

**“Letting Stories Breathe”: Using Patient Stories
for Organizational Learning and Improvement**

by

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Abstract

There has been a recent upsurge in the use of patient stories to better understand patients’ experiences of illness and of care, and to inspire leaders and staff for quality and safety within healthcare. However, to fully realize the potential of patient stories, a more nuanced understanding is needed of how they are used, who tells them, for what purpose, and in what context. Using a constructivist case study methodology with qualitative methods, this study examined four healthcare organizations that are known leaders in the systematic and deliberate use of patient stories, exploring the storytellers, the types of stories told and their purposes. It also examined the contexts that enable the use of stories and the impact they have had on organizational learning and quality improvement.

An interpretivist approach to analysis highlighted the specific types of stories told *by* patients and *of* patients, and how they were co-constructed from stories of chaos into quest stories for learning, “authorized stories” to be shared for particular purposes. The storytellers who emerged were those who had extended their involvement as patient advisors/members, determined by leaders to be the “right fit” and at the “right time” to share their stories. Strong leaders modeled and supported the philosophical orientation toward patient and family-centred care that patient stories helped to develop and sustain. Leaders also created the

organizational structures and processes required to gather and share stories, and to link them purposefully with learning and improvement.

The act of storytelling is not a simple one and tensions surfaced relating to what stories are told, how, by whom, and for what purposes. In many ways, the organizations demonstrated how they were thinking *with* stories and how learning occurred at individual, team, and organizational levels. However, leaders and organizations continued to retain control of which patient stories were shared, in what forum, and for what purposes. Despite their best intentions and explicit demonstrations to hear the patient voice, a more reflective practice is required to better appreciate the power and privilege that exists within organizations, making this an area to explore further in theory development for organizational learning.

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When I first embarked on this journey of a PhD, a friend told me that it was the loneliest thing he had ever done. While there have been many moments of reflective solitude, the culmination of this dissertation has been anything but a solo journey.

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Prologue

Grace's Story

Grace is an attractive young professional woman who was a caregiver and advocate for her parents while they were in hospital. Her mother was hospitalized and passed away in the intensive care unit (ICU). A number of months later, her father was hospitalized (in a different hospital in another city) and also had been admitted to ICU. Below, I recount one experience Grace shares of her mother's stay in the ICU.

Grace and her father had been staying in a hotel for approximately two weeks, with daily visits to the ICU to spend time with her mother. One morning, they had received a phone call from the doctor; the situation was dire. Her mother was nearing the end, and the doctor suggested that they come to the hospital immediately. Grace and her father were regular visitors to the ICU, which had strict policies regarding visiting hours and the process for being allowed access into the ICU. On this day, knowing of her mother's dire circumstances, Grace and her father entered the ICU without the perfunctory telephone call to gain entrance, which Grace calls "*mistake number one.*" Once in her mother's room, her cell phone rang ("*mistake number two*": forgetting to turn off her cell phone); she stepped out to take the call. Grace returned into the ICU when done, again, without the perfunctory call for re-entry ("*mistake number three*"). Later in the day, Grace is called out of her mother's room and introduced to a social worker, who had been called in to review the hospital policies regarding ICU visiting procedures with Grace. The social worker opened a folder that contained written documents regarding these policies, which she asked Grace to sign, to ensure that Grace understood what she needed to do in order to gain entry into the ICU and the authorized hours for visiting. Grace, in tears, signs the paper. On her way back

to her mother's ICU room, she passes the nursing station, feeling humiliated and ashamed.

Later, the nurse enters the room, and tapes the signed copy of written rules to the wall next to her mother's bed. Grace is sitting next to her mother's bed at the time.

The sentiments that Grace expresses is how she never felt welcomed into the ICU as a family member to support her mother in her dying days. Rather, she was made to feel like an intruder who broke the rules and felt humiliated as she was forced to sign a contract that outlined how she must behave in order to gain access to her dying mother.

Grace's story is one example of the type of story gathered in this dissertation, a story of an experience of care (told from the perspective of a family member), one that may be used by organizations for learning and improvement.

Chapter 1

Introduction

The value of storytelling in healthcare is immense, and virtually untapped. If we don't preserve the richness of narrative, we will fail to connect to our patients' deepest experiences, and to our own. (Berwick, 2006)

Storytelling, both oral and written, is an incredibly powerful mechanism to access the human experience. As such, there has been a recent upsurge of patient story use as a means to better understand patients' experiences of illness and their experiences of care. In the past decade, well-respected organizations—such as the Institute for Healthcare Improvement (IHI) in the United States and the National Health System (NHS) in the United Kingdom have fully embraced and endorsed the use of patient stories to inspire leaders and staff for quality and safety, and to engage patients and families in the process of improvement. For example, campaigns such as the IHI's "Getting Boards on Board" recommends the use of patient stories at the start of each Board of Directors meeting to engage board members in quality and safety efforts by highlighting deficiencies in care, and as a way to put a human face to harm that results from patient safety errors (Conway, 2008). To this end, the IHI also has developed guidelines for telling patient stories at board-level meetings, based on the work of Delnor Community Hospital in Illinois.¹

Beyond the boardroom, other "how-to" toolkits for patient stories have been produced (for example, see 1000 Lives Plus, 2010; Department of Health Western Australia, 2008; Maund, Espinosa, Kosnik, & Scharf, 2003) that include various methods of storytelling (e.g.,

¹ See www.ihl.org.

written texts, video-storytelling, in-person storytellers) for different storytellers (e.g., organizational leaders, patients, family members, clinical staff). In these examples, the use of patient stories is orientated as an improvement tool, a way in which to stimulate staff and leader discussion related to safety, leadership, patient satisfaction, cooperation, and change management (Maund et al., 2003). Some toolkits also offer specific step-by-step instruction to gather and structure patient stories, and also how to analyze stories using techniques such as mind mapping, and to evaluate the impact of stories (Royal College of Nursing, 2004).

The empirical literature reflects the increasing use of patient stories for quality and safety, with reports of structured methods for gathering and using stories specifically for improvement purposes (e.g., Discovery Interviews, experience-based co-design), and for the education of healthcare professionals. The organizational learning literature highlights how stories have been used as a mechanism for knowledge management and change, and specific to healthcare, responding to lapses in safety. While the act of storytelling appears to be a natural human condition that provides a window into the patient experience, absent in the literature is a critical examination of the types of stories that are told and by whom, and the contexts within organizations that enable the patient voice not only to be heard through their stories but also acted upon. Considering the rising popularity of using patient stories, and in order to maximize their potential for learning and improvement, we need to better understand how patient stories are used in purposeful ways. In essence, we need to understand what makes patient stories live and breathe within healthcare organizations.

Thus, the overall aim of this dissertation is to explore the use of patient stories in healthcare organizations that are known to be leaders in the systematic and deliberate use of patient stories for learning and improvement. In particular, guided by the following objectives, this work sought to explore and better understand:

- the types of patient stories that are told in these organizations and for what purposes;
- the storytellers within these organizations and in whose interests the stories are told;
- the contexts within these organizations that enables the use of patient stories;
- the impact that patient stories have had on organizational learning and quality improvement.

Background and context for storytelling in healthcare

Improving the patient experience of care is a high priority in many healthcare jurisdictions worldwide. Recent healthcare reports released in provincial jurisdictions across Canada and internationally speak of healthcare systems that are “patient-led,” “patient-centred” and “patient-focused,” and of the need for increased engagement of patients, not only in their own care, but also in the planning and design of the services delivered (see British Columbia Ministry of Health, 2007; Department of Health, 2012; Ontario Ministry of Health and Long-Term Care, 2015; Saskatchewan Ministry of Health, 2009). Patients are privileged witnesses of events because they are the single consistent person with experience across the entire spectrum of care. While their expertise may not be specific to the technical and clinical issues, they do observe and experience the human interactions in which care is provided (Coulter, Davies, Koutantji, & Vincent, 2005). Obtaining patient feedback of care and services has long been recognized as a valuable means of informing improvement initiatives for service quality and safety (Davies & Cleary, 2005; Tasa, Baker, & Murray, 1996; Wensing & Grol, 1998). This potential knowledge and insight of the patient (and family) represents a ‘knowledge reservoir’ (Argote & Ingram, 2000; McGrath & Argote, 2001) which to date has been an under-developed resource in healthcare (Coulter et al., 2005;

Vincent & Coulter, 2002). As a result, many organizations have become more attentive to their repertoire of listening posts, ways in which they elicit patient feedback and the experience of their care through both quantitative and qualitative means, such as patient experience and satisfaction surveys, focus groups or interviews, complaint and compliment letters, patient diaries, and leadership walkabouts. Real-time methods of collecting patient feedback are becoming more popular, with innovative methods such as handheld devices, bedside terminals and patient feedback kiosks increasingly being used in hospitals (Department of Health, 2009). While these varying sources of information provide insight into the needs and expectations of patients, organizations continue to struggle to learn from these experiences, to be able to routinely and systematically synthesize this information, and to translate it into knowledge that can be used to drive improvement efforts that will enhance the patient experience of care (Jenkinson, Coulter, Bruster, Richards, & Chandola, 2002; Robert & Cornwell, 2013; Robert et al., 2015).

