrative review of core elements of PCC to try to find common definitions of the term. Three core themes were identified: *context of care delivery*, *patient participation and involvement*, and *relationship formed between HCPs and patients*. Each HCP still emphasized their own or different elements within the themes. A further integrative review, however, conducted by Sidani and Fox (2014) of 178 articles found there was consistency in conceptualization of PCC across health professions (Sidani & Fox, 2014; Sidani et al., 2015). Three essential elements seem to comprise PCC within the HCP – patient therapeutic relationship: *holistic*, *responsive* and *collaborative* care (Sidani & Fox, 2014; Sidani et al., 2015). Of specific interest to this study is the collaborative care component of PCC which is considered to be a “process of facilitating patients’ engagement in treatment decision-making and in carrying out treatment or self-management recommendations” (Sidani et al., 2015, p.12). The Institute for Patient and Family-Centered Care (2012) and Kitson et al. (2013) both also found the importance of the collaborative care component in PCC which requires supporting patient participation and involvement in shared decision-making and empowerment.

In line with the above findings in relation to the core elements of PCC, there is a significant number of theoretical frameworks associated with it. Examples of commonly cited frameworks include Mead and Bower’s (2010) patient-centeredness framework, McCormack and

McCance's (2006) person-centered nursing framework, Small and Small's (2011) patient- and family- centered nursing practice model, Gerteis, Edgman-Levitan, Daley, and Delbanco's (1993) patient-centered care model, and Stewart, Belle Brown, Weston, McWhinney, and Freeman's (1995) Patient-Centered Clinical Method model. The frameworks have originated from different settings (from acute or primary care), from varied perspectives (HCPs', patients', family/caregivers'), and present variations in the conceptualization of PCC.

Considering this terminological quagmire, the definition of PCC selected for this study stems from the consensus of PCC elements most commonly discussed in relation to collaborative care delivery: engagement and integration, seeking out, and incorporating patient input in designing, executing, and evaluating care and services (Bainbridge et al., 2010; Greene, Tuzzio, & Cherkin, 2012; Wolf, Lehman, Quinlin, Zulio, & Hoffman, 2008). In addition, in a paper by Vanier et al. (2013) a proposal was made to change the label of PCC to partnering in care with patients. Thus, whenever the term PCC is discussed in this study, it connotes patient partnership in care with HCPs versus care being done on or to patients.

Interprofessional Patient-centred Collaborative Care

The above findings in relation to IPC and PCC support Orchard's (2010) definition for IPCC care that this study will refer to:

A partnership between a team of health providers and a client where the client retains control over his/her care and is provided access to the knowledge and skills of team members to arrive at a realistic team shared plan of care and access to the resources to achieve the plan (p. 249).

Study Purpose

The purpose of this study was *to construct a framework to understand, from patients' and HCPs' perspectives, the conditions and processes required for patients to assume active participant roles in their care within IPTs*. It was further hoped that a deeper understanding of

the relationship between interprofessional care and PCC will be gained. The outcome of this work was proposed to enhance roles of patients in their own care with HCPs in IPTs, ultimately to improve patients' health outcomes.

Research Questions

This study sought to answer the following research questions:

- 1) What are patients' perspectives of the roles they can enact within IPTs and how do these relate to HCPs' perspectives of their patients' roles?
- 2) What processes can patients use to gain 'voice' around their care with HCPs?
- 3) What conditions within patients' relationships with HCPs allow for these processes to occur?

Methodology and Methods

This study used the constructivist grounded theory (CGT) approach by Charmaz (2006, 2014). CGT combines theoretical constructs of interpretivism, critical theory, symbolic interactionism and importantly social constructivism. Social constructivism draws on understanding the *context* and *culture* people are situated within to comprehend what is happening to them within their environment to develop knowledge based on people's shared understanding (Derry, 1999; Kim & Orey, 2001).

In this study, the context was primary health care and the methodology allowed for understanding the culture that shaped patient and HCP experiences and roles in primary health care IPTs. Specifically, in this study the intent was to obtain insights, through knowledge gained from participants, into the culture that was embedded within hidden networks, relationships, and situations from hierarchies of opportunity, communication, power, and status in the context of primary health care (Charmaz, 2006, 2014).

Ten patients and 10 HCPs were recruited from two primary care Family Health Teams (FHTs) in Southwestern Ontario, Canada. The inclusion criteria for patient participants were: have at least one chronic disease diagnosis; and be a patient within each participating FHT for greater than three months. The inclusion criteria for HCP participants were: come from a variety of professional groups; and be direct care providers to patients as part of IPTs for greater than three months. An individual semi-structured interview lasting 30-45 minutes was completed with each participant. Data were concurrently analyzed using a constant comparative analysis method, memoing, coding (line-by-line and in vivo) and categorizing to generate the concepts for the final framework. Individual interviews were followed-up with some participants, who were available, taking part in member-checking interviews, lasting 30-45 minutes on average. The purpose of the member-checking interviews was to allow study participants to review and verify study findings as well as provide feedback on the emerging framework. This process resulted in the identification of three roles that patients can enact on future IPTs in primary care as well as five processes and four conditions required for these role enactments to take shape.

The following section will address the contribution this study makes to the literature and research on patient participation in IPTs in primary care.

Contribution of the Study

Patients need to become members of their health care team in a meaningful way and be able to enact roles that will not only benefit their HCPs, but themselves. There is currently a lack of understanding of what patients consider as being meaningfully involved in their care within IPTs. At the same time, HCPs have yet to understand how patients can be included in teams. This study is one of the few studies that seeks collective perspectives of both patients and HCPs on patient roles on primary care IPTs. It identifies three roles, that originated from both patient

and HCP participants, that patients can enact in future interactions with HCPs in IPTs: (1) *expert of own health*; (2) *(co)decision-maker*; and (3) *self-manager*. It provides an understanding of evolving processes, which are actions that both patients and HCPs need to perform for patients to be able to enact any of the three roles. The five linear processes are: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*. As well, it outlines four non-linear conditions, or elements that need to be in place, for patients to take part in the processes. These are: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4) *readiness*. In summary, the resultant framework of this study provides an understanding of what is needed by patients and HCPs to transform current practice towards patient inclusion on IPTs in primary care. The next section provides an overview of the chapters in this dissertation.

Chapter Overviews

This dissertation follows an integrated article format as regulated by the School of Graduate and Postdoctoral Studies at The University of Western Ontario, London, Ontario. Thus, chapters 2 and 3 are separate manuscripts. As such, some repetition in content can be evident between the two chapters.

Chapter 2 is a manuscript entitled *Patient Roles within Interprofessional Teams: A Scoping Review* and is the first of two articles. This article provides details of a scoping review that was undertaken to gain a general understanding of the current state of literature on patient roles in IPTs. A total of 466 sources underwent title and abstract review to deem their relevance to the topic of patient roles within IPTs. One hundred and twenty-three sources were identified as having high potential for inclusion and moved forward to full text review. This resulted in 65 sources moving forward to having their reference lists reviewed leading to an additional 13 sources. As well, 11 government or health organization documents discussed within these

sources were listed in a separate classification to deem relevance for final inclusion. Thus, a total of 89 sources were used to support the scoping review. The scoping review was organized as follows: (1) patient roles in IPTs; (2) processes for patient role enactments; and (3) conditions for patients to be able to enact roles on IPTs.

Through exploring the available literature, it became apparent that there is currently a lack of understanding of what patients consider to be meaningful ways they can be involved in and the roles they can enact in their IPTs. HCPs require further clarity on how patients can be included in teams in a meaningful way with some arguing that patient inclusion only adds to their workload (Bilodeau et al., 2015; Martin & Finn, 2011; Phillips et al., 2014). Therefore, if patients are to become team members in future IPTs and involved in partnerships in their care delivery, the need to identify and provide a theoretical understanding of what patient roles could be comprised of, from both patients' and HCPs' perspectives, was needed.

Chapter 3 is a manuscript entitled *Patient Roles in Primary Care Interprofessional Teams: A Constructivist Grounded Theory of Patient and HCP Perspectives*. The first part of this article provides an overview of this study exploring patient roles on IPTs in primary care from the collective perspective of both patients and their HCPs. It discusses the three theories that underpin this study: Tajfel's Social Identity Theory (1979), Allport's Contact Hypothesis (1954) and Pettigrew's Intergroup Contact Theory (ICT) (1998). It then identifies the study participants who took part in a two-phase data collection/verification process using both semi-structured and member-checking interviews within two FHTs in the Southwestern Ontario area in Canada. Data collection and analysis procedures as well as how rigour and reflexivity were achieved in the study are outlined. The second part of the article presents the study findings in the form of the resultant framework. This framework helps to understand the context and culture

within which patients may become members of their health care teams in meaningful ways and be able to enact roles that will not only benefit their HCPs, but themselves. The findings are centred around three main concepts: (1) *patient roles*; (2) *processes*; and (3) *conditions*. Each one of these concepts has a number of sub-concepts associated with it. First, the *patient roles* concept is comprised of three sub-concepts with each of the sub-concepts having two categories/descriptors: (1) *expert of own health* – expressive and advisor; (2) *(co)decision-maker* – active voice and trusting; and (3) *self-manager* – advocate and evaluator of care. The *processes* concept is comprised of five sub-concepts: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*. The *conditions* concept is comprised of four sub-concepts: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4) *readiness*. The study findings in the form of the resultant framework offer an understanding of the evolving processes and conditions associated with IPT patient role enactment. When the three identified concepts (*patient roles*, *processes*, and *conditions*) are put into place as part of patient-HCP interactions in primary care IPTs there is potential that patients will be able to enact roles that are beneficial to themselves and their HCPs.

Chapter 4 is the last chapter of this dissertation. It provides an overview of how the two separate manuscripts (chapters 2 and 3) are connected. Then, it discusses how the findings of this study and the resultant framework address each one of the study research questions. First, the patient participants' perspectives of the roles they can enact within IPTs and how these related to HCP participants' perspectives are outlined. Second, the processes patients can use to gain 'voice' around their care with HCPs are explored in detail. Third, the conditions within patients' relationships with HCPs that allow for these processes to occur are explained. A summary of the resultant framework including how all of the three concepts (*patient roles*, *processes*, and *conditions*) are connected follows. Implications of the study findings for practice, education and

policy as well as suggestions for future research and how to move this work forward are outlined.

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CHAPTER 2:
PATIENT ROLES WITHIN INTERPROFESSIONAL TEAMS:
A SCOPING REVIEW

Introduction

Changes within the Canadian health care system make care delivery increasingly more challenging. Lengths of stay in hospitals are being reduced, and care is shifting to different locations, resulting in more frequent transitions for patients. As the health system strives to reduce costs and find efficiencies, the work of health care providers (HCPs), and the mix of providers in various settings, is altering. The confluence of these trends raises challenges for HCPs engaged in interprofessional care and collaboration (van Dongen et al., 2016). At the same time, there is a growing emphasis nationally on interprofessional teams (IPTs) within primary and acute care settings. In acute care, IPTs are said to lower health care expenditures (Mitchell, Parker, & Giles, 2011; Reeves, Abramovich, Rice, & Goldman, 2007; Shaw, 2008), decrease length of hospital stay (Cutler, Morecroft, Crey, & Kennedy, 2019; Shah, Forsythe, & Murray, 2018), enhance patient health outcomes (Adams & Feudale, 2018; Chesluk et al., 2015; Dunn, Cragg, Graham, Medves, & Gaboury, 2018; Sidani et al., 2018), and achieve better quality of care (Bosch & Mansell, 2015; Hepp et al., 2015;). In primary health care, IPTs are said to increase focus on prevention of illness (Centre for Addiction and Mental Health [CAMH], 2016; Gocan, Laplante, & Woodend, 2014) , decrease wait times (CAMH, 2016), increase patients' access to mental health services (CAMH, 2016; Gocan et al., 2014), enhance patients' health knowledge and self-care (CAMH, 2016; Gocan et al., 2014), increase HCP job satisfaction, reduce emergency room visits (CAMH, 2016) and offset costs in other parts of the healthcare system (CAMH, 2016; Gocan et al., 2014). Studies can be located highlighting the benefits of IPTs for patients; however, all too few have examined the roles of patients on such teams. It appears that patients are neither constantly included as team members nor often asked to take

part in planning, implementation, or evaluation of their own care (Bombard et al., 2018; Cutler et al., Orchard, 2010).

The lack of research on patients' roles within IPTs is believed to inhibit their full inclusion. The manner in which patients are included could be crucial to ensuring those experiences are positive, not discouraging. What is needed is an understanding of how patients can be included as team members and assume roles that are meaningful to them. The purpose of this scoping review of literature was to gain an understanding of how patient roles within health care IPTs have been reported to date.

Methods

The Arksey and O'Malley method (2005) was employed for this review. To guide the review, the following question was identified -- What is known about patient inclusion in IPTs and roles patients can enact in these teams from HCPs' and patients' perspectives? A number of search strategies were employed: (1) electronic databases; (2) broad searches and 'search-everything' functions; (3) reference lists; and (4) government and health organization documents. English language only, peer-reviewed articles with a 30-year time frame (2020-1990) as well as any relevant sources such as organizational documents and books that could be accessed electronically were included. Sources outside of this time frame and/or considered as applicable seminal books, studies, articles, and documents, discussed in any of the retrieved sources, were also considered for inclusion in the review.

The following electronic databases were searched: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ovid, Medline, ProQuest, and SCOPUS. In addition, to broaden the search, Google Scholar and the 'search everything' function of the Ryerson University and The University of Western Ontario library websites were used. The terms

interprofessional care, IPC, IPT, interprofessional teamwork, nurse-patient team relationships, FHTs were searched in combination with *history of, roles, role clarification, role identity, process(es), condition(s), patient engagement, patient inclusion, and patient/client/person centred care*. IPTs in all care settings were considered and not specific to primary care or community-based IPTs, which are deemed as being more stable in composition when compared to acute care teams. A total of 808 sources were retrieved using this search strategy; 342 duplicates were removed from the 808 sources, leaving 466 sources for further review.

The titles and/or abstracts of all 466 sources were read to deem their relevance to the review. Only sources that discussed patient roles on IPTs, the steps required for such role enactments to take shape or the conditions that need to be in place in IPTs for patients to enact roles on IPTs were retained for further review. This resulted in a total of 123 sources moving forward to full-text reviews to deem their suitability for inclusion. If a source focused on the following, it was excluded from inclusion in the review: (1) HCPs providing care to patients, with patients not being included as team members; (2) only HCPs' role clarification, identity, and creation were discussed; and/or (3) conference abstracts, letters to the editor, or opinion pieces on how patient roles in teams should look.

These criteria resulted in 65 sources being retained for inclusion in this scoping review. Finally, reference lists of these 65 sources were further reviewed for access to and inclusion of any additional sources not found through the initial search. This yielded 13 additional sources. Within these 78 sources any government or health organization documents discussed were listed in a separate classification to deem relevance for final inclusion. This yielded an extra 11 documents. Thus, a total of 89 sources are used to support the question of this scoping review (see Figure 2-1: PRISMA flow chart).

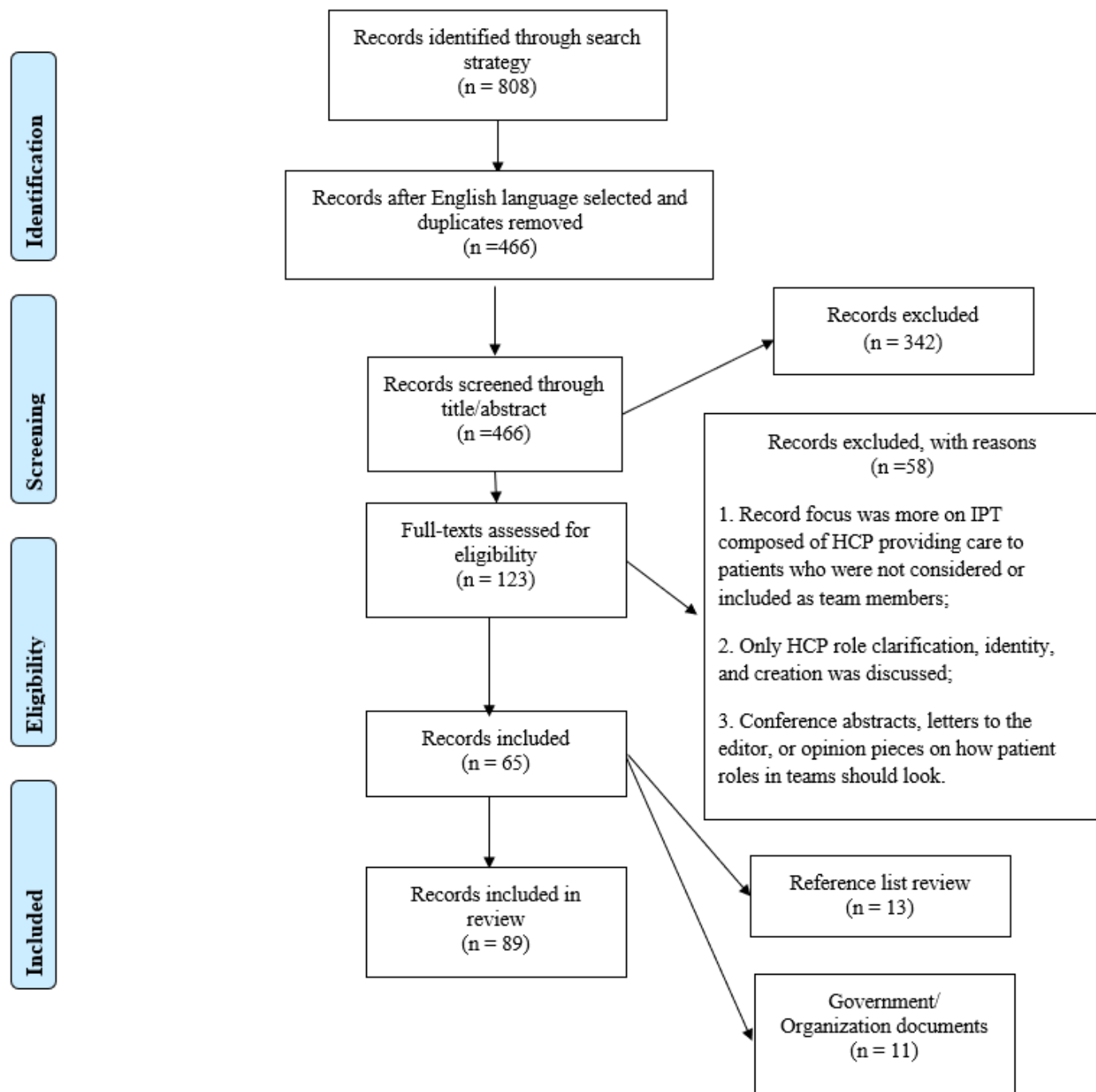


Figure 2-1: PRISMA flow chart

A ‘charting the data’ exercise, as described in Arksey and O’Malley (2005) was undertaken with these 89 sources including: (1) for research studies: author, year of publication, study aims/purpose, research question(s), study location, study population, methodology, and important results/outcomes; (2) for descriptive articles or books: author, year of publication, article/book purpose, and important discussion points pertaining to scoping review question; and (3) for government or organizational documents: author/organization, year of publication, topic of document, and important discussion points pertaining to scoping review question. These data tables can be made available upon request. A large number of the research-based articles came from Canada, USA, UK, Australia, and Sweden. This review is organized around three general themes: (1) patient roles in IPTs; (2) processes for patient role enactments; and (3) conditions for patients to be able to enact roles on IPTs.

Patient Roles in IPTs

Four concepts relate to this theme are presented: (1) evolution of teamwork; (2) evolution of patient involvement/participation in own care; (3) formation of IPTs in Canada; and (4) patient involvement/participation to patient roles on IPTs.

Evolution of Teamwork

The concept of teamwork has been around for over a century with the earliest medical journals addressing this topic in 1909 (Cooter, 2004). Initially, teamwork was centred on the doctor as team leader and all other players, mainly nurses and aids, serving in subordinate or ‘handmaiden’ roles (Frank, 2007; Oakley, 1984). This equated to physicians working uni-professionally while other team members were expected to carry out “his” instructions without any input on patient care (Henderson, 2006). Nursing roles evolved during World War II, as a result of physician shortages, as nurses took on many skills previously considered as

being within the physician's domain. A further shift occurred in the following decades with the introduction and expansion of new specialized HCP roles such as speech language pathologists and physiotherapists (Price, Doucet, & McGillis Hall, 2014). The professionalization of these new HCPs, along with others, prompted changes to traditional health care teams (Reeves, Nelson, & Zwarenstein, 2008; Weisz, 2005). Thus, care decisions would no longer be entirely dictated by physicians (Reeves et al., 2008). The intent of the historical "doctor-nurse game" – to borrow a term coined by Stein in 1967 – was to maintain as status quo the hierarchy that positioned medicine over nursing. This perspective was and is being challenged to foster more collaboration (Price et al., 2014). In the 1960s, the feminist and civil rights movements further challenged medicine's authority, resulting in a decline in public esteem for physicians, improving the status of women in the workplace and society, and expanding educational requirements for HCPs such as nurses (Sweet & Norman, 1995).

During this phase there were increasing calls for more team-based care, albeit still under physician leadership (Price et al., 2014). In industrialized societies like Canada, the expansion of post-secondary education led to a more educated public, and helped to foster consumer movements in the 1980s and 1990s (Price et al., 2014). The rising costs of health care led to government demands for accountability in health care delivery and efficiencies (Reeves et al., 2008). One response to these pressures was increased emphasis on evidence-based medicine, and randomized control trials as the primary evidence to guide health care for patients (Kaba & Sooriakumaran, 2007). This emphasis seemed to have an impact on team approaches as these were built on a model where patients were treated as external actors in their own care, while health care team members were encouraged to base treatment on external evidence, rather than patients' concerns or capacities. Finally, globalization and new public management movements,

with their emphasis on increasing productivity and lowering costs, have permeated the health care system in many countries, including Canada (Poochikian-Sarkissian et al., 2008).

Governments (and members of the public) are reluctant to endorse services that cost more and increase tax expenditures. In publicly funded health care systems, such as the one in Canada, this means 'doing more with less' financial and human resources. As a result of all of these trends, a growing number of patients are no longer satisfied with being told what to do by physicians and nurses, but are seeking input into their care decisions (Campbell, Stowe, & Ozanne, 2011; Metersky & Schwind, 2015; Politi et al., 2011). This trend is particularly emphasized by those living with chronic diseases who wish to 'own their own care', question treatments suggested, or request second opinions on a diagnosis (Ferguson, Ward, Card, Sheppard, & McMurtry, 2013).

