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Navigating, Negotiating, and Narrating: Re-Envisioning Patient-Centered Chronic Illness Care

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Abstract

Patient-centered care (PCC) is ubiquitous in how we think about patient-practitioner encounters. But such a taken-for granted stance may unknowingly obscure how conversations actually unfold in real life. The purpose of this work is to unravel the disconnect between how patient-centered care is talked about and how it is implemented in the real world. The overarching research question that framed this study was: *What are the influences that shape the unfolding of the conversations that occur at chronic illness health encounters and how does this unfolding influence the learning and execution of PCC*? The aim of this research was to offer a conceptualization of how patients' and practitioners' approaches to interactions at health encounters influence how stories unfold. Two major research studies framed this work addressing these research questions: (1) how do patients prepare and shape their stories of illness in order to interact productively with health practitioners and (2) how do interactions between patients and health practitioners shape the stories told at encounters?

Using a constructivist grounded theory approach (CGT) a total of 33 participants - patients and practitioners- were interviewed using a semi-structured interview guide. Data collection and analysis was iterative using the constant comparative method. We found that patients did a lot of *work* to engage in health interactions and that this work was invisible to practitioners. Despite this work, however, patients were often left feeling that the stories that unfolded at health encounters often remained incomplete. Combining the perspectives of both patients and practitioners, we described different types of incomplete stories, namely the hidden story, the interpreted story, and the tailored story. The shared dimensions of making choices, balancing time, and targeting priorities informed the conceptualization of 'Getting Airtime' as a framework to understand how chronic illness interactions unfold at encounters. Using the framework of Patient-Centered Clinical Method (PCCM) to address educational considerations and the framework of Minimally Disruptive Medicine (MDM) to address practice considerations, we propose a re-envisioning of patient-centered encounters that reduces patients' health

interaction work, builds information-sharing capacity, and prevents harmful gaps in storytelling.

Keywords

Summary for Lay Audience

During health encounters, patients and practitioners come together to discuss concerns or problems that impact their health. As each comes to the encounter with different ideas or agendas, the conversations may not proceed as expected. In this work, I attempt to pull apart how these discussions may be less than satisfactory, interfering with how patient-centered chronic illness care occurs in real life.

Two research studies framed this work to address the overarching question: *What are the influences that shape the unfolding of the conversations that occur at chronic illness health encounters and how does this unfolding influence the learning and execution of patient-centered care.* In the first study with twenty-one patients, interviews were conducted to understand how patients prepare for health encounters and how these actions may influence how the conversations unfold.

We found that patients did a lot of preparatory *work* to engage in health interactions that was invisible to practitioners. Despite this work, however, patients were often left feeling that the stories that unfolded at health encounters often remained incomplete. In a follow-up study with twelve practitioners about how they approached encounters, the theme of incomplete stories also developed. Combining the perspectives of both patients and practitioners, we described different types of incomplete stories, namely the *hidden story,* the *interpreted* story, and the *tailored story*. These types of stories came about at health encounters when both patients and practitioners made choices, balanced time, and targeted priorities in order to acquire 'airtime'.

With an emphasis on teaching and practicing patient-centered care, we propose that the framework of 'Minimally Disruptive Medicine' offers a way to reduce health interaction burden, build story-telling capacity, and prevent harmful gaps in stories, re-envisioning how we put patients at the centre of chronic illness care.

Co-Authorship Statement

This doctoral dissertation consists of three complementary manuscripts that represent the collaborative work of researchers and co-authors. The primary contributor is Wilma J. Koopman, who with the support, guidance and supervision of Dr. Christopher J. Watling, and the advisory committee members identified and researched the topic, designed the studies, collected, analyzed, and interpreted the data and drafted the manuscripts. Chapter 3 is an autoethnography and due to the collaborative nature of this work, the manuscript is co-authored by Dr. K. A. LaDonna and Dr C. Watling. Chapters 4 and 5 are manuscripts that represent the primary research for this dissertation, and are co-authored by Dr. C.J. Watling, Dr. K.A. LaDonna, Dr. E. A. Kinsella, and Dr. S. L. Venance. These co-authors supervised the research, provided insights into the research design, analysis, and findings, and reviewed, edited, and approved the final manuscripts prior to publication.

Acknowledgments

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Chapter 1

1 Introduction

Patient-centered care (PCC) is so embedded in the culture and language of health care that as practitioners we are in danger of thinking that our approaches to patient interactions are unquestionably patient-focused. We know that the tenets of PCC are taught to health professions learners, but many patients remain unsatisfied with their experiences[1]. This disconnect presents an opportunity to meaningfully reconsider how a 'taken for granted' stance to PCC risks premature closure on our efforts to re-examine, re-evaluate and re-envision patient-centeredness in health professions education.

1.1 Statement of Thesis Purpose

This doctoral dissertation is situated within the body of work attending to health encounters that occur between patients with chronic illness and practitioners. These conversations are critical as the starting point for everything that follows in health care. Unlike earlier work in health encounters, where studies often focused on the practitioner's side of the conversations, I will use a constructivist approach to understand health encounters from both the patient's and the practitioner's perspective. Through these studies, I begin to pull apart the facets of how patients' and practitioners' approaches to interactions at health encounters influence our understandings of patient-centered care. Specifically, by focusing on the patients' voice, I hope to revive PCC as an entity truly focused on the patient.

1.2 Overview of Chapters

This thesis consists of 5 chapters, following an integrated article format. In chapter 1, I explain how my interest in patient-centered care in chronic diseases developed, describe the current understandings about patient-centered care (PCC), patient-centered education,

and patient-centered encounters, and present the rationale for the research studies that frame the thesis. In chapter 2, I describe the methodology, Constructivist Grounded Theory (CGT), the approach I used to guide the research process. In qualitative research, the position of the researcher is intertwined with the entire research process. In chapter 3, the manuscript, *Autoethnography as a Strategy for Engaging in Reflexivity* offers my insider's approach to reflexivity, prior to embarking on a qualitative research program of study. Two research studies, using Constructive Grounded theory[2] were conducted to explore patients' and practitioners' perspectives of health encounters in a variety of chronic illnesses. In chapter 4, the findings of the first study are presented as a published manuscript "*Getting airtime": Exploring how patients shape the stories they tell health practitioners*, where I explored with patients how they prepared and shaped their stories for health encounters. In chapter 5, the findings of the second research study are being prepared for submission, *Archetypes of incomplete stories in chronic illness health encounters*, where I explored how stories constructed at health encounters are influenced by the perspectives of both patients and practitioners. In chapter 6, I provide a discussion of the integrated key insights from the autoethnography and the findings of the research studies, focusing on implications for future applications to patient centered education and practice.

1.3   Background and Significance

As a health practitioner focused on chronic neuromuscular diseases, I hear stories from patients about their health concerns daily. While I am knowledgeable about, obliged to perform and personally committed to patient-centeredness as a model of high quality and safe care, for various reasons I grapple with how to fulfill this goal with every encounter. Therefore, it is not surprising that our efforts to teach learners to practice in a patient-centered way may not always be ideal. The complexity of chronic illness care challenges clinicians and learners to successfully engage in conversations focused on listening to the patients[1]. While hearing, listening, and conversing with patients in a patient-centered way is essential, patients' preferences, values, and needs may be difficult to grasp, endorse and execute, hampering our efforts to teach and practice PCC.

For example, a few years ago, before non-invasive ventilation (NIV) techniques were commonplace to assist patients experiencing chronic respiratory failure, I had an individual attend an appointment where it was clear that NIV was essential for continued life. Although he agreed to NIV as a treatment plan, he refused the associated inpatient hospitalization that was required to establish him on this treatment. I struggled with balancing his need for medical care and his desire to receive that care outside of what I could readily offer. He conveyed to me his feeling that the hospital was ill-equipped to provide individualized care, something he had fully integrated in his home. He then told me that during a previous admission to hospital, he found practitioners had failed to provide the care he needed: they did not listen to him, they failed to understand his complex needs, and they did not have the time to support his personal care requirements. Reflecting on this experience, I thought about how we had failed him. Patient-centered care did not happen! And so, I asked myself "What is this all about? What has gone wrong here? And why is the aspiration of patient-centered care not being met?" With an aim to answer the question 'How do we put patients at the centre of everything we do in health care and how do we learn from it?' I embarked on a research journey to gain understandings about patient-centeredness with a focus on the patient's voice that echoes in the stories they bring to health encounters.

1.3.1   Patient-Centered Care (PCC)

The concept of patient-centeredness is widely endorsed as the pinnacle for safe and quality health care by "providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions".[3(p 40)] PCC is a philosophy that embraces principles that *value patients' perspectives and experiences while requesting their contribution and participation in care decisions.*[4-7] Some efforts have been made to theorize patient-centered care as a moral standard of care, but it has rarely been recognized in the PCC literature.[8,9]

The early works of physicians, Balint,[10] who pioneered the term "patient-centered medicine", differentiating it from "illness-centered medicine", and Engel[11,12] who used a

systems model to combine "biologic, psychologic and social data", were influential in developing a holistic model of care focusing on the unique aspects of individual patients. First inspired by Rogers's work on Client-centered Therapy,[13] medicine, nursing and other health disciplines complement the conceptualization of PCC by incorporating the ideas of 'therapeutic relationships'[10] 'the total patient approach to patient problems,'[14] and 'the two-body practice'.[15] Building on these influences, Stewart and others introduced the patient-centered clinical method (PCCM) that continues to offer a vital theoretical framework for the implementation of patient-centeredness in health professions education,[16-18]practice,[19]and care delivery.[20,21]

The well-accepted patient-centered clinical method (PCCM)[16,17] is comprised of four broad dimensions: exploring health, disease, and the illness experience; understanding the whole person; integrating health prevention and promotion while discovering common ground; and fostering the patient practitioner relationship.[17] Centering on various features of patient-practitioner relationships, Mead and Bower[22] expanded the early PCC model[16] with the following dimensions – biopsychosocial perspective, patient as a person, sharing power and responsibility, and therapeutic alliance. Langberg and others[23] further extended the model with the addition of 'coordination of care,' while others signaled the value of inter-professional engagement for coordinated and team-based PCC.[24-26]

While this tracing of the evolution of PCC is instructive, it hints at a growing problem: a lack of conceptual clarity, shared definition, and distinct theoretical underpinnings. This problem threatens the implementation, teaching, and quality appraisal of PCC[7,27-33] rendering true patient-centeredness possibly unattainable.[34,35]

1.3.2   Patient-Centered Medical Education

Even though patients are supposed to be at the center of care, efforts at conceptualizing and teaching PCC tend to be practitioner-centric.[18] Indeed, a recent review examining how PCC is included in undergraduate medical curricula confirms that a lack of clarity about how to teach and assess patient-centered competencies is problematic. While

references to patient-centeredness is noted in education modules related to communication and management of long-term conditions, particular attributes or skills expected in a patient-centered practitioner are missing.[36]

Efforts to include patients' voices in medical education are noteworthy. Patients' involvement in medical education occurs in varied venues – educational institutions, acute care units, ambulatory clinics, and in community health care settings. Customarily, patients carry out a passive educational role, often in clinical settings where 'bedside teaching rounds or medical assessments supervised by practitioners occur, and learners endorse these teaching moments as highly valuable.[37-39] Taking on a more active role, patients may also be invited to 'class' to tell their 'story' as a means of 'putting a face to the disease' or as 'real actors' to assist learners to practice assessments, communication techniques and professional skills.[40-44] With the recent need to provide virtual medical care due to the COVID-19 pandemic, the inclusion of patient educators in web-based encounters endorses the need to particularly involve patients in novel and innovative education and practice initiatives.[45]

Whether efforts like these translate to care that is more patient centered remains an open question[46] Inviting patients to the 'classroom' is important teaching tool, but issues arise when patient educators do not have an autonomous voice in curriculum development or when their knowledge is not viewed by learners to be credible.[47-49] In one study focused on teaching communication skills, learners reported that feedback on performance was more beneficial with simulated patients -individuals trained to model an illness- than with real patients.[50] We do know that when patients are involved in medical education, learners do gain knowledge about patient-centeredness,[51-54] but this learning may not be straight forward, take precedence or be modeled in real-world encounters,[56-58] making its value tenuous.

On the other hand, patient educators do report personal, professional, and emotional benefits from their participation in formal and informal medical education events.[59] For example, patients with rare chronic illnesses, where treatments are limited or non-

existent, may be motivated to attend clinic appointments in order to fulfill their self-described role of educating learners and practitioners, and to assure themselves that their diseases will not be overlooked.[60] Sharing the various elements of their rare disease – the biophysical experience, the lived experience, and the trajectory of chronic losses- patients are reminding and educating practitioners about the need to move beyond diagnosis to caring and cure.[61] Learning patient-centeredness is complex and often a two-way street, so while patients have varied roles as educators in classroom settings, the covert teaching efforts by patients at routine encounters suggest that our understandings of what patients offer to learners' education may be missed. In addition, practitioners may deem routine encounters as a way to check off components of the surveillance tick boxes rather than engaging in understanding how they can make a difference in a patient's health journey.

1.3.3   Chronic Illness Encounters

How PCC unfolds at health encounters is not a predictable process. Communication problems, time limitations, and contextual issues challenge practitioners to identify patients' individualized needs and priorities in the setting of routine care.[62] Individuals with chronic diseases may present distinctive challenges, given their illness trajectories are often progressive, complex, and life-limiting.

Chronic illness experiences are known to interrupt patients' everyday lives,[63,64] biography,[65,66] and health.[67-69] The *work* of engaging in household responsibilities, employment duties, and family/social activities is known to create challenges often unnoticed by others.[70,71] In addition, frequent, lifelong, and multi-practitioner encounters are commonplace, interrupting an already challenging life journey. Attending health encounters often require patients to prepare, plan, and organize their visits while also attending to the needs of family members, employment responsibilities and personal commitments.[63,70] Practitioners too, need to organize patient encounters amidst their other demands -urgent patient needs, administrative deadlines, and personal obligations. So, while both patients and practitioners may desire fruitful health interactions, the divergent

perspectives and experiences that are brought to chronic illness encounters may foster outcomes that are not always positive.[72-75]

With a nursing career focused on chronic neuromuscular diseases, I situated my thesis in chronic illness, as the place to figure out how patient stories are shaped and how these stories unfold at encounters in an attempt to uncover the nuances of learning and practicing patient-centeredness in this setting. At health encounters, patients and practitioners communicate in a manner where patients tell their story usually triggered by practitioners' questions and prompts. But we know that patients experience difficulties in sharing their story. They may fear that their problem is not important enough, they may have anxiety about disclosing their 'real' concerns, or they may be embarrassed to ask questions that appear irrelevant.[76] In contrast to acute illness encounters where the focus of the interaction is on the immediate problem, chronic illness encounters may be complex, taxing practitioners to gather information for productive decision-making. For example, we know that people with chronic illness are more likely to have other co-morbidities and this may also be associated with socioeconomically deprived backgrounds.[77] Therefore, considerations about patient-centeredness in chronic illness interactions may have distinguishing features important for care delivery.

Most commonly, chronic illness care is provided by primary care physicians in a patient's own community. But health encounters may also take place in ambulatory care centers, emergency rooms, inpatient hospital venues and other community sites often dictated by patients' complex needs. The multiplicity of venues, practitioners, and services bring with it the risk of fragmented care.[78] While improvements to coordinated and collaborative care for patients with chronic diseases are proposed,[79] the execution of patient-centered chronic disease care may also require distinctive communication strategies.

1.3.4   Chronic Illness Communication

Optimal patient-practitioner communication is known to be central to the effective

implementation of patient-centered care. Yet ineffective communication with practitioners is commonly cited by patients as the key contributor to unsatisfactory experiences with health care.[1,80] While learners are taught patient centered communication behaviours such as active listening while displaying empathy to foster positive interactions,[17,81] patients with chronic illnesses may require unique conversational approaches due to the multifaceted and protracted nature of their illness. Street[82] offers a comprehensive characterization of what constitutes patient-centered chronic illness communication. Key dimensions include: "fostering healing relationships, exchanging information, responding to emotions, making decisions, managing uncertainty, and enabling patient self-management which also include facilitating patient navigation and patient empowerment."[83(p391)] Communication in chronic illness care foregrounds the need to support patient-practitioner relationship building, but efforts to include longitudinal care in medical education remains problematic, limiting these distinctive learning experiences.[84,85]

Attempts to enhance patient-centered communication at chronic illness encounters have focused on engaging 'patients as partners' offering a fundamental dimension to the framework of patient-centered care.[17,86-90] One key partnering strategy -shared-decision making (SDM)- has been especially influential despite lacking a unified definition,[91,92] an ideal method on how to best implement or evaluate it.[93-96] This succinct definition of SDM emphasizes an active and collaborative process- "in shared decision making (SDM), clinicians and patients work together to understand the patient's situation and to determine how best to address it."[97(p1320)] But other commonly cited descriptions of SDM appear to emphasize conversations that are focused on making decisions that endorse the practice of evidence-based medicine rather than patient-centered communication.[98,99] For example, a leader in SDM research, Elwyn defines SDM as "a process in which decisions are made in a collaborative way, where trustworthy information is provided in accessible formats about a set of options, typically in situations where the concerns, personal circumstances, and contexts of patients and their families play a major role in decisions."[100(p1)] Of concern, is a recent systematic review that noted that a primary element of patient-centered care 'learning about the patient' was absent in 45% of all

SDM models, lacked prominence in recent SDM models,[101] and was seldom present in clinical practice.[97,99,102] In addition, patients with multiple chronic conditions are known to have poor health and cognitive/physical impairments challenging their ability to participate in SDM even more.[103,104] SDM may not be the answer to how we facilitate true patient-centered interactions, especially in chronic disease care.[101,105]

1.4 Gaps in Achieving Patient Centered Care

While we agree that patient centered care is a "philosophy of care that encourages: a) shared control of the consultation decisions about interventions or management of the health problems of the patient, and/or b) a focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts"[106(p2),107] how PCC is accomplished during encounters is dependent on the shared conversations that occur at health encounters. Importantly, PCC does not necessarily mean that practitioners do what patients want[108] but that interactions are focused on exploring the "patient's unique narrative, to understand the patients ideas about what is causing his or her concerns...and what the patient hopes the physician will do to help."[109(p270)] As health encounters are where patients and practitioners meet, the dimensions that influence how decisions are made during these interactions is fundamental to how we teach and implement patient-centered care.

Gaps in achieving patient-centered care is ongoing. Patient feedback is often elicited to learn how our efforts to provide care measure up to patients' expectations. For example, patients who are admitted to hospital have taught us that emotional support, care coordination and physical comfort are key aspects for quality care, yet they are not always achieved.[31] In contrast, chronic disease care commonly addresses non-emergent issues and patients may assess quality care differently. But of ongoing importance to all patients is the element of 'connecting' through enriching conversations, a concept central to our understandings of PCC.[110,111]

While the general philosophy of PCC is hard to argue with, we have not found a way to carefully and thoughtfully implement or teach the tenets of patient-centeredness. As a result, what we have is care that does not really meet those aspirations even though we claim that those are the ideals that are driving the way we teach and practice care.