Bate and Robert (2006) suggest that there is a continuum of patient influence: from complaining to giving information; to listening and responding; to consulting and advising; to the full engagement of patients through methods such as experience-based co-design (EBCD). Similarly, patient engagement models (see Carman et al., 2013; International Association for Public Participation, 2007) also highlight a continuum of patient (and public) participation (e.g., consultation, involvement, partnership and shared leadership) that occurs at micro (e.g., individual or direct level of care), meso (e.g., program or organizational level), and macro (e.g., policy-making) levels. As these models suggest, to maximize the potential of patient involvement, organizations need to move along the continuum to respond to what they have heard, and engage patients more fully as consultants, advisors, and co-designers of care. Developing specific roles for patients as advisors or representatives has helped

organizations move toward involvement and partnership modes of engagement, with patients serving as advisors on a variety of program or organizational committees (e.g., those tasked with governance, quality and safety, service redesign, educational activities) and on interview panels for new staff and leaders. These strategies look to involve patients beyond tokenistic levels in order to partner more with patients on decision-making activities.

The task of translating the needs and expectations of patients into learning and improvements is extremely complex (Davies & Cleary, 2005). From case studies of healthcare organizations that model a patient-centred approach, we know that engaging patients and responding to their input requires an organizational context that values patient involvement and a culture that expects to hear the voice of the patient as their way of doing business. Strong and visible support for the value of the patient experience is needed from senior leadership, a commitment that is consistently seen in the organizational strategy and resources dedicated to improvement and learning (Shaller & Darby, 2009). According to the *Seven leadership leverage points for organizational-level improvements*, Reinertsen and colleagues (2008) state that putting patients in a position of real power and influence, using their wisdom and experience to identify, inform, and redesign care to improve processes and systems is the most important force for driving change that is patient-focused and has the greatest potential for long-term transformation of the healthcare system.

Similarly, Balik (2011) also speaks of organizations moving through a continuum of “doing to”, “doing for”, with the goal of “doing with” as true partners in care, and in the design of systems of care. In order to do so, Balik and colleagues speak of five main drivers that help to create exceptional patient and family experience of care: strong and visible leadership for patient-centred care; hearts and minds of staff who are fully engaged; development of respectful partnerships; reliable care; and evidence-based care (Balik,

Conway, Zipperer, & Watson, 2011). Organizations that have been focused on the needs of patients and their experiences have had positive associations with decreased readmission rates, decreased rates of healthcare-acquired infections, improved delivery of preventive care services, reduced lengths of stay, improved adherence to treatment, improved functional status, higher patient and staff satisfaction, increased staff retention, and overall improved technical quality and safety (Australian Commission on Safety and Quality in Healthcare, 2011; Doyle, Lennox, & Bell, 2013).

In a current healthcare climate that demands more attention to the patient experience of care, organizations have been actively seeking ways to not only better understand the patient experience, but also to involve them patients in more robust ways both within their care and at organizational and systems levels of care. Patients and their stories are one way that they may be engaged, to better understand their experiences of illness and care, and to put them at the “heart of care” (Patient Voices, 2004). Patient stories make a significant contribution to not only understanding the patient experience, but acknowledging the patient’s own areas of expertise (Gabriel, 2004; Greenhalgh, Russell, & Swinglehurst, 2005).

Why patient stories? The capacity of stories

Stories hold the key to humanizing health services. In a field of practice criticized for the many ways it can dehumanize and detach, storytelling in healthcare helps to personalize and connect. (Bate, 2004, p.68)

The tradition of storytelling is not new. Storytelling extends across time and cultures of the world, and is a uniting and defining component of all communities. To create narratives about our lives is a way of seeking and passing on knowledge, creating understanding and coming to know who we are (Connect 4 Cymru Health Reconfiguration

Group, 2008; Snowden, 1999). Stories, and the metaphors they contain, can provide a new language for new forms of understanding, and they can act as a starting point for ongoing discussion, interpretation, and idea generation about the experiences, problems, needs, and practices perceived in the story (Snowden, 1999). In essence, stories are a way for us to make sense of our worlds (Gabriel, 2004).

The work of sociologist Arthur Frank (2010) and Trisha Greenhalgh and Brian Hurwitz (1998) show the capacity of stories and their immense potential within healthcare. Stories provide a means of tapping into the human experience and sharing it. Stories have the capacity to make sense of this experience: structuring devices of time and plot retrospectively align events and actions that may modify mental schemas. A story tells us something of those involved, not only through what they do, but also through their reasons for acting. In this way, stories provide an ethical dimension that informs people's inherent sense of right and wrong—of how to act and how not to act—thereby providing some sort of morality. Stories depict both acts and omissions, reflecting society's expectations about issues such as what a “good doctor” or a “good patient” should do in certain circumstances. Stories allow us to consider “what if” scenarios, and they engage us to think of different plausible outcomes. Stories also have the capacity to act in ways that tellers did not anticipate, producing moments of insight that inspire people to action, often making the unseen not only visible but compelling. Stories can inspire the imaginations of listeners to consider how the past might have gone differently and if the future is open to any possibility. Stories have the capacity to present events in ways that are open to interpretation, evoking different responses to—and uses for—the story. As Frank (2010) explains, “the story takes on a life of its own and it travels from person to person and it takes a different shape, but there's something the same...each person interprets slightly differently and yet it's really amazing how some

stories will persist” (p. 39). Stories work within a social context and may echo other stories, adding force to the present story. We need to consider each patient story individually, but we also must situate them within the larger context and among other stories in order to guide action.

While the capacities of stories are significant, their subjectivity puts them at odds with the evidence-based world of healthcare and the search for an objective, generalizable truth. But it is this very subjectivity of stories that is actually their strength: stories are not gathered because they are assumed to be objective, accurate, or verifiable, but because they are uniquely human and subjective, describing not a fact or a reality, but a recalled experience (Bate, 2004). In general, academic conventions have constrained, rather than enabled, the representation of subjective experience. However, qualitative methods—and more recently, the use of patient narratives—increasingly have been recognized as valuable tools for better understanding phenomena, particularly within the complex social environment of healthcare (Greenhalgh, 1999). Indeed, stories are a social act between the teller and listener(s), situated in the social and cultural milieu in which people live, which Frank (2010) describes as “our interpretive communities” that ultimately affect the experience and how stories are constructed and shared.

Stories and narratives

Many definitions for stories and narratives exist. A commonly cited narrative structure for stories has been proposed by Labov and Waletzky (1997), which consists of six components: (1) an abstract (how does it begin?; this alerts the audience to the story and potentially suggests its genre); (2) the orientation (who/what does it involve, and

where/when?); (3) the plot or complicating event (and then what happens?); (4) the resolution (what finally happened?); (5) the evaluation (so what?; the storyteller expresses some attitude toward what has happened); and (6) the coda (marks the end of the story; what does it all mean?). Frank (2010), however, notes that although most actual stories are built from this narrative structure, they are not fully formed narratives; some stages are missing or out of order.

One organizational studies scholar, Yiannis Gabriel (2004), defines narratives as particular types of text that involve temporal chains of interrelated events or actions, undertaken by characters. Stories are narratives with plots that “knit events together,” allowing us to understand the deeper significance of an event in the light of others. In particular, stories are able to articulate and communicate facts as experience, not as information. The link between stories and experience is of the greatest significance, since different people may experience the same events in very different ways; alternatively, they may experience very different events in the same ways. Experience is shaped by emotions, desire, perception, and interest, all of which have a direct bearing on the stories we tell and our responses to the stories we hear (or refuse to hear) (Gabriel, 2004).