Specifically, in Canada, the federal government and professional bodies such as the Canadian Nurses Association and the Canadian Medical Association, educators, researchers and even some HCPs began pushing for more patient inclusion in care as part of IPTs in the early 2010s (Cambell et al., 2011). Initially, tests of different models of patients' inclusive care were funded at the federal government level (Herbert, 2005). This funding was followed by funding from the Ontario provincial government for further project development through their HealthForceOntario Program that first emphasized interprofessional education (HealthForceOntario, 2010). This ensued in a further grant call for practice projects that culminated in the publication of what was termed the blueprint for action (HealthForceOntario, 2010). All of the above efforts were designed to determine how this type of care could be achieved. Although this discussion and modes of care centred on patients being more involved in IPTs, patient involvement in own care is not a novel idea.

Evolution of Patient Involvement/Participation in Own Care

Patient involvement in own care dates as far back as 1948, when the United Nations' International Declaration of Human Rights outlined the principles of equitable, free and just society (United Nations, 1948). Then, in 1973 the American Nurses Association (ANA) published its first ever Standards of Nursing Practice where it outlined the requirement for nursing actions to provide an opportunity for patients to participate in health promotion, maintenance and restoration (ANA, 2004). The World Health Organization (WHO) followed with its Alma-Ata Declaration proposing a social health model based on the premise that individuals have a right and responsibility to be involved in their own care delivery (WHO, 1978; Cahill, 1996; Gallant, Beaulieu, & Carnevale, 2002; Hook, 2006). Of the 134 countries that endorsed the Declaration, a large number used it to create healthy policies with a focus on patient involvement in health care and the elaboration of HCP and patient roles. Patient participation was able to quickly gain popularity at the time as there was increased dissatisfaction with paternalistic professionalism, centralized bureaucracy, and representative democracy (Cahill, 1996). This uptake of the concept was very evident in the UK where legislation was enacted by the government supporting this patient-based movement. Over the next decade, the UK Department of Health called for a number of initiatives to be in place to entice patients to participate in decision-making around their own care, and the planning and delivering of healthcare services (Fox, 2003; Hook, 2006).

Specifically, within this same timeframe in Canada, the LaLonde report of 1974 was released. In this report, public participation in care was projected as the future norm of practice due to the linkage suggested between patient health outcomes and lifestyle. This report highlighted the need to shift thinking from being centred on the disease individuals present with,

to health promotion and disease prevention through healthy behavior (Gallant et al., 2002). At the same time a number of social, economic and political changes were occurring; the general public was increasingly searching for more meaningful interactions, becoming better-educated, and more informed, as well as expressing desires to exercise their right to make decisions surrounding personal treatments and procedures (Frankel, 1994; Gallant et al., 2002). Thus, in 1988, the Canadian Nurses Association and the International Council of Nurses put forth the need for increased patient involvement in care and health system reform. This created the movement for change of the nurse-patient relationship to one of nurse and patient as partner in the relationship (Clarke, Beddome, & Whyte, 1993; Gallant et al., 2002). In research, relational care approaches to health (McWilliam, Stewart, Brown, Desai, & Coderre, 1996), well-being and empowerment (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; McWilliam, 2009; Piercy, 2000), and healing (Churchill & Schenck, 2008) care delivery can be found in earlier qualitative studies.

Currently, patient participation occurs at two of three levels: (1) policymaking; (2) organizational governance and design; and (3) direct care (Orchard, 2015). For example, patients can be found serving on quality improvement committees (Clavel, Pomey, & Ghadiri, 2019) or within recently established patient advisory committees at the organizational level and as invited participants at the government policy levels. Despite all the historical work on the movement for patient participation, a norm for inclusion of patients at the direct-care level has yet to occur widely in health systems (Orchard, 2015).

Formation of IPTs in Canada

In Canada, in 1969 a universal health insurance program jointly funded by federal, and provincial and territorial governments was adopted (Rosser, Colwill, Kasperski, & Wilson,

2011). Over the next decade, it appeared that this new health care system structure, with each province and territory being responsible for its own health care system, worked well. In the mid-1980s, however, family physicians, at that time the only primary care physician specialty in Canada, were struggling to meet demands of their practices and provide quality patient care (Rosser et al., 2011). With rising costs and minimal salary changes, family physicians felt pressured to see more patients in less amounts of time. Their ‘fee-for-service’ payment model seemed to reward high-volume practices at the expense of patient-centered care (PCC) (Rosser et al., 2011). Further pressure on primary care physicians came from the First Minister’s Health Accord in 2004 that established a goal of providing 50% of Canadians with 24 hours per seven days a week access to primary health care delivered by an IPT by 2011 (Gocan et al., 2014). At the time of this accord, only 10% of Canadian family physicians were working in IPT practices, with the majority being more multidisciplinary than interprofessional (Gocan et al., 2014). Thus, considerable effort was required to achieve the Accord goal.

In Ontario, Canada, the transition towards IPT delivery in primary health care settings had been occurring between 1999 and 2004 when a number of changes focused on these settings becoming more patient-centred. Examples of some of these changes are the publication of a number of documents by the College of Family Physicians’ Ontario Chapter and the election of a new political party in the province (Rosser et al., 2011). This political party introduced a new model to the Ontario’s health care landscape – Family Health Teams (FHTs).

Healthcare teams in Ontario was not a novel idea. In fact, Ontario introduced Community Health Centres in the 1980s to serve minority, low-income and rural populations at the time (Rosser et al., 2011). Other Ontario health care team initiatives in the community also included Family Health Networks (initiated in 2001) and Family Health Groups (initiated in 2003). In

Family Health Networks, physicians had responsibility over patients without the need to include other HCPs as part of the clinic structure; while Family Health Groups included a limited number of other HCPs (Rosser et al., 2011). FHTs essentially add a multitude of other HCPs, outside of the physician provider group, to assist the physician and expand provision of services (Rosser et al., 2011). The limitation of the FHT model related to funding. Physician salaries were not tied primarily to patient volumes. This allowed these clinics to offer a wide variety of services such as HCPs with enhanced scopes of practice (Gocan et al., 2014; Rosser et al., 2011), PCC (Gocan et al., 2014), various programs such as population-based health promotion and illness prevention initiatives (Gocan et al., 2014; Rosser et al., 2011), better community care for persons with chronic illnesses (Gocan et al., 2014; Rosser et al., 2011), extended care hours (Gocan et al., 2014), integrated electronic medical records (Rosser et al., 2011) and so on. The term interprofessional patient-centred collaborative (IPCC) care is often used as the label for the care delivery that occurred and continues to occur within Ontario's FHTs.

IPCC care promotes inclusion of patients into their own care decision-making within IPTs. The discussion for patient inclusion in their health care teams has been a policy emphasis of the present Canadian health care system. Today's health care systems are becoming more complex, faster paced, and difficult to maintain when challenged with patients having increasing number and type of chronic health and social conditions (van Dongen et al., 2016). Thus, current IPTs provide a means to involve a variety of individuals (patients and HCPs) who communicate, solve problems, make decisions, and create plans of care incorporating and utilizing the knowledge, skills, and expertise of all involved. More stable IPTs can be found in primary health care settings where turnover in team membership is not as high as in acute care. FHTs in Ontario are considered as being an ideal example of IPTs. However, each FHT varies in size, team

composition, spatial organization, governance models, range of programs offered (Gocan et al., 2014) and the level of IPCC care occurring. Quebec, three decades ago, introduced the first Interprofessional Community Health Care Centres. A study exploring team functioning at 150 of such Centres found that only levels of interprofessional collaboration occurred without a focus on the patient involvement in their care (Sicotte, D'Amour, & Moreault, 2002). Similar initiatives in other provinces also do not demonstrate the levels of collaboration intended to occur between HCPs and patients in IPTs. Therefore, although much rhetoric is found around IPTs in FHTs, the quest for full inclusion of patients in their care on IPTs is not fully realized or consistently applied.

In the early 2000's, D'Amour, Ferrada-Videla, Rodriguez, and Beaulieu (2005) presented an interprofessional framework again focusing on the healthcare team and organizational support for these teams. Through this process they found that available definitions of interprofessional care had the patient perspective be completely absent despite the notion that patients are seen as the ultimate reason for implementing collaborative practice. They reported:

...there was significant disagreement among the authors with respect to the role that the client should play on a health care team...Hence it is legitimate to ask if – according to a perspective under which the client is encouraged to take responsibility of his or her health, and where professional practice is based on a collaborative process – professionals are ready to question their professional “power” and start treating the client as a true partner (p. 126).

Within the last decade, a growing number of articles discuss patient care experiences (Beaver et al., 2009; Bilodeau, Dubois, & Pepin, 2015; Jones, Greenfield, & Jolly, 2009; Metersky & Schwind, 2015; Pomey, Ghadiri, Karazivan, Fernandez, & Clavel, 2015; Shaw, 2008; Szafran, Kennett, Bell & Green, 2018). In addition, a number of reports and reviews have called upon HCPs and researchers to engage patients in appropriate ways in their work (Barrett, Curran, Glynn, & Godwin, 2007; Enhancing Interdisciplinary Collaboration in Primary Health Care,

2006; Oandasan et al., 2004). The University of British Columbia's Centre for Health Services and Policy Research Report included patients' experiences within British Columbian emergency departments (Watson, Peterson, & Black, 2009). In Saskatchewan, the provincial government released its Patient First Strategy in 2009 and further revised this document again in 2015 to identify how patients experienced the health care system. The Australian Commission on Safety and Quality in Healthcare (2010) produced a document discussing measures of quality care in relation to PCC. All of these reports, although intended to discuss the way patients could become involved in their care within IPTs, only discussed the role of the patient as having 'a say' in their care. As Clancy states, "well intended initiatives often appear to fall short of collective aspirations that build a system responsible to the needs of patients and families" (2011, p. 390).

The Canadian Foundation for Health Care Improvement (formerly Health Services Research Foundation) and the Health Council of Canada participated in a synthesis of interprofessional and primary health care literature and found a lack of robustness about patient benefits from their participation in their care (Barrett et al., 2007). Most of the literature on patient experiences has largely focused on patient satisfaction ratings of care and services. Opportunities for patients to elaborate on or participate in more meaningful levels of experiential sharing are often absent (Edwards, 2002; Metersky & Schwind, 2015). Interestingly in much of this literature patients are asked to share their interprofessional care experiences, making the assumption that patients are involved as members in their IPTs. Thus, through this review it became evident that patients' voice as first-hand contributors to evidence of patient involvement in their care was minimal, if at all, sought.

Outside of Canada, a number of initiatives supporting patient participation in teams are reported. In the UK, patients acting as experts fully capable of managing significant aspects of

their care is part of the UK health system (Tattersall, 2002). In the USA, pre-licensure health profession programs are moving towards teaching patient interaction as being a professional value (Cottingham et al., 2008). In Canada, the ‘patients as partners’ approach was initially introduced in 2007 through the University of British Columbia’s Center for Health Professions. Patients have been used to guide students with skills to increase patient involvement and decision-making in the health care system as both a transformative approach and a philosophy through their provincial Ministry of Health (Bar, Grant, Asuri, & Holms, 2018). The Faculty of Medicine at the University of Montreal has a similar program, where a group of patient trainers are part of the faculty teaching students in the health sciences on patient lived experiences (Pomey et al., 2018; Vanier et al., 2013). Although these initiatives are a step in the right direction, patients becoming full partners and members of IPTs in their own health care is still not the norm in many health systems. It has been suggested that health professionals lack the trust that their patients have the capacity to be full participants in their own care. A trust relationship can only be developed if HCPs are willing to transfer their control over patient care to their patients (Ferguson et al., 2013).

Patient Involvement/Participation to Patient Roles in IPTs

Across the health care literature reviewed, collaboration and teamwork are seen as solutions to patients’ safe care and enhancement of their care experiences. If both are achieved, an increase in patient involvement in all aspects of their care may result (Martin & Finn, 2011). However, there is a paucity of studies on patient roles in IPTs, especially from patients’ perspectives. Martin and Finn (2011), in an evaluative study of teamwork carried out in the UK, focused on patient (service user) involvement in community-based project teams. They identified four key elements: (1) conceptualization of service user roles; (2) understanding of identity and

skill set they bring to the team; (3) feeling of being embedded in the social field of the organization; and (4) feeling a sense of trust between themselves and the HCPs (Martin & Finn, 2011). Further elements, obtained from two phases of a larger cross-sectional Australian study, were suggested by Phillips et al. (2014) that evaluated patient and carer experiences when ‘patient-as-professional’ role enactment occurred in interprofessional care interactions. Characteristics of this role included patients being able to: (1) discuss their health experiences/know their condition; (2) decide on appropriate plans of care with input from members of an IPT; (3) keep their own health record; and (4) identify both a health advocate and support network (Phillips et al., 2014). In a Canadian study using Constructivist Grounded Theory of 16 patients with chronic diseases, authors explored the value of patient interactions with HCPs (Pomey et al., 2015). They found that ‘patients’ ability to establish meaningful interactions with HCPs depended on their capacity to communicate their [own] experiential knowledge” (Pomey et al., 2015, p. 2). While these characteristics were identified, no further studies have been conducted to evaluate them further.

A recurrent theme related to patients needing a role within the team was discussed in an investigative study by Milewa, Valentine, and Calnan (1999) who addressed attitudes needed by HCPs for patient roles in teams to materialize. These included: (1) viewing patients as knowledge partners and less as lay persons; (2) sharing power and control over patient roles in providing input into teams; and (3) facilitating patient partnering roles with HCPs (Milewa et al., 1999). These attitudes continue to be part of the patient roles in IPTs discussions even two decades later. A further view of patient roles was presented in a USA discussion paper by Martin (2014) who identified five strategies that HCPs can use to involve patients in IPTs. These included: (1) providing support for patients in reduction of their risk factors for developing

further health diseases; (2) communicating/sharing information with them about the team and how it works; (3) partnering in formal and informal ways during care/treatment decision-making; (4) allowing patients access to their health records; and (5) setting goals and planning care with them to aid in managing their chronic diseases. While the roles identified provide a beginning perspective, they are presented solely from HCPs' perspectives. This implies control of patients rather than facilitating a collaborative partnership relationship. Thus, it seems HCPs' control, through exercising power and decision-making on what is to be shared with their patients, remains. In summary, patient inclusion in their care with HCPs remains associated with unequal power relationships between both parties and the degree of control to which HCPs are prepared to relinquish when entering into relationships with their patients. If there is a need to understand what the patient's role should be within IPTs, it is also key to know what processes need to be present to support the enactment of these roles.

Processes

No literature could be located that clearly articulated the required steps that patients and HCP need to undergo for successful patient role enactment on IPTs to occur. However, a number of processes were obtained across some of the literature retrieved for this review. These are grouped around the concepts of: (1) HCPs supporting patient involvement; (2) enhancing knowledge about enacting patient inclusion; (3) sharing power in relationships; and (4) developing trust in IPTs.

HCPs Supporting Patient Involvement

Across the literature reviewed, it is evident that HCPs must shift in their attitudes to embracing the value of shared decision-making with patients around what is important to patients to activate their participation on IPTs (Sahlsten, Larsson, Sjostrom, & Plos, 2008).

However, a major impediment to patient participation in IPTs is the absence of collaborative team and PCC training in HCPs' entry-to-practice educational programs (Lawlis, Anson, & Greenfield, 2014). Lawlis et al. (2014) conducted a literature review on the enablers and barriers for sustainable interprofessional education and found instructors and faculty members from across health professional programs did not know how to approach skill development for interprofessional and PCC teamwork.

Canada has formally moved nationally on interprofessional care and practice since the 2000s; the UK began this practice movement a decade before. In 2002, the Centre for Advancement of Interprofessional Education issued a definition of interprofessional education as teaching students "to learn with, from, and about each other" (Freeth, Hammick, Koppel, Reeves, & Barr, 2002, p. 12). At its onset, articles on interprofessional education were published in health care journals mostly consisting of expert opinions or anecdotal pieces of evidence about the type of teaching strategies that could be incorporated. There was a paucity of articles about evaluated outcomes of such strategies used for team teaching. Very limited number of articles evaluated outcomes of teaching HCPs about working with patients in IPTs, how to make their practice more patient-centred, or how to involve patients more in their care.

Enhancing Knowledge about Enacting Patient Inclusion

Another process identified is the need to enhance knowledge (patient and HCP) around patient participation and inclusion on IPTs. Even though IPCC practice has been proposed to address inclusion of patients in their care to improve their health outcomes, patients have not been aware that they could take part in IPCC teamwork or what roles they can assume on IPTs (Orchard, 2015). Confusion about how to achieve patient participation in IPCC care efforts exists among both, patients and HCPs. While it is theorized that having patients as part of IPTs can

empower them to be more involved with their own care, patients are still focusing on how to have a relationship solely with their physicians. They lack an understanding of team health care practice and HCP composition beyond the physician provider group (Cutler et al., 2019). In nursing, historically, care provision in all care contexts has been one of doing for patients stemming from the perspective of the expert model of helping (McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2001).

Sharing Power in Relationships

The next process is associated with working on limiting the imbalance of power between patients and HCP. Reported studies on power relationships in nurse-patient partnerships were reviewed (Brown, McWilliam, & Ward-Griffin, 2006; Florin, Ehrenberg, & Ehnfors, 2006; Henderson, 2003; Larsson, Sahlsten, Segesten, & Plos, 2011; Sahlsten, Larsson, Plos, & Lidercrona, 2005; Tobiano, Marshall, Bucknall, & Chaboyer, 2016; Upton et al., 2011; Wellard, Lillibridge, Beanland, & Lewis, 2003). In each of the studies, nurse participants reported holding positive views on partnering with patients during decision-making or when forming and working in care partnerships with their patients. However, when these same nurses were studied further through interviews or researcher observations of their practice, partnerships with patients were minimal or absent. For example, an interpretive phenomenological study conducted by Brown et al. (2006) within a Canadian home care programme sought to explore the perspectives of eight registered nurses on provision of client-centred care and the creation of client-empowering partnerships one year after the introduction of these concepts. Brown et al. (2006) found that nurses need to do more work around being mindful of how they use power inherent in their professional role and shift focus to sharing such power with their patients. In another example, Upton et al. (2011) conducted a qualitative, exploratory study of 20 UK nurses who had

experience with running asthma consultations with their patients in primary care. The authors reported finding a discrepancy between nurses' beliefs of partnering with patients during decision-making and what occurred in practice. Nurses used partnering relationships to further their own agenda as opposed to expressing equality between themselves and their patients (Upton et al., 2011).

Of the studies reviewed, a number were carried out in Australia in acute care producing results comparable to those found by Upton et al. in primary care (2011) (Henderson, 2003; Tobiano et al., 2016; Wellard et al., 2003). Henderson (2003) conducted a grounded theory study of 32 patients and 33 nurses from four acute care hospitals in Western Australia and reported observing a form of control that nurses attempted to exert over patients in their care. Nurses' reasons for this control related to perceiving themselves as 'knowing best' and patients as lacking medical knowledge. In a further Australian qualitative, interpretive study Wellard et al. (2003) focused on consumer participation in care and found nurses largely interacted with patients through asking patients to perform tasks, to make decisions on task types and when they would be delivered. Tobiano et al. (2016) conducted an observation study of two medical units at a public hospital in Australia of 28 nurse-patient dyads. Authors found that these nurse-patient relationships only promoted knowledge exchange and dialogue, but with less focus on patients being involved in care planning or self-care activities.

The remaining studies were also in acute care and located out in Sweden (Florin et al., 2006; Larsson et al., 2011; Sahlsten et al., 2005). In a comparative design study, carried out in an infectious disease ward of a regional hospital, 80 nurse-patient dyads were asked to complete a scale and a follow-up self-reporting questionnaire. Authors also found that nurses do not involve patients in care decisions as much as patients would prefer (Florin et al., 2006). Similarly,

Sahlsten et al. (2005), in a qualitative study using a Critical Incident Technique of 17 patients from a somatic inpatient care unit of an internal medical clinic, and Larsson et al. (2011) using focus group interviews with 31 nurses from five hospitals, found that nurse-patient partnerships do not utilize patients to their desired capacities.

Similar patterns were found amongst other health professions. A study by Bilodeau et al. (2015), exploring HCP, patient and family perspectives on IPCC care practice within cancer care in a Canadian teaching hospital, found three themes: ‘welcoming the person as a unique individual, but still requiring the patient to comply’, ‘paradoxical coexistence of patient-centred discourse and professional-centred practice’, and ‘triggering team collaboration with culmination of patient’s situation’. The reticence of HCPs to include patients as full team members with equal sharing of their expertise in living with their conditions seems to imply a lack of willingness by HCPs to share power within present health care environments. Power is synonymous with control and is often linked to trust development.

Developing Trust in IPTs

The last process found in the literature relates to formulation of trust in the IPT between all members involved, including patients and HCP. Three forms of needed trust have been identified by Newell and Swan (2000): (1) *companion* (having personal friendships and reciprocal exchanges with each other); (2) *competence* (perception of each other’s abilities to carry out assigned tasks); and (3) *commitment* (‘contractual agreement’ among members of an IPT entering into and continuing to facilitate collaborative teamwork). According to Martin and Finn (2011) however, these forms of trust have been difficult to achieve. The need to mitigate perceived power differentials between patients and their HCP team members is the first stage to gaining this trust (Martin & Finn, 2011), as the previous process from the review has articulated.

Furthermore, this process connects to the process of power sharing. Currently, patient participation in teams is seen as an ideal. Without patients participating meaningfully in their care, engagement in their ongoing health is not likely to reach the outcomes of quality care it advocates. Coulter and Ellins (2007) suggest success of patient participation in their care can only be realized with a buy-in from HCPs. This 'buy-in' must cause HCPs to gain trust in their patients and a new appreciation for the value of patients sharing their lived experiences of their daily lives to assist in shaping more effective care. Continuing in status quo practices needs to be challenged. It seems that HCPs hold the power to make the change to patient inclusion on teams. If this is the case then attention is needed in fully embracing a 'new' patient-HCP relationship and working with patients to build their own capacities to overcome barriers to their own self-care (Bilodeau et al., 2015). Lastly, the literature centred around the conditions, or things that need to be in place, for successful patient role enactments to occur is presented.

Conditions

Similar to processes, it was difficult to find literature that identified conditions needed to be in place for successful patient role enactment on IPTs to occur. Thus, the conditions are discussed as a whole as opposed to broken down into separate themes.