1.5   Gaps in Teaching Patient-Centered Care

Gaps in understanding how to best educate learners to deliver patient-centered care continue.[36] Concerted efforts such as engaging patients as educators, advancing the patient-centered clinical method to include relationship building, and promoting the use of SDM have not been able to address the complexity of learning and practicing patient-centeredness.[96,112] In addition, applying communication skills taught in the classroom to the real-world situation of complex chronic illness care may be challenging for learners as efforts focused on optimizing interactions are not often prioritized in the practice setting.[113] While patients with chronic illnesses have acquired expertise in interpreting their symptoms, managing their illness, and adopting a productive life, these key insights may go unexplored during health.[114] The prominent absence of patients' voices in chronic illness care is a disturbing reality, resulting in practitioners providing a service that may not fit in the patient's world.[115,116] While many PCC frameworks exist the lack of a shared definition to implement PCC,[117] an agreed upon way to examine PCC,[31] and a unified conceptual framework makes the teaching and learning of patient-centeredness challenging.[118]

How stories unfold, why stories unfold in that way and the consequences of that unfolding at health encounters are largely unknown, but important to further our efforts of understanding patient-centeredness. We know little about the process patients go through to construct stories that are safe and productive for the purpose of interacting with HPs so that they may receive PCC. In addition, how HPs engage in interactions to make clinical decisions might influence the stories that result from these interactions. Exploring the stories of health encounters from patients and practitioners with a

theoretically informed approach -constructivist grounded theory – may unfurl this disturbing and critical problem.

This is consistent with the research presented in this thesis, where I aimed to understand the social process that occurs with patients and practitioners to engage in health encounters. Specifically, I explored, what that interaction was like from the patient's perspective in terms of how their preparations, plans and agendas influenced how their story was told at health encounters and then from the practitioner's perspective in terms of what information they chose to gather during the encounter, and why they made those choices. These complementary studies looked at how stories are shaped at chronic illness health encounters from two different perspectives – patients and practitioners – to generate insights into how care conversations ultimately affect PCC. By listening to the perspectives of patients and practitioners, our conceptualization of PCC, educational efforts to teach learners the essence of PCC and the implementation of PCC may be re-envisioned, creating hope that true PCC may at some point be fully realized.

1.6   Setting the Stage

In this thesis, I use the term stories in keeping with what Clark & Mishler describe as - patient stories reflecting the voice of the 'lifeworld', a personal perspective of health or illness and the practitioners' stories reflecting the voice of the 'medicine-world'- a biomedical perspective.[119] In health care discussions, it is common to think about interactions as the combined story - what the patient told, and what the practitioner gathered? Practitioners use 'story' or 'account' to mean whatever information patients share during an encounter. From these perspectives, patients and practitioners shape the story that ultimately unfolds. A meshing of these two life worlds at health encounters are offered by Stewart and colleagues as a patient-centered care model for medical education[17], and it is within this framework, this research program of studying encounters is situated.

The purpose of this thesis work is to unravel the disconnect between how patient-

centered care is talked about and how it is implemented in the real world. This is not meant to critique patient-centered care as a concept, but instead it is meant to elevate our efforts to do what patient-centered care intended it to be – focused on the patient.

The aim of this research was to offer a conceptualization of how patients' and practitioners' approaches to interactions at health encounters influence how stories evolve. Using a multi-perspective approach to understand the consequences of the accounts that develop at encounters, I hope to revive PCC as an entity that is truly focused on listening to the patient.

The overarching research question: "What are the influences that shape the unfolding of the conversations that occur at health encounters and how does this unfolding influence the learning and execution of PCC?"
Two major research studies frame this work addressing these research questions.
1. How do patients prepare and shape their stories of illness in order to interact productively with health practitioners?
2. How do interactions between patients and health practitioners shape the story told at encounters?

1.7   Summary

In this chapter, current understandings regarding 'patient centeredness' as it pertains to education and practice are presented. As this research is focused on chronic illness care, some of the distinctive dimensions of chronic illness encounters are highlighted with a focus on advancing our knowledge in an area where patients' voices may be under-represented. The intention of this research is to add to the body of literature on patient-centered health encounters using a qualitative research approach, CGT. As our understandings of teaching and implementing PCC lacks a clear theoretical foundation, this research seeks to offer a new way of conceptualizing PCC with a theoretically informed approach. The following chapter presents a general overview of CGT along with some of the important issues pertaining to its use in this setting.

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Chapter 2

2   Research Methodology

This chapter describes the methodology, Constructivist Grounded Theory (CGT), that guided the research. The background and theoretical underpinnings, rationale for using CGT, some of the important issues related to using CGT– qualitative interviewing, sampling, sufficiency, constant comparative analysis - and the principles of rigour are discussed.

2.1   Background

Grounded theory (GT) has been a methodology in evolution. Sociologists, Barney Glaser and Anselm Strauss, introduced grounded theory (GT) methodology which some still try to adhere to and is called classic GT.[1] The methodology evolved from reflecting a positivist and objectivist perspective to more of a post positivist approach with the subsequent collaboration of Strauss with Juliet Corbin .[2] Charmaz[3,4] adapted GT methodology to emphasize subjectivity and the influences of perspectives and co-construction in theory building, creating a methodology she named Constructivist Grounded Theory (CGT). As CGT is the research methodology that I used to explore 'health encounters' for this thesis, a more in-depth discussion of CGT and specific issues related to this research process follows.

2.2   Constructivist Grounded Theory

Constructivist grounded theorists (CGT), represented by Charmaz[3,4] and others draw on the interpretive perspectives that arise from the interactions between participants and researchers. The co-construction of knowledge/theory depends not only on the how participants view their situations but also on the researchers' view of reality and knowledge. An inductive approach, CGT reflects multiple realities and perspectives.[5,6]

Constructivist Grounded theory is rooted in the theoretical perspective of symbolic interactionism (SI).[4] As a perspective, SI "sees people as active beings engaged in practical activities in their worlds and emphasizes how people accomplish these activities."[4(p 262)] This is consistent with the focus of my research, where I attempted to understand the social processes that occurred with patients and practitioners in order to engage in health encounters. Social contexts, interactions, sharing viewpoints, and interpretive understandings fit with gaining knowledge about what happens at health encounters.[4,7,8] As knowledge is a social product, the understandings gained using CGT from the following studies are considered to facilitate new ways to practice and teach patient-centered care (PCC).[9]

2.2.1 Choosing CGT

In qualitative inquiry, a strong research design requires researchers to choose a paradigm based on their underlying assumptions and beliefs about knowledge and reality in their discipline.[6] In addition, researchers need to select methodology and methods that are appropriate for and suited to their research questions. To explore the proposed research questions for this thesis, I chose CGT[4] because I viewed the sharing of stories at health encounters to be a fundamentally social process. An exploratory approach, CGT aims to understand what is going in particular situations or events. This approach is consistent with understanding social and social psychological processes and the meaning individuals or groups make of their actions.[10] CGT is compatible with the development of theoretical explanations of social processes, through data gathering and analysis, situated in the context of current relevant understandings of the subject and the perspectives of the researcher.[3,4] In this research, with a focus on the stories that are shared at health interactions, specifically what was happening and why it was happening, these tenets of CGT helped to uncover actions and meanings related to chronic illness health encounters. For example, as a clinician and researcher, I was specifically attuned to the realities of the work patients with chronic illnesses often needed to do to participate in clinic appointments. During the interviews with patients, a focus on this work and its influences

were explored together for a fuller understanding leading to the manuscript about getting airtime (Chapter 4).

The researcher who choses CGT methodology asserts that realities are social constructions and there exist as many constructions as there are individuals.[11] Therefore, from an ontological position, I see the world as comprised of multiple individual realities, influenced by context. Epistemologically, the researcher in CGT acknowledges their subjectivity and inter-relatedness in the research process and their contribution to interpretations.[12] A methodology that focuses on subjective experiences aligns with the principles of nursing where understanding the unique story of each patient is paramount to guiding, promoting, and providing individualized care.[13,14] In nursing research, CGT supports the investigation of interpersonal processes between practitioners and patients affirming its suitability to this research.[15]

Specifically, as a nurse practitioner, with many years working in health care, the encounters I have engaged in with patients and families have shaped the methods, analysis, conclusions, and implications of these research studies. Constructivist Grounded theory is a frequently used approach in medical education given its explanatory power to understand 'how and why' happenings come about, thus creating opportunities to rethink teaching strategies to optimize patient-centered care.[16]

I used the CGT methodology to explore the research questions aimed at understanding how stories are shaped by patients and practitioners, and to learn what that means for patient-centered health encounters. In using CGT methodology, I aim to understand the processes of patient-practitioners encounters and the consequences of those interactions from the accounts or stories they tell. I am specifically looking at these encounters through my lens as a practitioner where patient stories are the result of our interactions and making sense of these conversations are aimed at supporting patient-centered care.

Given the prominence of the term 'stories' in this research, there are other approaches I might have taken. But I use the term 'story' colloquially, rather than how it is defined in

certain methods or paradigms - discourse analysis, phenomenology, or narrative approaches. For example, narrative methodologists tend to focus on the resulting stories from individuals to understand experiences,[17] whereas I am focusing on the processes that construct these stories. Therefore, a CGT approach was appropriate.

2.2.2 Qualitative Interviewing and CGT

Constructivist grounded theorists use interviewing with an aim to collect stories for conceptual development and theoretical construction. Intensive interviewing is the most common method to gather rich and full descriptions about people's experiences. This form of qualitative interviewing utilizes open-ended inquiry shaped by directed, yet flexible pacing.[4] The length of the interviews is not predefined. However, the researcher is encouraged to balance hearing participants' stories while seeking analytical developments. Since grounded theory aims to study processes and construct theory, interviewing requires "attending to your research participants and constructing theoretical analyses."[4(p87)]

In CGT, initially, semi-structured interview guides are used to open conversations guided by the central problem under study. For example, *tell me a story about how...or can you tell me what is involved in...* but as the conversation progressed questions, prompts, and topics that are explored will evolve as data are co-constructed. During the interviews, following up on participants' stories by using their words or sentences as a way to gain a deeper understanding, helped to reveal distinctions that may be implicit.[4] For example, *I am interested in hearing more about how you make decisions about how a list of topics to discuss with your practitioner is used at encounters?* As CGT is an iterative research process, where data collection and analysis occur concurrently, subsequent interviews with other participants were used to enrich areas of interests, explore new topics and probe more deeply for details that enhanced the understandings of concepts of interest. Multiple, intensive, in-depth interviews and the iterative process of revisiting and reframing interesting leads, also offered opportunities to hone qualitative interviewing skills important to test out the evolving concepts. Another issue of import in CGT

research -constant comparative analysis- required ongoing team discussions as the research evolved.

2.2.3 Constant Comparative Analysis

In practice, CGT research is not linear.[4.] The researcher interacts with the data during simultaneous collection and analysis by coding and concurrent memo writing. An iterative approach, analysis in CGT is embedded in the methodological strategies of "systematic treatment of data through coding, constant comparisons and theoretical sampling."[18(p851)] Importantly, CGT analysis starts from the ground (data) to construct meanings from experiences.[4]

Coding in CGT is the framework of the analysis. Codes are defined and interrogated to check, develop, or elaborate tentative analytical categories. In CGT, the movement between data gathering and analysis aids in focusing subsequent data generation.[4] During initial coding, illustrations from original or new data may raise new questions or insights that are further explored with focused coding, categorization, constant comparison, and theoretical sampling. The constant comparative analysis approach to data, where you compare data with data to find patterns, then across interviews and incidents to test ideas, grounds the final theory.[4,12]

The initial coding stage, descriptive in nature, names words, lines, or sections of data by close reading of the interviews. An open and intimate positioning of the researcher to the data encourages simple and short codes. Using sensitizing concepts -actions, meanings, processes, etc.- help to start the coding process. A heuristic device -coding with gerunds- in line-by-line coding, brings action and sequences to the foreground and helps the researcher to locate hidden meanings.[4] For example, in the practitioner interviews, gerunds such as *getting the story through the back door* or *deciding what part of the story to keep* helped to focus the initial coding, with action words that were grounded in the data. The ongoing focusing of data helps to refine emerging interpretations.

Focused coding, -synthesizing common initial codes, and finding prominent codes to trial with larger data sets, -broadens the codes/categories and reveals patterns or gaps while moving to conceptualizing ideas. Decisions regarding focused codes allow removal of the 'excess' and formulates core codes (categories) that inform the identification of themes. As coding continues, the constant comparative process of considering 'incidents' within and across transcripts helps to particularize categories, identify new categories, and consider categories that may be missing or do not fit in the current conceptualization of the full data set.[4] Thereby, the constant comparative process facilitates the identification of theoretical categories. Other issues of import in CGT research -sampling and sufficiency - required ongoing team discussions as the research evolved.

2.2.4 Sampling and Sufficiency

In CGT, sampling is purposive, guided by the research aims, and focused on answering broad research questions. In addition, the quality of the data collection and analysis guide and support the iterative development of concepts and theory important to issues of achieving sufficiency in qualitative research.[4,19] An exploration of these elements follows, as they pertain to the research studies presented in this thesis.

The collection of rich data, diverse data and data outliers contribute to data sufficiency. As a starting point, initial purposive sampling strategies offer rich information pertinent to the research questions. Subsequent sampling -theoretical sampling- seeking purposefully, people, events, or information- are guided by the categories and concepts that develop from the data collected early on in the research process.[4,18,20] This may mean that the data collected provides analytical sufficiency to explain what is happening relative to the topic of interest. For example, in the patient study about 'health encounter work', patients with a variety of chronic illnesses told lengthy stories of their preparations for encounters. Identified as a topic of interest early on, an analytical focus on trying to understand what this preparation was all about and why it was happening followed in subsequent participant interviews. Sampling, therefore, is centered on achieving sufficiency from rich data guided by curiosity about the developing concepts -

information power[21]- rather than by the number of interviews, participants, or words that a research study reports[4,19]

In CGT, theoretical sampling is considered when the emerging theory requires further focused data collection to check, elaborate and refine existing categories. For example, in the patient study, we purposefully recruited patients with cancer to ensure a diversity of perspectives among our participants. As the perspectives and ideas expressed in the interviews with patients with cancer were extremely similar to the earlier interviews, we felt assured that we had collected sufficient data. In keeping with CGT, in this thesis we were aiming for a situated conceptual understanding of health encounters from the patients' and practitioners' perspectives rather than generating a theory.[4]

2.3   Principles of Rigour

In CGT, Charmaz[3,4] suggests that rigor depends on: 1) credibility -uses in-depth and variable data collection and systematic analytical process that supports the findings, 2) originality- produces new insights, important to the area of study, 3) resonance- the findings are meaningful to the participants and readers, and 4) usefulness- the understandings are of practical benefit to the intended audience.

Ultimately, these criteria must be judged by the readers and users of the research presented in this thesis. But there are some early indicators of rigour: the publication of an invited commentary,[22] and the airing of a podcast[23] regarding the manuscript *"Getting airtime": Exploring how patients shape the stories they tell health practitioners,*[24] and the engagement of seminar participants when the research was presented as 'works in progress' together suggest resonance and usefulness.

2.4   Statement of Reflexivity

In addition, researcher reflexivity with concurrent self-examination is considered an

essential element contributing to rigour. For this thesis work, I addressed reflexivity in-depth using autoethnography -presented in Chapter 3- prior to entering the research field followed by critical self-interrogation during the ongoing research process with memo-writing, questioning of research decisions and in discussions with the research team.

In my clinical work as a nurse practitioner, the stories I hear from patients are data to be interpreted and made sense of for diagnosis and treatment. The constructivist research approach acknowledges the roles of the researcher, the setting, the subject and the interactions for analysis and theory generation. Choosing CGT as a research methodology aligned with my clinical perspective on the import of collaborative development of stories in practice. Interrelatedness and subjectivity are features of CGT[4] consistent with my worldview. Therefore, as a specific qualitative research approach, CGT resonated with me. Engaging in ongoing reflexivity practices was essential to challenge and contextualize the understandings that influenced the analytical interpretations.[25]

2.5   Summary

This chapter described the general background of CGT methodology, the fundamental issues related to its use and strategies for ensuring rigour in qualitative research. Specific descriptions of each study's methods will be described in the relevant chapters.

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Chapter 3

3   Autoethnography as a Strategy for Engaging in Reflexivity

3.1   Abstract

Reflexivity is a key feature in qualitative research, essential for ensuring rigor. As a nurse practitioner with decades of experience with individuals who have chronic diseases, now embarking on a PhD, I am confronted with the question "how will my clinical experiences shape my research?" Since there are few guidelines to help researchers engage in reflexivity in a robust way, deeply buried aspects that may affect the research may be overlooked. The purpose of this paper is to consider the affordances of combining autoethnography (AE) with visual methods to facilitate richer reflexivity. Reflexive activities such as free writing of an autobiographical narrative, drawings of clinical vignettes, and interviews conducted by an experienced qualitative researcher were analyzed to probe and make visible perspectives that may impact knowledge production. Two key themes reflecting my values—fostering advocacy and favoring independence and autonomy were uncovered with this strategy.

3.2   Introduction

Reflexivity is a key feature of rigor in qualitative research.[1,2] Life experiences and personal characteristics such as gender, race, ethnicity, social class, and professional status draw us to our research questions, inform what we ask in interviews, focus what we pay attention to, and shape what we do not consider during the research process.[3,4] Often confused with reflection, which occurs after the fact, reflexivity is an 'in-the-moment' and ongoing self-scrutiny.[4] Although reflexivity is variably defined,[5] it is often described as the process of a continual internal dialogue and critical self-evaluation of researchers' positionality.[1] Importantly, the researcher is "having an ongoing conversation about the experience while simultaneously living in the moment."[6(pv111)] Reflexivity compels us to confront the choices we make regarding the research question, the people we involve in the research process, and the multiple identities that we bring and create in the research setting.[7,8,9] The ideal for reflexivity is that this self-appraisal be actively acknowledged and openly recognizable in the research process and product.[10]

But other than being philosophically embraced as a necessary element of rigor in qualitative research, the specifics of how to engage meaningfully in reflexivity are not well defined. Traditional approaches, such as sitting down and writing a reflexive paragraph or two about your positioning, having a conversation about your positioning with your research team, or addressing it post-hoc when writing a manuscript, may result in a superficial impression that misses hidden elements of one's perspectives.[11] Such a cursory overview may fail to reveal implicit knowledge and experiences that may impact research rigor. This is a particular risk for researchers who are also insiders in the research setting they are exploring. That is, researchers who are insiders "possess a priori intimate knowledge of the community and its members"[12(p484)] and therefore may face greater reflexivity challenges.[13] For instance, as an experienced nurse practitioner who works in a chronic disease setting, I am now embarking on a PhD, using constructivist grounded theory to understand how patients' stories inform health professionals' knowledge and patient-centered practice. Therefore, I am confronted with questions like 'how will my personal and clinical experiences influence my research?' and 'can innovations to

advance reflexivity be drawn from existing practices?' Autoethnographies embrace the use of personal experiences to examine and/or critique cultural experience[14] offering a novel avenue to engage in reflexivity. Robust qualitative research relies on researchers having innovative tools to facilitate engagement in deep reflexivity. Autoethnography (AE) may be one possible avenue.

AE acts as a mirror to examine the researcher's subjective experiences in the cultural context, and it offers a unique lens to engage researchers both emotionally and cognitively to stimulate critical thinking.[15] While AE has the capacity to strengthen reflexivity practices, methodological divides and ethical concerns may hinder and limit personal writings.[16] AE writings offer unique opportunities for readers to gain access to otherwise inaccessible private human experiences, such as family relations,[17] death and dying,[18] and childhood sexual abuse.[19] But methodological debates about whether AE should be evocative or analytical are ongoing[16]. Evocative AE, pioneered by Ellis[18] favors an 'emotional self-reflexivity' approach to writing stories of intimate personal matters such as loss, or abortion,[20] often aesthetically portrayed in poetry, music, or drawings. Analytical AE brought to the fore by Anderson[21] extends the subjectivity of evocative AE to also include others, more in keeping with ethnographic research, using a more traditional reporting style. For example, a Chicano activist used experiences that formed his racial identity development and research on transformative teaching to promote social justice.[22] As stories of self are intertwined with narratives from other lives, auto-ethnographic writings are limited by the necessary sensitivities to other people's contribution to the AE. Although permission from ethical institutions to engage in personal ethnographies is usually not required, the risk of having another person's identity revealed without proper consent may cause ethical dilemmas while writing up these stories.[23] Wall aptly advises researchers to link 'experiences to theory and literature"[16(p7)] thereby respecting themselves and others. While AE is fraught with legitimate concerns, the exploration of personal perspectives through the lens of culture and self-other interactions suggests a potential for the methodology to inform and improve the practice of reflexivity. Importantly, autoethnography lends itself to artful and aesthetic presentations adding a new dimension to qualitative researchers 'writing' lives.