For the purposes of this dissertation, while the terms “narrative” and “story” are used interchangeably, I subscribe to Gabriel’s description, which strongly links the notion of story to that of experience (in this case, the experience of patients).

Overview of chapters

This introductory chapter has framed the research area of concern for this dissertation, provided the background and context for storytelling within healthcare organizations, and

thus, the importance of better understanding how we may maximize the potential of patient stories for learning and improvement.

In Chapters 2 and 3, I begin the scholarly conversation by situating the use of patient stories within the healthcare literature and the literature of organizational learning and change. The review of the literature provides the current state of knowledge of storytelling in healthcare, thereby allowing me to situate my dissertation at the juncture where I note fissures in the literature. In Chapter 3, I provide a theoretical frame for this study, drawing from the work of scholars in the areas of sociology and organizational learning to consider the co-construction of stories for learning within these healthcare organizations.

Chapter 4 describes the methodological approach to this study, congruent with the theoretical frame. I describe in detail the methods and analytical techniques used in the interpretation of results, as well as the reflective practice and my positionality throughout this study.

Chapters 5, 6, and 7 constitute the key findings from this study and they are set in the analytic frame described in Chapter 4. In Chapter 5, I describe the stories told within these organizations, stories that are co-constructed between the teller and listener to become quest narratives for learning and improvement. While many types of stories exist in these organizations, quest stories are those where learning is most evident. In Chapter 6, I focus on the storytellers, that is, who tell the stories and the intended (and perhaps unintended) purposes that these stories serve. While the focus of this study has been on patient stories, the storytellers represent not only patients and family members, but also organizational leaders who tell stories *of* patients. In this chapter, I closely examine the storytellers chosen to tell their stories and consider who they represent and their identities as patients. Chapter 7 focuses on the context in which patient stories are told, that is, the organizational context that

allows stories to live and breathe. In particular, I examine the enabling culture that supports the use of patient stories, the structures and processes these organizations have developed to fully capitalize on the stories told, and the leadership required to support these storytelling efforts and the inclusion of patients at all levels of the organization.

Chapter 8 brings together the key learnings from this study, with considerations of their limitations. I discuss the underlying tensions that emerged in the use of patient stories, which have been co-constructed for specific purposes and intent. Lastly, I explore the implications that these findings have on the practice of using patient stories for learning and improvement, and how these findings have contributed to the theoretical and empirical literature. I conclude with potential future directions for a program of research in this area. The prologue and epilogue bring together the concepts of what was learned through this dissertation, highlighting a patient story shared in this study.

Chapter 2

Review of the Literature

Life has no meaning that exists independently of the stories told about it. (Greenhalgh & Hurwitz, 1998, p. 4)

The aim of this chapter is to provide a broad orientation to the vast amount of literature that touches upon stories and storytelling within healthcare, focusing the scholarly conversation specifically on how healthcare organizations have learned from patient stories. The breadth of narrative and storytelling is immense in the literature, and rightly so, as stories touch all facets of human life. Stories have a rich history in the arts, literature, history, anthropology, business, social sciences, and more recently, in medicine and healthcare. Interestingly, stories have generally not been viewed favorably by adherents of evidence-based medicine. Seen as “anecdotal,” Erikson (1995) claimed that “stories, in particular, haven’t been discussed much because they aren’t...well stories aren’t very respectable....stories are subjective....stories are ambiguous....stories are particular....they are at odds with the scientific drive toward objective, generalizable, respectable findings” (in Bate & Robert, 2007, p. 64). Similarly, Neumann (1996) argued that “academic conventions have constrained rather than enabled the representation of subjective experience” (in Bate and Robert, 2007, p. 64). However, stories are now increasingly used (even encouraged) in healthcare because they are a natural way to access the human experience, an experience that is indeed unique and subjective: “In a field of practice criticized for the many ways it can dehumanize and detach, storytelling in healthcare helps to personalize and connect” (Bate and Robert, 2007, p. 69).

Broadly speaking, the focus of patient stories found in the healthcare literature falls into two main areas: stories that depict experiences of illness, and those that depict experiences of care. The stories themselves serve a myriad of purposes, regardless of their focus on illness or care. I will begin this chapter with a brief examination of the literature regarding patient stories of illness and how these stories of illness are used for peer support and patient education, particularly for the education of health professionals and students. This literature helps us to understand how stories are vehicles for learning, and how this learning is translated at the individual level. However, for the purposes of this study, I focus on patient stories of experiences of care used to better understand and improve this experience. Well-described methods such as discovery interviews and EBCD, offer structured ways to use stories of experience to improve care and services. The stories of experience speak to the use of stories specifically with a focus on improvement, which acts as an explicit expression of learning within organizations. The organization learning literature highlights how stories are a way to make sense of organizational life and enable change processes and knowledge management. Through this literature, we also see how stories serve many purposes, and how these stories may be appropriated by others for their own purposes. Analysis of this literature has been instructive in helping to focus my study, leading me to the study objectives, which I re-articulate at the end of this chapter.

Patient stories of illness

Detailed ethnographic methods have produced extensive narrative works and life histories that give meaning to patient experience, shedding light on the experience of illness through the eyes of those affected. Chronicles of living with illness—such as chronic or life-

threatening disease, mental illness and end-of-life care—are readily found in the literature (for example, see Ellis & Bochner, 1996; Greenhalgh & Hurwitz, 1998), and provide us with a deeper understanding of the lived experiences of these individuals, helping us to see through their eyes and instill in us a greater sense of empathy.

With the explosion of social media over the past decade, there is a growing opportunity for everyone to post experiences of any facet of their lives, including their experiences of illness. A quick scan of healthcare organizations in North America and the United Kingdom, as well as disease-specific organizations and support groups, offers a plethora of patient experiences of living with disease and illness that have been posted as written narratives or video stories. The Database of Individual Patient Experience (DIPEX) provides an example of the systematic gathering of narratives of patient experiences worldwide. Developed in the United Kingdom, DIPEX was intended for use alongside the Cochrane Database of Systematic Reviews (Greenhalgh, 1999). DIPEX International was founded to promote the worldwide collection of patient narratives to better understand people's health experiences for the benefit of patients, their families and carers, healthcare providers, leaders, policy-makers and researchers. To gather patient narratives, members of DIPEX International use a qualitative research methodology developed at the University of Oxford. The results of the research are published on dedicated websites in the member countries, showing multimedia clips of people (patients or caregivers) talking about personal health experiences on a range of subjects, such as diagnosis, consultation with professionals, treatment decisions, and the effects on work, social life and relationships. In Canada, a DIPEX group was founded in 2010; it is currently housed at St. Mary's Hospital in Montreal,

Quebec.² To date, the Canadian group has created modules of experiences related to caregiving, and it is currently working on narratives related to breast cancer.

The Canadian Partnership against Cancer, in partnership with the Health Design Lab at the Li Ka Shing Knowledge Institute in Toronto, Ontario, offer another example of formal narratives that have been produced and widely available through a number of sources. In this series of stories entitled “The Truth of It: Unscripted Stories of Cancer,” cancer survivors speak of their experience living with cancer and their journeys through the healthcare system.³ This series is disseminated in a number of settings (e.g., cancer clinics and community agencies), and through a variety of media (e.g., YouTube and Twitter), reflecting the different ways patients access information. These stories were developed with the specific purpose of educating healthcare professionals and patients with cancer and their families; educational modules are provided with the video vignettes to facilitate their use.

Sharing stories of illness helps people to compare their experiences with those of others, informs patients about how others may be feeling and confirms that they are not alone in their experience (Swift & Dieppe, 2005). These stories act as a source of information and advice, and they can give tellers and listeners feelings of recognition, appreciation and understanding (Wachters-Kaufman, 2000). Frank (1995) suggests that the content of illness stories is valuable for a number of reasons, such as “for the teller’s reordering of her life story, as guidance to others who follow, and to provide caregivers with an understanding of what the ill experience” (p. 140).

In the section that follows, I will briefly outline how these stories of illness have contributed to the education of healthcare professionals and students, education that focuses

² See www.healthexperiences.ca.