Participation requires two elements: the act of participating and the state of being related to a larger whole (Merriam-Webster Dictionary, n.d.) such as the IPT. Specifically, within nursing, participation involves the following conditions that need to be in place: established relationship; surrendering of some power or control by the nurse; shared information and knowledge; and active mutual engagement in activities (Sahlsten, Larsson, Sjostrom, & Plos, 2008). Gittell, Godfrey, and Thistlethwaite (2013) and Henderson (2000) suggest patient participation means taking patient opinions into consideration, and treating patients as

individuals. Tutton (2005) adds patient participation necessitates understanding, facilitation, partnership and emotional work with their HCPs.

While patient participation literature discusses patients wanting to be involved in discussions and decisions surrounding their care (Bokhour et al., 2009; Coulter, 2012; Ferguson et al., 2013; Vranceanu, Cooper, & Ring, 2009), it is not clear whether this type of participation stems from patients' perspectives. Increased collaboration between HCPs and patients has been linked to positive care outcomes such as greater adherence to advice (Bissell, May, & Noyce, 2004); sharing in responsibility, power and decision-making (Carman et al., 2013); increase in self-care management (Barello, Graffigna, & Vegni, 2012); and increase in motivation for behavioural change (Carman et al., 2013). However, the impact of patient participation on their health outcomes is reported in the context of treatment adherence (thus, from the HCP's perspectives) and rarely on aspects of importance to patients themselves such as their health outcomes and quality of life. When such involvement occurs, it is theorized to result in increased patient satisfaction and potential for positive organizational changes (Crawford et al., 2002; Howe, 2006). HCPs suggest patient involvement is reported to result in positive consequences for patients such as care safety (Clancy, 2011). Despite these reported benefits, widespread inclusion or participation of patients is evident in neither research studies nor as the norm of practice (Orchard & Bainbridge, 2015).

Further conditions stem from differences in attitudes and worldviews, as well as length of time it takes and power relationships as these have been cited by patients as interfering with their participation (Fox & Reeves, 2015). Attitudinal differences include cultural barriers (professional defensiveness) (Howe, 2006) and other conditions at the intrapersonal level (physical and mental illness; psychological vulnerability and pain) (Orchard & Bainbridge, 2015; Fox & Reeves,

2015), and interpersonal level (effective communication; listening; open and honest interaction) (Gittell et al., 2013) impact participation. Professional defensiveness enacted through emotional distancing, negative attitudes, and professional resistance is reported to create a major barrier to both, patient participation and empowerment (Howe, 2006). Despite these barriers, there is general agreement that benefits of patient participation still outweigh the above barriers. In summary, for true patient participation to occur a number of conditions need to be in place in order for patients to be included in all aspects of care design and delivery leading to meaningful patient empowerment (Gittell et al., 2013).

Conclusion

In summary, this scoping review of the available literature, provided insight into the current lack of understanding of what patients believe are meaningful ways they can be involved in and/or the roles they can enact within IPTs. HCPs have yet to understand how their patients can be included in teams in meaningful ways (Bilodeau et al., 2015; Martin & Finn, 2011; Phillips et al., 2014). Without having a clear understanding of what roles patients can enact within IPTs, there is a risk that future IPTs formed with HCPs and patients as partners in their direct care will not succeed. Therefore, to achieve health system policy directives for patient inclusion, a theoretical understanding and framework are needed to identify roles, processes and conditions required for patients to assume active roles in IPTs from the collective perspectives of patients and their HCPs.

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CHAPTER 3:
PATIENT ROLES IN PRIMARY CARE INTERPROFESSIONAL TEAMS:
A CONSTRUCTIVIST GROUNDED THEORY OF PATIENT AND HEALTH CARE
PROVIDER PERSPECTIVES

Introduction

A scoping review of literature on patient roles in interprofessional teams (IPTs) revealed that there is minimal information available on patient roles and how these roles are enacted on IPTs (Metersky, Orchard, Hurlock-Chorostecki, & Adams, 2020). With the current rapid expansions to medical knowledge and technology as well as the growing chronicity of diseases, health care providers (HCP) are increasingly called upon to work together within IPTs to provide comprehensive care to their patients. IPTs have been depicted as being able to enhance patient health outcomes (Adams & Feudale, 2018; Chesluk et al., 2015; Dunn, Cragg, Graham, Medves, & Gaboury, 2018; Sidani et al., 2018) and increase patient satisfaction with care (Adams & Feudale, 2018; Cutler, Morecroft, Carey, & Kennedy, 2019; Dunn et al., 2018; Sidani et al., 2018), while decreasing hospital readmission rates (Shah, Forsythe, & Murray, 2018). However, there is little evidence on how to include patients in these teams to support their disease monitoring and management (Metersky et al., 2020). The purpose of this Constructivist Grounded Theory (CGT) study was to construct a framework to provide an interpretive understanding, from patients' and HCPs' perspectives, of the conditions and processes required for patients to assume active participatory roles in their care within primary care IPTs.

Background and Significance

The World Health Organization (WHO) reported that one-third of the world's population is suffering from a type of chronic disease such as cancer, cardiovascular disease, chronic respiratory disease and/or diabetes (2014). These four diseases alone are responsible for 80% of all premature noncommunicable disease deaths worldwide (WHO, 2018). It is projected that in 2020, chronic diseases will be contributing to 73% of all deaths and 60% of global burden of disease (WHO, 2019). Although these statistics will likely change due to the current pandemic

related to the coronavirus disease experienced globally, to address these projections the WHO advocated for the provision of interprofessional collaborative patient-centred (IPCC) team-based care for chronic and complex diseases (2010).

In 2017, the national health care expenditure by Canadian territorial and provincial governments was \$6,082 per person (Canadian Institute for Health Information [CIHI], 2018a) and by 2018 it totaled to \$253.5 billion (\$6,839 per person) (CIHI, 2019). While health care costs continue to rise, governments have focused on the growing costs of health care by introducing policies of transferring responsibility for care from nursing, other health care providers (HCP)s and the health care system to patients and their families (CIHI, 2018b; Fox & Reeves, 2015; Shaw, 2008).

The capacity of health care systems to meet the growing needs for people with chronic disease(s) is being challenged by both increasing demand for services and a nursing and health human resource shortage (van Dongen et al., 2017a). A greater emphasis has been placed on patients to assume more responsibility for managing their own self-care. However, their preparation to assume this role has been limited and there is a paucity of studies related to patients' own enactment of their self-care (Orchard, 2015; Szafran, Kennett, Bell, & Green, 2018). When authors have focused on patient participation in their own care, rarely are patients', nurses' or other HCPs' shared perspectives within IPTs mentioned. More commonly the emphasis is on patients' effectiveness in meeting a prescribed treatment plan. Only a small number of studies located have explored patients' roles in IPTs (Bilodeau, Dubois, & Pepin, 2015; Ferguson, Ward, Card, Sheppard, & McMurtry, 2013; Martin, 2014; Martin & Finn, 2011; Phillips et al., 2014; Pomey, Ghadiri, Karazivan, Fernandez, & Clavel, 2015; Szafran et al., 2018). The majority of studies found either did not provided in depth detail about the patient's

role or did not outline key requirements for successfully preparing patients for integration into IPTs (Bilodeau et al., 2015; Ferguson et al., 2013; Martin, 2014; Martin & Finn, 2011; Phillips et al., 2014; Pomey et al., 2015; Szafran et al., 2018). Only one study, a CGT by Pomey et al. (2015) carried out in Montreal, Canada explored 16 patients' views of their engagement practices about their role with HCPs. Three engagement practices were identified by patient participants: continuous learning, assessment and adaptation. While these practices are helpful, they do not specifically provide insight into the actual roles, processes, and conditions required for patients to gain full participation with their HCPs as part of IPTs. Thus, the need to identify patients roles within primary care IPTs is vital to develop an understanding how patients can be more involved in their own care.

For the purposes of this study an IPT is a team comprised of nurses (both registered nurses and nurse practitioners) and other social and health care providers (physicians, social workers, physiotherapists, occupational therapists, spiritual care providers and so on) who interact and work together with each other and the patient to enhance the patient's health outcomes (Orchard, 2010). In Canada, an emphasis has been placed on creation of IPTs within both primary and acute care settings. Outcomes of IPTs have been reported to lower health care expenditures (Brandt, Lutfiyya, King, & Chioreso, 2014; Mitchell, Parker, & Giles, 2011; Ulrich, Homberg, Karstens, & Mahler, 2019), decrease length of hospital stay (Mitchell et al., 2011; Ulrich et al., 2019), enhance patient health outcomes (Brandt et al., 2014; Ulrich et al., 2019), and achieve better quality and delivery of care (Shaw, 2008; Ulrich et al., 2019). However, these same IPTs and their members are less likely to communicate effectively with and support inclusion of patients as team members and active participants in planning, delivery, and evaluation of their own care (Bombard et al., 2018; Cutler et al., 2019). Pomey et al. (2015)

stressed it is not enough to invite patients into IPTs. Patients need to become members of IPTs where their voices are valued and they are able to enact roles that reflect meaningful inclusion.

While patient participation literature discusses patients wanting to be involved in decisions surrounding their care (Coulter, 2012; Ferguson et al., 2013; Metersky & Schwind, 2015; Szafran et al., 2018; van Dongen et al., 2017a) the parameters of such participation, especially from patients' perspectives, are not reported in detail. Although increased collaboration between HCPs and patients has been linked to positive care outcomes such as: greater adherence to advice (Bissell, May, & Noyce, 2004; Szafran et al., 2018); increase in self-care management (Barello, Graffigna, & Vegni, 2012; Szafran et al., 2018); and increase in motivation for behavioural change (Shortus, Kemp, McKenzie, & Harris, 2013), what health outcomes occurred as a result were not reported. It is theorized that patients' involvement in their own care will result in increased patient satisfaction and potentially bring positive organizational changes (Crawford et al., 2002; Howe, 2006). Despite these reported benefits, widespread inclusion or participation of patients in their IPTs has neither been and nor continues to be the norm of practice (Orchard & Bainbridge, 2015; Szafran et al., 2018).

Most patients with chronic disease(s) living within their communities are required to manage their own care 24 hours per day and seven days per week as patient interactions with their HCP are usually comprised of short episodic intervals of time. In reality it is patients who are 'in charge' of their ongoing care. Thus, patients need to develop their own expertise in their lived experience with their chronic disease(s). Given the above reality, effective health outcomes are likely to only be achieved when IPT members gain an understanding of and build onto the patients' lived experience in setting shared goals for the patient's overall care plan. Moreover, if patients are to have full roles as equal participants with HCPs in planning, implementation, and

evaluation of their care, then HCPs need to address how to strengthen IPCC care for those with health and social issues, which are often combined with chronic diseases (WHO, 2014). Thus, the need for HCPs to include patients in care delivery as partners necessitates patients to be prepared to manage their own care. Managing their own care also requires them to assume IPT roles to achieve the intended benefits of IPCC care.

To achieve the above, a greater understanding of the conditions and processes under which patients feel comfortable assuming roles within IPTs is critical to move forward in their self-care. The purpose of this study was *to construct a framework to understand, from patients' and HCPs' perspectives, the conditions and processes required for patients to assume roles of active participants in their care within primary care IPTs*. This paper reports on the study findings and presents the resultant framework on patient roles within IPTs in primary care.

Theoretical Framework

This study is underpinned by Tajfel's Social Identity Theory (1979), Allport's Contact Hypothesis (1954), and Pettigrew's Intergroup Contact Theory (ICT) (1998).

To begin, Social Identity Theory by Tajfel (1979) applies to IPT members in that both HCPs and patients develop their identity based on societal norms. These norms impact on the roles that patients and HCPs play as they interact with each other in IPTs. In the past, patients were assigned to a 'sick role' that allowed them to be passive and for HCPs to take control over their care (Parsons, 1951). However, at present, the health system is shifting away from the patient 'sick role' to encompass a shared role with their HCPs especially for those living and functioning with chronic diseases (Ferguson et al., 2013). To meet this new social identity, there is a need for patients to assume active roles with their own self-care, but a concomitant shift into these roles has yet to occur.

The longstanding educational preparation and socialization of HCPs within their own profession has provided a social identity for each professional that creates a societal valuing of them as experts who are to direct how people in their society should take care of themselves. Social Identity Theory (Tajfel, 1979) supports how profession-specific cohesive in-groups are created, and exclude those outside of their own profession (as out-group members) as being less expert than themselves (Tajfel, 1979). Until recently, limited attention was paid to preparing these varied professionals for interprofessional teamwork. Thus, HCP socialization resulted in cohesiveness within HCPs' own professional groups and led each professional group to view other team members as the out-group members leading to a level of distrust between these groupings.

To address this phenomena, Allport's Contact Hypothesis (1954) has been considered to be applicable in transforming uni-professional to interprofessional practice. This transformation requires HCPs to learn to work together as interprofessional groups. Allport (1954) specified four conditions that need to be present: (1) individual members need to hold equal status within the team and/or particular situation; (2) team members must be able to establish and share common goals; (3) all members need to display intergroup cooperation; and (4) the team needs to have authoritative, institutional and/or organizational support. For equal status within an IPT to occur, each participant needs to neither experience an inferior nor superior position amongst the team members. Some authors, since Allport (1954), have argued that equal team status should be present even before individuals come into a team (Brewer & Kramer, 1985; Pettigrew, 1998), while others argue for the meaning of 'equal status' (MacNaughton, Chreim, & Bourgeault, 2013). For all team members to succeed, interdependent effort overcoming intergroup competition needs to be present (Bettencourt, Brewer, Rogers-Croak, & Miller, 1992).

To achieve valuing of each other in the IPT all members need to learn to share in and work towards a common goal. In summary, the conditions for intergroup contact necessitate cooperative behaviors among team members arising from a valuing of each other's professional roles to support shared work in achieving common goals.

An ICT is built on the premise that bringing individuals together in a team¹ provides the best means for reducing hostilities, but contact by itself is not enough for trust to be developed within the team (Hewstone & Brown, 1986). Pettigrew (1998) identified four processes of change that occur as an outcome of intergroup contact: (1) learning about the out-group; (2) changing behavior; (3) generating affective ties; and (4) in-group reappraisal. Thus, achieving in-group status within the IPT is then challenged further by inclusion of patients (who represent out-group members) into their team. To include patients into IPTs means that the in-group (HCPs) need to know more about the out-group (patients) to create attitudinal shifts and collaborative work to occur between them. This includes how patients are viewed as team members, and the contributions they can make towards team goal fulfillment. Patients who have long accepted the expert role of their HCPs, directed treatments, and care, will be challenged to become in-charge of their own care. Pettigrew and Tropp (2008) identified three mediators to intergroup contact – anxiety, empathy and respect, and clarification of role. Thus, moving into an IPT as an in-group member likely will create anxiety about entering into interactions with those

¹ Although this section uses the terms 'groups' and 'teams' interchangeably, since ICT talks about groups; 'teams' is the term used in this study.

they do not know. Islam and Hewstone (1993) suggest that anxiety is often present in initial encounters between patients and HCPs. In turn, this anxiety about participating in their care with HCPs is likely to create hesitancy in willingness to be full members of their care team. However, as ICT posits, through continued contact between the two groups, patient anxiety with participating in an IPT can often be reduced. HCP team members' willingness to welcome patients' contributions to team discussions can demonstrate respect for patients' viewpoints, and display empathy towards patients. When provided, it is believed that a beginning sense of belonging for patients as in-group members can occur. If followed by HCPs helping patients identify the roles they can assume in their care, it is believed to generate affective ties. These affective ties are suggested to include learning about and valuing each other within their intergroup. When both in-group and out-group members (HCPs and patients) achieve the above it is theorized a reappraisal on how they feel about each other is likely to occur, leading to intergroup contact and feelings of being an in-group by all group members.

The three mediators identified by Pettigrew and Tropp (2008) align well with the findings from the Martin and Finn's (2011) evaluative study of UK teamwork which reported patients (service users) entering a team need to feel comfortable and have previous knowledge of, at least, some of the team members to reduce their anxiety of feeling less qualified than the HCPs. Patients need to be treated with openness and respect, and have their roles in the team clearly articulated. Thus, for optimal intergroup contact to occur in IPTs patients (the out-group) and HCPs (the in-group), must attend to all three mediators.

In this study, Social Identity Theory helped in understanding how societal norms and the IPT culture within study sites shaped patients' identity development with HCPs. The Contact Hypothesis aided in comprehending the conditions required for including patients on IPTs.

Overall, the ICT processes and mediators provided a framework for analysis of patients' and HCPs' perspectives on patient roles within their IPTs. Thus, using the combination of Social Identity Theory, ICT and Contact Hypothesis provided a complete theoretical lens for exploring patient roles in IPTs from both, the patients' and HCPs' perspectives. Furthermore, these theories assisted in exploring what patient roles in IPTs were present, and learning about the *processes* and *conditions* that needed to be in place for patients to embody the feelings of being an in-group during their partnering with the IPTs HCPs.

Methodology and Methods

This study employed the Constructivist Grounded Theory (CGT) approach by Charmaz (2006, 2014). CGT combines theoretical constructs of interpretivism, critical theory, symbolic interactionism and social constructivism. Social constructivism draws on understanding the *context* and *culture* people are situated in to comprehend what is happening to them within their environment in order to develop knowledge based on people's shared understanding (Derry, 1999; Kim & Orey, 2001). In this study, the *context* was primary health care Family Health Teams (FHT) and *culture* was associated with IPT interactions between patients and HCPs at the point of care. This methodology allows for understanding the *conditions* and *processes* existing in the current IPT culture that shape patient and HCP experiences and roles in IPTs. Specifically, in this study the intent was to obtain insight, through knowledge gained from participants, into the culture that is embedded within hidden networks, relationships and situations within hierarchies of *opportunity*, *communication*, *power* and *status* in the context of primary health care IPTs (Charmaz, 2006, 2014).

Settings

Two FHT sites within the Southwestern Ontario area were accessed. Utilizing two different care delivery sites allowed for gathering of a broader perspective on social constructs that could impact on how IPTs function and/or how patient roles are depicted within them, and whether these vary across these two settings. Forty-five executive directors from eligible FHTs in Southwestern Ontario, Canada were emailed a study information recruitment letter (see Appendix A). This process took six months to complete as some FHTs required two to three follow-up emails/phone calls, extensive details on the study, multiple in-person meetings, and board member meeting presentations before they considered study participation. The first two sites that displayed interest (see Appendix B1 and B2 for FHT willingness to participate letters) were utilized for participant recruitment. The FHTs are considered as being large and mid-size respectively. Combined, they have over 178,000 patients on their roster with 228 HCPs delivering services to these patients.

Sampling

Consistent with CGT methodology, purposive sampling was utilized for initial participant recruitment as it allows for selection of study participants who can provide the richest data on the topic of interest from their first-hand experience and knowledge (Charmaz, 2006, 2014). Subsequently, theoretical sampling was used to achieve theoretical saturation (Charmaz, 2006, 2014). Constant comparative analysis method allowed concepts and categories to emerge from study participants' interview transcripts. Theoretical validation occurred in the form of reaching out to the initial set of study participants to invite them to take part in a member-checking interview.

The CGT approach is a means to gain an understanding of emergent data related to the research questions. Therefore, the sample size reflects the number of participants required to provide breadth of data needed to fulfill the study purpose and answer the research questions (Charmaz, 2006, 2014). To achieve data saturation, Charmaz (2006, 2014) noted that 25 participants could be sufficient, while Stern (2007) suggested anywhere from 20 to 30 interviews or observation hours while Guest, Bunce, and Johnson (2006) suggested as few as 12 participants may be sufficient. The starting study sample size was 20 participants. Data saturation in this study occurred after 16 participant interviews. Thus, no additional participants were recruited.

Study participants. HCP participants were recruited first. The FHTs' executive directors or physician leads distributed the recruitment poster to all of their respective HCPs (see Appendix C: HCP study recruitment poster). They also instructed the HCPs to either post a poster in their work areas or distribute it to patients they interacted with (see Appendix D: patient study recruitment poster). If interested, HCPs instructed the patients to contact the study investigator directly for further study details. Patients were reminded that no aspect of their care with the FHT would be impacted based on whether they elected to participate or not.

This study sought to explore HCPs' and patients' perspectives. Thus, the first five patients and five HCP participants who expressed an interest in the study, fit the inclusion criteria and consented were recruited from each of the two FHTs for a total of 20 participants (see Appendix E: HCP letter of information and consent form and Appendix F: patient letter of information and consent form).

Inclusion criteria. The inclusion criteria for both HCP and patient participants were: over 18 years of age; male or female; and able to read and understand English. In

addition, patient participants must: (1) have had a chronic disease(s) diagnosis^{2,3}; (2) been patients of the FHT for at least three months; and (3) have had an ongoing contact with HCPs as part of an IPT. The HCP participant inclusion criteria were: working as part of the FHT's IPT for greater than three months; and coming from a variety of professional groups (i.e. medicine, nursing, pharmacy, social work, nutrition, and respiratory therapy).

A total of 10 HCPs were recruited from the two participating FHTs. The HCPs that took part included: nurses, social workers, dietitians, pharmacists, a nurse practitioner and a respiratory therapist. Demographically, a total of two male and eight female HCPs ranging from six – 39 years of work experience and two – 11 years as working part of their current FHT took part.

A total of 10 patients (five from each FHT) were recruited. All patient participants were over 18 years of age with a range of 46 – 77 years of age, and could read and understand English. One male and nine females, who had a chronic disease(s) diagnosis, and attended the FHT for at least three months with an ongoing contact with the IPT HCPs took part. Patient participants presented with a number of chronic diseases such as diabetes, chronic obstructive pulmonary disease, arthritis, hypertension, and Parkinson Disease.

² The WHO (2014) criteria for what constitutes a chronic disease were used. Thus, individuals who have experienced a disease(s) of long duration (greater than three months) with a generally slow progression were invited to participate.

³ The rationale behind recruiting participants with chronic disease(s) is that there is a greater chance that these individuals know their disease(s) and how to manage it more than patients who attend their FHT for acute issues.

Data Collection

In this CGT, once patient and HCP participants were recruited and informed consent obtained, a two-phase data collection approach was utilized: individual interviews and member-checking interviews.