Using AE before and during the research process promotes visibility of a researcher's perspectives.[24-26] Since the life experiences of 'insiders' are likely to be more deeply intertwined with both their research questions and how they collect and analyze data, the purpose of this paper is to consider the affordances of using tenets of AE to facilitate deeper engagement in reflexivity, particularly for researchers with insider status in their research settings.

3.3   Positioning the Researcher

For decades, I have worked in health care as a nurse. My graduate research is centered on the interactions of health providers, patients and their families, a world I am deeply embedded in as an insider. Being so entrenched in a professional context makes it difficult to achieve the depth of introspection required for reflexivity. Introspection does not come easily to me; without a structured approach, my efforts at reflexivity risk lacking the necessary depth and richness required for rigorous qualitive research. While reflexivity in qualitative research is often perceived as an informal process,[27] I explored the affordances of bringing the formal approaches of AE to bear on the process of reflexivity.[28]

3.4   Methods

Before embarking on my PhD thesis work, I purposefully engaged in reflexivity to examine how my clinical background will influence my research. To scrutinize both my personal and professional experiences and how they might impact my research questions, methodology, data collection and analysis, I engaged in both narrative autobiographical writing and in drawings of clinical vignettes followed by interviews.[28,29,30] The following questions guided each stage of the methodological process: How do my personal and professional experiences influence my understandings of patients' stories? How might these new insights shape and guide my conduct and thinking as a researcher? My advisors and I created questions aimed at generating insight into experiences that might be similar to those of my patients. For example, how do you manage a family work life balance? What is being a caregiver for ill family members like? And other personal questions such

as: What influenced you to become a nurse? What aspects of your clinical work are challenging or complex? Why did you choose to embark on doing a PhD? To begin answering these questions, I first engaged in autobiographical writing to record aspects of my life experiences that may meaningfully influence my research. I was encouraged to write freely and to add stories of any life events to the autobiographical narrative as they came to the surface. These writings were shared with one of my co- authors (KAL), a colleague and friend who also has expertise in qualitative research and visual methods.

Next, I engaged in two rich picture interviews in which I drew two clinical scenarios with colored markers on large pieces of paper. A rich picture "is a pictorial representation of a particular situation, including what happened, who was involved, how people felt, how people acted, how people behaved, and what external pressures were present."[29(p916)] Rich pictures may be particularly helpful for supporting rich reflexivity by helping researchers express complex experiences and situations in which aspects of events may be either implicit or difficult to articulate.[31-33] For example, in order to uncover experiences from my professional role that may impact my research, I described two complex and challenging patient encounters. These patient encounters provided me with an opportunity to critique my actions when patients requested care outside standard guidelines, generating thoughts of how to truly implement patient-centered care (PCC). One of the rich picture interviews was originally collected as part of a research study examining complexity in health care; with permission from the principal investigator, the visual and interview data were then re-purposed for this AE.[34] The other rich picture interview represented a new care initiative regarding transitioning individuals with congenital chronic illnesses from a pediatric to an adult clinic setting. I presented the drawings in story form to my colleague interviewer (KAL), who in turn asked questions about the pictures to facilitate reflexivity. For example, to probe for hidden perspectives, KAL asked a series of questions such as "is there a specific reason you chose this color to depict the patient, what does the title of your drawing mean, and what does this drawing tell me about you as a nurse? The interviews were audio-recorded and transcribed.
Finally, I analyzed my autobiographical writing, audio recordings and interview transcripts to identify themes. The qualitative data analysis strategy included inductive

open coding, thematic clustering, and analytical interpretation.[28,35] Understandings were drawn from analytical activities by searching for recurring themes, looking for cultural themes, analyzing for inclusion and omission of experiences, connecting the present with the past and analyzing relationships between self and others.[28] While writing this manuscript, both memos capturing my thoughts about the research process and discussions with PhD committee members, two of whom are included as co-authors on this work, facilitated deeper reflection about the connections between my narrative and the clinical stories that I did not uncover in my initial renderings.[36] A timeline of the methodological approach is presented in Figure 3.1. An ethics exemption was received from Western University.

Figure 3.1 Timeline of Data Collection
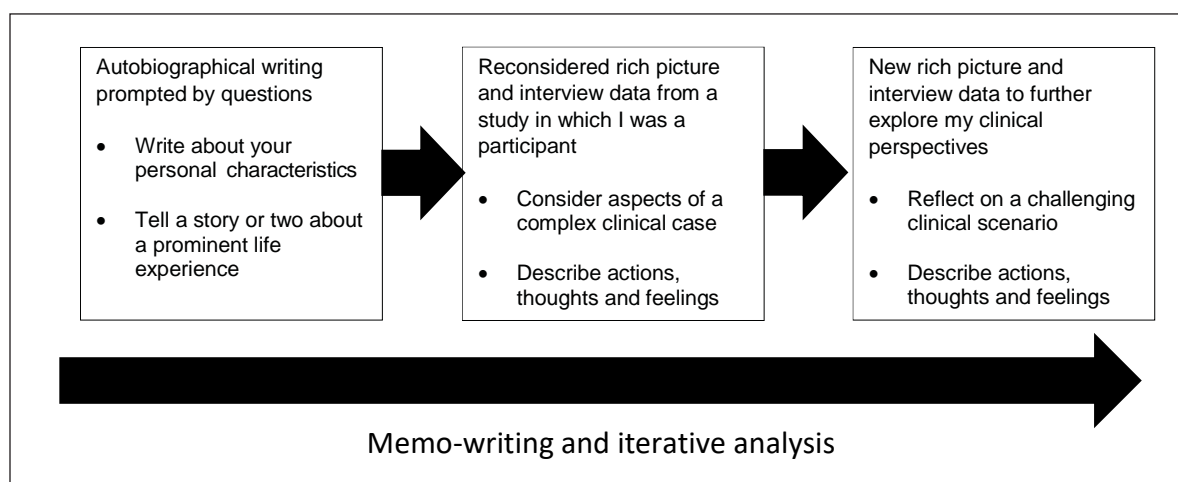
Note. Each box includes the approach and example of the kinds of specific prompts used.

3.5   Findings

Exemplars from the narrative data and clinical vignettes are presented to portray the learnings that were uncovered by using AE methodology and rich pictures for reflexivity purposes. While examining the struggles, attending to the silences, and making sense of the surprises in the autobiographical sketch and clinical scenarios, I uncovered two overarching themes: fostering advocacy and favoring independence and autonomy. For clarity, I have used italics to signal my personal thoughts and reflections on the data.

3.5.1 Autobiographical Narrative

Possibly, as a result of my experiences as a child of Dutch immigrant parents, tenacity, assertiveness and perseverance are visible characteristics in my personal writings. Stories of participating in hard work with my siblings while holding my own ground are not surprising themes. I wrote "we, three girls and two boys, all pitched in and helped our mom get the chores done while my father worked at the local salt mine . . . as a middle child of five siblings I made sure I was heard and not silenced by the others." And even years later, these personal characteristics remain firmly in evidence, both personally and professionally. For example, at the age of 61 years "I worked hard to qualify and run the world-renowned Boston Marathon. . .followed by an acceptance into the local university's PhD program." Although I am a mature runner and PhD student, "I was not going to be left behind!" While, I openly embraced the struggles and work associated with my personal and professional successes, *I wonder, how will I hear stories from my participants of unfinished work, lost opportunities, or personal failures? More importantly will I be able to listen to participants' stories with acceptance, curiosity, and uninterrupted space?*

Stories of trials, pain, and loss also created opportunities to discover personal understandings important for reflexivity. The passion to care for those in need has its roots in my childhood where I often tended to the animals who were injured or ill on our family farm and I wrote "I could be found giving aspirin crushed in warm milk to cats or dogs who were suffering lost limbs or broken bones in farm mishaps." Broken family relationships, the deaths of close family members and friends, and the evolving dementia in my elderly mother compelled me to be the ear, shoulder or voice that offered comfort and support. I wrote, "Now I am the protective voice for my 96-year-old frail mom who can no longer advocate for herself. I tell her—I've got your back!" Then, *I wonder how I will respond to the stories of research participants who may be suffering alone. Will I be able to listen to their story without shedding a tear or wanting to reach out and comfort them? It is hard for me to hear about suffering without doing 'something' to alleviate the sorrow?*

I realize that it will be very challenging for me to turn off my "nurse practitioner" self and fully engage in being a researcher. While my personal story portrays traits that may potentially hinder an openness to different perspectives, it is not surprising that these peculiarities are also prominent in my professional life. I write "Formal nursing education spanned 28 years culminating in a graduate degree and Nurse Practitioner designation. The determination to 'never give up' continues as I pursue a doctorate degree." And then I wonder, *so what? does this really matter? How can this element of perseverance shape my openness to new understandings? Perhaps, the stories I hear from chronically ill patients in my research interviews will be ones where the themes are "I just can't do it." And then I ask myself: Will I accept this?* But more importantly will I understand this? Taken together, I consider this reflexive question—how will my able-bodiedness and tenacity influence how I interact with and perceive those who may be struggling with mobility or fatigue that impacts their ability or drive to advocate or be independent?

Exploring the relationship of personal experiences with culture, and cultural identity is an essential element of both AE and reflexivity.[37] My biographical notes include stories of how limited funding for education, how my gender as a woman and how mandated credentialing shaped my personal and professional trajectories. For example, regarding my early nursing education, I wrote:

The transition from secondary education to nursing school began at the age of 17 years (1971). The 2-year nursing curriculum was practice-driven. . . a stipend was provided in return for on-site student nurse services with free food and lodging. . .this was the training norm, while university-based nursing degree programs began to appear in the 1960's. *I wonder how my initial experiences of 'on the job' nursing training will impact my research endeavors? Will I be open to new ways of thinking about health professions education? What about health care? Am I stuck in the past? Will I be open to hearing participants' stories from a futuristic perspective, i.e., from those who do not share in my past? More importantly, will I be curious about perspectives that may not match where I came from?*

While I succeeded in graduating as a registered nurse, the opportunities to maintain up-to-date professional credentialing were challenged by the gender and family norms of the 1970s. I wrote: "I was expected to be a 'stay at home mom'. But . . . in the 1980's, the College of Nurses of Ontario (CNO), our licensing body announced their goal to have all registered nurses achieve a university degree by the year 2000 and then in 2008, CNO legislated NP licensure[38]. Although I fulfilled some of the norms of the day—for example, my husband and I had five children—I circumvented other standards. I was not, for example, a stay-at-home mom; instead, I pursued ongoing education and finally achieved university training and a nurse practitioner designation. And so, I wonder why do my doctorate now? My nursing education has been a lifelong endeavor. Is this just another one of my life goals? To leave a nursing legacy. I suppose that is reasonable, but how will this personal aspiration shape how I hear stories from participants who may be unable to pursue their dreams due to the limitations of their illness or other personal circumstances. *Will I appreciate and understand their experiences? Will I even be interested?* While the biographical sketch revealed prominent personal characteristics of assertiveness, determination and single- mindedness, engaging in reflexivity using clinical practice stories uncovered how these attributes are also visible as an insider researcher.[13,39]

3.5.2 Clinical Vignettes

Since stories of practice encounters create novel opportunities for insider researchers to engage in reflexivity,[25,26,40-42] I embraced the opportunity to delve into some of the questions raised during my narrative exploration. The interviews prompted by rich pictures yielded a wealth of data. While I share one of the rich pictures associated with the clinical scenarios as an example of how the drawings contributed to the analysis and interpretations of the story, the findings will not focus on the aesthetic properties of using drawings but on how the two exemplars uncovered the themes of fostering advocacy (Working Magic) and favoring independence and autonomy (That's just me) as important considerations for reflexivity.

Exemplar: Working magic.

The first vignette recounts a discussion of initiating treatment with non-invasive ventilation (NIV) in an outpatient setting with a gentleman I had known for over a decade. While the trajectory of his illness is one of progressive respiratory failure and death, options to support breathing such as NIV were newly available as a life-extending treatment option. Following a lengthy discussion about the role of NIV in his current clinical situation, he agreed to a treatment trial. Due to the severity of his respiratory symptoms and the complexity of organizing and optimizing the use of NIV, a short hospitalization is a standard requirement. For various reasons, he refused an overnight stay in hospital. I remember thinking, if he does not start NIV today, he may die overnight. The respirologist in this case supported home initiation of NIV if the necessary medical supports were put in my place. That's my job. I thought to myself. . .*its Thurs day afternoon before a long holiday weekend, how will I ever be able to have home care in place with extra medical support and monitoring in such a short time*? **What are the chances that I can work this magic?**

The anecdote associated with this clinical scenario was initially portrayed with drawings in keeping with the method of rich pictures.[32,43]

The patient is colored red (to indicate an emergency, sitting in a wheelchair with a fan blowing, and the clinic door open while he performs "guppy-like" breathing. His two sons, depicted in grey give him "a reason to live," with an upcoming high school graduation (see orange diploma). His wife (W), the health care team (S, L, V) are located outside his blue circle while we wait to be invited into the conversation. I draw myself, small at the desk with fire coming from my head as I brainstorm solutions for the current challenge.

Figure 3.2 Drawing of "Working Magic"

While the pictorial representation of the clinical scenario was created when I was alone, the story was recounted to my collaborator (KAL) using the drawing and her questioning to facilitate reflexivity. I wrote: "As I gazed at the drawing, I was pleased to see the patient as the central image." When telling this story to the interviewer I said "You know how some patients move into the background? He never moved into the background; he was always in control and central to the discussions. I am relatively small, I facilitated things for him, but he made the decisions."

It was in this moment that I recalled how this gentleman often asked me questions for which I had no clear answers or how he requested help with a problem that had no perfect solution. I struggled with these thoughts, and I wrote: *he makes me feel inadequate and intimidated during these conversations. Sometimes, I felt attacked, especially when I couldn't answer his questions—hard questions like: How will I die? Will I be in pain? Will I suffocate? After I attempted to reassure him with my platitudes of "we will do the best for you" he would ask me "how can you know for sure? He made me squirm. I would think "Why don't you ask the doctor? They are supposed to know all the answers." I asked*

myself, was he taking advantage of my gender as a woman while he is a powerful businessman, or was he taking advantage of our long-term relationship? And yet I wanted to help him. There are no answers to his questions—only silent compassion. During this exercise I chose to refrain from sharing some of my thoughts and feelings with KAL. While they were too personal to recount here, I reflected about why I left these experiences and details out, and what it may mean about the usefulness of this exercise for reflexivity. I*s reflexivity too emotional for me to do well? I wonder why I can't be completely honest*. While struggles and silences are prominent themes in both clinical vignettes, the second vignette is noted for the uncovered surprises.

Exemplar: That's just me.

The second vignette involved a young man with a congenital progressive chronic disease who is transitioning from a pediatric to adult clinic setting. He currently lives with his parents who provide all his care and they accompanied him to this appointment. He has been in a wheelchair for 8 years. As I begin the conversation about future life planning, I say to him "have you ever thought of a work placement? Are you interested in discussing options about independent supported living?" The parents answer for him. "He will be with us; we take care of him." The patient does not respond. *I am surprised by his silence*. And then I write, *is that what he wants or is this what is expected of them, the parents? Are the parents struggling to both let go of long-standing care responsibilities and seeing their son as an autonomous decision-maker? I feel like both the patient and his parents are trapped in a care relationship that no longer works now that the patient is an adult?* I was frustrated that the patient did not speak up or exert his independence. I reflected on this conversation with KAL. I discovered that "I value independence, and that people who are not independent drive me crazy. I know I strongly encourage independence in patients as well.

My drawing and telling of this story revealed unexpected elements of my perspective as an NP namely, I used words such as "that's just me, that's just how I am," as if that validated my approach in advising him "to move on and be independent." But what does this mean

as I begin my research journey? *Will I be unable to hear stories of dependency? How will I react to stories that may not align with my drive for autonomy?*

While the learnings from these pre-emptive reflexivity exercises offered insights into who I am, ongoing intentional reflexivity during the research process will be important to discover and disclose how the themes of fostering advocacy and favoring independence and autonomy shape the understandings of my qualitative research endeavors.[44]

Figure 3.3 Drawing of "That's Just Me"
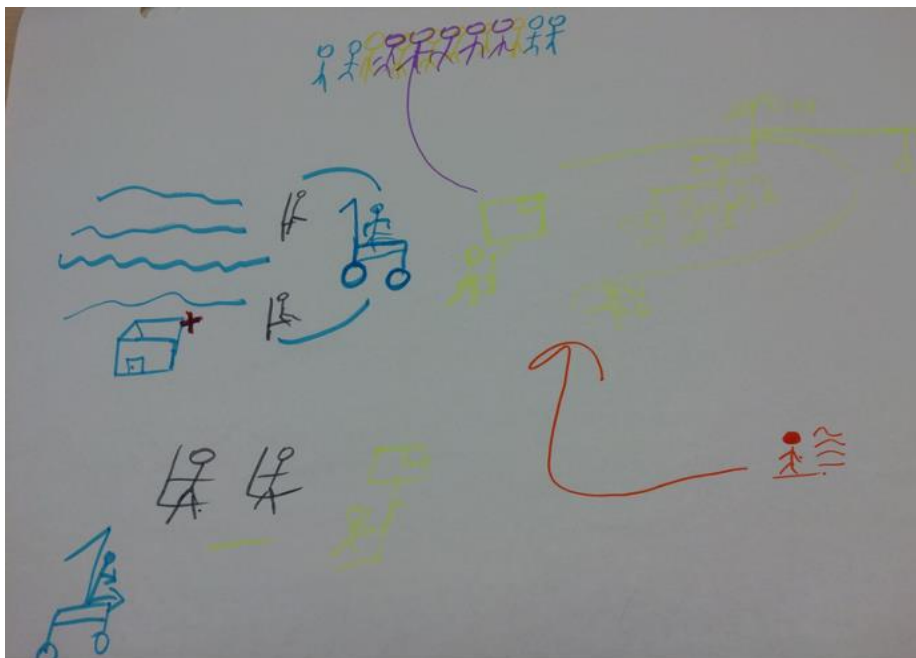
3.6   Discussion

Reflexivity is a valued strategy to promote validity and quality in qualitative research, especially for researchers who are insiders.[24,45-47] In insider research, reflexivity makes transparent the researchers' stance regarding the research question, methodology, process and interpretations.[24] In this discussion, I will focus not only on what I learned through this exercise and how it will impact my planned PhD research and ongoing clinical practice, but also how the features of this unique approach to AE helped generate these insights. While engaging in the analysis of my AE interviews, I became more attuned to how

individuals shape stories to present themselves to the world. And then I began to think about how my life story will impact my research and my practice. For example, although women's rights, educational grants and lifelong learning are no longer in its infancy, memories of a different time as I described in my autobiography, may close my mind to current perspectives about these challenges. In addition, my personal attributes of determination, tenacity and drive were prominent traits in the clinical vignette "that's just me" raising concerns about how I understand dependency or weakness in less-able-bodied patients. Because my research centers on hearing stories from individuals with chronic diseases, I can no longer disregard the potential influences of my personal tendency to favor independence and autonomy that could limit interpretations of research and practice stories. And specifically, as an insider researcher, with a long history of listening to stories from individuals with chronic illnesses, I may be at risk of dismissing aspects of the research stories as mundane or uninteresting due to their familiarity. In other words, as an insider, I need to be cautious about my nursing lens over-powering the research one. I will need to learn to hear patient stories in a way that's different from how I was trained to do so clinically. Specifically, I need to be mindful that details that might be clinically uninteresting may actually be interesting from a research perspective. While AE offers a novel way to discover important personal insights, the process may also be unsettling.