³ See www.cancerview.ca/thetruthofit.

on individual learning that may have bearing on how multi-level learning occurs in organizations.

Patient stories for the education of healthcare professionals and students

Illness narratives help to elucidate a person's experience of illness and, in doing so, provide a powerful mechanism for teaching patient-centred care to healthcare professionals and students to "bridge the gap between *knowing* the facts about the disease and understanding the patient's illness experience" [emphasis original] (Squier, 1998 in Kuper, 2006, p. s130). Dr. Rita Charon of Columbia University in New York has been a leader in this area of "narrative medicine," exploring the use of stories from patients, physicians, and other healthcare professionals that help humanize healthcare, highlighting the art of medicine as a caring, healing profession (Charon, 2006). Entire courses are offered in narrative medicine that feature stories and storytelling as a central feature.⁴ These tenets have spread to other medical and health professional programs across North America, such as the Family Centred Care Program at the University of Michigan, University of British Columbia's "Patient and Community Voices" program, and the Narrative Medicine Initiative at the University of Western Ontario.

Specific to the education of healthcare professional students, this literature points to many ways that patients are involved in education beyond sharing their experiences of illness and care. Patients have been involved in creating learning materials for students, as standardized or simulated patients, and as teachers and assessors of clinical skills, particularly communication. Students have identified how hearing about patients' lived experiences has created opportunities for experiential learning, providing the most impact to enrich their lecture-based biomedical learning (Oswald, Czupryn, Wiseman, & Snell, 2014).

⁴ For example, see the Program of Narrative Medicine at Columbia University (www.narrativemedicine.org).

Through patient stories, students appear to gain greater awareness of the needs of vulnerable populations, and previous opinions on chronic conditions, senior care, mental illness, and the importance of family involvement in care have changed as patient educators have interacted and addressed these issues with students (Towle, Bainbridge, Godolphin, Katz, & Kline, 2010). Similarly, work by Gidman (2013) suggests that discussions between patients and students who have opportunities to hear and explore the patients' experiences allow students to actively participate in dialogue (rather than being passive recipients of stories).

Technology also has allowed the broad dissemination of stories to be used for education purposes, and small-scale assessments have indicated that digital storytelling has been a positive way of providing students with greater insight into the experiences of patients and illness. However, these stories may have greater impact if they are supplemented with online discussion between patients and students, thus further enhancing the development of students' understanding, insight, and empathy (Terry, 2012).

Kumagai (2008) echoes this need to not only share the story, but to use it to generate “intentional dialogue”. Such dialogues require students to engage their whole selves—life experience, background, personal values, beliefs and perspectives—in exchanges with patients. According to Kumagai and Naidu (2015), “dialogues allow for the inclusion of affective and experiential dimensions in addition to intellectual/cognitive domains in learning, and for an emphasis on discovering new perspectives, insights, and questions instead of limiting participants solely to an instrumental search for solutions” (p. 283). The use of narratives in medical education has been grounded in theories of moral development and empathy that bring together cognitive and affective stages of development. Kumagai (2008) describes three ways that patient stories facilitate the development of empathy in physicians-in-training:

1. Narratives allow students to appreciate what it is like to experience an illness and help to develop an interpersonal link in affective, cognitive, and experiential domains, particularly when they are delivered face-to-face. By contrast, medically-based written scenarios, where there is no patient interaction, actually may dehumanize the patient and minimize observers' appreciation of the patients' experiences and suffering (Kenny & Beagan, 2004).
2. Narratives help communicate meaning by triggering fundamental emotional responses such as loss, anger, jealousy, guilt and sadness. This may arouse a sense of urgency in the learners to explore the causes of the patients' suffering beyond the medical domain, and to consider moral dilemmas, inequality and social justice.
3. Narratives allow learners to identify more closely with the patient. If the ideas and beliefs expressed by the patient are not congruent with their own, there may be a dissonance in terms of emotions or cognition, essentially creating a "cognitive disequilibrium" as described by Piaget (1985). This cognitive disequilibrium then stimulates critical self-reflection on one's own values and attitudes, leading to transformative learning (Merizow, 1997).

Stories do not teach empathy; rather, stories and the ensuing dialogues engage learners in different ways of thinking and knowing through these multiple domains of cognition, affect, and experience. The Family Centred Care Program at the University of Michigan, developed and lead by Dr. Kumagai (2008), creates opportunities for these intentional dialogues between patients and students.

This literature is instructive in that it demonstrates how stories are linked to moral development and empathy, and how they can influence learning in cognitive, affective, and experiential domains that can in turn lead to transformative learning. What is unclear is if this

learning is translated into behaviour and practice changes as student learners transition into their professional roles, and more generally, in individual healthcare providers. In the next sections of this chapter, I will explore patient stories as they relate to experiences of care, and how these stories impact beyond the individual level of learning, and how they influence learning at the organizational level, to enhance the patient's experience of care.

Patient stories of experiences of care

New studies on understanding the patient experience of care and its impact on improving service delivery and the patient experience offer particularly relevant insights. Entwined in the experience of illness are episodes of care; these patient experiences often are prompted by organizations (e.g., through surveys or patient interviews) or by patients themselves (e.g., through compliments and complaints). Increasingly, patient stories that highlight the patient experience of care have provided impetus for improvement efforts by individuals, within teams and organizations, and at the policy level. While patient surveys provide similar improvement priorities as those identified in stories, survey methods tend to emphasize the functional aspects of care, but without the details needed to identify specific improvement activities (Tsianakas et al., 2012). Patient stories, on the other hand, help to provide depth, and reveal more of the relational aspects of the patient experience, which patients appear more attentive to, more so than the technical or functional aspects of care (Hsu & McCormack, 2011). Thus, survey data may be better suited to act as a screening tool to identify problems; patient narratives can then delve into issues and elicit more details to guide next steps for service improvement, as well as potential solutions (Tsianakas et al., 2012).

Patient complaints also provide a valuable way of identifying safety and quality issues, and they form another source of patient stories. Patient complaints are often “expressions of grievance” and “disputes within a healthcare setting” (Reader, Gillespie, & Roberts, 2014, p. 679), and they are typically conveyed in formal letters written to healthcare organizations by patients or family members to express their dissatisfaction with care. Healthcare organizations generally have a role such as a Patient Relations Officer or Patient Ombudsman who deals with such complaints, initiating discussions with those involved, further investigating the issue and coming to some form of resolution for the individual patient (e.g., an apology, rejection, or compensation). Historically, there has been considerable variation in how patient complaints are categorized, resulting in complaint data that is unstandardized and difficult to compare within and across organizations. Lack of standardization also makes it difficult to demonstrate links between complaints and potential causes. Based on a systematic review of the literature, Reader et al. (2014) propose a taxonomy of patient complaints that includes three key domains: (1) complaints related to the safety and quality of clinical care, (2) management of healthcare organizations, and (3) problems in staff–patient relationships. While patient complaints have been identified as a valuable resource for monitoring safety (Reader et al., 2014) and managing risk (Hickson & Pichert, 2002), there is little in the literature to demonstrate how patient complaints are systematically used to drive quality improvement or organizational learning within healthcare institutions beyond their individual resolution (Hsieh, 2010). National reporting systems, such as those implemented in the United Kingdom and Australia, have made some attempts at the national policy level to link patient complaint management to national quality management systems (Hsieh, 2011).

As noted previously, video stories have proliferated on the Internet, where patients share not only their stories of illness and disease, but also their experiences of care within the health system. Like DIPEX and the Canadian Partnership Against Cancer, the Pilgrim Project in the United Kingdom showcases a number of stories—not only of illness, but also of the experience of care from the perspective of patients, caregivers, and health providers. The “Patient Voices” program within the Pilgrim Project has created a series of digital stories that are meant to provide learning opportunities for healthcare professionals and leaders to better understand the needs of patients and reinforce the notion of “patients at the heart of care.”⁵ Similarly, organizations like Patients for Patient Safety Canada (within the Canadian Patient Safety Institute) have created a series of video stories that represent numerous patient safety issues—some with tragic outcomes—and the impacts these errors have had on the patients and their loved ones.⁶ However, as is the case for other digital stories, little exists in the literature regarding their impact more broadly, beyond the immediate emotional response that they elicit.