Phase 1: Individual interviews with HCPs/patients. All interviews with HCPs occurred either in their private offices or in the FHTs' meeting rooms. The location was selected to provide privacy and openness for sharing their feelings and/or emotions about their patients' participation in their IPT. Similar interview location (a private FHT meeting room) and conditions were provided for patients. Four patient participants, who were not able to travel due to health reasons or lack of access to transportation services, participated in a telephone interview. A total of 20 individual interviews (five patient and five HCP at each FHT) were conducted using a semi-structured interview guide and digitally recorded. The interview guide contained generative questions on patient participation in the FHT's IPT. Probing questions were also utilized, but only in rare instances where discussion stalled or further depth of information was needed (see Appendix G for the initial HCP interview guide and Appendix H for the initial patient interview guide). Each individual interview lasted approximately 30-45 minutes.

Transcripts. All phase 1 recorded interviews were transcribed using a secure online transcription service following each interview.

Data analysis was conducted following each interview. This process influenced the order and type of questions that were asked in subsequent interviews causing modifications to the interview guide to occur over time. For example, in an earlier HCP interview the idea of compensation for service was raised. Thus, subsequent HCP interviews brought forth this idea to explore what other HCPs thought on this topic.

Phase 2: Follow-up member-checking interviews with HCPs/patients. Six to eight months after phase 1, follow-up member-checking interviews occurred (see Appendix I for HCP member-checking interview guide and Appendix J for patient member-checking interview guide). All participants who took part in phase 1 of the study were invited to take part in a 30 to 45-minute member-checking interview as a group or individually. The purpose of the member-checking interview was to provide participants with an opportunity to review the preliminary framework formulated from participants' interviews collected in phase 1. This was to ensure that the preliminary framework accurately represented HCPs' and patients' perspectives on patient roles in IPTs. Although the study plan was to hold two focus groups (one with HCP participants and one with patient participants) only four patient and four HCP participants agreed to take part in phase 2 and not all of their schedules allowed for a collective focus group. However, the two FHT sites were represented by both patient and HCP participants. Patient participants took part in a three-participant member-checking interview meeting and one individual (researcher-participant) member-checking interview, while HCP participants took part in a two-participant member-checking interview meeting and two individual member-checking interviews. All of the patient follow-ups occurred in a meeting room at one of the FHTs, while all HCP follow-ups occurred via the online meeting platform ZOOM (www.zoom.us) from the convenience of HCPs' private work or home offices.

Data Analysis

Data collection and analysis occurred iteratively; as one interview was completed, its analysis commenced, when possible, prior to initiation of the subsequent interview. Similar to data collection, there were two phases to the data analysis. During phase 1, patient and HCP

individual interviews were analyzed using the constant comparative analysis method. Phase 2 analysis included looking at data from the follow-up member-checking interviews.

Phase 1: Analysis of individual interviews with HCPs and patients. Once transcribed, data analysis of HCP and patient individual interviews included the following processes: memoing, coding using constant comparative analysis method, construction of tentative categories, raising such categories to major theoretical categories and main concept(s), and finally formation of the framework. At each of these processes, data were initially analyzed as independent groupings; patient and HCP perspectives were examined separately. Subsequently, these two data sets were compared for commonalities, differences and other variations in participants' perspectives. Thus, harmonization of codes, categories and concepts from each grouping, and refining as needed took place to gain depth of the analysis and subsequent framework generation.

Memoing. Memoing was used throughout the entire data collection process as a major methodological study tool. It provided a means for engagement and questioning of ideas to occur as the abstraction and depth of ideas increased throughout the study (Charmaz, 2006, 2014). At the conclusion of each interview brief memos were written related to any concepts, phrases, comments or key words that emerged throughout the discussion, including any distractions, and cultural or contextual influences. Each memo was dated and titled to reflect its meaning to the study questions.

Coding. Once an interview was transcribed, initial coding of the collected content took place. The coding occurred both line-by-line and in vivo.

Line-by-line coding. Line-by-line coding followed recommendations by Charmaz (2006, 2014) including: (1) remaining open to the data; (2) keeping codes simple and precise; (3)

constructing short codes; (4) comparing data with data; and (5) moving quickly through the data. Codes were also constructed using gerunds (“-ing” words constructed from verbs and used as nouns) to ensure the analysis occurred from the participants’ point of view (Charmaz, 2006, 2014).

In vivo coding. Any specialized terms participants identified were retained to preserve “participants’ meanings of their views and actions in the coding itself” (Charmaz, 2006, p. 55). Thus, these codes included general common knowledge terms, participant invented terms, and/or insider shorthand terms.

As more data were collected and transcripts coded, the process became less linear and more circular in nature by re-examining earlier data for any similarities, differences, or gaps resulting in further coding as required. Through this process, comparisons of data-to-data and data-to-codes were carried out. Hence, codes were compared: (1) within each interview transcript; (2) between interview transcripts; and (3) between line-by-line codes and in vivo codes, leading to emergent process(es). This allowed for properties of codes to be identified and for coding to become more conceptual as the study progressed (Charmaz, 2006, 2014). The above coding strategy occurred among the patient set of and HCP set of interviews separately. Once this took place, memoing was used to draw connections, identify any patterns and areas of concern between the two groups (patient and HCP) of codes. Divergent codes were explored to assist in further defining categories and their properties and to consider how they may influence the formation of and relationships between concepts of the final framework. Upon completion of these steps, the coding was then ready for categorization (Charmaz, 2006, 2014).

Categories. To aid in this data analysis stage, researcher self-questioning occurred in relation to: (1) what was occurring was reflective of participant’s or researcher’s perspectives;

(2) what properties were being shared; (3) what processes were happening in the category; (4) under what conditions were these processes occurring or changing; (5) what unstated assumptions, if any, were present; (6) why was this category relevant and for whom; (7) what were the consequences of the categorization; (8) how could the process(es) be defined. In addition, for each category, the following were considered: (1) the basic social/psychological processes between patients and HCPs in their interactions; (2) how could they be defined; (3) how did they develop/occur; (4) how did patients and HCPs act while involved in the process; and (5) when, why, and how did these processes change (Charmaz, 2006, 2014).

Categorizing occurred through on-going and more in-depth immersion in the data, through re-reading and re-coding of earlier transcripts and memos. Throughout this process, each category was analyzed for relationships and underlying properties it had to other categories. This comparison of the properties of each category aided in identifying any convergent and divergent perspectives. These perspectives aided in merging and abstracting categories within the framework to support a multi-perspective view on patient roles in primary care IPTs.

Concepts. Categories were critically reflected upon and transformed into theoretical concepts using similar processes (as moving from codes to categories), but also utilizing deeper levels of theoretical analysis. Each concept was then defined and its properties and relationships with each other were identified. This process led to production of a framework for understanding of patient roles in IPTs and perspectives of what conditions and processes need to be in place to support a change in the current culture within primary health care FHT practices.

Phase 2: Follow-up member-checking interviews with HCPs and patients. No separation of data occurred during this phase. Constant comparative analysis method was used between member-checking interview meeting and individual interview transcripts for both

groupings: patients and HCPs. These data sets were compared for commonalities, differences and other variations in participants' perspectives on this theoretical understanding of patient roles in primary care IPTs that emerged from phase 1. This led to refinement of some understandings, mainly in the area of roles patients can enact on IPTs. Thus, the final product of this CGT emerged as a framework for understanding patient roles in IPTs within the context, culture, reality, knowledge, and learning from patients' and their HCPs' primary health care experiences.

Rigor and Reflexivity

For this CGT, researcher reflexivity was achieved through making any biases, values and experiences brought forth through conducting this study explicit. A brainstorming session and a sensitizing researcher self-interview were conducted prior to the study onset. For the brainstorming session, memoing was used to record any personal or literature-based sensitizing concepts to be aware of prior to commencing the study. Memoes continued to be constructed throughout the study with particular attention on impact of biases, values and experiences during the data collection and analysis stages. For the sensitizing researcher self-interview, questioning centred around preconceived assumptions held about the study topic. The interview was audio-taped, transcribed and placed beside the memoing record. Both documents were accessed during data analysis to identify which perspective was being brought forth in the collected data: HCP participant's, patient participant's or the study investigator's.

To address rigor, Charmaz's (2006, 2014) evaluation criteria were used: *credibility*, *originality*, *resonance* and *usefulness*.

Credibility

To achieve transparency of methodological processes memoing was used, which began before participant recruitment or data collection occurred and progressed through the duration of

the study. Written recordings of memos along with deep insight into the study's context demonstrated logical associations between data, arguments, and analysis that aided in framework construction.

Originality

Originality was established by demonstrating how categories produced through the study provided new insights into the conceptual rendering of patient roles in IPTs (Charmaz, 2006, 2014). Originality was also supported through a focus on culture within the FHTs and how the social and theoretical significance of it influenced this study (Charmaz, 2006, 2014). Lastly, this study brought new learning to the field of interprofessional practice.

Resonance

Resonance was created through this CGT's formulation. Effort was made to present this framework in a form that makes sense and gives meaning to study participants and/or people who have, do or will share in a similar experience (Charmaz, 2006, 2014). Resonance occurred through follow-up member-checking interviews where emergent study findings were discussed with participants.

Usefulness

Lastly, usefulness will be established as other patients and HCPs see the study's applicability in their everyday lives and/or how the study contributes to advancing knowledge or generates further research (Charmaz, 2006, 2014). In this study, the CGT approach in which patients' and HCPs' perspectives were made explicit in and of itself helps with the evaluation of the study's usefulness (Charmaz, 2006, 2014).

Ethics

This study received ethics approval from The University of Western Ontario's Human Subjects Research Ethics Board. The University approval was accepted by each participating FHT and no additional ethical approval was required from the FHTs. (see Appendix K for ethics certificate).

Results

This study set out to address the following study research questions:

- 1) What are patients' perspectives of the roles they can enact within IPTs and how do these relate to HCPs' perspectives of their patients' roles?
- 2) What processes have patients used to gain 'voice' around their care with HCPs?
- 3) What conditions within patients' relationships with HCPs allowed for these processes to occur?

This section will begin with outlining the theory subtraction model that emerged from the findings (see Figure 4-1 for the model). This will follow by an in-depth presenting of each of the final framework's components reflecting perspectives shared by patients and HCPs on the roles, processes, and conditions under which patients can become involved in a primary care IPT. Lastly, the section will discuss the meaning of the resultant framework.

Overall, the findings from the study identified three concepts: (1) *patient roles*; (2) *processes*; and (3) *conditions*.

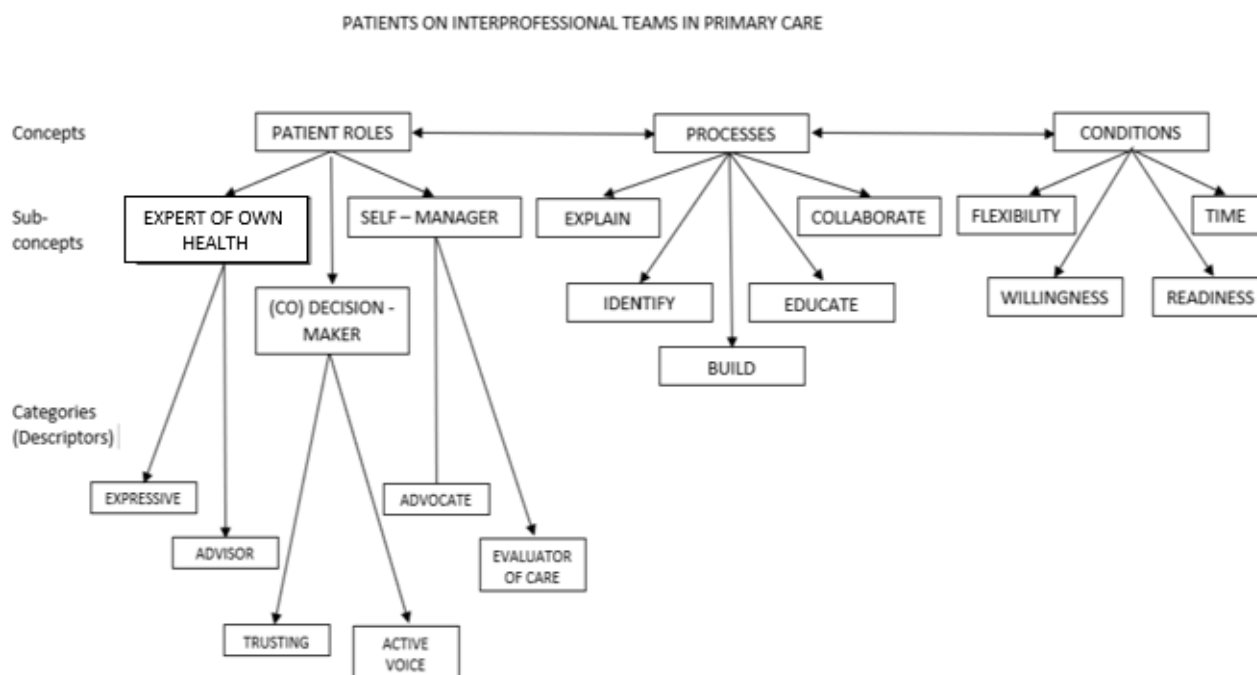


Figure 4-1: Theory subtraction model

The *patient roles* concept has three sub-concepts that identify potential roles patients can enact on IPTs in primary care, from the collective perspective of participating patients and HCPs: (1) *expert of own health*; (2) *(co)decision-maker*; and (3) *self-manager*. These three sub-concept roles are interconnected and/or can be enacted by a patient in a circular fashion. For example, a patient with a chronic disease diagnosis can start with enacting any one of the three roles depending on their chronic disease trajectory. For patients recently diagnosed with a chronic disease they may start interacting with the IPT in the role of *expert of own health*. They may know about how the disease(s) is making them feel, but at the same time they can lack having the medical understanding of the disease(s) to make care decisions (*(co)decision-maker role*) or to be able to take care of themselves within the community in which they reside (*self-manager*). In contrast, patients who have lived with the chronic disease(s) for some time can enter the IPT enacting the *self-manager* role first. If an exacerbation or another symptom occurs, they

may not have the required knowledge or skill level to deal with this change in disease(s) and may need to shift into the *(co)decision-maker* role. Thus, based on the analysis of study data there are three roles that patients can enact within their primary care IPTs depending on their capacity to be participants in their own care. Each role has two categories associated with it which are termed descriptors of the role. Descriptors help define and differentiate the roles from each other. For example, for the role *expert of own health*, the two descriptors are *expressive* and *advisor*. Within this role patients are able to express and voice their concerns within the IPT on what they are feeling and experiencing on a daily basis living with their chronic disease(s). At the same time, the patients can also be *advisors* to the team on their life, environment, support systems, and disease manifestation and progression.

The second concept of *processes* contains five sub-concepts that occur throughout each of the three patient role sub-concepts. These five sub-concepts are: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*.

Finally, the third concept of *conditions*, that must be in place for patients to be involved in primary care IPTs, contains four sub-concepts including: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4) *readiness*. Each of the concepts (*patient roles*, *processes* and *conditions*) will be presented with descriptions of their sub-concepts and categories, where applicable. Pseudonyms for both participant groups will be used. Consent was received from participants for their quotes to be revealed. Each of the concepts will be discussed in depth below.

Roles

Role 1: Expert of own health. As an expert of their own health, patients bring to the primary care IPT their experience of living with their chronic disease(s). Patients over time become experts of their own health through navigating community supports, their support group

networks, and obtaining knowledge from various print and online sources. As a patient commented:

“I’m the expert of how I feel. They don’t know that part. But I’m the expert on how it has affected me.”

In this role, patients are not clinical experts of their diagnosed disease(s) (for example diabetes); they are experts of how they manage their *own* health (i.e. how the disease(s) is manifested within themselves and how they feel) on a daily basis. As an HCP stated:

“Their knowledge base is their own experience and they are the experts of their own experience and so valuing that on equal footing as everything else...”

Within *expert of own health* role, two categories or descriptors were found – expressive and advisor.

Descriptor 1: Expressive. Not every patient coming into the primary care IPT will want to adopt *expert of own health* role even though they live with their disease(s) on a daily basis. Those who would like to assume this role may wish to adopt it immediately upon their initial contact with their IPT, while for others it may take some time to feel comfortable with this role enactment. For this role to develop, however, patients need to be able to express what and how they are feeling and experiencing their lives within their chronic disease(s). As an HCP suggested:

“... an engaging conversation...they don’t shut down or say no or, you know, or it’s just body language or its presence in the room. It’s not a one-way conversation...”

Trust in the team and empowerment by other team members are key for this to occur. As a patient shared about the IPT members:

“... acknowledging that each of us brings our own strengths to the team. I bring a knowledge of myself.”

Descriptor 2: Advisor. When serving as an advisor, patients continue to share what actions they have taken and what their impacts are on how they are feeling and experiencing living with their chronic disease(s). As an HCP and patient commented respectively:

“They’re the expert, they’re the ones telling you what happened because we have nothing in our EMR [electronic medical record] to show us that...”

“I feel that I know myself and my disease quite well, so I'm the primary advisor I feel. What works for me and what doesn't.”

In summary, patients bring to the team the knowledge of self and their daily living with their chronic disease(s). They also share their desired level of involvement in the team as well as advise HCPs on how they are living with their disease in their own environment.

Another sub-concept or role the patient can enact in an IPT is being the *(co)decision-maker*.

Role 2: (Co)decision-maker. When patients feel empowered by their accumulated knowledge, confidence and skills related to their own self-care and that they have the capacity to play an active role in making informed decisions, they can become a (co)decision-maker about their care maintenance along with the other team members. In IPCC care where patients are considered as full partners in the IPT the patients are the ones who make the final decision in relation to their plan of care that has been co-created by themselves and HCP IPT members. As a patient shared:

“...will get the diagnosis and suggestions, and then I can make the choice of, "Okay, do I follow that or not?"

Success of the plan of care or treatment is believed to be contingent upon it fitting into the patients’ life context. If patients select something that other IPT members do not agree with, respect needs to be shown by the HCPs in the form of trust that the patients have made a decision that is most applicable to their life context. As a patient and HCP commented respectively:

“Whatever I take is not made for you, or you. It's made for me, and my body. If I choose something that you don't agree with, it's still my body and if I die, it's my body.”

“... patient who was of Aboriginal decent and the, I think he had high cholesterol ... was not interested in kind of what he considered to be Western medicine and he wanted to follow traditional medicine, which involved some sort of herbs ... and came back later and it, it had not made a difference. The cholesterol had not changed, but the patient felt heard, the patient felt respected, the patient felt that his view of how to manage his own health was respected”

The categories of active voice and trusting capture dimensions of the *(co)decision-maker* role.

Descriptor 1: Active voice. For patients to be able to assume the role of *(co)decision-maker* well, they need to have the capacity to actively participate in the IPT. For this to occur patients need to be seen by IPT members as capable and responsible decisions-makers regarding their chronic disease(s). This active voice extends to their input into development of their plan of care, selection of treatment options, and self-identified outcome measures. As a patient shared:

“... if you're true to yourself and you have a disease you will learn as much about it as you can, and you will try to, again, express your voice...”

Patients who can actively voice their perspectives are able to have an impact on the quality of care they receive as was commented on by one HCP:

“...if you don't instigate, follow, probe, do things, you don't get looked after well.”

Descriptor 2: Trusting. Trust plays a big factor in the ability of patients to be *(co)decision-makers*. Trust evolves when there is consistency in information provided by HCPs to patients. When this does not occur, it leads to conflicting messages that can cause doubt in patients as to what direction they should be following. Consistency causes patients to feel as if they are in the middle of the discussion between the HCPs challenging each other in what should be done. As a patient shared about the importance of this consistency in information sharing:

“I’m in the middle. That’s how I pictured myself. Here’s all these people around me. I’m in the centre, and they’re all looking at me trying to figure this out. And each one of them actually provided me with consistent information, not someone saying something different than the other.”

Patients need to feel like they are on an equal playing field with other members of the IPT. This includes team members demonstrating mutual respect for the knowledge, skills and expertise that each member brings into the IPT. A patient shared:

“...a sense of trust and mutual respect, and that kind of thing ...mutual respect. I respect [their] skill, and experience, and I feel respected for my knowledge, and experience. That’s big for me.”

In summary, the *(co)decision-maker* sub-concept outlines the importance of trust, mutual respect, and competent/responsible active patient participation on IPTs. The patients feel empowered by their accumulated knowledge and other IPT members to take part in the decision-making around their plan of care. The last sub-concept or role for patients, as identified by the patient and HCP study participants, is that of *self-manager*.

Role 3: Self-manager. Patients, when provided with sufficient knowledge, confidence and skills to play an active role in managing their chronic disease(s) in the community, are able to be their own self-managers. As an HCP reflected:

“Patient has to keep their eye on goals, what they’re hoping to achieve.”
“Every other minute they are self-managing their disease at home.”

They know how to take care of themselves with this chronic disease(s), what to watch out for symptoms-wise, when to re-see care, and who to seek care from. As a patient shared about patients as *self-managers*:

“...knowing yourself and when you need to access the care. Knowing what care to ask for.”

Within the *self-manager* role, the sub-concepts of advocate and evaluator of care helped to delineate what this role entails.

Descriptor 1: Advocate. For the *self-manager* role to materialize, patients need to be *advocates* for themselves to successfully manage providing ongoing care of their chronic disease(s). This advocacy necessitates their ability to know which members of the IPT need to be contacted to help address issues when required. As an HCP commented:

“...articulating what they need, what type of care they would like to receive, what is happening in their personal life and how it affects care.”

To be *advocates* for themselves, patients need to voice their care needs, to question care decisions or suggestions, and provide feedback to members of the IPT on how their support can be better suited to their unique needs. As a patient and HCP commented respectively:

“...not only just do what they tell you to do, but to question it...”

“... a voice in terms of how it operates, feedback about their experiences, how we can improve...”

Descriptor 2: Evaluator of care. To enact the role of a *self-manager*, patients need to keep an eye on the progress that they are making towards their own care goal fulfillment. As a patient shared:

“... keep track of the care that is happening...”

This needs to be done along with evaluating how the IPT is helping patients to reach care goals. Thus, the *self-care* role involves sharing between patients and their IPT members. Another patient commented:

“I think it really just all comes back to that communication...You know that everybody knows what's going on with you.”

Both patients and their team members need to communicate progress towards shared goals of care within the entire IPT. When such a partnership exists, it facilitates patients feeling supported by the team while receiving feedback about the effectiveness of their ability to be a *self-manager* of their chronic disease(s). As an HCP shared:

“Having them remind us and keep us on track at each of our contact points on, “Am I achieving my goals?”