Reflexivity sometimes reveals hard truths that require opportunities to process and debrief the understandings that are revealed. While I initiated this facilitated autoethnography, the vulnerability I experienced in this undertaking opened my eyes to how research participants may make deliberate choices about what story to share and to whom they will share it. I wrote "Now I truly know what it is like. I have walked in their shoes." I recall instances where KAL 'pushed and poked me' to reveal more of the story during the interviews. And I felt uncomfortable, struggling to tell my stories, perhaps like patients who tell their stories for clinical or research purposes. I have a new understanding of how patients might experience vulnerability during interactions with health care professionals. I remember thinking *she wouldn't understand why I felt unable to continue the story.* I wrote "We live in two different worlds. She is not like me. We did not share

the same values." I was worried that she might not understand or empathize with some of the experiences I chose to keep silent about. In some instances, these experiences were particularly upsetting, and I did not want to revisit these incidents again. Other areas of silence were in stories I wished to keep private to avoid feelings of weakness or exposure. In many ways I wonder what I would have shared if the interviewer was a nurse. Would I have shared deeper nuances that surround the challenges of complex clinical experiences scenarios? Nurses often do not know how to communicate what they do as our work lacks articulation and visibility.[48] While, I found the AE reflexivity exercise beneficial, researchers choosing to engage in this way should consider the affordances and limitations of those they chose to help them facilitate the process. For example, I chose to use a non-clinician who was an expert in qualitative research and reflexivity. Perhaps the questions asked seemed naïve to me, yet they helped me to think differently about my practice. On the other hand, if I had asked a nurse colleague, I may have been able to overcome the challenges of articulating the ways we think about engaging in patient care. But perhaps having a shared language would have prevented me from un-packing items that are taken-for-granted or implicit in our profession.

As qualitative researchers, our voices are essential instruments for data collection, yet analytical techniques are largely based on transcribed interviews. While some researchers may transcribe their interviews, others may use a transcription service where the nuances of pauses, laughing, or crying may be noted but not heard by the researcher. As I engaged in analyzing the research interviews by audio and text, I was surprised by the sound of my voice. And I wrote "the intonations in my voice are sharp when I was speaking about patient encounters and family interactions. I thought my voice would be soft and caring. I recall feeling empathy for the patients." *And then I asked myself, Are my words really that harsh? How will these 'sounds' affect the stories I collect for my research?* Efforts at reflexivity may merit thoughtful consideration of how we use our voice to gain understandings from research participants. In addition, the pauses, hesitations, and silences in the narratives may be a lost opportunity for knowledge production when we read transcripts rather than listening to interviews. I remember thinking . . . *Why did I not tell a complete story? Why did I pause? Was I afraid to reveal*

my true feelings or emotions that may not be characteristic of what a health professional should portray? Are participants also telling us only what they think we want to hear? This may be especially important for researchers who are insiders to think about. While meaningful, empathetic, and gentle questioning during interviews safeguards the experiences of participants[36] enhanced reflexivity by qualitative researchers regarding how their interview techniques may unknowingly influence data collection by listening to the audiotapes may also be enlightening.[49]

While taking an analytical gaze at the autobiographical sketch and the clinical vignettes interviews, overt struggles, covert silences, and unanticipated surprises uncovered prominent life experiences and personal characteristics that I bring to the research process. Struggles were apparent in the stories of finding my voice as a middle child and as an adult while caring for my mother; silences appeared at key moments when my personal narrative was incomplete leaving many secrets untold; and unanticipated surprises included discovering my inner strengths as an age group runner and becoming a PhD mature student. The experience of writing and analyzing my life story suggests that full disclosure of intimate personal details may be impossible, and our efforts at reflexivity may also be incomplete. While advocacy, autonomy and independence as a child, woman and nurse were themes in the autobiography, engaging in reflexivity using clinical practice stories uncovered how these attributes are also visible as an insider researcher.[13,39] As my inner voice is one that values independence, hard work and success as a person and a nurse, I am more sensitized to the perspective that I may bring to the research process especially when collecting and interpreting data. The awareness of how advocacy, independence and autonomy are key personal attributes may prompt deliberate efforts to consider alternate explanations or interpretations for the stories and problems that unfold in the data. With the recognition of a personal tendency 'to jump to conclusions', the possibility that I may project my personal values on patients deserves ongoing reflection in conversations with patients about their needs and goals. Importantly, thoughtful, and deliberate accountability of these characteristics in future research are now transparent, enhancing my skills as an interpretive researcher.

Although autoethnographies are generally presented by a single author, for the purposes of reflexivity, facilitated activities may prove useful. There were points along the way, like being interviewed (KAL), writing this paper and having ongoing discussions (KAL, CW) about my experiences, that revealed perspectives necessary to consider during my PhD journey. For example, the drawing and telling of a complex case from my practice jarred my assumptions of how I deliver patient centered care (PCC). Specifically, I was surprised about how I responded to the litany of inquiries about death in the "Working Magic" scenario. I am trained in palliative care, yet I wanted to defer the hard questions to physicians, not meeting the patients' need for an end-of-life conversation with me. In addition, the questioning and probing around aspects of the drawings such as color choices and individuals' positionings and my thoughts and feelings associated with the pictures and their stories uncovered the realities of how implementing PCC is not always what I really wanted to do— "It's a lot of work." The drawings afforded me a tool to dig into not only how I see and do my clinical work from a new vantage point, but also how my ways of caring may impact the research process.

I am not reflective by nature and the 'forced' aspects of confronting the clinical vignettes revealed sensitive and potentially problematic personal attributes. In many ways, for me, the ability to do this type of in-depth scrutiny was essential. Sitting in a room thinking and reflecting on my own, which is often how reflexivity unfolds, would have been shallow and insufficient. For various reasons, researchers and practitioners may choose not to do the often uncomfortable work of reflexivity, possibly limiting the richness of the data and lifelong learning opportunities. The discussions with my co-authors and the use of rich pictures to reflect, think and confront who I am as a person, a nurse and a novice researcher aptly strengthened the outcome of this reflexivity process.

While using analytical autoethnography[28] is a systematic approach to reflexivity, the efforts were time-consuming and emotionally taxing, but also rewarding. This experience humbled me both as a researcher and a nurse practitioner. But it also gave me a very real sense that no matter what I do and no matter what kind of sensitivity I bring to the table, interview participants and patients will shape their stories in the way they wish to or are

able to; there may be some limits to what their stories will offer. This insight matters because we often think there is 'something important' in there, and we just need to read carefully through the transcripts. Perhaps, this is a nice reminder that sometimes there are things that are areas of silence and if they were said it may change our impression of what is going on. In addition, this autoethnography fostered in me a kind of empathy for the research participants which may be useful to how I approach qualitative interviews and analysis. Although it may not be realistic for all qualitative researchers and health professionals to undertake such an in-depth method to reflexivity, researchers who are 'insiders' to the topic of inquiry may find as I did that a more comprehensive approach to reflexivity especially useful.

3.7   Future Considerations for Reflexivity

Autoethnography, visual methods and collaborative activities are underexplored approaches to reflexivity. Given the strengths of using auto-ethnography for reflexivity, the addition of collaborative and visual activities offers innovative strategies to articulate buried perspectives that require visibility in my future research work. In addition, as an experienced nurse working in hospitals for a long time the cultural aspects of health care including how the work of nurses may be challenging to communicate raises an important theoretical perspective. Using aspects of autoethnography to further explore nurses' work may give voice to an underexplored yet important aspect of how PCC is practiced and taught in health care settings and educational institutions.

3.8   Conclusion

In this paper, we present ways to make reflexivity actionable. The tenets of autoethnography[28] coupled with collaborative and creative activities are presented as an example of novel, stimulating and provocative approaches to lay bare the lens of a novice researcher who is also an insider. While the 'work' involved in this reflexivity exercise should not be overlooked, we feel that this effort is worthwhile, as it can yield critical insights that sharpen the analytical lens of the researcher and strengthen the quality of their research.

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Chapter 4

4 Getting Airtime: Exploring How Patients Shape the Stories They Tell Health Practitioners

4.1 Abstract

Introduction: Effective communication during health encounters is known to decrease patient complaints, increase patient adherence and optimize health outcomes. While the aim of patient-centered care is to find common ground, health practitioners tend to drive the encounter, often interrupting patients within the first minute of the clinical conversation. Optimal care for people with chronic illnesses requires individuals to interact with health practitioners regarding their health concerns, but given these constraints, we know little about how patients strategize conversations with their care providers. This understanding may further our efforts to educate health practitioners and trainees to learn and practice patient-centered care.

Methods: A constructivist grounded theory approach with iterative data collection and analysis was used to explore the processes patients use to present and shape their stories for interactions with health practitioners. Twenty-one patients (n = 16 female; 5 male) representing a variety of chronic illnesses participated in semi- structured interviews. Using the constant comparative method of analysis, salient themes were ascertained.

Results: Patients engage in extensive strategic preparations for productive health encounters. From the data, we identified four related elements comprising patients' process of planning, preparing, and strategizing for health encounters: deciding to go, organizing to get airtime, rehearsing a game plan, and anticipating external forces. By

focusing on the extensive preparatory work patients engage in, our study expands the dimensions of how we understand illness-related work. Assembling personal health information, gathering disease information, and achieving equanimity represent the dimensions of this 'health interaction work'.

Conclusion: The work patients engage in for health encounters is noteworthy yet often invisible. And work that is unseen may also be undervalued. Acknowledging, illuminating, and valuing patients' preparatory work for health encounters add to how we understand patient-centered care, and this offers new targets for us to effectively teach and deliver it.

4.2   Introduction

Effective communication during health encounters is known to decrease patient complaints, increase patient adherence and optimize health outcomes.[1-3] Although health practitioners learn patient-centered communication skills early on in their education, the complexity of illness in clinical settings may challenge trainees to successfully engage in conversations focused on listening to the patient.[4] Indeed, health practitioners tend to interrupt patients early on within the first thirty seconds of a clinical encounter[5] suggesting a disconnect in how communication skills are taught, observed and enacted in clinical care.[6] Even though patient-centered behaviours such as active listening while displaying empathy and personal attention are valued by patients,[7] the implementation of these actions by practitioners may be difficult when time pressures or competing duties are prominent.[8]

Patient-centered care is uniformly embraced as the standard for quality and safety in health care organisations.[9] Yet, ongoing debates regarding how it is defined,[10,11] measured[12-14] and taught[15] suggest ongoing tensions in its implementation.[16] Current attempts to teach patient-centered care approaches are largely centered on communication skills that support eliciting patients' needs, wants and concerns in order to provide choices that fit their individual situations.[17] But efforts to teach communication skills focused on providing patient-centered care are challenging without unified learning

outcomes,[14] clear patient involvement in curriculum development and practitioners'
lifelong training.[18-20] In addition, although we know that many health practitioners
participate in explicit teaching about patient-centeredness, the reinforcement of these
elements is not always prominent in clinical settings.[21] With limited role modelling of
patient-centeredness during health encounters, learners may be challenged to hone
communication skills important for patient-centered interactions.

To date, the understanding regarding the implementation of patient-centered care has
largely focused on patient-practitioner interactions during health encounters, with less
emphasis on what patients do, think about, and deliberate before these encounters. We
know that barriers to access health encounters exist such as socio-economic factors—
transportation, finances and education[22] and that specific demographic factors—
including language, culture, gender and age—may hinder their ability to attend or con-
tribute fully during health interactions.[23] Whether privileged or disadvantaged,
navigating the health care system for diagnostic services,[24] chronic pain
management,[25] routine health care[26] or treatment execution[27] is known to be
burdensome for patients, potentially influencing how health interactions evolve. In
addition, as health practitioners are considered experts in medical evidence and
patients are well-acquainted with personal illness experiences, diverse knowledge
perspectives challenge how we gain mutual understandings about illness and health.[28]
In addition, social media offers experiential and medical information, albeit it not
filtered, that patients may use to educate themselves, potentially influencing how
stories are told at health encounters.[29-31] While socio-cultural factors, health navigation
work and diverse illness knowledge perspectives may influence health interactions, how
these elements shape the stories patients bring to health encounters require further study.

As the dimensions of patient-centered care focus on practitioners' actions during health
encounters[32,33] the opportunity for patients to tell their story may be limited, offering only
a glimpse of the 'life' of the person.[34] And as health interactions are often dominated by
the topic that is most pressing, it is possible—even likely—that information important for
clinical decision making may not arise during the conversation. Although patients and
health practitioners are mutually accountable to productive encounters,[35] the knowledge

required by health practitioners to deliver patient-centered care remains tenuous without a more fulsome understanding of patients' entire health journey.

The purpose of this study was to gain an understanding of the processes patients with chronic illnesses may use to present and shape their stories for interactions with health practitioners. Garnering a patient's perspective about how they prepare and plan to tell their stories for health encounters and the hidden work they do before they even come to the encounter may further our efforts to educate health practitioners and trainees to learn and practice patient-centered care.

4.3 Methods

A constructivist grounded theory (CGT)[36] approach guided the research. The understanding of how patients decide what story to tell and what they hope to accomplish by that telling during health encounters is a social process appropriate for exploration using CGT. In keeping with CGT, we are aiming for a situated conceptual understanding of health encounters from the patients' perspectives.

4.3.1 Setting, Participants and Sampling

We conducted this research in one mid-sized Canadian city, with two university-affiliated hospitals. Twenty-one patients (n = 16 female; 5 male) who ranged in age from 28 to 73 years participated in interviews lasting up to one hour. The sample represented a variety of chronic illnesses (13 neurological, 3 rheumatological, 1 psychiatric, 4 cancer). All patients had ongoing contact with their respective treating specialist. Initial recruitment consisted of posting flyers in waiting rooms of out-patient chronic disease clinics. In addition, we asked physicians with a large cohort of patients with chronic diseases to approach patients about participating in the study. Notices were also distributed through chronic disease patient support group newsletters. As recruitment unfolded, we recognized that patients with neurological illnesses were over- represented in our sample. To ensure a diversity of perspectives among our

participants, we shifted our sampling strategy, recruiting purposively from patients with cancer. We were reassured to find that the perspectives and ideas expressed in the interviews with patients with cancer were extremely similar to the earlier interviews with neurological (and other) chronic illness patients, which assured us that we had collected sufficient data.[37] In keeping with CGT sampling, interview questions and analysis developed iteratively in response to the themes identified.

4.3.2 Data Collection

Interviews were conducted by the researcher (WJK), with 2 interviews carried out by a research assistant as the participants were known to the researcher. Initially, a deliberate open-ended approach was used to give patients uninterrupted time and space to tell a story or two of encounters with health practitioners. These opening sentences were used—'When you come to a health care provider for a particular problem, especially if it is a new problem, you may need to give some thought to how that conversation will go. For instance, you may give some thought to what you are going to tell and how you are going to tell your story during this encounter. Do you want to talk me through the last time you went to a health practitioner for a new problem or a regular follow-up and how you thought about how to express yourself?' This was followed by questioning using a semi-structured interview guide with probes that were modified over the course of the study to enable deeper exploration. For example, we asked how they prepare for a visit, how they decide what to talk about at the encounter and how they know when they have been heard. Questions with probes were modified over the course of the study including topics around incomplete stories as we did not think this theme was fully developed in the patient study and the theme also emerged in the practitioner data. All interviews were audio recorded and transcribed verbatim.

4.3.3 Data Analysis

Iterative inductive analysis was undertaken using the constant comparative approach.[36]

Initial line by line coding of 3 interviews by WJK and CW and one other salient interview by WJK, SLV, EAK and KAL identified a diverse set of ideas within the data. These ideas were then sorted into broader categories, which were defined, described, and then used to guide the coding of subsequent interviews. Coding continued using the constant comparative method, where incidents were compared with other incidents across interviews and within categories. The research team met to review the final coding framework that was developed to recode all the transcripts. CW and WJK met frequently to discuss coding and analysis. NVivo©, a qualitative research software program was used to organize the data. This study was approved by the institutional Health Sciences Ethics Board (Appendix A, B, C, D), and Lawson Health Research Institute (Appendix E).

4.4   Reflexivity

In CGT, the researcher is an active participant in the research process and along with participants co-constructs the experiences and meaning making.[37] WJK is a PhD candidate and Nurse Practitioner with decades of experience with patients living with chronic diseases. All team members are experienced qualitative researchers. CW and SLV are also practicing neurologists in chronic diseases. Reflexivity with memo-writing, team discussions and active critique of personal perspectives was ongoing during the data collection, analysis and writing phases.

4.5   Results

The stories shared included patients' encounters during emergent and regular follow-up appointments with family physicians, nurse practitioners, emergency room physicians and disease-specific specialists. From the data, we identified four related elements comprising patients' processes of planning, preparing, and strategizing for health encounters: deciding to go, organizing to get airtime, rehearsing a game plan and anticipating external forces. We elaborate each of these facets below, supporting our interpretations with representative quotations from our data.

4.5.1 Planning for the Encounter: 'Should I Go'?

The decision to arrange a medical appointment may not always be straightforward. In this study, participants described the influences on their decisions about who to call, when to call and why not to call for help from health practitioners when experiencing disease exacerbations or negative treatment effects. For some, they called the person whom they perceived as most responsive to their concerns or questions. For example, one participant commented 'My rheumatologist is usually the one that I'll go to first. She's a woman and I find that women often help more' (P1). Others requested an appointment with their family practitioner to seek validation regarding the decision to call the specialist, so they were confident that they were not bothering specialists with minor or irrelevant symptoms. How long participants waited before they called for an appointment often depended on how convinced they were that what they experienced was a disease relapse or if they thought waiting could be dangerous to their health. As one participant noted:

> Acute things started happening days before, but I knew if I were to call in, I wouldn't get an appointment sooner than my already scheduled appointment. So, I waited for my scheduled appointment. It was only a couple of days and *I knew I wasn't in danger* (P3).

While some participants made choices about initiating appointments based on past experiences with health practitioners, others made decisions centered on how the current symptoms could affect their long-term health. Participants commonly described stories of denial, wishful thinking or apprehension as reasons that may cause them to delay their interactions with health practitioners. One participant related their hesitancy about deciding their symptoms warranted a medical appointment: 'It's like "I'll be ok' … 'just give me a few more days—it's not as serious, or it's a little different"' (P18). Another was hopeful that the symptoms would disappear quickly: 'You worry about it for two weeks and think "Should I go?"' (P4)? Still others expressed distress and anxiety thinking about having to voice their concerns to health practitioners: 'Every time I phone a doctor, I really

have to talk myself into being able to actually talk to the doctor about my issues'
(P11). Chronic frustration with unsatisfying medical encounters led one participant
to ongoing avoidance of health practitioners, even if they experienced symptoms
that may be concerning: 'I was so sick of getting the doctor eye roll… I didn't go to
doctors for years' (P3). In this study, participants' decisions to seek help from
health practitioners were complicated ones filled with apprehension regarding
sharing their stories, what may be found, and how it might change their future.