Like stories of illness, patient stories of experiences of care—particularly those stories of care gone wrong—are well suited for narrative-based teaching. Stories that depict lapses in safety allow for the exploration of factors that contribute to errors, have the potential to increase awareness of the personal impact of such errors on patients and families, and facilitate a wider discussion of safety issues. Jha et al. (2014) conducted a randomized controlled trial on the implementation of patient stories in patient safety curriculum of medical trainees, comparing the impact on attitudes and affect between groups of students who heard patient stories of harm, and those who received training only from medical

⁵ See www.patientvoices.org.uk.

⁶ See www.patientsforpatientsafety.ca.

faculty. While they found no evidence of difference between the two groups in post-intervention scores on the Attitude to Patient Safety Questionnaire, there was a statistically significant difference in both post-positive and post-negative affect scores between the groups, with indications of both higher positive and negative affect scores in the group that heard from, and interacted with, patients. The control group put greater focus on the technical aspects of risk management as they relate to organizational factors and policy, and less on the communication and emotional aspects of the patient incidents. Hearing real stories of patient safety tended to trigger strong emotional responses in students, which in turn facilitated greater empathy and engagement with (and better retention of) the learning messages. The literature points to the influence of attitudes on behaviour, either directly through affect (short-term likes and dislikes) or indirectly through cognitive changes in behaviour (Jha et al., 2014). However, the challenge of much of this work on stories and storytelling lies in being able to demonstrate and evaluate changes in behaviour that have resulted.

Like patient stories used for student learning, stories also are used for healthcare professional learning within organizations. For example, patient and family advisors often are included in hospital orientation and other staff education initiatives. In these sessions, advisors provide education to help staff link principles of patient- and family-centred care to experiences of care (Smith & Greenhalgh, 2011). Advisors generally draw on narrative approaches to share their experiences of care, and as a way of challenging the views of professionals about the quality of services and how services are delivered to patients. Similar to education of health professional students, embedding patients as teachers of healthcare providers also can change the dynamic between patient-provider roles, allowing patients to be seen not as passive recipients of care, but rather as experts by experience and as active partners in learning and teaching (Smith & Greenhalgh, 2011). This interaction combines the

experiential knowledge of the patient with the technical expertise of the professional, where both are seen as experts in their own domains (Health Foundation, 2011).

In the domain of healthcare, physicians have traditionally occupied an elevated status in concert with scientific discoveries (e.g., vaccines, x-rays) that strengthened the professional status of medicine, with physicians seen as experts granted power and authority (Roberts, 1999). Initially noted by Parsons (1951) in his book *The Social System*, he describes the “sick role, where patients are passive and relinquish control to the competent physician who has full responsibility and control for their health, thereby creating a dichotomy of the expert–lay person and its related power structures. While this vision has waned over the past decades, vestiges of the ‘expert-lay person’ model continue to exist, and with it, the professionalized power of those with expertise and those without remains (Roberts, 1999). The use of patient narratives in examples described above, however, draws attention to the expertise the patient brings of their own illness, thus creating a more balanced expert–expert dyad to share power and responsibility for care. While much has been written about physician–patient relations, particularly with respect to communication and decision-making (for example, see Elwyn, Edwards, Kinnersley, & Grol, 2000; Stewart, 1995), there also is literature that discusses the evolution of professions in general, highlighting the conflict and strain between professions that is triggered by gender and social class issues, and the demarcation of professional boundaries (Hall, 2005). The recent focus on interprofessional education and collaboration looks to reorient the traditional hierarchical power structure of the physician in control (Hall, 2005). Paradoxically, Kuper & Whitehead (2012) suggest that the current discourse in interprofessional education may actually be perpetuating the status quo of physicians’ professional power. Advocates of a more patient-centred approach see the patient at the centre of these interprofessional teams, with their own

expertise and knowledge. The use of patient stories is one way to tap into this experiential expertise, to foster collaboration and partnership.

In a study by Blickem and Priyadharshini (2007), stories are shown to help unveil many taken-for-granted assumptions about professional and institutional power, thus helping staff reshape their practices. Blickem and Priyadharshini (2007) created patient narratives from a series of interviews with different patients, amalgamating various issues raised into one common narrative. These reconstructed narratives were shared in writing with an interprofessional team as a means of engaging them in group discussions to raise greater awareness of patient-centred care. The narratives were framed in the first person to induce an affective understanding in order to tap into values, morals, feelings, and emotions, rather than the cognitive response usually elicited within these professionalized settings. By reflecting on the patient perspective, the narratives raised staff awareness of how patients were often pitted against professionals in daily interactions. Patient stories that cut across the continuum of care and across organizational boundaries, job descriptions, and professional routines allowed providers to see the wider patient experience and the journey of care over time and location; it also redirected their attention towards the workings of their own interprofessional teams. Blickem and Priyadharshini (2007) advocate the need for a reflective approach taken in this study that provides professionals with the opportunity to engage in intentional dialogue with the team and reflect on and recognize the complexity and ambiguity of perspectives, the underlying values and assumptions about care, and the challenges to patient-centred practices.

Patient experiences of care linked to quality improvement

From the literature, I highlight two structured methods for gathering and using patient stories to facilitate quality improvement. These two strategies, “discovery interviews” and

EBCD, were first developed and introduced in the United Kingdom as a means in which to systematically put patient stories and storytelling at the heart of improvement efforts at the national level.

Discovery interviews

Discovery interviews aim to put the patient at the centre of care by using specific interviewing techniques for listening to patients and their caregivers, and then using their narratives to improve care based on an understanding of the experience (Wilcock et al., 2003). A key aspect of discovery interviews is that patients and their caregivers are encouraged to tell their stories with a focus on the impact of illness on their lives, giving them control to take the story in directions of their choosing, rather than answering specific questions about the services they have received. The aim is to create opportunities for patients and their caregivers to provide information that is not constrained by thinking inside the box that is based on previous experiences of care.

The discovery interviews are gathered by trained interviewers within Local Health Trusts. Once the stories have been gathered, the interprofessional care team listen to the interview (via audiotape) or read the transcript; this serves as a launching point for further discussion and linking what they learn with their own professional knowledge and experience. Together, these experiences are meant to shape future quality initiatives.

However, there have been concerns raised regarding the quality of data gathered in discovery interviews and the breadth of their reach, particularly as the use of this technique has spread across the United Kingdom. All interviewers receive training, but a great variation in the quality of interviews has been noted, ranging from a lack of probing of some responses, the brevity and/or lack of depth of interviews, and blurring of the practitioner–patient boundaries. While not meant to be research in the strictest sense, discovery

interviews still require rigorous interview skills in order to gather information, actively listen to the experience of patients, and minimize professional bias. Concerns also have been raised about sampling strategies, particularly about the narrow representation of patients, the number of interviews performed on a service, and whose voice is heard through the interview. A tension exists between discovering what is important to participants in recounting their experience and specifically eliciting patient information for improvement purposes (Bridges & Nicholson, 2008).

While early anecdotal evidence suggests varying impact in service delivery and care resulting from the use of discovery interviews (Wilcock et al., 2003), more recent findings indicate that the connection between the patient stories gathered in discovery interviews, service design, and action or improvement may actually be quite weak. Staff in a cardiac program where discovery interviews were conducted were clearly moved by the stories they heard, and their attitudes toward patients demonstrated some change, but more than half of the staff admitted that there had been no change in their everyday behaviour or actions (CHD Collaborative, 2004). The evaluation concluded that discovery interviews appear to have greater power to change people's perceptions of patients and carers on an individual basis, but do not necessarily lead to individual changes in behaviour. Furthermore, the majority of those interviewed felt that the process had not resulted in changes in care, services, or facilities at the departmental level (55%) or the clinical team level (68%). In fact, 62% of the respondents felt that discovery interviews had had no impact on the use of structured care pathways (CHD Collaborative, 2004).

Thus, telling a moving story may be insufficient to motivate action. Stories may inspire and energize change, but they do not bring about change themselves. Structures are needed to support processes of change and actively engage staff and patients in this change

process. Discovery interviews in their current form—and, it could be argued, other narrative programs as well (e.g. DIPEX, Patient Voices, The Truth of It)—create stories that too often stand alone without any connection to organizational development or service improvement processes. While healthcare providers and patients may learn from them, and indeed be moved by them, the lack of connection to improvement activity potentially renders these stories impotent, as patients are essentially “stories donors” who have no further role in shaping improvements in care (Bate, Robert, & Maher, 2007). Frank (2010) suggests that stories breathe in their “doing”, not just in their “telling”.