In summary, the *self-manager* sub-concept discusses patients as having the sufficient resources needed for them to live with their chronic disease in the community. They are aware of when they need to seek care and who they can access to address any problems or concerns they may be having. Lastly, patients are able to evaluate own and team progress towards mutually agreed upon goal fulfilment.

Processes

Five *processes* are theorized to describe how each of the roles are enacted including: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*. These *processes* are believed to be required for both patients and HCPs to enact any or all of the three roles described above. In a partnership between patients and their primary care IPTs these become part of care that supports patients feeling comfortable in enacting any of the three roles. Although this may be challenging, ideally, these *processes* should be enacted linearly to facilitate successful role enactment for patients and their HCPs. Achievement of each one of the *processes* is dependent on patient’s and HCPs’ characteristics.

Process 1: Explain. Explanation of vital information needs to be provided by IPT members to each other at the initial interaction to ensure subsequent sessions are effective. At the intake session information gained from patients and introduction of all the members of the IPT in terms of their role, expectations, and how they work with patients needs to occur. As an HCP stated:

“... everybody gets introduced at the beginning, who they are and what their roles are ...”

Second, the work HCP team members do behind the scenes (i.e. setting referrals, reviewing results of tests) when the patient is not present can be explained to patients. Third, how

communication on disease status including any progression in deterioration that can or may occur and the type of services the FHT and HCP members can offer to patients can be discussed.

An HCP team member shared how information about the IPT is provided:

“In the patient waiting area there is a tv that talks about that this particular health team does see 20,000 patients and it does provide a description of some of the services that we offer and talks about patients as being a part of the team.”

Process 2: Identify. The primary care IPT HCP team members work to identify patients’ desired level of involvement in their care, care preferences, and the role they wish to have within the team. As an HCP shared:

“... practitioners identify what the patient priorities really are, you know and if that’s something that’s important because I think it’s easy as a practitioner to assume that we know what they should be doing...”

This can occur at the initial patient and IPT encounter as well as be expanded across subsequent FHT visits by patients. For example, patients’ role in the team or care preferences can change as the patients’ chronic disease(s) progresses, the patients become more empowered and/or develop a sense of trust in the other team members. A patient shared how preferences are explored:

“... have them take time and ask what I like and what I didn't like and what's bothering me.”

Part of the process of *identify* is also discussion of the purpose of each visit, the time required, items to be discussed, and patients’ (SMART-Specific, Measurable, Attainable, Relevant and Timely) goals for their care. As two patients shared:

“Purpose of why we're getting together? Do we have a mission and a vision? If we do, are we following it?”

“I usually have my own agenda of what I want to talk about.”

Not only is it important for patients to set their goals for care early in the caring relationship, but these need to be continuously revisited, revised if needed, and measured for achievement. Both

patient and HCP participants considered it important for patients to be held accountable for their goal achievement as jointly constructed with the IPT members. An HCP commented:

“Patients need to change the way they’re thinking about illness and chronic illness as really a responsibility or a shared responsibility.”

Process 3: Educate. Education is a two-way process – that of patients by HCPs and HCPs by patients, and is an ongoing part of any care encounter. Specific attention is needed to be given to patients about their chronic disease(s), and pros and cons of each treatment option. As an HCP shared:

“... give them enough knowledge about the diagnosis and management of disease so it’s something that can be self-managed.”

As part of the education process, it is also important to educate patients about FHT and other community resources that are available. An example of one such resource is group education sessions provided within their FHT for those patients with like chronic disease(s). These can provide an internal support group for patients. As an HCP shared:

“Equipping patients with education and tools to feel comfortable to be in that more of a leadership role ... patients may not know what they don’t know...”

Process 4: Build. The process of building a shared plan of care with patients creates an environment where trust within the team and patient empowerment can be nurtured and sustained. Thus, a welcoming environment for patients to process information, and provision of continuity of care by the HCPs within the IPT are essential for helping to *build* the capacity in patients to take responsibility for their own care. Stability in the HCPs allowing for both continuity and relational trust within the IPT is essential for this *build* process to be successful. As an HCP commented:

“...they have to be involved in creating their own interim care plan ...goals and objectives that are set by that circle of care are centred around the needs of that particular patient, whether it's personal needs, medical, nutritional needs, and whatever needs that are needed.”

When there is a trusting environment with continuity of care, patients are more likely to move towards building a sense of responsibility for their own care with HCPs in the IPT. As patients gain these capabilities, they are more likely to enter into discussions related to their treatment plan and select their personal choices for care. As an HCP shared a patient example:

“It really took a team approach to really get him motivated, but now he’s feeling this active part of his care. Even the questions he’s asking are more autonomous and empowered and again it was this, this team approach.”

Process 5: Collaborate. Collaboration cannot occur until the four other *processes* have already been navigated through. Collaboration necessitates a close working relationship between patients and HCP members of the IPT. This relationship is largely based on mutual respect between all HCPs and the patient. Respect needs to extend to the patients making their own decisions (even if choices may not be what the HCPs would recommend) as well as to HCPs for their expertise, knowledge, skills, treatment recommendations. A patient shared:

“...Respecting that I may be right or wrong, but it's my way of thinking. The rest of the team sharing that's how they see it and that's how they've been trained, and then somehow come to a consensus that there's no right or wrong.”

Collaboration necessitates the need for HCPs in an IPT to see patients as persons first and their chronic disease(s) second, meeting patients within their knowledge and feelings about their health situation. An HCP shared:

“... managing the whole patient, not just the specific disease we are seeing them for...they should be involved and aware of every part of the circle. They should know exactly what their management plan with me looks like, exactly what their management plan with their physician...”

In summary, the concept of *processes* contains five sub-concepts that address what patients and HCPs may need to undergo within an IPT for patients to be able to enact any or all of the three roles – *expert of own health*, *(co)decision-maker*, and *self-manager*.

The last concept of *conditions* outlines what needs to be in place within an IPT for successful patient role enactment.

Conditions

The *patient roles* concept and its sub-concepts and categories (descriptors) are influenced by the enactment of the above *processes*. At the same time role enactment is also dependent on the concept of *conditions* and its four sub-concepts that influence actions. The four sub-concepts identified include: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4) *readiness*. These condition sub-concepts need to be considered for any of the three presented roles to take shape. Unlike the *processes*, these *conditions* do not have to be put in place in a step-like fashion. In an ideal patient-HCPs interaction as part of an IPT, all of these condition sub-concepts would be in place as they all influence how and when roles can be enacted. Achievement of each one of the *conditions* is also, like the *processes*, dependent on patients' and HCPs' characteristics and their partnering relationship formation.

Condition 1: Flexibility. Both patients and HCPs need to be flexible in how they function to ensure patients are able to evolve in their roles with HCPs in IPTs. From the HCPs' perspective, the team needs to be able to adapt to and negotiate care with patients from diverse backgrounds and varying personalities. As an HCP commented:

“... look, actually, at the patient, to see what they need and their expectations because each patient ... It's not a cookie cutter medicine.”

Thus, *flexibility* occurs through development and implementation of individualized care plans jointly created by patients and the other members of the IPT. As a patient shared:

“It's not a one size fits all.”

Being flexible also necessitates patients and HCPs in the IPT to share power to ensure that both sets of expertise (lived experience of patients and professional knowledge, skills and expertise of HCPs) are brought together to achieve a shared care plan. Two HCPs commented:

“... giving them that ability to, not necessarily have the same power as the health care providers, but get to that level where they can break those power differences...”

“The team has to be willing to allow patients to lead or guide the direction of care a little bit more.”

Condition 2: Time. Both patients and HCPs need to set aside *time*, to gain an understanding of the person within the patient through an interactive understanding of each other. This is particularly important at the onset of their relationship development as patients gain a sense of self-efficacy to take on roles within their IPT. As an HCP shared:

“Before we even start any education or anything, it’s really about listening to their story and really understanding the history because there is a story behind the fact that they’re morbidly obese ... understanding their story and really building that trust and rapport, and building that relationship and figuring out what’s important to them. Before you even start any education, doing all that background piece. So, that takes time.”

Time is needed to also establish the support systems available to patients including their roles and responsibilities as patients in the IPT FHT and HCP availability including scheduling visits and access to resources. As an HCP shared:

“... listening and letting the patient guide and outline their own needs and offering them, sometimes that takes time, to uncover their needs, but also they need our help.”

Condition 3: Willingness. HCP team members need to be willing to recognise patient’s vulnerabilities and focus on each patient using a warm, genuine, and caring approach. As a patient shared:

“...they are good staff, they've a sense of humor, they're warm, they accept me and I don't feel judged and I think that's really important.”

Patients are provided with opportunities to lead or guide their own care based on their willingness to participate. Thus, *willingness* is explored by IPT members to determine patients' viewpoints or choices about their care. As an HCP stressed:

“...they determine what their needs are and how the session is being driven. So, I'm just a vehicle and I can provide them with resources, but ... they're in the driver's seat.”

For this to occur a shift from physician as leader and decision-maker and HCP as controller needs to be altered by both the HCP team members and patients. The environment within the IPT needs to encourage engagement for patients to feel motivated to participate in their own care. A patient shared:

“I have a responsibility to myself to say what is my truth, my understanding of myself, so there's no point in me just giving half of what's happening, or half of what I know...”

Condition 4: Readiness. For patients (and HCPs) to feel able to enact any of the three roles an assessment of patients' *readiness* to be team members needs to occur. As an HCP commented:

“You can run it perfectly with all the professionals, but if the patient is not ready to listen to the information or learn on that particular given day, it really is of very little value and considering the resources that go into it, we really should make sure the patients are on board, ah, you know right from the beginning.”

As identified by both study participant groups, *readiness* can be impacted by patients'/HCP's previous health care experiences, and their ability to take ownership of their own health. This shift necessitates patients assuming a share in their care responsibilities. As an HCP discussed:

“If somebody comes in as a newly diagnosed, they may not be in the driver's seat to start with because they're a little frightened and unsure of this new diagnosis that they're received.”

In summary, the four *conditions* sub-concepts outline what patients and HCPs need to consider for successful patient role enactment in IPTs in primary care. When each one of these *conditions* is addressed there is potential that roles patients enact within IPTs benefit both patient

and HCP team members. Based on the categories, sub-concepts and the concepts identified in this section, the resultant framework on patient roles in teams has been formulated (Figure 4-2).

The resultant framework depicts the three concepts: (1) *patient roles*; (2) *processes*; and (3) *conditions*. The concepts are not demonstrated in order of importance with *processes* listed at the top of the framework, *patient roles* in the middle and *conditions* on the bottom. The three concepts, however, are dependent on one another for successful patient role formation on IPTs in primary care.

PATIENTS ON INTERPROFESSIONAL TEAMS IN PRIMARY CARE: A FRAMEWORK FOR TEAMWORK

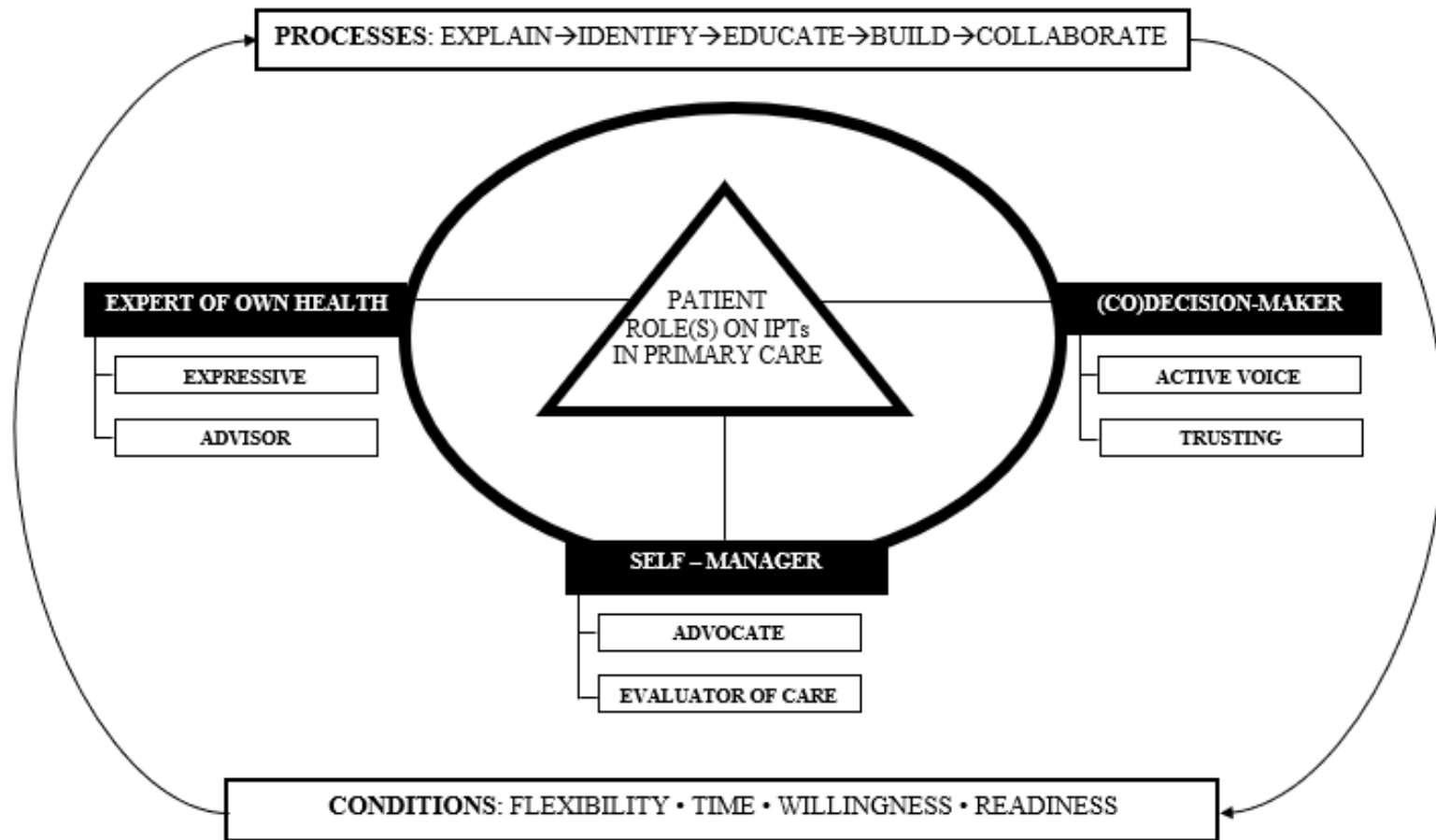


Figure 4-2: Resultant framework on patient roles on interprofessional

The *processes* concept presents the five sub-concepts in a long rectangular box with arrows leading from the first process to the last demonstrating linearity: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*. The *patient roles* concept outlines the three sub-concepts that present potential roles patients can enact on IPTs in primary care: (1) *expert of own health*; (2) *(co)decision-maker*; and (3) *self-manager*. These three sub-concept roles are interconnected and/or can be enacted by patients in a circular fashion, as depicted by a circle connecting all three sides of a ‘triangle’ and its core. The incorporation of the triangular symbol into this framework was a suggestion from one of the HCPs during the member-checking interview. This HCP stated:

“I’m thinking, instead of a circle, if you only had the three, will a triangle seem to work? Because triangles in health care, we look at all the time.”

Each role has two categories or descriptors accompanying it which are encased in a rectangular box and can be seen coming down from each of the sub-concepts. Finally, the third concept of *conditions* presents four sub-concepts, similar to *processes*, in a long rectangular box separated by bullet points, including: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4) *readiness*. The arrows leading from the processes to the conditions and the conditions to the processes represent that each aspect of the framework is in constant interaction to ensure successful patient role enactment on IPTs in primary care. The following section presents a discussion on the study findings and the resultant framework.

Discussion

The aim of this study was to generate a greater understanding of the processes and conditions under which patients will feel comfortable assuming active partnering roles within their primary care IPTs. If patients are to become team members in future IPTs by being more

involved in their care delivery, an understanding of what is needed to succeed from the collective perspectives of patients and HCPs was needed.

According to Tajfel's Social Identity Theory (1979), both HCPs and patients develop their IPT identity based on societal norms which, in turn, impact on the roles that team members enact within IPTs. The collective findings from this study produced three patient roles: (1) *expert of own health*; (2) *(co)decision-maker*; and (3) *self-manager*. None of these roles see patients enacting the historic 'sick role' (Parson, 1951) that viewed them as being passive care recipients with HCPs exerting full control over care delivered. These findings are in line with Ferguson et al.'s (2013) interpretive, descriptive study of the shifting 'sick' (lack of participation in own care) to 'active' (participation in own care) role of patients in their own care among 18 patients and eight family members on an acute care Canadian medical unit. The increasing number of people living and functioning with chronic disease(s) is necessitating patients to assume a new social identity as self-managers.

This study identified four conditions that need to be in place for patients to be able to enact the three roles identified: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4) *readiness*. These align well with Allport's Contact Hypotheses (1954) which are: (1) individual members need to hold equal status within the team and/or particular situation; (2) team members must be able to establish and share common goals; (3) all members need to display intergroup cooperation; and (4) the team needs to have authoritative, institutional and/or organizational support. *Flexibility* includes the need for equal status on teams. Each participant, in this case specifically the patient, needs to neither experience an inferior nor superior position amongst the team members. This transition can be problematic for team members who feel they hold positions of less power in their IPT that may cause them to be less cooperative with team members and question the value

of interprofessional collaboration (Rutherford & McArthur, 2004). For equal power to occur, HCP team members need to be comfortable with sharing their power with both other HCP and patient participants (Soklaridis et al., 2017). This can take time, especially at the onset of HCP-patient relationships when both groups of participants are having to unlearn past patterns for newly evolving ones (Fox & Reeves, 2015; Gaboury, Bujold, Boon, & Moher, 2009; Phillips et al., 2014; Thylefors, 2012; van Dongen et al., 2017a),

In contrast, both HCP and patient participants in this study did not see patient participation on teams as taking a lot of time. In fact, both participant groups identified the importance of sufficient time for patient role enactment on IPTs. HCP participants themselves stated that setting enough, uninterrupted time at the onset of the relationship equated to the need for less time in subsequent encounters with patients. Gittel et al. (2013) supported this perspective by outlining the value of time for relationship development.

Smith-Carrier and Neysmith (2014) commented on the importance of seeing the value of complementarity of HCPs' roles that each bring into a team and its value for sharing in care of patients. This ties in with Allport's (1954) second and third conditions of team members establishing and sharing common goals, and all members needing to display intergroup cooperation. For all team members to succeed, interdependent effort without intergroup competition needs to be present (Bettencourt et al., 1992; Cutler et al., 2019). Interdependent efforts can result in all members sharing in and working towards common goals. Study participants identified the conditions of *readiness* and *willingness* for participation. Van Dongen, Habets, Beurskens, and van Bokhoven (2017b), in a qualitative study of 11 patients/relatives, eight HCPs and eight team meetings within eight health care settings in Southern Netherlands, found that both HCPs and patients need to be willing and have the ability to work in a

collaborative relationship to formulate team-patient goals. This supports the importance of assessing patient *willingness* and ability for participation on IPTs. However, they did not discuss the need to assess HCP's *readiness* and *willingness* to work with patients on IPTs as this study has. Allport's (1954) last condition of authoritative support was not identified as a condition in this study, but it did come up in relation to FHT teamwork culture. HCP participants shared the importance of their FHT culture as accepting of patient inclusion on their teams using a patient-centred practice approach. Clinic (FHT) and organizational culture are often considered as the precondition for IPCC care. In a multi-centre cross-sectional study of 275 members of health care teams in 15 rehabilitation clinics within southwest Germany, Korner, Wirtz, Bengel, and Goritz (2015) found that organizational culture and teamwork were predictive of job satisfaction. The higher the organizational culture and teamwork were rated, the more satisfied the team members were with their jobs (Korner et al., 2015).

In Intergroup Contact Theory bringing individuals together in a team provides the best means for reducing hostilities, but contact by itself is not enough for a trusting therapeutic relationship to be developed between team members (Hewstone & Brown, 1986). This study identified five processes required for patients and HCPs to collaboratively navigate through for patients to be able to enact any or all of the three described roles: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*. These five processes align well with Pettigrew's (1998) four processes of change that occur as an outcome of intergroup contact: (1) learning about the out-group; (2) changing behavior; (3) generating affective ties; and (4) in-group reappraisal. Learning about the out-group (patients) means that the more the in-group (HCPs) knows about the out-group the less resistance there will be for attitudinal shifts and collaborative work to occur (Pettigrew, 1998). Thus, the more HCPs know about patients and the contributions they

can make towards team goal fulfillment, the greater the acceptance of patients as team members. In *explain*, *identify* and *educate*, both parties are learning about each other. This learning includes what their level of involvement could be, and what learning gaps they need addressed. When HCPs work with patients to explain and identify roles patients can assume in their care, more affective ties may emerge including learning and valuing each other within their intergroup (Pettigrew, 1998). Intergroup members (patients and HCPs) might then reappraise how they feel about each other leading to intergroup contact. As a re-formulated group, all members can build feelings of being an in-group and potentially becoming more collaborative (Pettigrew, 1998).

Studies located to date that explore the roles of patients in IPTs (Bilodeau et al., 2015; Ferguson et al., 2013; Martin, 2014; Martin & Finn, 2011; Phillips et al., 2014; Pomey et al., 2015) provided minimal details about processes required for successful integration of patient roles into teams. As an example, in the Martin and Finn's (2011) qualitative, UK study exploring service user (patient) involvement in IPTs, four key elements were identified by patients to become active team members: (1) a clear conceptualization of patient roles; (2) required identity and skill set; (3) feeling of being embedded in the social field of the organization; and (4) development of trust between HCPs and patients. These elements are evident in the five processes identified in this study. As an example, development of trust is part of *identify* and *build* processes. However, Martin and Finn (2011) did not go into detail as to how these elements can materialize or be put into place. This study adds to this field of research in that it clearly identifies and explains the processes and conditions required by both, patients and HCP, for patients to become active IPT members.