4.5.2 Preparing for the Encounter: 'Getting Airtime'

As participants considered the potential initiation of appointments with health
practitioners, they also deliberated about how to direct the encounter for a productive
interaction. In this study, participants discussed how emergent follow-ups, or visits at
which they had new problems to discuss, required more energy and preparation.
Participants prepared for appointments by ruminating about the value of doing their
'homework' and prioritizing their needs and concerns. For some participants,
documenting pertinent personal health data, gathering knowledge about their health issue
or formulating questions before their health encounters mitigated potential threats to their
'airtime' (P9). In addition, many participants discussed their concerns that health
practitioners were burdened with multiple clinical and administrative duties. Therefore,
preparing for an appointment by knowing or bringing a copy of their laboratory and X-
ray results, deliberating about what the problem might be or exploring options for
diagnosis or treatment were strategies that participants described as ways to save health
practitioners' time during their encounter, while also generating personal 'airtime' (P9).
One participant described preparing to prompt the specialist about their imaging history:

> I know the information is in my files on the computer, but they don't have
> time to scroll back to 'oh, he had an MRI a year ago'. That would be more
> up to me to say 'Well, I did have an MRI that showed this, blah, blah, blah'.
> (P6)

Others described how knowing their test results gave them the knowledge they needed to speak up for themselves. For example, one participant commented 'I can compare my blood work from a year ago to now, and I can compare my last MRI of my spine to this one…and patients who know what's going on can better advocate for themselves' (P1). Participants described how their targeted groundwork might facilitate self-advocacy and more personally focused conversations by reducing the work that health practitioners needed to do during time- crunched encounters. But, even if participants did their homework to facilitate the interaction by alleviating the workload of health practitioners, some considered this work an added burden of their chronic illness without reaping the benefits of more airtime, as the following example illustrates:

> I keep it [the 'health diary'] and I look at it often and, especially before an appointment. I reorder it by priority. I reexamine whether things are getting worse. You know, a patient really shouldn't have to do all of that when they're dealing with everything else… You used to be able to give that information to your family doctor and they would take the necessary steps and they would record how things were going. But they're too overloaded with information now and they're too overcrowded, so they don't know what's going on with their patients. (P4)

Another participant expressed similar resentment at the work they had to do before and during the encounter:

> which kind of defeats the purpose because you're going to a physician hoping they can tell you what's wrong with you. But for some reason, you have to narrow it down yourself and point them in the right direction. So, you're doing half the work for them already. I've noticed that a lot at my visits and I would love to just go in and say, 'I'm not feeling well, you figure it out'. But instead, it's been the other way around. (P9)

For these individuals, the experience of attending appointments shifted the balance of labour firmly and uncomfortably in their direction.

4.5.3 Strategizing for the Encounter: Rehearsing the 'Game Plan'

While participants described the challenges of how to be organized and prepared to share their health concerns with practitioners so that their needs might be met, considerations for a well-executed interaction also required thoughtful strategic planning. Participants described practicing their 'game plan' (P4) to manage what they might be up against at appointments, anticipating challenges such as anxiety, fatigue, recall issues, delays, time constraints, unwelcome news, other sick patients, or personal and caregiver meltdowns. Some strategies described to circumvent possible difficulties included 'preparing mentally for that appointment' (P9), or 'practicing your story with family or in your head before the appointment' (P1). Some participants also described requesting input and support from family members in their preparations. For example, 'I would often ask my wife: "How do you think I am doing? Have you noticed anything different?"' (P10). When participants considered their health issue to be of a very concerning nature, they described having a plan B if the health practitioners they were seeing would not assist them in the way they wanted to be helped. One participant, for example described an alternate strategy in the event that the general practitioner was unable to accommodate their request: 'if he couldn't I was just going to keep driving to the emergency' (P20).

Many participants discussed that giving careful thought to the appointments preemptively helped them to be in control of how they were perceived by practitioners and what topics they would or would not talk about during the encounter. For example, participants would talk about their physical symptoms with health practitioners, whereas feelings, emotions or the day-to-day struggles related to living with the disease did not dominate the conversations. For some, it was about trying to minimize the problem by putting a healthy face on, so they appeared rational and put together, not only for themselves but also for the health practitioners. As one participant noted: 'I try to be really up when I go to see the doctor, because I don't want to sit down and make them feel like, "Oh, poor me, *this is my life*"' (P1).

4.5.4 Considering How the Story may Unfold: 'It's Tricky'

Participants acknowledged that the story that unfolds during a health interaction could be influenced by external factors despite careful planning. In this study, participants described how the presence of family members during health interactions could potentially constrain, support, or disrupt health conversations. For some, the presence of a spouse resulted in stories that were edited so as not to provoke unnecessary worrying: 'It's tricky because in some respects if my husband is there, I don't want to alarm him right now' (P8). For other participants, the presence of support persons caused them to moderate the conversation they had with health practitioners in order to avoid disruptive or embarrassing outbursts from their family member: 'I can tell he is getting frustrated, so then I need to chill out a bit, so he stays calm' (P3). Although the presence of significant others at encounters was described by some participants negatively, others described their positive influences.

> So, when we go in at that point it was my wife who was more forceful than I was because I was sort of out of it. I didn't know I was just so weak. She was the one that carried the conversation, and she didn't have to carry it very long because he looked and says 'Yeah, we're going to admit you', but if I hadn't had her, I'm sure he would have admitted me anyway, but you can't be 100% certain. (P9)

Participants also described appointment delays, communication approaches and corporate challenges to productive health encounters. For some, this meant that they would not even tell their story:

> My boyfriend, he won't go to the doctor. He called today (October) for something he needs an appointment for and because he was told that they're booking into the middle of January, he hung up. 'It just wasn't worth it to him'. (P2)

Others who were composed during health encounters blamed themselves for delayed diagnosis while many advocated for themselves. But as one participant commented, such self-advocacy 'took a lot of work' (P20).

4.6   Discussion

Patients work hard to ready themselves and their stories for health interactions. Our elaboration of how patients with chronic illnesses engage in strategic preparation for productive storytelling during health encounters represents a novel contribution to the literature on patient-centeredness.

While we have long thought about how health practitioners are trained to do their research in preparation for patient encounters, this study shows us that patients are also doing extensive preparations for their health interactions and that these preparations may have a variety of effects, some positive and some negative. Corbin & Strauss[38] talk about three lines of work people living with chronic illness engage in—illness-related work, everyday life work and biographical work. Illness-related work refers to what is done to define, treat and manage their illness, everyday life work is related to the household and family tasks that are done to maintain daily regimens, and biographical work relates to how common life events may reconstruct one's life's work.[39] Illness-related work is multifaceted, encompassing elements such as tracking personal health using self-monitoring technologies,[40] engaging in activities to acquire a diagnosis,[24] participating in self-management strategies[41] and executing post-encounter activities.[27] Our research expands the understanding of illness-related work by adding another, previously under-recognized element: the work patients do to prepare themselves and to prepare their stories for clinical encounters. Collectively, these activities create a significant burden of responsibility. The need to foster an awareness in health practitioners of this 'behind the scenes' preparatory work is important to how we educate practitioners to deliver patient-centered care during health encounters.

By focusing on the extensive preparatory work patients engage in, our study expands the dimensions of how we understand illness-related work. What we have called *health interaction work*—the work patients engage in to participate in clinical encounters—is a distinct form of chronic illness work that serves specific and strategic functions. Below, we explore three key dimensions of this health interaction work—assembling personal health information, gathering disease information, and achieving equanimity.

The dimension of 'assembling personal health information' encompasses the efforts of maintaining up-to-date medical records and accruing current knowledge regarding disease interventions. In this study, participants described positive aspects of how their up-to-date health records enhanced interactions with practitioners. When accurate health records were maintained by patients, time during visits could be freed up for discussion of patients' agenda items. Furthermore, the process of assembling this information represented an investment in their personal health—an investment whose dividends included feeling sufficiently knowledgeable to engage productively with health practitioners in conversations. But although accurate personal health records may be empowering for patients, the preparations may discourage the conversational aspects of health encounters that serve to encourage trust and relationship building with health practitioners. On the other hand, individuals with chronic diseases are especially challenged to complete up-to-date health documents while often navigating multiple co-morbidities, various health practitioners and complex treatment regimens.[40,42-45] While other studies have highlighted the work people engage in to manage their health and everyday life in chronic diseases such as managing self-attendant care,[46] implementing home peritoneal dialysis,[47] adhering to medication schedules[48] and engaging in self-monitoring technologies,[48,49] the work patients do to prepare and maintain their personal health diaries occurs largely in the shadows.[45] And as Montori[50] aptly notes: 'all this work takes effort, attention and time, but limited research exists about how much time this takes; current estimates place that time at two hours per day, a part-time job'.[50(p53)] Ancker et al[45] endorse patients' efforts to sustain accurate health data among practitioners, pointing out that 'one of the biggest issues facing patients is the enormous amount of difficult, frustrating and emotionally tiring work involved in addressing informational errors'.[45(p9)] While patients self-tracking of their health allows for autonomous decision making in keeping with patient-centeredness, the responsibilities associated with engaging in independent health behaviours adds another level of burden to their everyday 'illness work'.

The dimension of 'gathering disease information' relates to the activities of locating, understanding, and interpreting information about their symptoms or condition. While

gathering disease information is widespread, with studies showing that up to 80% of people who use the internet have looked online for health information,[51] this activity may take on a particular urgency for those living with chronic illness. Engaging in disease information pursuits might help patients focus attention to potential therapies or investigations not yet considered by health practitioners. Avenues to research potential diseases and their treatments are plentiful with internet access to disease-specific foundations, chat rooms and blogs,[52] and patients often come to health interactions armed with stories from 'others' to share at health encounters. In our study, the proactive information-seeking behaviour that patients engaged in often helped them to make sense of their symptoms or learn about interventions for their condition, which shaped their interactions with health practitioners. While the information patients gain from social media does not necessarily trump health practitioners' recommendations,[53] the knowledge accrued may be an avenue to equalize the relationship between patients and health practitioners,[28] thereby empowering patients for health in- teractions.[30,31,54] Preemptive knowledge-seeking appeared to help participants in our study to conceive a backup plan in case they were not satisfied with the outcome of their health interactions. Although the activities patients engage in prior to health encounters may positively enhance their overall experience with health practitioners, by appearing knowledgeable about their condition,[28,30] feeling empowered to discuss their symptoms and being supported by peers,[31,55] the negative personal effects such as time disruptions, physical fatigue and reduced mental energy, may offset their relative value.[56,57] The preparatory personal health and disease information-seeking endeavours engaged in by patients are not only largely invisible; this study affirms that they are also a free service that may benefit both health professionals and patients.[50] In addition, the energy used to prepare for encounters may limit patients' overall health and wellness and it may not result in them getting more airtime.

The dimension of 'achieving equanimity'—the task of being composed, calm and self-controlled for health encounters—may be especially challenging. Hochschild's[58(p7)] description of preemptive emotion work—'the work of inducing or inhibiting emotions to render them appropriate for the situation' fits with our study

where patients work at presenting their story during health encounters to save themselves or their loved ones from unpredictable behaviours or spare health practitioners from taking the time or effort to attend to emotions. In keeping with the results of our study, participants' concerns about how their spouse/family member would support or disrupt the health encounter included varied emotions—sadness, surprise, or anger. These anticipated reactions often required pre-emptive conversations to protect oneself or the family member from eliciting emotional responses that may interrupt the flow of the encounter. For some, this may mean that they attend the appointment alone or limit the information they tell during the encounter. In a systematic review of physician-patient-companion communication, the role of the companion in health encounters was perceived differently by each member of the physician-patient-companion triad. For example, these persons may be—'an active partner', 'a welcome guest' or 'an intruder' and their individual functions are often not articulated prior to the health interactions.[59(p10)] The lack of predictability regarding how the interactions will evolve with or without a companion challenges a productive health encounter.

In our study, the efforts of practicing their story alone or with others, appearing put together with appropriate clothes and makeup, or delivering a story with a positive spin suggest that equanimity may be strategic. As noted by Werner & Malterud,[60] patients that may be overreacting or embellishing their symptoms while showing their fears and anxieties during health encounters may risk inappropriate health management. In addition, women with chronic pain 'worked' to balance how their story was told—'not to appear too strong or too weak, too healthy or too sick, or too smart or too deranged'[60(p1409)]—in order to make their stories credible to health practitioners. We wonder whether the impetus to do this proactive interaction work is not only emotionally protective, but it is also used by patients to facilitate a positive outcome. As health practitioners are often the gatekeepers to treatments required by patients with chronic illnesses, the need to balance their story may be an essential part of having their needs met.[61] Health encounters in chronic illness may occur as seminal initial interactions for diagnosis and treatment, followed by ongoing monitoring appointments that are often

lifelong. Interruptions such as acute relapses, new medical issues, alternate treating health practitioners and ever-changing learners may alter how interactions unfold in a patient-centered way. While health practitioners are called to understand the patients' context, develop caring relationships and provide coordinated care,[9,62] single encounters are often used to study avenues to improve patient-health practitioner communication, advocating for the use of shared decision-making techniques,[63] showing empathy[17] and building trust.[64] However, what patients share at health encounters may only represent a snippet of their health journey, and not what happens before or after these encounters.[34] Recent efforts to give voice to patients' experiences post-encounter[27] and this current study acknowledge the invisible work that has largely been ignored, expanding how we think about patient-centered care. In a recent review of educational interventions specifically involving patients,[65] the need for further research in developing learning processes that consider the 'whole illness trajectory' is highlighted. By taking a patient's view of how health encounters may unfold due to the work that they engage in pre-emptively, we get a glimpse of how health interactions may not always deliver what we as health practitioners may expect. Perhaps by embracing a vision to educate practitioners to inquire, hear, and understand each patient's story within the realm of their entire health journey we will truly deliver care that is minimally disruptive[50] and patient focused.

4.7   Implications

From this study, we now understand better the concept of 'patient-centeredness', and how this may translate to education. Patient-centeredness demands a sensitivity to the substantial health interaction work in which patients must engage, and to the potential consequences (positive and negative) of that work. While educating practitioners to explicitly inquire about patients' preparatory work is important, practitioners may also benefit from engaging with patients about their preemptive efforts. As we think about how both practitioners and patients prepare for mutually productive interactions, what each individual's responsibilities are in terms of this preparation and how best to accomplish it, patient-centered care may be advanced.

Firstly, as patients with chronic diseases engage in physical and emotional 'work' for their health interactions, health practitioners need to be aware, interested and responsive to these efforts in order to foster conversations that are patient focused. Practitioners may ask patients early on in the conversation about these preemptive preparations, gathering patients' knowledge, thoughts and concerns about their current symptoms. In addition, practitioners may need to think about their own efforts to prepare for health encounters. Training learners to be knowledgeable about patients' past and current health problems prior to health encounters may reassure patients that practitioners are starting from a point of sufficient understanding, thereby reducing patient's anxiety about the amount of work they need to do. As practitioners learn to leave aside checklists, instead fostering discussions about expectations for health encounters from both sides of the conversation, mutually beneficial airtime may be achieved. Secondly, practitioners need to be sensitive to patients' effort of gathering, documenting, and sharing their health experiences, data, and knowledge by not dismissing these efforts without acknowledging their work. Health practitioners and learners may need to have an explicit conversation focusing on educating patients about how to organize their health data, what are reliable internet sources for health information and how to sift through peer support group blogs for effectual interactions. Setting aside time during health encounters to educate patients about when to seek help, what symptoms are concerning or can wait, and how to do deal with that uncertainty at home may also support future health encounters. Adding counselling and information management skills training may help practitioners and learners learn to establish a mutually agreed upon agenda for the next appointment. Thirdly, as patients may want to protect health practitioners from learning how they truly experience illness by limiting their storytelling, placating family members, or appearing in control, ensuring opportunities for patients to feel safe during health interactions is important. As patients may present a particular version of themselves at health encounters, we need to think about how to teach health practitioners and learners to engage in interactions where patients will have a space to express their anxieties, vulnerabilities, and concerns. As practitioners learn how to build trusting relationships, a heightened focus

on training learners to display empathy, compassion and caring during health interactions are paramount. Lastly, health practitioners and learners may find it useful to learn that there may be a disconnect between their goals and the patient's goals for the health encounter. Strategies to explore, understand and resolve these tensions by engaging in reflection and peer/educator debriefs may provide unique learning opportunities.

Educating practitioners to deliver patient-centered care is complex. This is not cry for a new curriculum but an avenue to make explicit what work patients do engage in prior to health encounters. Shifting our efforts at educating health practitioners to incorporate health interaction work as a component of history taking, we may gain important understandings of what patients think about, deal with and are most concerned about for their current encounter. To date education regarding patient-centered care has focused on patient interactions during health encounters. But as pointed out by Humphris,[27] if we more clearly recognize the work patients do before and need to do after the encounter, we may forward the current thinking about patient-centered care to involve the entire health journey more explicitly.

4.8   Limitations

This collective account of stories shared with health practitioners is presented as an understanding of the work that goes on behind the scenes by patients with a variety of chronic diseases as they prepare and attend health encounters. As the majority of participants had a neurological chronic disease, we may not have captured fully the perspectives of other chronic disease patients. However, we were assured that the themes we identified from the cancer patients we theoretically sampled were remarkably aligned with those from the patients with chronic neurological illnesses diseases. As female participants accounted for about three quarters of the sample, there may be potentially diverse renderings of how men and women prepare, tell, and reflect on their encounters with health practitioners that are not portrayed in this study.

We did not collect socio-economic demographics such as race, financial resources, language, or cultural background, and therefore, this study does not speak to the unique challenges diverse groups may experience while preparing for interactions, but these factors warrant further exploration.

4.9 Conclusion

Much behind-the-scenes work shapes the nature of stories in ways that may or may not always further the aims of why we collect and interpret these stories in the first place. An understanding of the preparatory work associated with patients' efforts to participate in health encounters, although unseen, should not be undervalued. As we educate learners to garner conversations that put patients at the center of health encounters, patients' preparatory work for these interactions requires visibility, giving patients due recognition for their role in successful health outcomes that encompass the entire health journey.

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Chapter 5

5   Archetypes of Incomplete Stories in Chronic Illness

5.1   Abstract

Introduction: During clinical encounters, patients and practitioners engage in conversations to address health concerns. Because these interactions are time-pressured events, it may be inevitable that any story exchanged during these encounters will be incomplete in some way, potentially jeopardizing how quality and safe care is delivered. In this study, we explored how and why incomplete stories might arise in health interactions.

Methods: A constructivist grounded theory approach was used to explore how patients and practitioners approach their interactions during health encounters. In this two-phase study, we interviewed patients (n=21) and then health practitioners (n=12) using a semi structured interview guide. Using constant comparative analysis, we identified several themes related to story completeness in the patient data. We then explored these themes more fully by bringing in the perspectives of practitioners.

Results: We identified three distinct archetypes of incomplete storytelling - the hidden story, the interpreted story, and the tailored story. Measured information sharing, triadic encounters and pre-planned agendas influenced these storylines. Patient participants made decisions about what to tell during an encounter based on what they believed was valuable to practitioners, what they felt there would be time for, and what they decided to share. Practitioner participants made decisions about what information to gather based on what they thought would be relevant, what would constitute the best use of their time, and what they needed to know to facilitate optimal health care.

Conclusion: Both patient and practitioner participants engaged in thoughtful, time-sensitive interactions focused on what each considered important, appropriate, and useful for productive encounters. While incomplete stories may be a reality, educating practitioners/learners about how incomplete stories come about from both sides of the conversation creates new opportunities to think about optimizing interactions that are patient centered.

5.2   Introduction

Sound medical care for people with chronic illness requires sufficient information about individuals' concerns regarding their health. For all kinds of reasons, we understand that the stories that are exchanged in the context of time limited health encounters are bound to be incomplete.[1-3] Some of these reasons have been elaborated by researchers: for example, practitioners tend to interrupt early[4] and avoid lengthy conversations,[5] and patients sometimes withhold information.[6] Realizing that the promise of patient-centered communication appears to be difficult to achieve in practice, a better understanding is required – one that brings patient and provider perspectives together.