Experience-based co-design

Bate and Robert (2006) describe EBCD as extending patient influence and providing the next generation of improvement methods, through which services are co-designed with the patient through storytelling and appreciative inquiry. Three fundamental design science principles are incorporated in EBCD: functionality (whether it fits the purpose), safety (how safe, well-engineered and reliable it is) and usability (how the whole interaction with the product or service feels or is experienced). EBCD gives equal weighting to experience goals of patients and other process and clinical goals. Experience is at the core of the design: the subjective, personal feelings of patients, caregivers, and staff are elicited through storytelling methods, thus highlighting crucial points in care experience that require improvement. Through sharing their stories, participants gain a deep appreciative understanding of the strengths and weaknesses of the current service and what needs to be redesigned for the future. The participatory process of co-design brings together patients and staff to work together to effect sustained improvements in those experiences (Bate & Robert, 2006). Thus, EBCD aims to move beyond simply telling and sharing stories; it provides the structures and

processes to create partnerships between patients and staff to analyze their experiences and implement changes together (Bate & Robert, 2006; Bate et al., 2007).

Since its first pilot in a head and neck cancer service in England in 2005, the implementation of EBCD has been expanded internationally in a number of areas, including cancer care, emergency services, chronically sick adolescents and dementia care. From 2005-2013, 59 EBCD projects have been carried out in six countries (Australia, Canada, England, the Netherlands, New Zealand and Sweden), and a further 27 projects are in the planning stage (Robert et al., 2015). Co-design methods can be slow and resource intensive, taking nine to 12 months per project, with many patients, staff, and leaders involved throughout. Formative evaluation of EBCD has been positive by both patients and staff, with many changes in attitudes, behaviour, and service delivery as a result (Bate et al., 2007). For example, complete redesign has been noted in areas such as sexual health services, resulting in decreased waiting times and the number of visits required, increased respect for privacy concerns and dignity of patients, and improved physical environment of the clinic itself (Baraitser, Pearce, Blake, Collander-Brown, & Ridley, 2005; Pearce, Baraitser, Smith, & Greenhalgh, 2011).

While these changes demonstrate results of a co-design process, perhaps the greatest value of EBCD lies in the partnerships and new understandings that are developed, which lead to deeper, long-term changes in attitudes and behaviours (Robert et al., 2015). As Iedema et al. (2010) explain, the success of EBCD lies in its ability to bring

stakeholders together across previously impervious boundaries, producing new understandings, relationships and engagements. Its challenges reside in these new understandings, relationships, and engagements only becoming possible and only continuing to be relevant if and when stakeholders are prepared to adopt and adapt to the new discourse needed to realize them, implicating them in what has been referred to as the 'design competency spiral'. (Iedema et al., 2010, p.73)

Appropriation of patient stories

Patient stories of experiences of illness and of care serve many purposes, some of which may be unintended. For example, Costa et al. (2012) demonstrate how stories told by mental health users have been employed instrumentally to reinforce current structures rather than to expose them. Costa et al. highlight the commodification of personal stories of lived experiences in mental health that have been used to support research, education, and fundraising to further the interests of institutions rather than their intended purpose of sparking radical movement away from only medical interventions and toward a more comprehensive agenda of respect and inclusion within the broader social milieu. They speak of “disability tourism” where stories of mental health users are commodities to help others sell their products, programs, and services (Costa et al., 2012). Costa et al. (2012) go on to suggest that institutions have coopted the language of social justice itself, using terms such as “resilience” and “recovery” from patient narratives to support their own agenda and maintain their dominant practices. Mental health systems have re-oriented these stories toward so-called “biomedical storytelling”, choosing particular parts of stories that speak to the pursuit of a normal existence, rather than stories as “agents of change”, conveniently omitting parts of stories that challenge how the mental health system functions, issues of systemic poverty and discrimination, and the abysmal lack of choice in services and mistreatment (Costa et al., 2012). Thus, storytellers are challenged to consider in whose interest is their story being told. They are also cautioned to consider the purpose of their stories: are they intended to serve as means to build community or personal resistance, or are they solicited to fit the specific agenda of an institution, organization or agency (Costa et al., 2012)?

Similarly, the work of Waring (2009) also highlights the complexity of narratives in their construction and reconstruction: for whom, and for what purpose, particularly bearing in mind the intricate social and cultural context in which stories are created, and how such stories may be a source of conflict as different groups compete to establish particular constructions of knowledge. In his study, Waring (2009) examines the construction of patient safety incident reports and shows how narratives can overlap and compete as groups negotiate their divergent interpretations, acting as a source of power through informing shared responses, delineating and reinforcing social boundaries, and acting as a vehicle for control. As such, “the narrative perspective is attentive to the links between knowledge and power, recognizing that storytelling can provide a discursive basis for defining social reality, contesting alternate truths and privileging particular forms of social action” (Foucault, 1980, in Waring, 2009, p. 1723).

Fear (2014) provides yet another example of the appropriation of patient stories for professional purposes. As noted previously, campaigns such as “Getting Boards on Board” have advocated the use of stories to win what Balik (2011) calls the “hearts and minds” of senior leaders, and to engage these high-level leaders to become more attentive to issues of quality and safety. Fear (2014) examined the patient stories told at the Local Health Board meetings in the Welsh NHS at the start of the “1000 Lives” campaign, an initiative aimed at improving quality and safety within the Welsh NHS. The program had a number of elements, one of which was the use of patient stories during board meetings as a means to bring about changes in the organization. Patient stories were conceptualized as a learning tool, and similar to the “Getting Boards on Board” campaign in the United States, each board meeting would open its agenda with a patient story. Three documents articulating the nature and use of patient stories are available from the *1000 Lives Campaign: Guidance on the Use of*

Patient Stories (2009), *Patient Stories for Quality Improvement* (2010) and *Learning to Use Patient Stories* (2011). From these documents, the initial intent of stories clearly relates to sharing the experience of the patient, using patient stories to bring about organizational change in culture and services, and to influence decision-making at the board level. However, Fear (2014) notes that over time, the definition of patient story in these guidance documents and board meetings was expanded and changed to incorporate a wider range of content, including stories of staff; this gradually led to a deviation away from the patient experience. Fear (2014) traces through the board meeting minutes how one particular professional group legitimizes their own stories (initially patient stories demonstrating the value of their profession) to reinforce their professional identity as heroic, worthy, and deserving of resources. In this way, the patient story becomes an artifact in its own right, and it is used instrumentally by one professional group to pursue and legitimize their own professional identity and interests.

Overall, the literature demonstrates the growing interest in patient stories. Most recently, stories have been used as vehicles to better understand the patient experience of care, and gathered in deliberate ways for quality improvement and safety. While the intent may be honorable, the examples provided in the section above give us pause for how stories may shift from potentially being agents of change to a commodity that can be taken and used instrumentally for the purposes of others. Many authors suggest the need to engage in intentional dialogue in order to promote critical reflection that can tap into affective, cognitive, and experiential modes of learning. The use of stories as stand-alone vehicles to invoke change appears more susceptible to appropriation and co-optation than when structures and processes exist to further engage patients, staff, and leaders together in dialogue and change activities.