Contribution to Knowledge Development

There is minimal evidence available, especially from patients' perspectives, on how to include patients on IPTs in a collaborative manner with HCPs to support patient disease monitoring and management (Metersky et al., 2020). A scoping review by Metersky et al. (2020) found that a clearer understanding is needed of what roles patients would like to or can enact within their IPTs. Without this understanding a risk is posed on future collaborative efforts between patients and their HCPs not being successful. This study utilized Charmaz's (2006, 2014) CGT approach to gain a theoretical understanding from the collective perspective of patients and HCPs on patient roles in primary care IPTs. The use of CGT as a methodology for the topic of patient-centred care is not a novel idea. Brown, Ryan, and Thorpe (2016) conducted a CGT study to explore HCPs' perspectives on patients' care processes at 20 Ontario, Canada FHTs. Pomey et al. (2015) used elements of CGT in their study to explore 16 patients' (who have been sensitized to the concept of 'patients as partners') views on their engagement during direct care with their HCPs in Montreal, Quebec, Canada. This study is novel in that it utilized the CGT methodology to solicit perspectives of both patients and HCPs on interprofessional teamwork as well as explore the study findings through the combined lenses of Tajfel's Social Identity Theory (1979), Allport's Contact Hypothesis (1954) and Pettigrew's ICT (1998). Studying both participant groups allowed for comparisons in views on patient participation in IPTs to be conducted. Also, the three theoretical works aided in the comprehension of culture's and norms' influences on patients' identity development with HCPs on IPTs (Social Identity Theory), the conditions required for patient inclusion on these IPTs (Contact Hypothesis), and the processes patients and HCPs need to undergo for successful patient role enactments on IPTs (ICT).

To move forward with patient successful participation and inclusion on IPTs, adopting new theoretical models or frameworks was needed. An additional aim of the study was to transform knowledge gained from the study participants into a framework that included the required processes and conditions for patient roles to be enacted on teams. The resultant framework was produced from individual semi-structured interviews collected from HCP and patient participants with the initial version undergoing follow-up member-checking interviews to ensure the framework accurately captured participants' perspectives. Not only was this study able to fulfill its purpose, but through using the CGT methodology, it was possible to also gain knowledge on the extent of work needed to be done with current teams to ensure the resultant framework would succeed in its future applications within primary care FHT IPTs. CGT allowed for clinic culture and team context to be considered and explored along with the participants' perspectives. Considering that this is the first framework of this type there is high chance of its usability and applicability.

Strengths and Limitations

Eliciting the perspectives of and triangulating the data from both HCPs and patients on patient roles in IPTs are the methodological strengths of this study. Two different FHTs, that varied in size in relation to the number of HCPs they had and the patient population they served, were used to recruit study participants. HCP participants came from a wide variety of professions with no profession duplication occurring within the same FHT. The individual semi-structured interviews and follow-up member-checking interviews offered both verification of the findings and flexibility to study participants in providing them with a choice of in-person, telephone or an online meeting platform ZOOM participation option.

The limitations of this study include HCP participant groups, age and sex of patient participants, FHT locations, and ability to host follow-up member-checking interviews with all the participants. This study sought to include HCP participants from a variety of professions. Although this was achieved, no physicians agreed to participate from either FHT. The study findings and the resultant framework might have appeared differently based on physician perspectives. It is hoped that this limitation does not have a significant impact on the final outcome of this study as there was representation from another primary care provider professional group (nurse practitioners). In addition, physician leads of FHTs were heavily involved in participant recruitment, providing support for the study, and commenting on the importance of this research. Next, all patient participants were over 45 years of age. Having a diverse sample in relation to age with inclusion of a few participants from the young adult age group might have enriched the findings of the study. As well, there was only one male participant. Males and females may conceptualize health and participation in own care differently. The perspective of this male participant, however, largely matched the perspectives obtained from nine female participants. In line with sex of the participants, another limitation of this study was with one of the inclusion criteria being for study participants needing to be either male or female. This limited other genders from taking part. To continue, although two FHT locations were used for the study, both of the FHTs were located in the same region of Ontario. Having FHTs from two different cities might have enhanced transferability of the results. However, the two FHTs did differ on the size of the patient population they served. One FHT was considered one of the largest FHTs in the province, while the second was medium in size. Thus, this may contribute to enhancing the transferability of the results. Lastly, not all

participants were able to partake in the follow-up member-checking interviews due to disease progression, changing careers and relocating.

Conclusion

Patients need to become members of their health care teams in a meaningful way and be able to enact roles that will not only benefit their HCPs, but themselves. A total of 10 patient and 10 HCP participants, from two FHTs in Southwestern Ontario area took part in a two-phase data collection strategy which included semi-structured interviews and follow-up member-checking interviews. Data analysis procedures were designed to reveal a theoretical understanding of the roles patients can enact in IPTs in primary care. The resultant framework and this study offer an understanding of evolving *processes* and *conditions* associated with patients assuming IPT roles. Thus, three concepts were presented: (1) *patient roles*; (2) *processes*; and (3) *conditions*. The *patient roles* concept has three sub-concepts with each of the sub-concepts having two categories/descriptors associated with it: (1) *expert of own health* – expressive and advisor; (2) *(co)decision-maker* – active voice and trusting; and (3) *self-manager* – advocate and evaluator of care. The *processes* concept has five sub-concepts: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*. The *conditions* concept has four sub-concepts: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4) *readiness*. This study is the first of its kind to combine CGT methodology with the lenses of Tajfel's Social Identity Theory (1979), Allport's Contact Hypothesis (1954) and Pettigrew's ICT (1998) when interpreting findings. When the identified concepts are put in place through the collective effort of patients and HCPs in IPTs in primary care there is potential that patients can enact roles beneficial to both themselves and HCPs. When role assumptions occur, it is proposed that transformation of current HCP centric practice towards patient inclusion within these teams can take place.

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CHAPTER 4:
DISCUSSION

Overview

The purpose of this study was to construct a framework on the processes and conditions required for patients to assume active participant roles in their care within primary health care interprofessional teams (IPTs). This dissertation was written using the integrated article format. Chapter 1 provided an overview of the problem that this study had sought out to address and what can be expected from this dissertation, including what each of the subsequent chapters include. Chapter 2 discussed the method and the results of the scoping review undertaken to identify the current state of literature on patient roles in IPTs. The review demonstrated that there is a current lack of understanding of what patients consider to be meaningful ways they can be involved in their IPTs. Chapter 3 built on the findings of the scoping review, provided a detailed overview of this study, identified the three theoretical works that underpinned the study (Tajfel's Social Identity Theory (1979), Allport's Contact Hypothesis (1954) and Pettigrew's Intergroup Contact Theory (ICT) (1998)), and presented the study findings and the resultant framework. The framework is comprised of three patient roles that are dependant on five processes and four conditions needed for patients to be able to participate in primary care IPTs. Social Identity Theory, Contact Hypothesis and ICT were incorporated in the discussion of the findings section as they underpinned the resultant framework and helped navigate and make sense of the study results. The chapter concluded with a discussion on what contributions this study makes to the field of interprofessional patient-centred collaborative (IPCC) care delivery in primary care and FHTs.

This study is one of few studies exploring patients' roles on IPTs. While previous research largely studied health care providers' (HCPs) perspectives on patients' roles in teams, this is one of the first studies seeking perspectives of both patients and HCPs on patient roles in

primary care IPTs in Ontario, Canada. This study expanded other studies by defining and describing parameters associated with patient and HCP identified patient roles that can be assumed within IPTs. In addition, this study is unique in presenting conditions and processes needed by both patients and HCPs for role enactments to take place in primary care IPTs.

This chapter will first discuss how study findings address each one of the three study research questions:

- 1) What are patients' perspectives of the roles they can enact within IPTs and how do these relate to HCPs' perspectives of their patients' roles?
- 2) What processes have patients used to gain 'voice' around their care with HCPs?
- 3) What conditions within patients' relationships with HCPs allowed for these processes to occur?

Second, the strengths and limitations of this study will be provided. Third, study implications for practice, education and policy and future research will be presented.

Findings Related to Research Questions

Research Question 1: What Are Patients' Perspectives of the Roles They Can Enact within IPTs and How Do These Relate to HCPs' Perspectives of Their Patients' Roles?

This study identified three patient roles in primary care IPTs from the collective perspective of patients and HCPs: (1) *expert of own health*; (2) *(co)decision-maker*; (3) *self-manager*. The study participants included 10 patients and 10 HCPs within two primary care teams who participated in individual semi-structured interviews. Interview transcripts were first analyzed separately by each participant group (HCP and patient interviews). The transcripts were then analyzed for connections to any patterns and/or areas of concern between the two participant groups. Coincidentally, patients and HCPs identified two of the same roles: *expert of*

own health and *self-manager*. Pomey et al. (2015a), in a descriptive article of a patient-HCP partnership model named the Montreal Model, also recognised the importance of seeing patients as *experts of own health*. It is theorized that as experts HCPs bring their professional knowledge into discussions whereas patients bring knowledge of themselves into a team. In reality only patients know what it is like to live with their chronic disease(s) on a daily basis and have knowledge of their past and future life goals (Pomey et al., 2018b). In another descriptive article on the patient-as-partner approach Karazivan et al. (2015) outlined the need for HCPs to view patients as having a certain expertise that they bring to the team which is comparable to the expertise nurses, physicians, social workers and other HCPs bring. Karazivan et al. (2015) also recognized the self-management role that patients assumed and supported the view that patients need to be seen as capable of carrying out their own self-care. Patients seem to be taking care of themselves more than HCPs believe to be the case. Thus, they concluded when HCPs share with patients their historical HCP owned 'healer role', patients can create a sense of being more in control of their chronic disease(s) (Karazivan et al., 2015).

Other authors have outlined that patients who participated in decision-making surrounding their care have reported more positive care experiences (Baker, Denis, Pomey, & MacIntosh-Murray, 2010; Pomey, Clavel, Aho-Glele, Ferré, & Fernandez-McAuley, 2018a; Weingard et al., 2011); better health outcomes (Baker et al., 2010; Pomey et al., 2018a; Weingard et al., 2011); as well as contributing to improvements in their own safety (Pomey et al., 2018a; Stevens, 2010; Szafran, Kennett, Bell, & Green, 2018; Weingard et al., 2011) and care quality (Pomey et al., 2018a; Stevens, 2010; Szafran et al., 2018; Weingard et al., 2011) more than patients who do not take part. Patients assuming the role of *(co)decision-maker* is widely supported in the literature (Pomey et al., 2018a), and was a potential role identified by

both study participant groups. However, the two participant groups differed in their descriptions of this decision-making role. HCPs saw patients as being the ‘boss’ of the project, capable of outlining team goals and guiding the team by making important care-decisions. Patients, on the other hand, did not want to be solely responsible for making care decisions. They did not feel they had the medical expertise to lead the team and wanted instead to share in decision-making in relation to their care plan. Pomey et al. (2018b) concluded that when patients’ own health experiences, expectations and preferences are coupled with HCPs’ professional knowledge, there is an improved potential for making the best care decisions possible.

Similarly, HCPs saw patients as being ‘team persons’ while patients wanted to be referred to as ‘team partners’ sharing in decision-making regarding their fit into the IPT. Both patient and HCP participants viewed patients as being in the middle of the group (circle) with the other HCPs sitting around the patient. In IPCC care, however, it is advocated that all members of the team are in the circle as equal partners. Although the view shared in this study is an improvement on the paternalistic view of patients as passive recipients of care with a limited voice into their care, positioning patients in the middle of team interactions only demonstrates a presence and not a partnering role in team discussions (Pomey & Lebel, 2016). It does not indicate patients being co-leaders or co-building participation that is believed to occur when patients are full participants with the other HCP team members (Pomey & Lebel, 2016). Study patient participants wanted to have the label of ‘team partner’ which is more in-line with positioning themselves as part of the circle with other HCPs versus the current study participants’ understanding of patients being positioned in the middle of table or circle of care. On the other hand, patients being positioned in the ‘middle’ was more in-line with the title ‘team person’ that HCP participants wanted to use for patients. In summary, the patient role of

(co)decision-maker contains the ‘co’ prefix in brackets to symbolize this discrepancy between participants’ views, knowledge and understanding of patients’ involvement in their own decision-making and positioning in teams.

Approximately six to eight months following the individual interviews and analysis of data, patients and HCPs were invited to participate in follow-up member-checking interviews where the roles identified above and the emergent framework were shared to see if they accurately represented their initial collected perspectives. Not all participants from the initial semi-structured interviews were able to take part in the follow-up interview. The member-checking interviews were done separately for each participant group: one for patients and one for HCPs. To ensure as many participants as possible could share their insight from the findings some participants (three in total) completed individual member-checking interviews. At this phase, there was agreement by all participants on the patient roles identified in the framework.

This study provided research support for understanding the roles patients would like to be able to enact within primary care IPTs. Thus, this set of findings will enlarge the existing literature that was primarily explored HCPs’, researchers’ or academics’ perspectives about patient roles on IPTs. This study is therefore a reflection of the voices and perspectives of patients (and HCPs) on the roles they would like to enact in future collaborations with HCPs within primary care IPTs.

Research Question 2: What Processes Can Patients Use to Gain ‘Voice’ Around Their Care with HCPs?

This study identified five processes that patients can use to gain ‘voice’ around their care with HCPs in IPTs: (1) *explain*; (2) *identify*; (3) *educate*; (4) *build*; and (5) *collaborate*. These processes were constructed from collective perspectives of patient and HCP study participants.

Thus, these processes represent steps that both patients and HCPs can take individually and together, where appropriate, to ensure successful integration of patients into meaningful IPT roles in primary care settings. Ideally, these processes would occur linearly within an IPT to ensure optimal patient-HCP collaboration takes place.

In the first process, *explain*, vital information is discussed among HCP team members and among patients and HCP team members. This is where HCPs' direct and indirect roles and expectations of teamwork are articulated. This allows for an open discussion around care needs. As well, when individuals are aware of other team members' roles it allows them to understand how their own roles are complementary to others on the team (Cutler, Morecroft, Carey, & Kennedy, 2019). Part of this process, communication regarding disease(s) progression needs to occur between the patient and other IPT members.

Explain as a process is achieved in the first visit between the patient and HCP team members, and facilitates moving forward to *identify* as the second process. This process can also take place at the initial visit or within the first few visits and be expanded on, during subsequent visits. This is because in *identify*, the HCP team members work with the patients to identify the patients' role on the team, care preferences and desired level of involvement in their own care as well as setting care goals, how their achievement will occur and accountability for outcomes. These can change based on patients' characteristics and chronic disease(s) related factors throughout the HCP-patient relationship as part of an IPT. Patients' characteristics influencing this process can include things such as ethnicity, language literacy, age, education level, and mental/cognitive capacity (Cutler et al., 2019; Fox & Reeves, 2015; Stacey et al., 2016). Other patients' characteristics can include mental state, current health status, and knowledge of disease(s) (Cutler et al., 2019; Howe, 2006). Additionally, patients' personality traits (i.e.

extrovert vs. introvert), trust in HCPs, previous interactions with an IPT, and length of time living with a chronic disease(s) may also impact their desire to be involved in own care during the relationship formation and ongoing enactment over time. A grounded theory study by Pomey, Ghadiri, Karazivan, Fernandez, and Clavel (2015b) of 16 chronically ill patient trainers recruited from the Faculty of Medicine of the University of Montreal found patients evaluated their interactions with HCPs to determine the value of what they gained through such interactions. If the interactions produced little value patients reverted back to their own self-care. Researchers also found in some circumstances patients were willing to give up their autonomy completely, without any restrictions, and defer care planning and decision-making to their HCPs. This often occurred during times when their chronic disease(s) was in an active state, pain was present or patients were feeling overwhelmed (Pomey et al, 2015b). HCPs who seemed to be able to work with patients in identifying what care was needed have previous experience working as part of an IPT, with patients as part of IPTs, and with delivery of patient-centred care (PCC). Those HCPs who demonstrated an ability to relinquish some of their power and possess trust in their patients were able to have patients assume a role in their own care and achieve the *identify* process.

The third process of *educate* includes both groups (patients and HCPs) educating each other on information needed for a successful care relationship to occur. As an example, HCPs provide some education to patients on their chronic disease(s) as well as the various treatment options and community resources available. Patients, on the other hand, are educating the HCPs on what it is like to live with their chronic disease(s) within their living accommodations and what a meaningful life looks like to them.

The fourth process of *build* includes formulation of a shared plan of care within a welcoming, trusting and empowering team environment. It has been reported that trust and transparency facilitate patient engagement (Cutler et al., 2019; Soklaridis et al., 2017). In a qualitative observational study of eight IPT meetings in eight institutions in southern Netherlands, researchers found a pleasant atmosphere to be important for effective patient engagement (van Dongen, Habets, Beurskens, & van Bokhoven, 2017). All of this can ensure successful navigation through the developed plan of care towards identification and achievement of care goals in support of planned outcomes.

The last process of *collaborate* can only be achieved when all the other four processes have already been navigated through. Collaboration requires a close working relationship between HCP and patient team members where patients are seen as equals and an integral part of the IPT. Moreover, mutual respect among all individuals involved with sharing of each other's expertise they bring into the team is needed for IPCC care to exist.

The next section addresses the third and last research question looking at the conditions that allow for the above processes to occur within the patient-HCP relationship.

Research Question 3: What Conditions within Patients' Relationships with HCPs Allow for These Processes to Occur?

This study identified four conditions within patients' relationships with HCPs that allow for the above processes to occur: (1) *flexibility*; (2) *time*; (3) *willingness*; and (4) *readiness*. The condition of *flexibility* requires patients and HCPs to be flexible in how they interact and work with each other in support of patient participation within IPTs. *Flexibility* also necessitates power sharing to occur for a shared plan of care to develop. Power dynamics between patients and HCPs can be very intimidating for patients and impact on their participation in teamwork

(Soklaridis et al., 2017). Power is synonymous with control. HCPs must share power and control with patients through considering patient input and preference regarding patients adopting more of a partnership role with HCPs (Milewa, Valentine, & Calnan, 1999).

Flexibility is needed so must *time* be considered. A condition of *time* includes the ability of patients and HCPs to set aside enough time for patients to gain a sense of self-efficacy to participate in discussions about their care within their IPTs. *Time* is also required to identify support systems needed to be in place, such as scheduling of visits and access to needed resources. Even when *flexibility* and *time* have been considered a *willingness* by HCPs to demonstrate a caring, warm and genuine approach is needed that takes into account patients' vulnerabilities to enable them to be team members (van Dongen et al., 2017). This condition needs to encourage feelings of motivation for patients to engage with the IPT and participate in their own care. Lastly, patients' level of *readiness* to be team members needs to be assessed. This *readiness* can be impacted by patients' previous health care and IPT experiences, and their ability to take ownership of their own health.

Unlike processes, the above conditions occur in a non-linear fashion. They are navigated through between patients and their HCPs and may be re-considered as needed during care planning discussions. As Pomey et al. (2015b) found, there are instances where patients "may become active partners even when conditions for partnership are not met" (p. 15) or require modifications. The context/setting of where the IPCC care and teamwork are taking place can also impact on conditions. In this study, it was fortunate that HCP and patient participants were recruited from two Family Health Teams (FHT) that are already quite committed to IPCC care, interprofessional teamwork and PCC. However, there may be settings where this is not the case. As an example, there may be clinics where their culture does not prioritize patients as team

members or HCPs working as part of IPTs. Some clinics might have a small number or variety of HCPs on staff; the clinic design might not allow for HCPs (and patients) to interact easily; and/or the clinic might be located significant distances away from patients, limiting frequency of interactions with their IPTs.

No matter what conditions might be present, alterations in how the roles are enacted will always need to be considered to achieve the process of *collaboration* between all parties (Morgan, Pullon, & McKinlay, 2015). As an example, for *flexibility* and *time* HCPs need to be able to provide some *flexibility* in functioning and set aside enough *time*, at the onset of the relationship, for most optimal collaboration to occur through the achievement of the five processes. In some clinics, *flexibility* in relation to power sharing might take longer to occur because of the need for the clinic culture to first shift to support patients as full members in teams. To shift to a new ‘culture’ requires buy-in from key players (for example some HCP professional groups such as physicians and clinic administrators) (Morgan et al., 2015) who are willing to consider this view of patients as team members and partners in care to help HCPs and patients develop successful collaborative relationships (Pomey et al., 2015b). During cultural transitions, an HCP-patient liaison might need to be appointed to communicate with patients and orientate them to changes in functioning of the team. In a Narrative Inquiry study of three patients’ experiences receiving care from an IPT in an urban acute care setting in Ontario, Canada, Metersky and Schwind (2015) found that patients often saw nurse practitioners on the team as being the bridge between HCPs and patients in relation to the work that the HCPs were doing outside of patient-HCP encounters. Cutler et al. (2019) reported on the value and use of the term ‘central coordinators’ for this role. When it comes to flexibility in relation to setting of the FHT, if the physical clinic space is not conducive to IPCC care delivery, executing common

activities and formulating a shared vision allow for team building to occur (Ryan, Brown, & Thorpe, 2019). To connect to the condition of *time*, if longer meetings cannot be arranged at the onset of the relationship, booking shorter, but more frequent meetings, at the beginning, might work in some clinic situations. Thus, it is believed that the conditions of *flexibility* and *time* may tend to be common conditions that vary in order for all of the processes to be navigated through for patients to enact their desired role(s) on IPTs in all clinic types.

Similar to processes, HCPs' characteristics and previous interactions with patients can impact on how the four conditions are attended to. As well, patients' characteristics, personality traits, previous HCP/IPT experiences, and current disease(s) factors (for example, length of time living with the disease and health status) can also impact on how the framework conditions are enacted. For example, if the patients have had a chronic disease(s) for some time, had experienced interacting with a number of different HCPs, and were extroverts, they might be more ready to share in responsibility for their own health care management (meeting the conditions of *readiness* and *willingness*) and may readily navigate through the processes in a meaningful way with the IPT members. Similarly, if the HCPs these patients are interacting with have had some experience working closely with patients in teams, found the experience beneficial to both parties, and have been trained through their education to practice IPCC care, there is a higher likelihood that this patient-HCPs partnership will lead to a strong collaborative relationship. However, if the patients are newly diagnosed with a second or subsequent chronic disease(s), or experiencing an exacerbation of their disease(s) and have had negative previous interactions with their HCPs, they might not be as ready to participate within their IPT. Similarly, if the HCPs found in the past that working with patients as part of an IPT took up too

much of their time or was not beneficial to the work the team was doing, those HCPs would be less willing to engage patients in care planning, implementation and evaluation.

In another example, if the patients had a mental or cognitive impairment, such as an elderly individual with dementia, they may require a family member or friend to be present to support participation through the conditions (and processes) to enact meaningful participation in the IPT within the patients' capacity. Van Dongen et al. (2017) found that providing persons with dementia information in multiple different ways and scheduling longer meetings allowed them time to process the information, and helped them integrate and participate well in a team. However, this may only be helpful for people in early stages of dementia. Thus, patients enacting the framework roles will be influenced by their capacity to participate in the processes and conditions which might require adjustments to ensure effective care outcomes occur. Therefore, there might need, under differing situations, for there to be more *flexibility*, provided *time* or demonstration of *willingness* to listen to patients before the condition of *readiness* can be met.