Patient centered communication techniques such as applying active listening skills, using open ended questions, and eliciting patients' concerns[7-12] are associated with adherence to therapy, patient satisfaction, and positive outcomes. Real-world studies suggest that the ideal of patient-centered communication is often not reached, compounding the issue of partial story-telling.[13]Although clinical care is supposed to be patient-centered, clinicians use a variety of strategies to keep communication physician-centric possibly limiting opportunities for patients to fully participate in decision-making.[14,15] Other factors that may compromise story completeness may include patients' perceived resistance to proposed management strategies and the reality of time pressures.[16.17]

Patients, too, may experience barriers that hinder information sharing.[18-22] For example, patients may fear being judged regarding how their current behaviours may be contributing to poor health, may withhold information as they do not want to be

perceived as difficult patients, or may hold views that are not aligned with what practitioners propose as treatment options.[6,24,25] What patients do not communicate in health encounters may also include unexpressed desires[22,23,26-28] which potentially lead to dissatisfaction with the health encounters.[29] Importantly, patients with chronic illnesses are expected to take on more of a participatory role in health management, creating a greater need for open communication[30,31]. Yet, even in chronic illness encounters, patients' information sharing may be hampered by perceived time limitations, potential lack of relevance, or situational recall issues[25]. So, while patients do seek care from health practitioners, our efforts to gain fulsome information at encounters is not straightforward, also challenging how we teach communication skills to learners.

One approach in the literature regarding practitioner-patient interactions has focused on understanding communication practices during encounters using various methodologies. Quantitative methods such as observational accounts,[32] self-report surveys[18,33,34] or specific interactional coding systems are commonly used.[35-39] Others have used quantitative or qualitative methodologies focusing on detailed conversational analyses[39-43] or mixed methodologies[44-46] contributing to the development of strategies to improve patient-centered communication skills. In addition, communication practices during encounters are often examined, explained, and understood with an eye to the systematic approach of the medical interview[42,47-49] yet history-taking and communication frameworks such as Calgary Cambridge guide or the Kalamazoo Consensus statement were developed with limited input from patients. And even when patients participated in evaluating learners' communication skills, the noted lack of consensus about what constitutes 'good communication' among patients and practitioners[24,52] supports the ongoing challenge of how to achieve patient-centered interactions. While understandings about health interactions remain an area of active research,[53-55] we are taking a novel approach that has not been seen as much in the past in patient-centered communication research - exploring story completeness with both patients and practitioners.

We acknowledge that all stories by their very nature are incomplete. For all kinds of reasons including time constraints, but not limited to that, the stories that are going to be

exchanged in health encounters are also going to be incomplete. That's not always problematic, but it can be problematic. For example, there are times when the story is sufficient, it serves its purpose to be able to make decisions that are patient-centered, and people leave feeling like the care encounter has been valuable and productive. And then there are circumstances when the story is insufficient and those are potentially the risky circumstances. So, if we understand the ways in which incomplete stories occur, we can better assess the ways in which that could lead to stories that are insufficient.

Practitioners use "story" or 'account' to mean whatever information patients share or practitioners gather during an encounter[50(p22),52(p391)] and it is in this way we also use the term 'story'. In health care discussions, it is common to think about interactions as the combined story -what the patient told, and what the practitioner gathered? From these perspectives, patients and practitioners shape the story that ultimately unfolds.

The aim of this paper is to advance the understanding of how patients' and practitioners' agendas and intentions shape their approach to health interactions and influence the stories that ultimately unfold. In this research, we put patient and provider data side by side in the same study relevant to the same question: How do interactions between patients and health practitioners shape the story told at encounters? This kind of approach in patient-centered care research where we try to bring together both perspectives around the issue of health interactions may help to further our understanding of the chronic challenges of how information is conveyed at encounters. What we don't understand as well is the process by which sometimes patients' and practitioners' competing agendas come together, how they are reconciled (or not), and what impact that may have on the stories that arise. Understanding the influences at work during encounters from both patient' and practitioner' perspectives may inform how we further our efforts to teach effective patient-centered communication.

5.3   Methods

 A constructivist grounded theory (CGT) approach guided the exploration of how patients

and practitioners approach their interactions during health encounters. A grounded theory approach is appropriate when we seek to understand social processes and the meaning individuals or groups make of their actions.[56] Our study focused on the complexity of health interactions; - *how* stories are shaped for encounters and *why* stories may remain incomplete - with the aim of developing a situated understanding of a process useful for informing current educational practices.[57]

5.3.1 Setting, Participants, and Sampling

We conducted this research in one mid-sized Canadian city, with two university affiliated hospitals, in two separate phases with a total of thirty- three participants. Twenty-one patients (P) living with a chronic disease (phase one) and twelve health practitioners (HP) with a chronic disease focused practice (phase two) participated in semi-structured interviews lasting up to one hour (Table 1).

Table 1. Characteristics of 33 Participants, from a Qualitative Study Exploring How Stories Unfold at Health Encounters

Characteristic	Patient Numbers n=21	Practitioner Numbers n=12
Gender		
Female	16	10
Male	5	2
Age Range		
25-50 years	10	4
50-75 years	11	8
Chronic disease/Specialty		
Neurology	13	3
Rheumatology	3	0
Psychiatry	1	0
Cancer/Palliative Care	4	3
Internal Medicine	0	6

Patients were recruited through notices placed in outpatient waiting areas, distributed by chronic disease specialists or through patient support group communications. Health practitioners (n= 6 Nurse Practitioners; 6 Physicians) were recruited through an email invitation distributed by the hospitals directors' office of both the Nurse Practitioners (NP) and Department of Medicine groups. The patient interviews occurred from October 2018 to April 2019, while practitioner interviews occurred from Nov 2019 to Nov 2020. Recruitment ceased when the data collected seemed sufficient for exploring the stories that unfold at health encounters from both perspectives.

5.3.2 Data collection

Although the first phase of this study was initially focused on exploring how patients prepare and shape their stories for health encounters (details reported elsewhere),[58] we identified several themes in our analysis that related to the completeness (or incompleteness) of the stories that were ultimately told. We decided to explore this compelling notion more fully by engaging in a second phase of the research that brought forward the perspectives of practitioners. Accordingly, all practitioners were asked to reflect on a recent or complex clinical encounter, thinking about how they gathered the story, asked questions during health interactions, and dealt with challenges eliciting the story. A semi-structured interview guide with probes was modified iteratively in response to insights uncovered during the analysis of the patient and practitioner data. In response to how the theme of incomplete stories resonated with the research team, interview questions focusing on understanding incomplete stories from practitioners were developed to probe further around this topic. In our first study, as there was a suggestion that patients' efforts to get 'airtime' and achieve 'equanimity' for encounters may influence storytelling at encounters, we incorporated these themes as we gathered, analysed, and formulated our results. All interviews were audio-recorded and transcribed verbatim for analysis.

5.3.3 Data Analysis

Iterative inductive analysis was undertaken using the constant comparative approach.[57] I began with initial line-by-line coding, then developed broad categories followed by a final coding framework. The research team (EAK, KAL, SLV, CW and WJK) met to review the coding framework that was developed.

As the theme that we identified in the patient study - incomplete stories- also developed in the practitioner data, we re-examined all the data from the patient phase of the study that related to incomplete stories and combined that data with new data from the practitioner interviews. We then re-analysed and re-coded the complete data set using constant comparative analysis. The final framework of combined practitioner and patient codes focused on how the intentions, agendas and plans brought to the encounters influenced the developing storyline. CW and WJK continued to meet frequently to discuss coding and analysis throughout the study. In keeping with the CGT analytical process, during the writing of the findings, ongoing refinement of the results occurred. NVivo©, a qualitative research software program was used to organize the data. This study was approved by the institutional Health Sciences Ethics Board (Appendix A, B, C, D), and Lawson Health Research Institute (Appendix E).

5.4   Reflexivity

In CGT, the researcher is an active participant in the research process and along with participants co-constructs the experiences and meaning making[59]. WJK is a PhD candidate and Nurse Practitioner with decades of experience with patients living with chronic neurological diseases. CW and SLV are practicing neurologists in chronic diseases. The team also included individuals (CW, KAL, EAK, SLV) with research experience related to health professions education. As a PhD student, WJK, engaged in memo-writing, team discussions and reflexive interrogation of personal perspectives shaping data collection, analysis, and writing phases of this work.

5.5   Findings

This multi-perspective exploration of how stories unfolded during health interactions reinforced the idea that health care providers obtain, at best, an incomplete picture of patients' health concerns. Patients shared stories of encounters during emergent and regular follow-up appointments with family physicians, nurse practitioners, emergency room physicians and disease-specific specialists, while practitioners shared stories of both initial and follow-up interactions with individuals living with a chronic illness. Within these stories we identified a range of reasons for story incompleteness, some related to the patient and some related to the practitioner. Patients made decisions about what to tell during an encounter based on what they believed counted, what they considered there would be time for, and what they decided to share. Practitioners made decisions about what information to gather based on what they thought would be relevant, what would constitute the best use of their time, and what they needed to know to give safe and quality care. In both patient and practitioner's data we identified three distinct archetypes of incomplete storytelling - the hidden story, the interpreted story, and the tailored story. We elaborate each of these story archetypes below with both patient and practitioner data. Our interpretations are supported with representative quotations.

5.5.1 The Hidden Story

During health interactions certain details of the story may be left unspoken by design. In this study, practitioners described varied techniques of how they gained more fulsome stories, while patients shared stories of purposely withholding personal data that may be uncomfortable to reveal. For example, a few patients acknowledged that they have 'secrets' that they do not discuss with anyone, while others indicated that they have information that they have no intention of telling their practitioners ever. "I've been on and off a smoker, and I will lie about that ... there's a huge stigma around smoking ... it's like this secret thing" (P11). Another described limiting the information shared with practitioners to be assured equitable health care. "If I leave parts of the story out, it's

because I think I'm going to be judged and ... that I am not maybe worthy of getting better treatment" (P3).

Patients made deliberate decisions about what information they shared with practitioners guided by a desire for autonomy while making health choices, and for impartiality in what treatments may be offered. Of concern is that patient's lack of disclosure regarding personal health choices or social situation may get in the way of practitioners offering psychosocial support options.

Practitioners recognized the risk that patients might withhold information, at least to some degree. As one practitioner shared: "They may give us a story that they can function much higher than they actually can, in fear of being placed somewhere" (HP11). Gaps in patients' stories were also suspected when the verbal account and the diagnostic data did not make sense: "I'm finding we're getting one presentation of the issue and then we do the work up, for example tox screen ... and it's not consistent" (HP8). Another stated: "I find it around compliance ... the patient is saying they're following this diet ... they're taking all their meds but ... when you're looking at the blood work there is a disconnect" (HP12).

While a lack of unity between data and story during a single interaction may cue practitioners to hidden stories, getting the full story may follow in later encounters. For example, one practitioner shared how during a re-assessment visit, the patient "unloaded all of her personal issues with a death in the family, wills, money and all that stuff which she hadn't said before" (HP3). For another practitioner a fuller story unfolded over time in short anecdotes:

> He just keeps saying, 'I can't cope with this, and this surgery isn't good.' I kind of got pieces of it as time passed, but I thought, 'wow, there is way more here. And I don't know if it's the surgery ... But now that I'm seeing him more often, I think I'm also hearing more about it'. So, it's unmasked this whole family dynamic that I was not aware of, although I'd followed him for years (HP4).

As these data show, 'hidden' stories might be revealed gradually over time, with persistence, purpose, and patience.

5.5.2 The Interpreted Story

During health encounters incomplete storylines may be influenced by contextual factors. Practitioners and patients shared stories of how the participation of learners or family members might create stories that were shaped by others' interpretations. For example, one practitioner described an awareness of how the learner's version of the patient's story may lose important details when shared with the team:

> So, a patient comes in with a full story, after four handovers it's reduced to two sentences, and ... every day there is somebody different, I think in that system the patient's story, consequently, gets lost (HP2).

While learners may be the norm in teaching hospitals, patients described experiences with learners as challenging, fatiguing and anxiety-provoking, possibly influencing their willingness to tell full stories. One patient shared this:

> I had to tell these medical students my whole story again. 'Can you just do the examination'? ... Sometimes you're just not into telling everybody your story repeatedly ... they always say, 'well, what happened with your first major flare-up'? And that wasn't a very good time, and I don't like to talk about that (P3).

In addition to learners, patient stories are often filtered through the lens of others which could some cases both make stories incomplete or more fulsome. As one practitioner shared:

> So, the patient won't say that they don't walk too much if the family member is saying they walk more than what they actually do. And I don't know if it's the family member not wanting their loved one to be denied a therapy that they think would be some benefit ... the patients won't correct the kids to say, 'oh, I don't walk very much' (HP11).

And while substitute story tellers may necessarily create interpreted stories, practitioners described knowing that this may be all that can be available in that moment:

> I find it is not just the patient's story. It's the patient's story that's shared with you through whoever their substitute decision-maker is (HP9).

Our data suggests that patient and practitioner conversations are frequently centered around everyone but the patient, and practitioners seem to know this, sometimes using strategies to ensure that practitioner agendas are prioritized. And as stories that are shared by others at health encounters are necessarily chronicled as interpreted accounts, the stories at encounters may not be the patient's story at all but a combination of people's stories.

5.5.3 The Tailored Story

Recognizing that health interactions would be time-limited, both patients and practitioners made decisions about what information was relevant, what was credible, and what was appropriate for productive interactions forming purposeful stories. Patients described how they perceived practitioner-led interactions as a standard format for health encounters. One patient shared "I'll give them a little story of what has happened, and then they will ask me direct questions of how long or whatever, the level of pain or whatever it is" (P14). Another shared this perspective of how they expected health interactions to unfold:

> Doctors are all relatively smart people, so I think they're all able to deduce if you're having problems, say, 'I've got a stomach problem', they're going to understand that … I feel like you don't have to explain stuff to them because that's what they know about. ...That's why I just give them the facts because that's what their job is (P6).

Although patients described knowing that they had a role in launching the conversation at health encounters, they also expected that practitioners would intuitively know what was going on and quickly begin to interpret and guide how the interaction evolves.

Patients' stories were guided by their expectations that practitioners would lead the information gathering process, and practitioners reinforced this expectation employing a medically focused approach to gather patients' stories. For example, one practitioner

shared how a systematic method of obtaining patients health information may benefit the outcome of the encounter: "it's more helpful for me to ask the questions in a particular way and order, that helps me to sort it out in this moment" (HP3). Another noted the potential risk of missing important elements with a structured approach:

> We are trained to take a patient's story and turn it into a medical balance in some way. ... But it loses some of the flavour as well of what makes a patient, and how you remember a patient (HP2).

Given the commonplace nature of health encounters in chronic illness, patients described coming to know the routines and the rhythms of conversations so as not to waste time on irrelevant details:

> I understand how it works now ... okay, 'I'm here for pain meds' so I know in the ER, they don't want to give out narcotics because they don't want you to be a drug addict ... so, I'll just lay it out ... 'I've probably got a flare-up. Because I've been through it before, I can explain that this is what's happening, and this is kind of what I need solved. I don't need you to figure out what the pain is' (P6).

Like practitioners, patients focused health interactions by shifting the conversation in ways that met their agenda for this encounter.

Practitioners expressed awareness that the routines created through multiple rounds of encounters with various practitioners could begin to limit the stories in problematic ways. This practitioner recognized that asking questions a bit differently may be a useful counterbalance:

> I think they are sometimes just tailoring it ... they know the kinds of questions because the nurse has maybe already asked those questions and then I've already asked those questions and the dietician has already asked those questions, so I think ... they might just change it a little bit if they've been asked the question a little bit differently (HP12).

Within these recognized routines of information-sharing, practitioners and patients did describe tailoring their conversations to the scope of practice, credible data, and time

allotment. One patient shared this:

> The truth is they are body doctors ... they're not mental health practitioners ... I'll just go see my therapist if I want to talk about my mental health because that is not why I am here ... it's how I feel in myself, that I'm here for my body and that's what their job is (P11).

Other patients described how accommodating their practitioner's specialty-focused practice by telling appropriate stories was either a negative or positive experience. One patient shared: "some of the other doctors ... they don't care as much about issues that don't fall under their umbrella" (P1). Another patient shared how limiting the topics of conversation to the practitioner's specialty was considered conventional behaviour at health encounters: "if you're going to see a specialist, you maybe shouldn't overwhelm the brain specialist with your big toe problems. They give you a very limited amount of time" (P4). Patients described an understanding that focusing on information they perceived as relevant might be an appropriate and credible way to engage in time pressured conversations.

Similarly, practitioners described how they engaged in conversations that were applicable to the presenting problem. Some used a direct approach to interrupt the tangential story line. For example,

> I've been frank …and said 'okay, we only have a limited amount of time, and there's a lot of information that I still need to know. I apologize if it's not what you expected, but can we start with that, deal with that, and then we can look at some other things (HP9)?

Others worked hard to "find a way of pivoting" (HP6) the storyline to one that was relevant when the conversation was going off track. Both patients and practitioners considered appropriate topics of conversation for a specific encounter, limiting extraneous details while recognizing that time is an ever-present constraint.

In addition to practitioners, patients also described how potential time limitations influenced the evolution of the encounters. Patients described how they edited stories anticipating limited time to share the details of their experiences. One patient shared

"They've never heard my whole story … they don't have time to hear my whole story. They don't get the full picture" (P4). Another acknowledged how perceived lack of time could change the dynamics of the interaction to one that is practitioner-focused: "They have their own questions that they go through and because of timing and so -forth, you kind of skip over what you want to talk about" (P9). Others responded to unspoken signals, such as body language, from practitioners that resulted in limiting information sharing: "Our specialist is very busy ... she just stands and entertains our questions" (P18).

While perceived lack of time influenced what patients disclosed during encounters, some patients described speaking in ways that not only saved practitioners' time but also would be perceived as credible. For example, "I guess I try to use some of the words that Dr X has relayed to me in our conversations ... just so that this new doctor doesn't think I am a complete imbecile" (P3). Practitioners, however, expressed misgivings about patients "medicalizing" their stories, preferring instead a first-hand account. One practitioner shared:

> I would prefer they tell us the way it is. Just describe objectively their feelings or the difficulties they have. Sometimes patients do add a lot of their own assessment and … if I say, 'I know you are referred for shortness of breath and he may just tell me, oh yeah, I have pneumonia'(HP1)?

Tensions regarding information sharing at health encounters were described by patients and practitioners, potentially created by mis-aligned agendas.

5.6   Discussion

In this study, patients made conscious choices about what to include in the 'stories' they present due to their understanding of what information would be relevant, and how much time was available. This was further encouraged by clinicians who actively worked to shape the story that was revealed. While these story edits may be purposeful and, in some instances, appropriate, we offer 'incomplete stories' as an avenue to understand the consequences of how interactions unfold at health encounters.