Organizational learning and stories

Since the mid-1960's, the concept of organizational learning has emerged and gained increasing popularity in the management literature (Crossan, Lane, & White, 1999). The release of the Institute of Medicine report in 1999 highlighted evidence of the incidence of adverse events in hospitals, drawing attention to the need for healthcare organizations to better understand these events in order to learn from them (Kohn, Corrigan, & Donaldson, 1999) and from the perspective of patients receiving care (Gallagher, Waterman, Ebers, Fraser, & Levinson, 2003). Organizations are viewed as living entities that are dynamic, organic, and capable of change (Yeo, 2005). In any organic system, learning is vital to the growth and development of the organization. Scholars in the area of organizational learning have taken different foci for learning (e.g., for strategic renewal, informational processing, product innovation), but there is general agreement that organizational learning incorporates multiple levels of learning across individuals, teams, and the organization (Chuang, Ginsburg, & Berta, 2007; Crossan et al., 1999; Easterly-Smith, Crossan, & Nicolini, 2000). Organizational learning is the process of creating, retaining, and transferring knowledge to improve organizational performance and capabilities (Argote, 1999; Fiol & Lyles, 1985). The learning process is a cycle of action and reflection; that is, doing and thinking, performing and conversing. Organizations learn by institutionalizing individual learning into team and organizational routines and processes (Carroll & Edmondson, 2002). Within the healthcare literature, there has been much recent focus on organizational learning for quality improvement and learning from adverse events (Edmondson, 2004; Jeffs, Berta, Lingard, & Baker, 2012; Weingart et al., 2005). Cyert and March (1992) suggest that changes in individual, group, and organizational behaviour are based on outcomes of their previous

experience. Thus, unsatisfactory outcomes (such as those noted in adverse events) may be important drivers for learning (Miner, Kim, Holzinger, & Haunschild, 1999). In relation to patient safety, failures in care may draw attention to roots of problems and potential solutions, and modify procedures. Thus, healthcare organizations develop knowledge and capabilities to reduce the occurrence of similar events, ultimately improving patient safety (Chuang et al., 2007). Edmondson (2004) suggests that an important part of learning from failure in complex systems such as hospitals is attention to small, everyday process failures, rather than just sentinel events and formal investigations. If these small failures are detected and addressed, they may help to avoid consequential failures in the future (Sitkin, 1996).

The notion that healthcare organizations should learn from failures—small and large, their own and those of others—has obvious appeal. Yet healthcare organizations that systematically and effectively learn from failures occurring in the care delivery process are rare (Edmondson, 1999). Edmondson suggests that a number of pervasive barriers are embedded in healthcare’s organizational systems, making shared or organizational learning from failure difficult. For example, an interpersonal climate that promotes open and honest discussions enables learning across all levels. Tucker and Edmondson (2003) found that people tacitly assess the interpersonal climate in which they work and that these assessments profoundly affect behaviour (such as the discussion and analysis of mistakes and problems), behaviour that is integral to organizational learning. In their study, they noted wide variation in the social environments across units, influenced by the nurse managers and their leadership styles. Of particular note is the concept of “psychological safety,” a term coined by Edmondson (1999) to refer to a climate where the risk that staff perceive as being associated with openly discussing issues is minimized. Leaders help to create environments of psychological safety so that staff members are comfortable engaging in open discussions

that support learning from error. Similarly, teams that are able to discuss their experiences openly learned faster than those teams (with equal experience) that did not, particularly when team members felt valued and recognized for the role and contribution they had in the learning effort (Pisano, Bohmer, & Edmondson, 2001). Leaders also must empower and support team learning throughout their organizations as a way of identifying, analyzing and removing hazards that threaten patient safety (Edmondson, 2004).

Tucker and Edmondson (2003) note healthcare's emphasis on individual vigilance encourages healthcare professionals to take personal responsibility for solving problems as they arise, which in turn creates a barrier to organizational learning. In their study, Tucker and Edmondson highlight the frequency of problems encountered in everyday life within the hospital that make it difficult for nurses to track these many problems to their root causes. They found that nurses were allowed—even encouraged—to resolve problems alone, without having to consider the impact on the system. Ironically, those behavioural norms (which encourage independence and workarounds) do so at the expense of system learning, discouraging involving others in problem solving. While nurses created quick fixes and workarounds that allowed them to continue with their work, the quick resolution of problems negates any opportunity for collective learning. These workarounds constitute first order problem solving: an immediate solution is found but it does nothing to alter the chances of the problem's recurrence. By contrast, second order problem solving involves more concerted effort to assess what went wrong and why, and to implement changes accordingly.

Edmondson (2004) emphasizes the critical role of leadership in overcoming these barriers. She suggests that leaders must create a compelling vision that motivates and communicates urgency for change. In Peter Senge's bestseller on the learning organization, *The Fifth Discipline* (1990), he provides a simple, coherent structure to coach leaders in five

inter-related disciplines that build a learning organization. One of the disciplines requires leaders to develop a shared vision of the future, one that fosters genuine commitment and enrolment rather than compliance, in order to help focus and energize staff. Particularly in the area of patient safety, stories are seen as powerful vehicles for putting a face on errors and reinforcing a culture of safety. Stories may be the impetus to mobilize people's internal energies and drivers for change (i.e., putting a face to change) rather than on the metrics and measurement, technical systems, and process design side of quality improvement.

Much has been written about the role that stories have in developing this shared vision, inspiring staff and leaders, galvanizing people in collective efforts, and building an organizational culture, by prominent management authors such as Stephen Denning who has written many books that guide leaders in the art of storytelling (for example, see *The Springboard: How Storytelling Ignites Action in Knowledge-Era Organizations*, 2011; *The Leader's Guide to Storytelling: Mastering the Art and Discipline of Business Narrative*, 2005). Stories have the ability to communicate complex meaning and reinforce common values, particularly if the story self-propagates throughout the organization to reinforce organizational culture and values. The story of Betsy Lehmann at the Dana Farber Cancer Institute is a prime example of a story that has acted as a lightning rod for change. This very public story of a 40 year-old Boston Globe health reporter who died of an accidental chemotherapy overdose has epitomized the power of a story as a unifying force that has inspired a transformational shift of culture, and it set Dana Farber on a course that has put a focus on the patient and their involvement at all levels of the organization (Conway, 2008).

Bate (2004) attributes the use of stories and storytelling to the ability of the 'Modernization team' not only to create a compelling vision for the future, but also to manage successfully a massive change initiative in a large hospital in the United Kingdom. In

essence, stories are sense-making devices, helping infuse events with meaning, and they allow us to process our experiences, communicate them to others, and rearrange them within larger narratives of identity and selfhood (Gabriel, 2004). Bate (2004) describes four types of narratives that emerged at different stages throughout the change journey (from conception and the development of purpose, through to implementation). These four narratives are as follows:

1. the personal narrative, which helped build personal awareness of one's place along the journey and an understanding of the change process itself, particularly as the team was starting out;
2. the communal narrative, which helped participants become aware of alternative perspectives and overlapping values, aims, and purposes to finding a common voice, merging personal and collective identities to build a community of practice;
3. the counter-narrative, in which the present status was critiqued and a call to action was made with the creation of a new common vision; and
4. the mobilizing narrative, in which this vision was translated into commitments for action, moving forward together, and sustaining the momentum.

Bate (2004) quotes Kling's description of the creation of such communities as one step removed from a social movement, and points to the importance of stories and storytelling in their creation:

Social movements are constituted by the stories people tell to themselves and to one another. They reflect the deepest ways in which people understand who they are and to whom they are connected. . . . they are constructed from the interweaving of personal and social biographies—from the narrative people rehearse to themselves about the nature of their lives. . . . The construction of collective action, therefore, is inseparable from the construction of personal biography, from the ways, that is, we experience the imprecation of our individual and social selves. (Kling 1996, in Bate 2004, p. 337)

Thus, stories are the mechanism that brings together multiple identities under a common social vision and act as a springboard for collective action: “Stories are not a symptom of culture, culture is a symptom of storytelling.” (Weick and Browning, 1986, in Bate, 2004, p. 339).

While Bate speaks of the use of stories for organizational change, that change is, in essence, a manifestation of learning (Chuang et al., 2007). Boje’s study of story and storytelling in an office supply firm (1991) provides an in-depth look at the use of stories as a key part of members’ ability to make sense of their experiences (the personal narrative), and as a means to supplement individual memories with institutional memory (the communal narrative). The stories that Boje describes are dynamic and varied in context; at times, listeners silently fill in elements of the storyline with their own interpretations and implications. Using participant observation methods, Boje (1991) explored these stories as performance (rather than as static texts) within the social context in which they were created and told, highlighting their co-construction and varied purposes.

In Julian Orr’s oft-cited ethnographic study, *Talking about Machines* (1996), we see how stories are prime actors in the creation and management of knowledge. Orr characterizes the work of photocopy repair technicians as a continuous highly skilled improvisation within a triangular relationship of technician, customer, and machine. His analysis of the way repair people talk about their work reveals that talk is, in fact, a crucial dimension of their practice: the narrative process they use demonstrates how they use stories as a means to make sense of the troubled machine and create a coherent description of it, essentially reflecting their experiences. As these stories circulate and are told (and retold) among technicians, they offer a way of transmitting knowledge and creating collective memory amongst their group.