Study Framework Summary

This study sought out to gain an in depth understanding of patient roles within primary care IPTs and to transform the knowledge gained from patient and HCP participants into a framework that discusses the required processes and conditions for these roles to be enacted. Three varying roles were identified (*expert of own health*, *(co)decision-maker*, and *self-manager*) that are enacted through five linear processes (*explain*, *identify*, *educate*, *build*, and *collaborate*) and impacted by four non-linear conditions (*flexibility*, *time*, *willingness*, and *readiness*). The capacity of patients to enact the roles is dependent on a number of patient characteristics (ethnicity, language literacy, age, education level, mental/cognitive capacity, knowledge of disease(s), personality traits, and trust in HCPs) and experiences (previous interactions with

HCPs in IPTs, current health status, mental state and length of time living with a chronic disease(s)) that impact on their ability to fully participate in primary care IPTs. HCPs need to also accept patients as partners in their care for patients' participation in own care to be realized. Hence, all aspects of the framework can impact one another at any given time or for any situation that patients find themselves in when interacting with HCPs as part of a primary care IPT.

Limitations and Strengths of the Study

The study findings should be considered along with some potential limitations. This study is based on participants coming from one Canadian province. The FHTs contacted for participant recruitment were both located in one region of Ontario. However, the two FHTs varied in size with one being one of the largest and the other medium-sized FHT in the province. Considering that the two study sites are FHTs, the findings are limited to primary care clinics versus hospital-based acute care areas. The inclusion criteria of patient participants having at least a three-month chronic disease diagnosis precluded patients with acute disease(s), those newly diagnosed with a chronic disease, or individuals attending the FHTs for health maintenance or health promotion purposes. These other participants may have experienced different interactions from those studied, impacting the resultant framework. As well, there was only one male participant. Males and females may conceptualize health and participation in own care differently. The perspective of this male participant, however, largely matched the perspectives obtained from nine female participants. In line with sex of the participants, another limitation of this study was with one of the inclusion criteria being for study participants needing to be either male or female. This limited other genders from taking part. For HCP participants, although the intention was to recruit a variety of HCPs from each FHT, the physician professional group was underrepresented; however, nurse practitioners were included. Despite

this, physician leads of FHTs were heavily involved in participant recruitment, providing support for the study, and commenting on the importance of this research. The findings are also limited to the specific situational, social, historical and health care contexts from which the participants were drawn.

Despite the limitations, this study has a number of significant strengths. This study obtained both patients' and HCPs' perspectives on patient roles in primary care IPTs. Thus, the resultant framework roles, conditions, and processes came about as a result of data triangulation of the two participant groups. The HCP participants came from a variety of professional groups with no identical profession being recruited from each FHT. The data collection methods of individual semi-structured interviews and follow-up member-checking interviews provided flexibility in terms of participation methods for study participants: in person, via telephone, or through an online meeting platform called ZOOM. Finally, the follow-up member-checking interviews allowed participants to review the emergent framework and provide further feedback to ensure accurate representation of participants' perspectives occurred.

Implications for Practice, Education, Policy and Future Research

The findings of this study fulfilled the study purpose through outlining three potential patient roles on IPTs in primary care as well as the processes and conditions required for role enactments to occur.

Practice

For practice, this study brought forth the notion that patients want to be included, and HCPs are welcoming of, patient inclusion on IPTs in primary care. The roles identified are three potential and varying roles patients can enact on IPTs. The choice and modification of the patients' role are dependent on clinic context and culture, team composition, HCPs'

characteristics including previous experience working with patients, and patients' characteristics and experiences such as previous experience with being members of or interacting with HCPs as part of IPTs. The processes and conditions identified can aid in working more closely with patients and increasingly involve patients more in their own care.

Education

For education, the findings of this study, the three potential patient roles, and the processes and conditions required for these role enactments, can enhance existing or future interprofessional education courses or sessions for prelicensure students as well as current HCPs working as part of IPTs. Providing education using the study's resultant framework can assist students and HCPs to explore ways patients would like to be members of IPTs and how their practice can be more centred on the person. Specifically, through presenting the processes and conditions, this can further demonstrate how facilitating patient roles in IPTs may help change HCPs' practice toward working more closely with patients. Including this framework and the idea of patients having roles on IPTs in primary care within interprofessional courses may make future collaborations between HCPs and patients a reality in practice. Considering that this research focused on two participant groups, equally there is merit to share the study's resultant framework with patients. FHTs often hold a wide variety of education sessions for their patients on their health condition. Hosting an education session on the components of the resultant framework (potential patient roles, the steps required and the things that need to be in place for these roles to be enacted) might provide patients with an opportunity to start a discussion or generate ideas around their own involvement with HCPs in their IPTs.

Policy

The understanding that evolved from this study's 20 participants' perspectives on patient roles in IPTs may be used to start the conversation or assist in changing organizational or governmental health care policies. Twenty participants' perspectives are not likely to change policies, but they certainly can be used to supplement discussion on the need for policies, whether governmental, organizational, or clinic/unit specific, to recognize that patients would like to be more involved in their care and involved in ways meaningful to them. The current trend in the Ontario government towards Health Care Teams may make the findings from this study a valuable asset to emerging policy related to patients' voice in their care and toward patients' inclusion on IPTs within IPTs.

Future Research

It is evident that a greater number of studies are needed in the area of patient involvement in their IPTs to support or add to the findings. This study explored perspectives of patients and HCPs in FHTs in primary care in one city within one Canadian province. To test the resultant framework, further studies with patient and HCP participants in other provinces and clinic structures such as community health centres or nurse-practitioner led clinics may be beneficial. As well, testing the framework on patients within specific age groups such as adolescents, young adults, the elderly, especially with the rising in the ageing of the Canadian population (Government of Canada, 2018), or new immigrants and the Indigenous, might further add strength to the processes and conditions required for patients to enact roles in IPTs. Studies are also needed around perspectives of patients and HCPs in hospital or acute care as well as home care settings, to replicate or expand on the understanding of patient roles, processes, and conditions required for their inclusion as members of such teams. As well, broadening the

participant list to include family members and/or support persons could further enhance the results of this study. In any future research on this work, extending the invitation for patients to be part of the research team and involved in the planning, preparing, writing, conducting the study, and disseminating results will also be considered.

Knowledge Translation Plan

First, the knowledge gained through conducting this study has already been and will continue to be disseminated using conventional methods such as oral and poster presentations at national and international conferences. As well, at least three manuscripts will be submitted for publication in a number of interprofessional (topic: scoping review on patient roles in IPTs), grounded theory (topic: use of CGT in interprofessional research) and PCC journals (topic: framework on patient roles in IPTs in primary care).

Second, a connection will be made with leadership teams at a number of primary care institutions in Southwestern Ontario, but potentially expanding to other regions across Canada to share the findings through their teams so that all interested HCPs and patients, who currently are or have not yet been, members of IPTs can attend. These presentations will discuss perspectives of HCPs and patients on roles patients can enact within their IPTs. They will also include an overview of the conditions and processes required for patients' role enactments to occur. At the end of the presentations, an open discussion will take place on how to best incorporate this information within participants' respective practice settings. These presentations may extend to acute care settings, despite the findings of this study stemming from primary care. The reason behind this is that some HCPs work in both settings and may benefit from the study findings through gaining insight into variations that might lead to further studies related to acute care settings.

Third, educators or instructors of interprofessional courses within a number of academic institutions nationally will be contacted to discuss how the knowledge gained through this study can be disseminated to their students who will become future HCPs to influence their future forming of partnerships with patients.

Fourth, as this research aims to provide patients with an ability to share their voice in relation to their involvement within IPTs, it would only be appropriate to conduct a form of knowledge dissemination specifically with patients. Thus, Patients Canada will be approached to discuss their interest in the provision of a webinar to their members on the study findings to further continue the dialogue on patient roles in IPTs.

Conclusion

This study provided a comprehensive understanding of patient-HCP interactions within IPTs in primary care. It put forth dimensions of patient roles within such teams and explained why patient role clarity within IPTs remains difficult to comprehend. This study offers an understanding of the processes and conditions associated with patients assuming IPT roles to transform current HCPs' centric practice towards patient inclusion within these teams. Further research should utilize these findings and the resultant framework to continue to build knowledge on patient roles on IPTs within a multitude of settings such as acute care, nurse-practitioner led clinics, and community health centres.

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APPENDICES

Appendix A: Study Information Recruitment Letter



Date

Executive Director Name
Family Health Team Name

Dear Name,

RE: Invitation to Participate in a Research Study

My name is Kateryna Metersky and I am a Doctor of Philosophy in Nursing student at Western University. I am conducting a study as part of my degree requirements entitled *Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and HCP Perspective*.

The aim of this letter is to explore your FHT's interest in participating in this research study. The purpose of the study is to generate an *understanding of the patient roles in interprofessional patient-centred collaborative care teams through: (1.) exploration of patient perception in relation to what roles patients can enact within their respective interprofessional teams and; (2.) exploration of health care provider perception in relation to what roles patients can enact within their interprofessional teams.*

The research team will be delighted if you and your FHT are willing to participate in this study.

A short overview of the study and what it entails:

- The number of patients needed from your FHT is 5 patients. It is the intention to recruit patients who have been members of the FHT for at least 3 months and have been diagnosed with a chronic health condition 3 or more months ago.
- The study will need to be introduced to potential study participants and if patients display further interest, their names to be given to the investigators of the research team for follow up. Please note, to protect your patients, this will only occur once the study has received ethics approval from Western University and will follow strict ethical guidelines for dealing with patient participants.
- Selected patients will be asked to take part in one individual semi-structured interview lasting 60 minutes.
- The number of health care providers needed from each FHT is 5. It is the intention to recruit health care providers from a variety of different professional backgrounds.
- Health care providers that will display interest will be asked to take part in one individual semi-structured interview lasting 30-60 minutes.

The benefits of having your FHT participating in this study include:

1. Address Health Quality Ontario primary care sector performance indicator of “patient involvement in decisions about their care and treatment”, among others.
2. To be able to enhance patient-centred collaborative practice within your organization.
3. Identify key aspects of what patient roles within interprofessional teams can be and the impact that can result of having patients as team members on overall health outcomes and satisfaction with care received/given.

Attached with this invitation to participate is a consent form with further details on the study.

Please let me know by [date] if you are interested in being part of this study. If you agree, the only action you would require at this time, is to submit a letter of support for the study, a draft of which has been provided for you.

If you wish to discuss your involvement more fully, please do not hesitate contacting me at (phone#) or through email at (email address). Alternatively, you may also contact the study Principal Investigator and dissertation advisor Dr. Carole Orchard at (phone number) or through email at (email address).

Thank you for considering this request.
Sincerely,

Kateryna Metersky, RN, MN, PhD (student).
Study Investigator

Appendix B1: FHT 1 Willingness to Participate Letter

Thursday, April-13-17

Kateryna Metersky
Arthur Labatt Family School of Nursing
Western University

Dear Kateryna,

RE: Interest in Participating in the Study entitled *Patient Roles within Interprofessional Collaborative Patient-Centered Care Teams: The Patient and HCP Perspective*

On behalf of [REDACTED] I am pleased to indicate our willingness to participate in the above study. This study will allow teams to develop a common understanding of patients' needs and build on team members' skill set to offer comprehensive patient-centered care. Gain resources and knowledge to strengthen collaboration between practices within [REDACTED]. This study will attempt to identify the patient roles within interprofessional teams from both the patient and healthcare provider perspective.

This study is timely in providing the opportunity to develop more patient-centered collaborative practice within our FHT and in future formations of interprofessional teams by including patients in their care in a meaningful way.

Sincerely,

[REDACTED]

[REDACTED]

Appendix B2: FHT 2 Willingness to Participate Letter

LETTER OF SUPPORT

June 16, 2017

Kateryna Metersky
Arthur Labatt Family School of Nursing
Western University

Dear Kateryna,

RE: Interest in Participating in the Study entitled *Patient Roles within Interprofessional Collaborative Patient-Centered Care Teams: The Patient and HCP Perspective*

On behalf of [REDACTED] I am pleased to indicate our willingness to participate in the above study. This study will assist us in determining how to best move forward to involve our patients in the planning of our programs and services to meet their health care needs. This study will attempt to identify the patient roles within interprofessional teams from both the patient and healthcare provider perspective.

This study is timely in providing the opportunity to develop more patient-centered collaborative practice within our FHT and in future formations of interprofessional teams by including patients in their care in a meaningful way.

Sincerely,

[REDACTED]

Appendix C: HCP Study Recruitment Poster

**Recruitment Poster – Health Care Provider**

Patient Roles within Interprofessional Collaborative Patient-Centred
Care Teams:
The Patient and Health Care Provider Perspective

Doctoral Candidate: Kateryna Metersky, RN PhD (c)

Supervisor: Dr. Carole Orchard, RN EdD

*Interested in sharing your perspectives on roles
patients can hold in interprofessional teams*?*

Your participation in this study includes:

1. Individual interview lasting 30-45 minutes
2. Focus group interview with other patient participants lasting up to 60 minutes approximately 4 to 6 weeks after individual interview

If you meet the following criteria you may be eligible to take part in this study:

1. Over the age of 18
2. Speak, read and understand English
3. Work as part of an interprofessional team with other health care provider groups

Known or anticipated risks related to participating in this study are minimal and participation is completely voluntary.

Light refreshments will be available at both sessions.

If you would like more information about the study and/or are interested in participating, please contact Kateryna Metersky at (phone number) or email at (email address)

*Interprofessional teams are teams made up of at least two different health professions and may or may not include the patient

Appendix D: Patient Study Recruitment Poster

**Recruitment Poster – Patient**

Patient Roles within Interprofessional Collaborative Patient-Centred
Care Teams:
The Patient and Health Care Provider Perspective

Doctoral Candidate: Kateryna Metersky, RN PhD (c)

Supervisor: Dr. Carole Orchard, RN EdD

*Interested in sharing your perspectives on roles
patients can hold in interprofessional teams*?*

Your participation in this study includes:

3. Individual interview lasting 30-45 minutes
4. Focus group interview with other patient participants lasting up to 60 minutes approximately 4 to 6 weeks after individual interview

If you meet the following criteria you may be eligible to take part in this study:

4. Over the age of 18
5. Speak, read and understand English
6. Have been a patient at this Family Health Team for over three months
7. Diagnosed with a chronic disease more than three months ago

Known or anticipated risks related to participating in this study are minimal and participation is completely voluntary.

Light refreshments will be available at both sessions.

If you would like more information about the study and/or are interested in participating, please contact Kateryna Metersky at (phone number) or email at (email address).

*Interprofessional teams are teams made up of at least two different health professions and may or may not include the patient

Appendix E: HCP Letter of Information and Consent Form

**LETTER OF INFORMATION AND CONSENT– HEALTH CARE PROVIDER**

Study Title: *Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and Health Care Provider Perspectives*

Principal Investigator:

Carole Orchard, EdD, Professor, Arthur Labatt Family School of Nursing
Western University
Tel: phone number

Co-Investigator

Kateryna Metersky, RN, MN, PhD (c), Arthur Labatt Family School of Nursing
Western University
Tel: phone number

Conflict of Interest

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

Introduction

You are being invited to consider an alteration in how the follow up focus group interviews will be provided using an online meeting platform, 'ZOOM'. You will recall that you agreed to participate in this study about patient roles in interprofessional teams because you are a health care provider working as part of this Ontario Family Health Team/Nurse Practitioner-Led Clinic. This study is conducted by a Western University graduate student as part of her Doctor of Philosophy in Nursing degree requirement. Please read this explanation about the study and its alteration identified above, its risks and benefits before you decide if you would like to take part in a focus group interview using an online meeting platform 'ZOOM'. You should take as much time as you need to make your decision. You should ask the study investigators to explain anything that you do not understand and make sure that all of your questions have been answered before signing the consent form. Before you make your decision, feel free to talk about this change in the focus group for this study with anyone you wish. You will be provided with a copy of this document once it has been signed.

Background/Purpose

Research shows that when health care providers and patients collaborate at the point of care as part of interprofessional teams, both groups experience benefits in care delivery. However, the current role(s) patients can hold within these teams is unclear. The purpose of this study is to learn about your previous experiences with patients as members of your interprofessional team in terms of the roles, if any, that patients held. If you have never had a patient as part of your interprofessional team, the purpose of this study is to learn from your perspective as a health care

provider of the roles patients can hold/you could see them holding within future interprofessional teams.

This study seeks 5 health care providers from each of the two Ontario Family Health Team/Nurse Practitioner-Led Clinics for a total of 10 health care providers.

Study Design

You have already participated in an individual semi-structured interview and the plan was to provide one face-to-face focus group session with other health care provider participants. You are now being offered to take part in a focus group interview using the online meeting platform, 'ZOOM'. Due to health professionals' busy schedules you are being asked to consider participating in the focus group interview via the above online meeting platform from any convenient location to you. Your agreement to take part in this study also implies that you gave previous permission to be audio-taped during the individual interview and 'ZOOM' will provide a similar recording of the focus group sessions. The individual interview took place at your clinic's conference room. The online focus group session will be held via ZOOM and can be accessed from any location most convenient for you.

As with the individual interview, the focus group interview will last approximately 30-60 minutes and ask you questions about your validation of the initial findings from the study about patient roles within interprofessional teams.

For the online focus group interview you will be emailed a unique link that you will use to join our focus group at a scheduled time. You will use your selected pseudonym from the start of the study to enter the focus group. ZOOM does not retain a copy what we will discuss during the focus group so everything will still be kept confidential. The purpose of the focus group interview will be to allow you to collectively review the information provided in the individual interviews to ensure it accurately represents your perspectives of patient roles in interprofessional teams.

Voluntary Participation

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your employment with your Family Health Team/Nurse Practitioner-Led Clinic or any affiliation you may have with Western University.

Withdrawal from Study

If you decide to leave the study after consenting to participate, you have the right to request the investigators to withdraw the information collected about you during the individual interview. Please note, although every effort will be taken to do so, it is not always possible to withdraw information collected from you as part of a focus group. No new information will be collected without your permission.

Risks

There are no medical risks if you take part in this study. However, being in this study and sharing your experiences and/or perspectives might make you feel uncomfortable. Should this occur, you

may refuse to answer any question or stop the interview altogether, without penalty. If you become distressed during the study, the investigator will provide you with a list of free local counselling services you can access for further assistance.

Benefits

You may or may not receive any direct benefit from being in this study. Information learned from this study may or may not help you, other health care providers and any future patients who will become members of interprofessional teams. It is hoped that this study will offer a benefit to our society through providing a collective understanding into meaningful roles patients can enact within interprofessional teams

Reminders and Responsibilities

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. Your decision to take part or not to take part in the study, at any point in the study process, will have no effect upon your affiliation, if any, with Western University and/or your employment at the Family Health Team/Nurse Practitioner Led Clinic. Your supervisor(s) at the Family Health Team/Nurse Practitioner-Led Clinic will not have any knowledge of what is discussed and shared between you and the study investigators. Also, you may refuse to answer any question you do not want to answer by saying “pass”.

Alternatives to Being in the Study

An alternative to participating is not to take part in the study at all and continue on as you do now.

Confidentiality

Personal Information

If you agree to join this study, the investigators will collect only the personal information needed for this study. Personal information is any information that could be used to identify you and includes your:

- Name
- Contact telephone number
- Professional title
- Years in practice
- Years practicing interprofessional care or working as part of an interprofessional team

During the study, you were asked to select a unique pseudonym that will be tracked on the master list of identifiable information. You will continue to use this unique pseudonym for the focus group interview. All study data, such as audio-recordings and transcripts, will be labelled with this unique pseudonym only.

The personal information that is collected through this study will be kept in a locked, confidential location and separated from the interview data by the study investigators for 5 years. After this time, it will be destroyed. Only the study team or representatives of the Western University Health Sciences Research Ethics Board that oversee the conduct of this study will be allowed to look at the study data.

If you do not agree to participate in this study, all of the above personal information will be shredded (securely disposed of).

Focus Groups

Information collected as part of individual interviews will be discussed during the focus group session in the form of any collective similarities, differences and/or gaps identified. No direct quotes or individual identifiable information will be presented.

Study Information that Does Not Identify You

Direct quotes collected during individual interviews and/or focus groups may be used in reports, publications, or presentations that may come from this study. However, you will not be named or connected to such quotes in any reports, publications or presentations.

Collected study data will be stored on a remote Western University network drive on an encrypted, password protected laptop computer which only the study Principal Investigator and co-investigator will have access to.

Costs

You will not have to pay for taking part in any aspect of the study.

Compensation

There is no payment for study participation. However, you will be provided with refreshments during the interview.

Rights as a Participant

If you become emotionally uncomfortable or distressed as a result of taking part in this study, you will receive care. In no way does signing this consent form waive your legal rights or relieve the investigators and their involved institutions from their legal and professional responsibilities.

Questions about the Study

If you have any questions about the study now or at a later time, please contact Kateryna Metersky at email address and phone number or Dr. Carole Orchard at email address and phone number

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, email: ethics@uwo.ca.

Study Title: *Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and Health Care Provider Perspectives*

Principal Investigator:

Carole Orchard, EdD, Professor, Arthur Labatt Family School of Nursing
Western University
Tel: phone number

Co-Investigator

Kateryna Metersky, RN, MN, PhD (c), Arthur Labatt Family School of Nursing
Western University
Tel: phone number

Consent

Participant Consent:

This study has been explained to me and any questions I had have been answered.
I know that I may leave the study at any time. I agree to take part in this study and be audio-taped during the individual interviews.

Print Study Participant's Name Signature Date (DD-MMM-YYYY)

I agree to take part in the online focus group via ZOOM and be audio-taped during the online focus group.

Print Study Participant's Name Signature Date (DD-MMM-YYYY)

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the focus group to others.

I agree to keep what is discussed in the focus group interview by other study participants confidential.

Print Study Participant's Name Signature Date (DD-MMM-YYYY)

I agree to let the researchers use my direct quotes in reports, publications and presentations related to this study so long as the direct quotes do not identify me.