An awareness by practitioners of how incomplete stories come about, acknowledging their part in the process, and transforming how communication evolves during health encounters is central to thinking about patient-centered care as a partnership. And while it is known that patients may withhold information[6,60] and practitioners may garner less than complete data during health encounters[21,61] our work adds a more nuanced understanding of how sometimes misaligned or competing agendas may create distinct types of incomplete stories. In this study, three distinct archetypes - the hidden story, the interpreted story, and the tailored story - raise varied explanations for incomplete stories from both practitioners' and patients' perspectives

The archetype of 'hidden stories' illustrates a purposeful withholding of information for personal motives. Our study found that when patients with chronic illnesses talk about deliberately concealing information during health encounters, there is a hint that patients are concerned that their needs, wishes or dignity will be discredited if they share the full story. Although our study did not set out to study differences between patients based on age, race gender, education or socioeconomic status, other researchers have described how demographic elements may affect how interactions unfold incompletely,[18,27,28,62-64] highlighting issues of inequities and medical mistrust as a critical matter in health encounters.[65] In addition, social norms may influence the ease with which certain health topics are discussed; body pain, skin rashes, or muscle weakness may be easy to discuss, while sexual issues, addiction concerns, or psychosocial problems may cause discomfort for both patient and practitioner and limit full disclosure.[66] Withholding information is not unique to health interactions; partial stories also exist in non-health care encounters such as academic environments[64] and everyday social interactions.[67] While people may consider filtering information during interactions as protective, purposeful, or practical, an indirect story may also influence the breadth of information that is shared critical for health management.

The archetype of 'interpreted stories' offers an additional rendering of how incomplete stories may occur during multi-voiced health encounters. Stories gathered from family

members or learners may result in stories that are précised, losing potentially valuable nuances. Although the beneficial effects of family supported interactions, decision-making, and care are well-known,[8,68-71] a comprehensive understanding of the communicative processes in triadic encounters is lacking.[72] Our study points to how the presence of family-members may shape the way that stories unfold, in both helpful and unhelpful ways. We learned that important elements of the 'lived experience' may be missing when family members augment, clarify or, communicate the story with or for patients at encounters. An alertness to how triadic interactions may create crafted, calculated, and constrained accounts may sensitize practitioners and learners to the potential for incomplete storytelling.

Although learners are commonplace in medical encounters, patients may be challenged to tell their whole story when the interactions are also perceived as an educational event. While learners require astute diagnostic reasoning skills, efforts to promote the use of systematic frameworks[73] as finely tuned data gathering tools may undermine the conversational aspects of health encounters that promote relationship-building. We already know that sensitive information may not be shared with medical students frequently due to privacy concerns.[74-76] Our study offers further insights into patients' concerns about interacting with learners such as increasing fatigue, anxieties and uncertainties that may be intensified by re-telling their story. Because learners themselves inevitably must re-tell these stories, often in settings with their own time constraints, the problem of incompleteness may be compounded. The benefits of learners in health professions' education are obvious, but we also need to be aware of the potential associated risks as they pertain to story completeness.

While the archetypes of hidden stories and interpreted stories flag how information may be overlooked, misconstrued, or lost during health interactions, the archetype of 'tailored stories' offers understandings of how incomplete stories may relate to the perceived relevance of information, scope of practice, and available time. In our study, tailored stories developed from both sides of the equation - the ways practitioners are trained and are comfortable with gathering information *and* the ways patients have been socialized

into the routines of health encounters. In this research, patients perceived that they had a role in launching the conversation, but they also recognized that a practitioner-led encounter may be 'normal' interaction etiquette. And although practitioners may be critiqued for creating power imbalances that undermine patient-centeredness, this study supports the notion that in certain circumstances patients may want practitioners to direct the conversation,[77] acknowledging the need for their medical expertise. In doing so patients do not abdicate their active role in clinical conversations but support an interaction where each party has specific insights to offer. In contrast, limiting conversations to the perceived reason for the visit is known to constrain topics for discussion during interactions and possibly have some bearing on the outcomes of health encounters.[43,44,77-79]

Time is an ever-present dimension that may benefit or hinder health encounters. In this study patients were acutely aware of time pressures during interactions with practitioners. While worrying about wasting a doctor's time is known to be a barrier to seeking help for potentially concerning health symptoms[45,79] this study shows that patients accepted limited interactions, used strategies to give a succinct story, and justified practitioners' behaviours as understandable. Recent research indicates that trust and time are frequently missing links to full disclosure.[80] Although not explored in this study, trust is relational, highly emotional and constructed through interpersonal relationships[82] creating challenges in obtaining complete stories in time-limited encounters. In our study, practitioners gained new understandings over repeated encounters and even over many years. Chronic disease care affords opportunities for longitudinal conversations, and those opportunities might offset the negative influence of time over the longer term.

5.7   Implications

The process of story creation at health encounters is shaped by the agendas and intentions of the participants, with a predictable product: a story that is incomplete. This work challenges us to think about how to teach, mentor and strengthen patient-centered communication[36] emphasizing the need to be aware of what goes *unsaid* in health

encounters and why. First, practitioners may cultivate more fulsome conversations during health interactions by focusing their efforts at getting a clear sense of the patients' concerns, understanding specific contextual considerations, and gathering patients' goals for health encounters. While focusing on displaying empathy, avoiding interruptions, and engaging in unhurried conversations may be challenging for practitioners, sharing with patients the desire to reach a mutual resolution to their problem, albeit time-limited, may be the first avenue to build rapport and trust. Second, the importance of caregivers/family members' presence in the encounter needs to be acknowledged while emphasizing patients' authority to invite them (or not) to participate in the conversations. Practitioners/learners need to be aware of how triadic interactions may foster multi-dimensional knowledge about the person, but also potentially interfere with full disclosure. Third, practitioners/learners need to thoughtfully consider how, for patients, retelling their story may be anxiety-provoking, fatiguing and disturbing, giving rise to incomplete stories. And while practitioner educators may never hear patients' stories firsthand, efforts to have students recount the story to the practitioner with the patient present may enhance complete storytelling. During that time, patients may have the opportunity to augment/correct their storylines. Lastly, practitioners/learners with a chronic disease-focused population may need to specifically allow extra time for complex patients, create additional appointments, and offer telephone or electronic conversations as an avenue to gain ancillary information, build trust, and develop lasting relationships. Promoting ongoing lines of conversations that "build a history rather than taking it"[83p1135] may further our efforts to learn more and expand the story longitudinally and gather more complete patient' stories.

5.8   Limitations

While we interviewed both patients and practitioners, we did not interview patient-practitioner dyads about shared encounters, limiting our insights. Although practitioners represented a variety of chronic illness practices, chronic neurologic disease was over-represented in our patient-population. We were reassured that our participants who spoke about non-neurological illnesses described similar experiences, suggesting we had tapped

into ideas that transcended particular illness states. As female participants represented over 75% of the 33 individuals interviewed, different perspectives might have been garnered from a more gender-balanced sample. In addition, our study did not address how distinct socio-economic, cultural, gender, and age composites might influence incomplete storytelling. And as our study was not designed to look at storytelling in acute care settings, this may be an important direction for future learning.

5.9   Conclusion

Patients and practitioners mutually foster incomplete storytelling at health encounters despite thoughtful efforts to engage in productive interactions. By considering the archetypes of hidden, interpreted, and tailored stories as red flags for unspoken storylines, we may mitigate threats to safe, high-quality care. Patient-centered communication might be enhanced if practitioners and learners periodically reflect on these questions during their interactions with patients:

1. Are our agendas aligned?

2. Do we have a shared understanding of what concerns are relevant or not relevant for the current health issue?

3. Are there others in the conversation who may be influencing the story?

4. Do we acknowledge that important parts of the story may be uncomfortable or embarrassing to ask or tell?

As we educate learners to engage in interactions that are patient-centered, a sensitivity to how incomplete stories may develop from both sides of the conversation creates new opportunities to listen, observe, and think about stories during health encounters. Importantly in chronic illness care, practitioners need to consider the conversations that occur over the lifetime of their shared encounters as unique opportunities for more fulsome stories.

6.0   References

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Chapter 6

6   Discussion

6.1   Summary of Study Findings

The phrase 'patient-centered care' (PCC) indicates that patients should be at the center of care and teaching, yet despite 30+ years of calling for this, it remains inconsistent in practice.[1,2] Perhaps it is therefore unsurprising that patients are so often dissatisfied with their health encounters,[3] and treatment plans are not always followed[4,5]. Efforts to foreground the patient's perspective in health encounters remain difficult, especially true in chronic illness care. Multiple health issues, different treatment strategies, and a focus on illness surveillance rather than cure may result in health interactions that are complex, and a practitioner-focused approach may take precedence.[6] Efforts to bring together patient and practitioner perspectives have been surprisingly limited in PCC research to date. With the research studies described in this thesis, we have gained a better understanding of the interacting influences on patient-practitioner health encounters. In this chapter, I will briefly summarize what I learned from the autoethnography (a personal perspective), the research study with patients (the patients' perspectives), and the research study with practitioners and patients (a combined perspective), and then I will integrate these findings to re-envision the concept of patient-centeredness in health professionals' education and practice pertinent to chronic illness health encounters.

6.2   Key Insights

6.2.1 The Personal Perspective

Exploring patient-practitioner health encounters from a personal perspective afforded an opportunity for me to reflect on my experience as a practitioner, and to connect this to how interactions may inevitably be incomplete. As a practitioner with 48 years of

experience, the autoethnography (AE) comprising Chapter 3 is also a good example of the kind of practitioner participant experiences we were trying to tap into with this research, providing conceptual linkages to the two studies that frame this thesis.

Engaging in autoethnography was an illuminating exercise that facilitated both research reflexivity and reflective practice. Reflexivity is rooted in social science, calling attention to the idea that the generation of knowledge is situated, the knower shapes the interpretation, and that assumptions and taken-for-granted perspectives must be interrogated.[7,8] Reflection is often rooted in a pragmatist paradigm-learning from experience.[8] Conceptually autoethnography and reflective practice share some commonalities. According to Lake,[9(p683)] "both are orientated towards the possibility of empowering individuals and giving them the ability to better understand who they are, why they act in the ways they do, and how they might act differently in the future". But the concepts -reflection and reflexivity- are philosophically distinct creating tensions in how we engage in these practices.[8]

Indeed, reflective practice is challenged by the lack of a uniform way to define it, a harmonized process on how to think reflectively, and an agreed upon method to evaluate its usefulness.[10-16] Recent efforts to "reclaim a theoretical orientation to reflection"[17(p1)] holds promise of advancing how we consider reflective practice in health professions education. Despite these challenges, reflective practice is widely endorsed in varied professional practices, - education,[18,19,] medicine,[9,20] nursing[21], and social work.[14] Of importance, practitioners who engaged in reflective practices regarding complex and challenging experiences may gain new insights and learnings.[14,22,23]

Reflexivity is often viewed as central dimension of AE. Autoethnography complements the dimension of -reflection-on-action- found in the seminal work by Schon "the Reflective Practitioner".[22] Unlike -reflection-in-action- that revolves around the idea that you respond to a critical or complex event in the moment, whilst connecting with prior experiences, reflection-on action- is the idea that practitioners look back on a seminal event, reflect on the consequences of that event and consider how to act in the future.

While using AE as an intentional method for reflective practice is less common, l too found this process useful for thinking about my professional practice in alignment with the literature from other health professionals and disciplines.[9,18-20,24-27] AE offers an avenue to engage in reflection about our professional practices and gain new practice-based knowledge with an aim to improve future experiences.[17,27]

From the vantage point of a practitioner committed to providing patient-centered care, the clinical vignettes presented in the AE offer a personal perspective pertinent to the focus of this thesis: patient-practitioner health encounters. Circling back to and reflecting anew on the autoethnography in light of the two studies, I recognized themes that were also present in the patient-practitioner data. For example, how I centered myself and my goals rather the patients or the caregivers, how I left patients' questions unanswered as "that was not my job", and how I limited conversations by discouraging caregivers to join in the conversation. Redirecting storylines, disregarding requests, and inhibiting triadic conversations are not in keeping with the tenets of patient-centered interactions. Autoethnography made visible blind spots in my current practice, illuminating inconsistencies between my practice and the values I claim to hold- patient-centered care. With these new understandings, I am now more open to foregrounding patients' and caregivers' stories, diminishing my role in leading the conversations, and emphasizing patients' needs not mine. Having shared the AE with a practitioner colleague, our collaborative efforts to critically revisit our practices has been beneficial.

6.2.2 The Patients' Perspectives

Informative as the autoethnography was about how health interactions may unfold undesirably from a personal perspective, additional questions remained open for consideration. Ultimately, stories begin with patients, but their approach to preparing and shaping these stories has largely been invisible. In Chapter 4, we illuminated the process, and proposed that patients engaged in *health interaction work* that comprised of physical, cognitive, and emotive tasks, and that these efforts were invisible to practitioners.

Corbin and Strauss's[28] influential heuristic of chronic illness work, while useful, neglects important dimensions of communication. Donovan-Kicken and others,[29,30] in their research with cancer patients, introduced the element of interpersonal communication activities- divulging a diagnosis, describing illness symptoms, and giving treatment details to family, friends, or co-workers- as a nuanced form of illness work, previously un-recognized. While there are some parallels to our research on *health interaction work*, we think that the work patients engage in for productive conversations with practitioners is distinctive and warrants careful attention.

Patients' health interaction work centres on engaging in encounters that support their goals. Because this work occurs in the background, before health interactions occur, it lacks visibility. In our research, the health interaction work of planning, preparing, and strategizing for encounters was hidden from caregivers, invisible to practitioners and also burdensome for patients. Notably, invisible work is known to consume resources, -time, energy, or supports- limiting individuals' capacities to maintain their daily productivity.[31,32] Despite the pervasiveness of everyday chronic illness work, health interactions are the currency patients have to engage with practitioners and these limited opportunities may cause patients to neglect other important activities. In our study, the purposeful efforts of personal information gathering, disease knowledge acquisition, and reflective formulation of their story suggest that patients invest in pursuing a successful encounter by "getting airtime" despite the work it demands. A more complete understanding of the consequences of patients' health interaction work on the story that evolves at these encounters required us to take a closer look at what was happening from both sides of the conversation.

6.2.3 The Combined Perspectives: Patients and Practitioners

From the patient perspectives study, we learned that health interaction work may sometimes be strategic, suggesting that gathering and sharing information at health encounters is not as straightforward as practitioners may think. We found that patients engaged in conversations with varied practitioners and these contexts influenced the type

of work, the impetus to do the work, and the information that was shared. Several themes were identified in our analysis of the patients' study that related to the completeness (or incompleteness) of their stories. We felt, however, that any exploration of how and why stories are incomplete would itself be incomplete unless we also heard from those on the other side of these interactions: practitioners. A combined perspective of patients and practitioners was pursued to elucidate and elaborate the key features of this notion further (Chapter 5).

Incomplete stories resulting from withholding information are often understood as patients purposefully concealing data,[33] but we also know that physicians may contribute to limited storytelling[34,35]. Our research builds on this work by drawing attention to what stories evolve at encounters from both sides of the conversation. In our initial research study, - "Getting Airtime"- (Chapter 4) we found that patients worked hard to plan, prepare, and strategize for their engagement in health encounters and that these efforts sometimes resulted in limited information sharing. In the combined patient-physician perspective study (Chapter 5) we found that practitioners also engaged in communication work protecting their own 'airtime'. Strategies like redirecting the conversation, contemplating how to gain further information, and deliberating about how to obtain necessary data in a time-limited encounter were used by practitioners to engage in encounters that met *their* needs. The combined patients and practitioners' perspectives of health interactions shared elements important to our understanding what 'story' unfolded at encounters. Patients' purposeful withholding of information for personal reasons, modifying information sharing due to triadic encounters, and the combined patient-practitioners' decision-making strategies about what information to tell or gather at encounters due to time constraints made incomplete story-telling a shared issue. What goes unsaid at health encounters challenges us to re-think how we teach, mentor, and strengthen patient-centered interactions.

6.3   Conceptual Diagram of Chronic Disease Interactions

In Figure 6.1, I illustrate the understandings elucidated from the combined perspectives of chronic disease interactions, as a conceptual diagram. "Getting Airtime" was initially presented in the patient study as a key finding related to patients' interaction work. Examining encounters from a combined perspective, "Getting Airtime" was also noted and therefore is presented as a shared core category. The key concepts of *making choices*, *targeting priorities*, and *balancing time* are shared concepts in the patient and practitioner perspectives of health encounters. The influences of patients, family members, practitioners, and learners are embedded in this process, contributing to the evolution of incomplete stories. Figure 6.1 illustrates the "*Getting Airtime*" conceptual diagram.

Figure 6.1. A Conceptual Diagram of How Incomplete Story-Telling Develops at Health Encounters
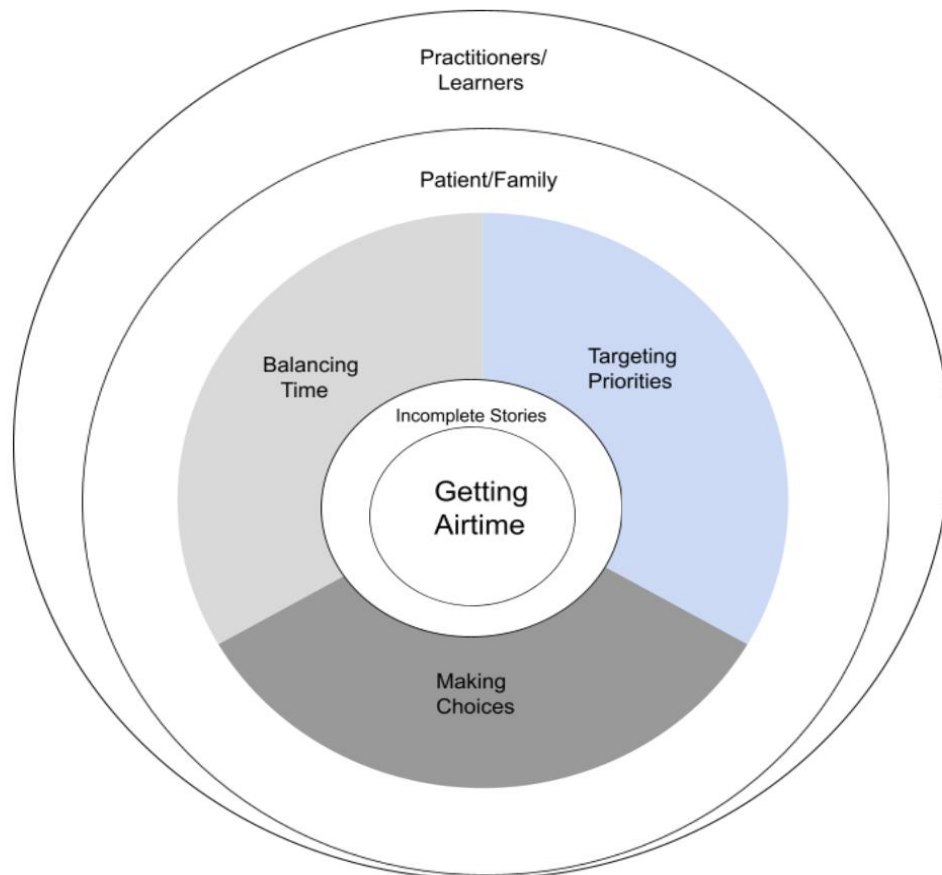
6.4   Situating Incomplete Stories in Patient Centered Care

We situate this work in the patient-centered clinical method (PCCM), often used to teach learners how to approach practitioner-patient interactions.[36,37] PCCM represents an effort to bridge the gap between the theory of PCC and the practice of PCC, by offering targets for the education of health practitioners (primarily physicians). By centering how patients' voices may be curtailed resulting in limited storytelling at health encounters, we highlight the tensions in teaching and practicing patient-centered care.

6.4.1 Considering the Patient-Centered Clinical Method

The well- accepted domains of PCC - Biopsychosocial Approach, Patient as Person, Sharing Power and Responsibility, and Therapeutic Alliance - overlap with the Patient-Centered Clinical Method (PCCM) that frames health professionals' learning. The PCCM comprises four components that support the structure for interactions at health encounters: (1) exploring health, disease, and illness, (2) understanding the whole person (3) finding common ground, and (4) enhancing the patient-doctor relationship.[37] And by incorporating the elements of patient-centered communication, learners are encouraged to prioritize and focus on the patient's perspective.[38] But as our research points out, patients' voices may not always be in the foreground, suggesting a disconnect between theory and practice.