Print Study Participant's Name Signature Date (DD-MMM-YYYY)

Person Obtaining Consent:

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining

Signature

Date (*DD-MMM-YYYY*)

Appendix F: Patient Letter of Information and Consent Form

**LETTER OF INFORMATION AND CONSENT – PATIENT**

Study Title: *Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and Health Care Provider Perspectives*

Principal Investigator:

Carole Orchard, EdD, Professor, Arthur Labatt Family School of Nursing
Western University
Tel: phone number

Co-Investigator

Kateryna Metersky, RN, MN, PhD (c), Arthur Labatt Family School of Nursing
Western University
Tel: phone number

Conflict of Interest

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

Introduction

You are being invited to participate in this study about patient roles within interprofessional teams because you are a patient of this Ontario Family Health Team/Nurse Practitioner-Led Clinic. This study is conducted by a Western University graduate student as part of her Doctor of Philosophy in Nursing degree requirement. Please read this explanation about the study to decide if you would like to take part. You should take as much time as you need to make your decision. You may ask the study investigators to explain anything that you do not understand and make sure that all of your questions have been answered before signing the consent form. You will be provided with a copy of this document once it has been signed.

Background/Purpose

Research shows that when health care providers and patients work together as part of interprofessional teams, both groups experience benefits in care delivery. However, the current role(s) patients can hold within these teams is unclear. The purpose of this study is to learn about your previous experiences, as a patient, of being a part of an interprofessional team and the role(s) you held during your team experiences. When we use the term interprofessional team we mean a team that is comprised of two or more *different* health care providers who interact and work together with each other and ideally with you as the patient for more enhanced health outcomes. An example of an interprofessional team is when a nurse, a social worker, and a respiratory therapist work together with you as the patient and involve you in planning and implementing your care. If you have never been a member of an interprofessional team, the

purpose of this study is to learn from your perspective, as a patient, of the role you would like to hold within interprofessional teams.

This study seeks 5 patients from each of two Ontario Family Health Team/Nurse Practitioner-Led Clinics for a total of 10 patients.

Study Design

Should you decide to take part in this study, you will be asked to participate in one individual semi-structured interview and one focus group session with other patient participants. Your agreement to take part in this study also implies that you give permission to be audio-taped during the individual interview and focus group sessions. Both sessions will take place at the clinic's conference room with closed doors.

The individual interview will last approximately 60-90 minutes and ask you questions about your patient role within interprofessional teams.

The focus group interview will occur approximately 4 to 6 weeks after the individual interview and last approximately 60 minutes. The purpose of the focus group interview will be to allow you to collectively review the information provided in the individual interviews to ensure it accurately represents your perspectives of the role of patients in interprofessional teams.

Voluntary Participation

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your care at your Family Health Team/Nurse Practitioner-Led Clinic or any connection you may have with Western University.

Withdrawal from Study

If you decide to leave the study after consenting to participate, you have the right to request the investigators to withdraw the information collected about you. Please note, although every effort will be taken to do so, it is not always possible to withdraw information collected from you as part of a focus group. No new information will be collected without your permission.

Risks

There are no medical risks if you take part in this study. However, sharing your experiences and/or perspectives might make you feel uncomfortable. Should this occur, you may refuse to answer any question or stop the interview altogether, without penalty. If you become distressed during the study, the investigator will ask your permission to refer you to a designated member of your Family Health Team/Nurse Practitioner-Led Clinic to talk about your feelings. If you do not wish to use this resource, you will be provided with a list of free local counselling services you can access for further assistance.

Benefits

You may or may not receive any direct benefit from being in this study. Information learned from this study may or may not help you and/or future patients to gain an understanding of their role when becoming members of interprofessional teams. It is hoped that this study will offer a

benefit to our society through providing a collective understanding into meaningful roles patients can enact within interprofessional teams.

Alternatives to Being in the Study

An alternative to taking part in the study design described above is not to participate in the study and continue on just as you do now.

Confidentiality

Personal Health Information

If you agree to join this study, the investigators will collect only your personal information needed for this study. Personal information is any information that could be used to identify you and includes your:

- Name
- Contact telephone number
- Age
- Name of chronic condition(s) (Note: your medical records will not be accessed or viewed by any member of the research team)

During the study, you will be asked to select a unique pseudonym that will be tracked on the master list of identifiable information. All study data, such as audio-recordings and transcripts, will be labelled with this unique pseudonym only.

The personal information that is collected through this study will be kept in a locked, confidential location and separated from the interview data/transcripts by the study investigators for 5 years, after which it will be destroyed. Only the study team or representatives of the Western University Health Sciences Research Ethics Board, who oversee the conduct of this study, will be allowed to look at the study data.

If you withdraw from the study at any time, all of the above personal information will be shredded (securely disposed of).

Focus Groups

Information collected as part of individual interviews may be discussed during the focus group session in the form of any similarities, differences and/or gaps identified. No direct quotes or identifiable information will be presented.

Study Information that Does Not Identify You

Direct quotes collected during individual interviews and/or focus groups may be used in reports, publications, or presentations that may come from this study. However, you will not be named or connected to such quotes in any reports, publications or presentations.

Collected study data will be stored on a remote Western University network drive on an encrypted, password protected laptop computer which only the study Principal Investigator and co-investigator will have access to.

Costs

You will not have to pay for taking part in any aspect of the study.

Compensation

You will be provided up to \$10.00 worth of travel compensation for attending each session. Light refreshments will be available at both sessions.

Rights as a Participant

If you become emotionally uncomfortable or distressed as a result of taking part in this study, you will receive care at no additional cost to you. In no way does signing this consent form waive your legal rights or relieve the investigators and their involved institutions from their legal and professional responsibilities.

Questions about the Study

If you have any questions about the study now or at a later time, please contact Kateryna Metersky at email address and phone number or Dr. Carole Orchard at email address and phone number.

If you have any questions about your rights as a research participant or the conduct of this study, you may contact The Office of Human Research Ethics (519) 661-3036, email: ethics@uwo.ca.

Study Title: *Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and Health Care Provider Perspectives*

Principal Investigator:

Carole Orchard, EdD, Professor, Arthur Labatt Family School of Nursing
Western University
Tel: phone number

Co-Investigator

Kateryna Metersky, RN, MN, PhD (c), Arthur Labatt Family School of Nursing
Western University
Tel: phone number

Consent

Participant Consent:

This study has been explained to me and any questions I had have been answered.
I know that I may leave the study at any time. I agree to take part in this study and be audio-taped during the individual and focus group interviews.

Print Study Participant's Name

Signature

Date (DD-MMM-YYYY)

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the focus group to others.

I agree to keep what is discussed in the focus group interview by other study participants confidential.

Print Study Participant's Name

Signature

Date (DD-MMM-YYYY)

I agree to let the researchers use my direct quotes in reports, publications and presentations related to this study so long as the direct quotes do not identify me.

Print Study Participant's Name

Signature

Date (DD-MMM-YYYY)

Person Obtaining Consent:

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining
Consent

Signature

Date (DD-MMM-YYYY)

Appendix G: HCP Initial Interview Guide

**Health Care Provider Individual Interview Guide**

Dear health care provider,

Thank you for agreeing to participate in an individual semi-structured interview for this research study entitled **Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and Health Care Provider Perspectives**. My name is Kateryna Metersky and I will be the investigator conducting this interview.

The interview should last approximately 60 minutes and may end earlier depending on the discussion we will have. During the session, you will be asked a series of questions in relation to patient roles within interprofessional teams. Mainly, I would like to hear about any of your previous experiences with having patients as a part of your team. Specifically, I am interested in obtaining your perspective on the roles patients can hold within your interprofessional team.

Please feel free to share as many stories, examples, thoughts, opinions, perspectives, etc. as they emerge about patient roles on your team. The goal of this semi-structured interview is to generate as rich a discussion on the topic as possible. However, I would like to remind you to please refrain from sharing any confidential/identifiable information within the interview. The interview will be audio-taped so that I can transcribe it into a written form at a later time. As a participant, you are free to leave at any time, move around and take breaks if you need to. If there is any aspect of the interview you do not want respond to, you are not obligated to do so. Light refreshments have been provided.

Before we begin, can you please select a pseudonym that you would like to be referred to retain your anonymity. Your real name will never be used in any report or publication of the study.

Are there any questions before we get started?

The following are the possible questions for the semi-structured interview:

Introduction: Please state your pseudonym, professional title, years in practice and years working as part of an interprofessional team.

- 1) What does interprofessional care mean to you?
 Probe:
 - What does working as part of an interprofessional team mean to you?
- 2) What is your perception of the patient role(s) in your interprofessional team?

Probes:

- What roles, if any, did/do patients enact within the team?
- How do these roles come about?

3) What would be an ideal role/ideal roles for patients to enact within your interprofessional team?

Probes:

- What is needed for these roles to be enacted?
- What processes do the patient and/or the team need to undertake for this to occur?
- What conditions need to be in place?

4) What positives or challenges can occur with patients as team members?

Additional Questions:

- 1) Is there anything else you would like to add to your perspective of patient as team member? Patient roles in interprofessional teams?
- 2) Is there anything that you might not have thought about before that occurred to you during this interview?
- 3) Is there anything you would like to ask me?

Appendix H: Patient Initial Interview Guide

**Patient Individual Interview Guide**

Dear Patient,

Thank you for agreeing to participate in an individual semi-structured interview for this study entitled **Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and Health Care Provider Perspectives**. My name is Kateryna Metersky and I will be conducting this interview.

The interview should last approximately 60 minutes and may end earlier depending on the discussion. During the session, you will be asked a series of questions in relation to the roles patients can hold within interprofessional teams. For your reference, when I use the term interprofessional team I mean a team that is comprised of two or more *different* health care providers who interact and work together with each other and ideally with you as the patient for more enhanced health outcomes. An example of an interprofessional team is when a nurse, a social worker, and a respiratory therapist work together with you as the patient and involve you in planning and implementing your care. Thus, I would like to hear about your previous experiences, as a patient, being a member of an interprofessional team. As well I would like to obtain your perspective of the roles you can hold/would like to hold within interprofessional teams you may be part of.

Please feel free to share as many stories, examples, thoughts, opinions, perspectives, etc. as they emerge. The goal of this interview is to generate as rich discussion on the topic as possible. However, I would like to remind you to please refrain from sharing any confidential/identifiable information within the interview. The interview will be audio-taped so that I can transcribe it into a written form at a later time. You are free to leave at any time, move around and take breaks if you need to. If there is any aspect of the interview you do not want to take part of, you are not obligated to do so. Light refreshments are provided.

Before we begin, can you please select a pseudonym that you would like to be referred to as to retain your anonymity. Your real name will never be used in any report or publication of the study. Are there any questions before we get started?

The following are the possible questions for the interview:

Introduction: Please state your pseudonym, age or year of birth, and chronic conditions(s).

- 1) What does interprofessional care mean to you?

2) Can you share your experience as a patient receiving care from this interprofessional team?

Probe:

- If you could dream of the perfect way that you could receive care from this interprofessional team, what would it be?

3) What is your perception of the patient role(s) in your interprofessional team?

Probes:

- What roles, if any, did/do you enact within the team?
- How do these roles come about?

4) What would be your ideal role/roles in an interprofessional team?

Probes:

- What is needed for these roles to be enacted?
- What processes do you and/or the team need to undertake for this to occur?
- What conditions need to be in place?

5) What positives or challenges can occur with you becoming a team member?

Additional Questions:

- 1) Is there anything else you would like to add to your perspective of you as team member?
Your roles in interprofessional teams?
- 2) Is there anything that you might not have thought about before that occurred to you during this interview?
- 3) Is there anything you would like to ask me?

Appendix I: HCP Member-Checking Interview Guide



Health Care Provider Member-Checking Interview Guide

Dear health care providers,

Thank you for continuing to display your interest in this study entitled **Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and Health Care Provider Perspectives** and agreeing to participate in this online interview. My name is Kateryna Metersky and I will be the investigator conducting this interview.

The interview should last approximately 30-60 minutes and may end earlier depending on the discussion we will have. During the session, you will be asked to review the framework on patient roles within interprofessional teams. I will share the framework with you using the screen share function. The framework will appear on your screens shortly after these instructions. Please note this may not be the final version of the framework as based on the discussion we have today, some further modifications to it are possible.

This framework has been composed from your and patient participants' collective perspective that was obtained during the individual interview portion of this study. Mainly, I would like to hear your opinion about the framework and whether it captured what we discussed during the individual interviews. I also want to give you an opportunity to comment on any similarities, differences and/or gaps that you may see between health care provider and patient perspectives on patient roles in teams.

As with the individual interview, I would like to remind you to please refrain from sharing any confidential/identifiable information within the interview. In addition, part of the consent form, you all have agreed to keep what has been shared and discussed by other participants confidential. The interview will be audio-taped so that I can transcribe it into a written form at a later time. As a participant, you are free to leave at any time, move around and take breaks if you need to. If there is any aspect of the interview you do not want respond to, you are not obligated to do so.

Are there any questions before we get started?

Introduction: Please state your pseudonym and professional title to other participants.

I will spend the first 5 minutes of this session explaining the framework in detail to the participants and follow with these possible questions:

- 1) What is your initial reaction of the framework?

- 2) Does the framework reflect the conversation we had during the individual interview?
 - a. If yes, how so?
 - b. If no, how does it not?
- 3) What do you like about the framework?
- 4) What do you dislike about the framework?
- 5) Is there anything missing in the framework? Anything you would like to add to the framework
 - a. If yes, what specifically?
- 6) Is there anything you would like to remove from the framework?
 - a. If yes, why?
 - b. What specifically?
- 7) Do you have any stylistic suggestions for the framework?
 - a. If yes, what would they be?
- 8) There are aspects of the framework that are similar in relation to what was found from the collective perspective of health care providers and patients. However, there are also aspects that are different. An example of this is the role of team player vs. team person.
 - a. What is your perception of these differences in health care provider and patient perspectives on patient roles in teams?

Additional Questions:

- 1) Having reviewed the framework and hearing your colleagues' perspectives, is there anything else you would like to add to your perspective of patient as team member? Patient roles in interprofessional teams?
- 2) Is there anything that you might not have thought about before that occurred to you during this interview?
- 3) Is there anything you would like to ask me?

Appendix J: Patient Member-Checking Interview Guide

**Patient Member-Checking Interview Guide**

Dear patients,

Thank you for continuing to display your interest in this study entitled **Patient Roles within Interprofessional Collaborative Patient-Centred Care Teams: The Patient and Health Care Provider Perspectives** and agreeing to participate in this in-person interview. My name is Kateryna Metersky and I will be the investigator conducting this interview.

The interview should last approximately 30-60 minutes and may end earlier depending on the discussion we will have. During the session, you will be asked to review the framework on patient roles within interprofessional teams. I will share the framework with you on a handout. I will need to collect the handout at the end of our session, but feel free to make markings and/or write on it if you need to. Please note this may not be the final version of the framework as based on the discussion we have today, some further modifications to it are possible.

This framework has been composed from your and health care provider participants' collective perspective that was obtained during the individual interview portion of this study. Mainly, I would like to hear your opinion about the framework and whether it captured what we discussed during the individual interviews. I also want to give you an opportunity to comment on any similarities, differences and/or gaps that you may see between health care provider and patient perspectives on patient roles in teams.

As with the individual interview, I would like to remind you to please refrain from sharing any confidential/identifiable information within the interview. In addition, part of the consent form, you all have agreed to keep what has been shared and discussed by other participants confidential. The interview will be audio-taped so that I can transcribe it into a written form at a later time. As a participant, you are free to leave at any time, move around and take breaks if you need to. If there is any aspect of the interview you do not want respond to, you are not obligated to do so. Light refreshments have been provided for you.

Are there any questions before we get started?

Introduction: Please state your pseudonym.

I will spend the first 5 minutes of this session explaining the framework in detail to the participants and follow with these possible questions:

- 1) What is your initial reaction of the framework?

- 2) Does the framework reflect the conversation we had during the individual interview?
 - a. If yes, how so?
 - b. If no, how does it not?
- 3) What do you like about the framework?
- 4) What do you dislike about the framework?
- 5) Is there anything missing in the framework? Anything you would like to add to the framework
 - a. If yes, what specifically?
- 6) Is there anything you would like to remove from the framework?
 - a. If yes, why?
 - b. What specifically?
- 7) Do you have any stylistic suggestions for the framework?
 - a. If yes, what would they be?
- 8) There are aspects of the framework that are similar in relation to what was found from the collective perspective of health care providers and patients. However, there are also aspects that are different. An example of this is the role of team player vs. team person.
 - a. What is your perception of these differences in health care provider and patient perspectives on patient roles in teams?

Additional Questions:

- 1) Having reviewed the framework and hearing your colleagues' perspectives, is there anything else you would like to add to your perspective of patient as team member? Patient roles in interprofessional teams?
- 2) Is there anything that you might not have thought about before that occurred to you during this interview?
- 3) Is there anything you would like to ask me?

Appendix K: UWO Ethics Certificate



Research Ethics

**Western University Health Science Research Ethics Board
HSREB Delegated Initial Approval Notice**

Principal Investigator: Dr. Carole Orchard
Department & Institution: Health Sciences/Nursing, Western University

Review Type: Delegated
HSREB File Number: 109490
Study Title: Patient Roles within Interprofessional Collaborative Patient - Centered Care Teams: The Patient and Health Care Provider Perspective

HSREB Initial Approval Date: August 31, 2017
HSREB Expiry Date: August 31, 2018

Documents Approved and/or Received for Information:

Document Name	Comments	Version Date
Western University Protocol		2017/08/28
Recruitment Items	Clinic Recruitment Letter	2017/08/03
Recruitment Items	Clinic Draft Letter of Support	2017/05/31
Recruitment Items	Patient Recruitment Poster	2017/08/28
Letter of Information & Consent	HCP	2017/08/28
Letter of Information & Consent	Patient	2017/08/28
Data Collection Form/Case Report Form	HCP Individual Interview Guide	2017/08/03
Data Collection Form/Case Report Form	Patient Individual Interview Guide	2017/08/03

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above named study, as of the HSREB Initial Approval Date noted above.

HSREB approval for this study remains valid until the HSREB Expiry Date noted above, conditional to timely submission and acceptance of HSREB Continuing Ethics Review.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice Practices (ICH E6 R1), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940

[Redacted Signature]

Ethics Officer: [Redacted Signature]

EO: [Redacted Signature]

Curriculum Vitae

Name: Kateryna Metersky

Post-secondary Education and Degrees:

Ryerson University
Toronto, Ontario, Canada
Minor in Psychology
2007-2010

Ryerson University
Toronto, Ontario, Canada
Bachelor of Science in Nursing
2007-2011

Ryerson University
Toronto, Ontario, Canada
Master of Nursing (thesis stream)
2011-2013

The University of Western Ontario
London, Ontario, Canada
Doctor of Philosophy
2013-2020

Honours and Awards:

The University of Western Ontario
Arthur Labatt Family School of Nursing
Arthur Labatt Family Graduate Scholarship in Nursing
2013

Ontario Graduate Scholarship
2013-2016

The University of Western Ontario
Graduate Research Scholarship
2013-2016

Faculty of Health Sciences
Graduate Conference Travel Award
2014, 2017, 2018

Registered Nurses' Foundation of Ontario
Nursing Education Initiative Grant
2016 - 2019

Canadian Nurses Foundation
 Bianca Beyer Award
 2017

Canadian Nursing Students Association
 Award for the Recognition of Preceptors and Mentors
 2017

Irene E. Norwich Foundation
 Graduate Award
 2017

University Health Network
 MSA Award for Excellence
 2017
 Maud Rogers Webb-Wilson Nursing Scholarship
 2018
 Nursing and Health Professional Service Staff Scholarship
 2019

Sigma Theta Tau International
 Iota Omicron Chapter
 Research Grant
 2018

**Related Work
 Experience:**

Research Assistant/Research Team Member
 Ryerson University
 2009-2018, 2020
 University of Calgary
 2010
 Registered Nurses' Association of Ontario
 2012
 The University of Western Ontario
 2018-2020

Teaching Assistant
 Ryerson University
 2011-2012
 The University of Western Ontario
 2014, 2016, 2018

Registered Nurse
 University Health Network – Toronto Western Hospital
 2012-2020

Project Advisor
 Canadian Foundation for Healthcare Improvement Collaborative
 2014-2018

Instructor/Contract Lecturer
 Ryerson University
 2016-2020
 University of Toronto
 2018-2019
 George Brown College
 2020

Competency Learning Plan Advisor
 Trent University
 2020

Publications:

- Miller, K., Hamza, A., **Metersky, K.**, & Gaffney, D. (2018). Transfer of accountability: Piloting a new initiative in rural Ontario hospitals. *Journal of Nursing Care Quality*, 5(1), 90-96.
- Zanchetta, M. Bailey, A., Kolisnyk, O., Baku, L., Schwind, J., Osino, E., **Aksenchuk-Metersky, K.**, ... & Yu, L. (2017). Mentors' and mentees' intellectual-partnership through the lens of the Transformative Learning Theory. *Nurse Education in Practice*, 25, 111-120.
- Schwind, J. K., McCay, E., **Metersky, K.**, & Martin, J. (2016). Development and implementation of an advanced therapeutic communication course: An interprofessional collaboration. *Journal of Nursing Education*, 55(10), p. 592-597.
- Metersky, K.**, & Schwind, J. K., (2015). Interprofessional person centered care: Stories and metaphors of experience. *International Journal of Person Centered Medicine*, 5(2), 78-87. <http://www.ijpcm.org/index.php/IJPCM/article/view/528>
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- Schwind, J. K., Santa Mina, E., **Metersky, K.**, & Patterson, E. (2015). Using the Narrative Reflective Process to explore how students learn about caring in their nursing program: An arts-informed Narrative Inquiry. *Reflective Practice*, 16(3), p. 390-402. doi: 10.1080/14623943.2015.1052385
- Schwind, J., Zanchetta, M., **Aksenchuk, K.**, & Gorospe, F. (2013) Nursing students' international placement experience: An Arts-Informed Narrative Inquiry. *Reflective Practice*, 14(6), p. 705-716. doi:10.1080/14623943.2013.810619
- Zanchetta, M., Schwind, J., **Aksenchuk, K.**, Gorospe, F., & Santiago, L. (2013). An international internship on social development led by Canadian nursing students: Empowering learning. *Nurse Education Today*, 33(7), 757-764. doi: 10.1016/j.nedt.2013.04.019
- Fredericks, S., Schwind, J. K., & **Aksenchuk, K.** (2012). Information access and systematic reviews: A discussion. *Canadian Journal of Nursing Informatics*, 7(1), <http://cjni.net/journal/?=1966>