In chronic illness care once the diagnosis has been established, health encounters often focus on treatment and management of patients' diseases.[39] In this setting, focused history-taking, agenda topics, and physical examinations may influence how patient-centered interactions unfold, perhaps limiting storytelling. Taking the components of the teaching method, PCCM, we can examine more closely how the findings of our research -patients' invisible work and their constrained voices- shape the telling and gathering of stories at health encounters. In component one- "exploring health, disease and illness experience",[37(p59)] -practitioners gather signs and symptoms of illness coupled with understanding the patient's experience of their medical problems. Practitioners will often

focus their history taking on the immediate health issue, potentially missing elements that may seem unrelated. This may be especially problematic in complex situations.[40] And when patients provide medication lists, agenda items, and questions for discussion at health encounters, practitioners may be less inclined to elicit the experiential aspects of a patient's illness. Although these efforts may support efficient information sharing, practitioners may be forfeiting the opportunity to hear first-hand the thinking, reasoning, or feelings that built the documented story.

In component two-understanding the whole person-, "the patients' position in the life cycle"[37(p67)] and the "contextual nuances of where the patient and practitioner reside"[37(p104)] – play an important part in providing individualized care. While gaining personal and other sociodemographic information is beneficial for practitioners' history taking, as we found in our study, certain aspects may be not be readily shared by patients. Family members often accompany patients on clinic visits to offer support or augment information sharing. And when companions speak 'on behalf of, for, about', and 'alongside' patients at health encounters, the combined storylines may contribute positively to decision-making.[41,42] But as our research and others have found, companions can change the dynamics of the encounter, negatively influencing rapport-building with practitioners and complicating how the interactions evolve[43]. In addition, we found that the pre-emptive invisible work patients did to achieve equanimity during encounters favoured the needs of others in order to foster interactions that were not disruptive, emotionally taxing, or disorganized. Coupled with how patients may also self-censor information sharing, stories that encompass half-truths may limit knowing the essential details required for decision-making. Even though we know that there are advantages to having family members present at encounters, practitioners and learners require an alertness to how triadic interactions may create a story where the patient's voice is sometimes quieted.

In component three -finding common ground- patients and practitioners are focused on reaching "a mutual understanding and mutual agreement on the nature of the problems, the goals and priorities of treatments and their respective roles."[37(p138)] Often linked to

promoting patient-centeredness by empowering patients, supporting patient autonomy, and fostering collaborative care, shared decision making (SDM) continues to be offered as the pinnacle of PCC.[44] Our research problematizes this notion when we consider how incomplete stories may interfere with obtaining a full shared understanding of the problem necessary for mutual goal setting. 'Finding common ground' conveys a sense of partnership, aligning with how we think about PCC. But without making patients' health interaction work visible, understood, and acknowledged, practitioners are unlikely to garner the 'whole story', nor achieve true therapeutic engagement.

In component four- enhancing the patient-doctor relationship- "the interactive components of the PCCM occur within the ongoing relationship"[37(p159)] and are accomplished by building therapeutic alliances. Our research supports the notion of more complete information sharing over time from relationship building efforts where ongoing patient-centered interactions may foster empathy, compassion, and caring. But for patients with chronic illnesses, the ongoing work of storytelling may also become increasingly difficult. As patients experience the realities of communication fatigue, progressive loss of function, or associated psychosocial burdens, practitioners need to be especially skilled in interpersonal communication. So, while our research supports the notion that relationship building in chronic disease is longitudinal, and that practitioners should remain open to new disclosures and elaborated stories over time, single encounters are still consequential. Each patient encounter may be one piece of how a 'full' story is eventually constructed.

6.5 Where does this Research Fit?

Primarily focused on amplifying the patients' voice in chronic illness care, our research supports a disconnect between the theory and practice of PCC which has critical implications for teaching and learning. While chronic illness care has recently been re-envisioned with the embrace of a minimally disruptive model,[45] there is no literature to my knowledge that supports its use in Canadian practices.

Coined in 2009, *minimally disruptive medicine* (MDM) is defined as "a patient-centered approach to care that focuses on achieving patient goals for life and health while imposing the smallest possible treatment burden on patient's lives".[45,46(p51),47] Since its introduction, the conceptualization of the MDM model, its approach to care and its implementation has been taken up in diverse chronic conditions,[48-50] multiple countries[51] and varied practice settings.[52,53] In contrast to previous models, - Chronic Care Model (CCM)[54-56] for example, MDM acknowledges patients' work and cultivates efforts to reduce patients' illness burden while enhancing capacity.[57] Efforts to address illness burden defined as "the mismatch between the work required of patients and the resources or abilities patients have to carry out this work".[52(p118)] are mainly focused on managing treatments, promoting healthy behaviours, and enabling selfcare.[49,50,53] While important, these efforts may miss the work health interactions entail and incomplete storytelling may not always be recognized as a factor that limits practitioners' knowledge of the patient. Our work adds important new dimensions to how we think about care that is minimally disruptive. How can we, for example, reduce the burden of interaction work? How can we reduce the risk of harmful gaps in stories that ultimately increase rather than reduce patient burden?

Guidance for implementing MDM is simple: "identifying the right care and then making the right care happen."[46(p52)] But if and how MDM aligns with the facets of PCC remains an open question.

Consider the story of the patient I presented in the introduction -an individual with a chronic progressive neurological illness, presenting to clinic with increasing difficulty breathing. We both agreed that the breathing issues were life-limiting, and that non-invasive supported ventilation could extend his life. He agreed to this management strategy, but the initiation of this treatment required a hospital admission. He told me that an admission to hospital was non-negotiable saying "they have no idea how to take care of me". While I had been following this gentleman for a number of years, our conversations usually circled around his questions about 'being cured' from his disease. I knew very little about his everyday life, and more importantly I knew very little about

what he required nor had in place to manage his illness. And when considering the MDM framework with a view to finding the right care and making the right care happen, I knew little of his capacity. But this gentleman told me enough. He knew how this treatment would fit in his life; we just needed me to make it happen. So perhaps incomplete stories are less of an issue than we may think. What may be more important is to ask the patient what works for them and then make it happen!

PCC as a concept is so embedded in health care that re-envisioning PCC to include MDM may be difficult, yet important. The current PCCM is centered on identifying the right care as we partner with patients but there is less of a focus on how to make that right care happen. The integration of the principles of MDM in the current method of teaching practitioners may help to rekindle the essence of PCC: listening to the patient.

6.6   Future Directions

6.6.1 Implications for Education

Chronic illness encounters are uniquely situated from other health interactions and medical education efforts may benefit from a re-envisioning that focuses on what practitioners do to be patient-centered. From this research, we offer these suggestions:
1.   The idea of patients' interaction work needs to be explicitly taught. For example, introductory questions may include "how did this appointment come about, what did you need to do to get here, and are there any specific problems you experienced that I need to know that may be important to our discussions today?" As patients may not know what preparatory *work* is worthwhile, practitioners can make explicit what issues are most relevant for decision-making. For example, suggesting patients pay particular attention to function – i.e., how long it takes to do certain critical activities, or how far they can walk without needing to sit down – rather than telling practitioners how fatigued they are on a scale of 1-10.
2.   Health communication education that addresses how incomplete stories come about from both sides of the conversation is important to further our efforts of achieving

patient-centered interactions. Having learners think about how aspects of the story may be hidden in triadic conversations, missed when using checklists and patients' diaries to collect information, or withheld so that negative illness experiences are not revisited, may open up opportunities for relationship building.

3. Learners may benefit from engaging in reflective practices with peers or teachers to consider how they may be contributing to gathering stories that are incomplete.

4. Educators need to examine how to best model, critique and embed the dimensions of patient-centered communication when positioned as a chronicler and recipient of a patient's story. Professional development work for practicing clinicians needs to focus on learning how to communicate in a patient-centered way.

5. Models for teaching patient centered care would benefit from further research specific to chronic illness care where patients' lived experience and their knowledge is made visible and incorporated into decision-making.

6. Integrating the elements of MDM in health professions education research may be one avenue to elicit understandings on how to teach communication skills pertinent to assessing patients' burden of illness and capacity.

7. Learners may benefit from opportunities to collaborate with interdisciplinary team members, to broaden their orientation of how patient-centered communication is practiced.

6.6.2 Implications for Practice

Our efforts to teach and mentor patient-centered interactions are important to how PCC is enacted at health encounters. Importantly, the delivery of PCC in chronic illness may require a nuanced approach to patients' stories. While there is some overlap with the implications for learners, we offer these suggestions for practitioners:

1. Practitioners need to recognize and acknowledge patient's health interaction work in order to fully understand and integrate the patient's story at health encounters. For example, beginning conversations with "I know you work hard to prepare for these encounters. Let's talk about how to use your preparatory efforts as efficiently as

possible", explicitly recognizes their efforts, while offering to discuss how to lessen the workload.

2. Practitioners need to consider when story incompleteness is consequential and when it is less relevant. Trusting patients will make decisions that 'fit' their world, even it is antithetical to our best advice may lay the foundation for fuller conversations at future encounters.

3. In keeping with #2 -practitioners need to consider how re-visiting a patient's story at regular intervals may garner some of the missing elements not shared in the first rendering.

4. In chronic illness care, centering interactions on relationship-building rather than getting all the 'data' at health encounters invites connectiveness and may promote more complete storytelling over time.

5. Reflective practice using innovative strategies such as autoethnography, arts-based methods, or collaborative efforts may elucidate interaction challenges and transform how practitioners deliver PCC in chronic illness encounters. Practitioners might also want to ask themselves: How often might the stories I hear be incomplete? What is my role in limiting the story? In chronic illness care where long-term follow-ups may be the norm, practitioners may be blinded by the familiarity of the patient's case, limiting how they interact with the story from a fresh perspective.

6. Research efforts to build a PCC competency skills framework may support our efforts to teach, learn, and evaluate the practice of patient-centeredness in the real-world.

6.7   Limitations and Strengths

This research is located at one university affiliated hospital where medical students are the norm, thus creating health encounters as teaching moments, and possibly influencing how patient-centeredness evolves. Perspectives from participants linked to community-focused specialty practices may have afforded alternate insights where practitioners engage with patients' stories directly. In addition, as the PCCM was founded with faculty from this centre, many practitioner participants recruited for this study are accustomed to thinking about PCC as usual care, perhaps limiting how they problematized patient

encounters. As a nurse practitioner, the lens of nursing was brought to how this research was developed, interpreted, and presented. While offering focused applicability, placing a nursing lens to physician-patient encounters in chronic illness care may also inform interprofessional learning and practice. As neurological patients and female participants were over-represented in our studies, a more diverse group may bring different perspectives.

Despite these limitations, our efforts to focus on the patients' voice have allowed us to further the understandings of chronic illness work and storytelling at patient-practitioner encounters. As learners incorporate the elements of patients' voices at university and clinical settings, early recognition of patients' interaction work may augment our efforts to achieve a re-envisioned PCC model. While I have suggested that MDM offers links to how PCC may be refreshed, further research would help to elucidate its utility and fit to improving how we educate learners to practice patient-centered chronic illness care.

6.8   Conclusion

Storytelling in the context of health encounters is a complex and dynamic event. Competing agendas shape these stories and often render them incomplete. While the dogma of patient-centered care is comprehensive, far-reaching, and central to health professions education, re-envisioning patient-centered care requires our unending efforts to elicit, hear and consider patients' stories at every juncture of their health journey.

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Appendix A

Western Ethics Approval – October 16, 2018

Western Research

Date: 16 October 2018

To: Dr. Christopher Watling

Project ID: 112093

Study Title: An exploration of how patients stories inform health professionals' knowledge and practice

Reference Number/ID: N/A

Application Type: HSREB Amendment Form

Review Type: Delegated

Full Board Reporting Date: 06Nov2018

Date Approval Issued: 16/Oct/2018 09:53

REB Approval Expiry Date: 23/Aug/2019

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Dear Dr. Christopher Watling ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
LOI HP; Health Practioners Knowledge v4	Consent Form	15/Oct/2018	4
Patient LOI Health Practioners Knowledge v4	Consent Form	15/Oct/2018	4

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

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

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

Sincerely,

███████████████████████████████ HSREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix B

Western Ethics Approval – November 8, 2018

**Western
Research**

Date: 8 November 2018

To: Dr. Christopher Watling

Project ID: 112093

Study Title: An exploration of how patients stories inform health professionals' knowledge and practice

Reference Number/ID: N/A

Application Type: HSREB Amendment Form

Review Type: Delegated

Full Board Reporting Date: 20November2018

Date Approval Issued: 08/Nov/2018 11:29

REB Approval Expiry Date: 23/Aug/2019

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Dear Dr. Christopher Watling ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Recruitment Patient Handout v1	Recruitment Materials	23/Oct/2018	1
Research Studies and Design V2	Protocol	22/Oct/2018	2

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

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

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

Sincerely,

███████████████████████████████ , HSREB Vice-Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix C

Western Ethics Approval – December 20, 2018

Western Research

Date: 20 December 2018

To: Dr. Christopher Watling

Project ID: 112093

Study Title: An exploration of how patients stories inform health professionals' knowledge and practice

Application Type: HSREB Amendment Form

Review Type: Delegated

Full Board Reporting Date: 15January2019

Date Approval Issued: 20/Dec/2018 14:35

REB Approval Expiry Date: 23/Aug/2019

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Dear Dr. Christopher Watling ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
LOI HP; Health Practioners Knowledge v5	Consent Form	17/Dec/2018	5
Research Studies and Design V3 Dec 2019	Protocol	20/Dec/2018	3

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

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

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

Sincerely,

██████████████████████████████ HSREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix D

Western Ethics Approval – January 28, 2019

Western Research

Date: 28 January 2019

To: Dr. Christopher Watling

Project ID: 112093

Study Title: An exploration of how patients stories inform health professionals' knowledge and practice

Reference Number/ID: Amendment 4

Application Type: HSREB Amendment Form

Review Type: Delegated

Full Board Reporting Date: 12February2019

Date Approval Issued: 28/Jan/2019 14:34

REB Approval Expiry Date: 23/Aug/2019

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Dear Dr. Christopher Watling ,

The Western University Health Sciences Research Ethics Board (HSREB) has reviewed and approved the WREM application form for the amendment, as of the date noted above.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Patient LOI Health Practioners Knowledge v5	Consent Form	28/Jan/2019	5

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

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

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

Sincerely,

██████████████████████████████ HSREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Appendix E

Lawson Health Research Institute Approval

LAWSON FINAL APPROVAL NOTICE

LAWSON APPROVAL NUMBER: R-18-540 HMM

PROJECT TITLE: An exploration of how patients stories inform health professionals' knowledge and practice

PRINCIPAL INVESTIGATOR: Dr. Christopher Watling

LAWSON APPROVAL DATE: Wednesday, 26 September 2018

ReDA ID: 5394

Overall Study Status: Active

Please be advised that the above project was reviewed by Lawson Administration and the project:

Please provide your Lawson Approval Number (R#) to the appropriate contact(s) in supporting departments (eg. Lab Services, Diagnostic Imaging, etc.) to inform them that your study is starting. The Lawson Approval Number must be provided each time services are requested.

V.P. Research

Lawson Health Research Institute

Curriculum Vitae

Name:	Wilma J. Koopman

Post-secondary Education and Degrees:

Hamilton Civic Hospitals
Hamilton, Ontario, Canada
1971-1973 Registered Nurse Diploma (RN)

Western University
London, Ontario, Canada
1985-1992 BScN
1995-1998 MScN
1998-2000 Nurse Practitioner (NP)
2015-2022 PhD Health Professions Education

Honours and Awards:

PhD Related:
CERI Symposium: Best Abstract/Presentation Award
2018

NPAO Christina Hurlock Chorostecki Research Scholarship
2018

CANN Marlene Reimer Research Award
2018

MGFA Nurses Research Award
2018

Related Work Experience:

Nurse Clinician/Nurse Practitioner - Neuromuscular Service
London Health Sciences Center, London, Ontario, Canada
1982-1995, 1999-present

Nurse Clinician – Multiple Sclerosis Service

Western University, Faculty of Health Sciences, London, Ontario, Canada

1996-1999

Clinical Instructor (Simulation Lab)

School of Nursing, Limited Duties Faculty Positions

2nd Year Nursing Students

Lecturer – 4th Year Nursing Students Focused Clinical Concepts

Lecturer – 3rd Year Nursing Students Nursing Statistics N3318 online

2006-2015

Preceptorship:

Fanshawe College: Post RN Neuroscience Students

1987, 1998, 2000

UWO: Masters Nursing Program, NP

2003, 2005, 2010, 2022

UWO: Nursing Research Practicum, BScN and MScN students

2008-2014

PhD Publications:

Koopman WJ, Watling CJ, LaDonna KA. Autoethnography as a strategy for engaging in reflexivity. *Global Qual Nurs Res*. 2020;7:2333393620970508–2333393620970508. https://doi.org/10.1177/2333393620970508

Koopman WJ, LaDonna KA, Kinsella EA, Venance SL, Watling CJ. Getting airtime: Exploring how patients shape the stories they tell health practitioners. *Med Educ*. 2021;33:10-14. https://doi.org/10.1111/medu.14561

Other Selected Publications:

Koopman WJ, Schweitzer A. The journey to multiple sclerosis: A qualitative study. *J Neurosci Nurs*. 1999;31(1), 17-26.

Koopman WJ. Needs assessment of persons with multiple sclerosis and significant others: Using the literature review and focus groups for preliminary survey questionnaire development. *Axon*. 2003;24(4):10-15.

Koopman WJ, Wiebe S, Colton-Hudson A, Moosa T, Smith D, Bach D, Nicolle MW. The prediction of aspiration in myasthenia gravis. *Muscle Nerve.* 2004;29:256-260.

Nicolle MW, Rask S, Koopman WJ, George CFP, Adams J, Wiebe S. Sleep apnea in patients with myasthenia gravis. *Neurology.* 2006;67:140-142.

Koopman WJ, Benbow CL, Vandervoort M. Top 10 needs of people with multiple sclerosis and their significant others. *J Neurosci Nurs.* 2006;38:369-373.

Krause-Bachand J, Koopman WJ. Living with oculopharyngeal muscular Dystrophy: A phenomenological study. *Can. J Neurosci Nurs.* 2008 30(1):35-39.

Venance SL, Koopman, WJ. Dystrophinopathies in adulthood. *Contin - Lifelong Learn Neurol*. 2009;15:15-29.

LaDonna KA, Koopman WJ, Venance SL. Myotonic dystrophy (DM1) and dysphagia: The need for dysphagia management guidelines and an assessment tool. *Can J Neurosci Nurs.* 2011;33:42-6. 27.

La Donna KA, Koopman WJ, Ray SJ, Venance SL. Hard to swallow: A phenomenological exploration of the experience of caring for individuals with myotonic dystrophy (DM1) and dysphagia. *J Neurosci Nurs*. 2016;48(1):42-51.

Koopman WJ, LeBlanc N, Fowler S, Nicolle MW, Hulley D. Hope, coping and quality of life in adults with myasthenia gravis. *Can J Neurosci Nurs*. 2016;38(1):56-64.

Book Chapters:

Koopman WJ. Neuromuscular disorders core curriculum (chapter editor and author). *AANN.* 6th ed. 2016.

Koopman WJ. Myasthenia Gravis. In: Hickey J, Strayer AL. *The Clinical Practice Neurological and Neurosurgical Nursing.* 8th ed. Philadelphia: Wouters Kluwer; 2018.