Stories of notable experiences are part of a cultural system reflected in the conventional wisdom of the team members.

Another scholar of storytelling in organizations, Yiannis Gabriel, speaks of the psychological contracts that exist within these cultural systems of organizations. Termed ‘narrative contracts’ (Gabriel, 2004), these are usually tacit agreements that exist between teller and audience of what is possible. Gabriel (2004) describes this contract as one that regulates the terms of the story, the acceptable deviations from documentable reality, the drawing of inferences and making of connections, the legitimate exaggerations and omissions – essentially what is the “poetic license” of the teller as they make sense of events and of what is deemed acceptable within that particular milieu. This contract points to the relational aspects of storytelling between teller and audience, and different types of narratives will involve different types of contracts. The significance of the contract becomes clear when it becomes tested, violated, or broken, prompting these questions to be asked: “So what?” (the story fails to carry shared meaning); and “Did it really?” (the story fails to carry truth, authenticity, credibility). Storytellers and the experiences they share are constantly being processed, interpreted, and reinterpreted in light of subsequent events, and thus, stories continue to shift and change as their meanings are reconsidered and reassessed (Gabriel, 2004). In this way, we see how stories are less about the revelation of truth than about the crafting of truth in certain ways (Bruner, 1986 in Adams, Robert, & Maben, 2015).

Thus, stories are devices that help us to make sense of our experiences. Stories are relational and told in the context of the cultural milieu of teller and audience. The experiences represented in these stories are a source of knowledge, and that the act of storytelling is a means of sharing and managing this knowledge. Different types of narratives

exist (i.e., personal, communal, counter and mobilizing stories) for different purposes, supporting and enabling organizational learning and change.

Where does the literature lead us?

The literature helps us to see the power of stories, and specifically how patient stories of illness and those that describe experiences of care have been used to inspire, evoke emotional responses, and act as a source of reflection and change. Stories help people make sense of their experiences, and storytelling acts as a vehicle for sharing these experiences. The literature demonstrates how stories have been used as an educational tool for patients, and as described in this chapter, in the education of healthcare professionals and students. Individual learning, primarily through personal narratives, affects changes in attitudes, values, and beliefs, challenging assumptions of what the ill experience, both in their illness and in their care. However, we see how these personal narratives may be appropriated and co-opted for purposes beyond their original intent, and how they are most susceptible when they are presented as stand-alone vehicles of change.

The improvement and learning literature is instructive in this way, demonstrating how structures and processes to support stories (particularly as described in EBCD) can create more meaningful and lasting change, not only in service redesign, but also in relationships between patients and providers. The different narratives articulated by Bate (2004) that emerged in an organizational change process are useful in considering the many uses of stories, including personal narratives that help to challenge and produce counter-narratives, communal narratives, and mobilizing narratives that may surface throughout the change journey. Stories are ways for people and organizations to make sense of experience, but they also are ways to create and manage knowledge within organizations.

What is not explicitly evident in the literature is a more nuanced understanding of what allows stories to perform their work for learning and improvement, specifically within the highly professionalized domains of health. In particular, while we see that many stories abound, little has been said about what makes for a “good story,” for what purpose, for whom, and with what impact. In addition, very little has been noted about the storytellers themselves—that is, which patients tell their stories, why, and for what purposes. Furthermore, we know little about the organizational conditions that allow stories to be gathered and told, or just as importantly, what leads to them being heard and acted upon. Overall, there appears to be a dearth of critical understanding and evidence of factors that may elucidate more fully the potential of patient stories in healthcare, particularly in the realm of organizational learning and improvement.

Thus, the overall aim of this dissertation is to explore the use of patient stories in healthcare organizations that are leaders in the systematic and deliberate use of patient stories for learning and improvement. The dissertation research has been guided by the following objectives, to explore and better understand:

- The types of patient stories that are told in these organizations and for what purposes
- The storytellers within these organizations and in whose interests do they tell their stories
- The context within these organizations that enables the use of patient stories
- The impact patient stories have had on organizational learning and quality improvement

The following two chapters articulate the theoretical and methodological principles underpinning this study, and describe the methods used for data generation and analysis. I also discuss my own positionality and reflexivity throughout all phases of the research.

Chapter 3

Theoretical Underpinnings: Constructivist Perspectives for Using Patient Stories for Organizational Learning

Broad-ranging theoretical perspectives have influenced my thinking regarding patient stories as a mechanism for learning and change. In this chapter, I discuss the theoretical underpinnings that have shaped the evolution of this study, bringing together perspectives from sociology and organizational learning. I will begin with considerations of stories, what are they and how is it that they do their work. In this, I have been greatly influenced by the work of Arthur Frank, a sociology scholar in healthcare whose writings in *The Wounded Storyteller* (1995) and *Letting Stories Breathe: A Socio-Narratology* (2010) are threaded throughout this dissertation. In particular, I consider a typology of stories proposed by Frank, and the notion of thinking *with* stories, rather than thinking *about* stories.

I also employ literature from so-called storytelling organizations, as presented by organizational learning scholar David Boje (1991), who (like Frank) speaks of the co-construction of stories, particularly the performative act of storytelling. I then draw on a model of organizational learning proposed by Chuang et al. (2007), who present a multi-level model of learning from failure in healthcare to consider how organizations may learn from patient stories. Finally, I draw from other organizational learning scholars to consider exploitation and exploration of new knowledge to promote learning across levels, and I consider the influences of power and reflection on organizational learning. Together, these perspectives help provide an informed understanding of how stories do their work for learning and improvement.

A typology of stories

In his book *The Wounded Storyteller*, Arthur Frank (1995) attempts to orient the considerations of illness away from the traditionally ascribed scientific basis for illness that focuses on medical diagnosis, treatment and cure, instead moving toward an account of the meanings of illness. He highlights first-person accounts of experiences of illness, giving privilege to these stories of experience often not heard. Frank recognizes the need to tell personal narratives of struggles faced, and he describes three types of stories that people tend to tell in the wake of illness and suffering: the restitution narrative, the chaos narrative, and the quest narrative. These stories are fluid in nature; people move back and forth among these narratives, which intersect and overlap.

Briefly, the restitution narrative of illness describes a person who becomes ill, obtains treatment and successfully recovers. These are comforting narratives, in that the person is restored to a life that is close to what existed before illness; suspense in this narrative is derived from the question of whether the person will be restored.

The second kind of narrative is the chaos narrative, the type of narrative that results when the restitution narrative breaks down. A chaos narrative is the opposite of a restitution narrative; its plot imagines life never getting better. Chaos narratives are hard to experience, and also hard to tell and to hear. The narratives describe multiple problems, crystallized by an illness, but usually not limited to that illness. Instead, life is collapsing around this person—efforts to stop the collapse are futile, as all avenues have been exhausted. The actors in this kind of narrative are buffeted by forces beyond their control, and ultimately, the plot does not lead to a resolution: this is the final assertion of its chaos. The sense of simultaneity creates

the suspense; one thing happens after another, but they go nowhere. Getting out of chaos is desired, but people can only be helped by those who bear witness to the story.

Lastly, Frank (1995) describes the quest narrative of illness, where the person meets the suffering head on; they accept illness and seek to use it. Using a journey metaphor, Frank describes three stages of the quest:

1. The departure. This begins with some kind of call, such as a symptom or a diagnosis that can no longer be denied.
2. The initiation. This stage (which may be lengthy) involves a “road of trials” where the person comes to a reckoning. The hero or heroine is tested or tempted, and in the end is changed or transformed.
3. The return. Here, the teller returns marked by experience, generally in one of two ways: the hero returns as one who has overcome the obstacle(s) and boasts of the accomplishment, or the hero returns somewhat humbled (what Frank calls the “postmodern” hero). The character has encountered a sequence of difficulties and gains wisdom and stature through the process of overcoming these barriers.

In this way, quest narratives build narrative resources by helping others imagine different endings.

In this study, the stories of interest are those about experiences of care (rather than stories of illness), and specifically how organizations use these stories of patient experiences of care for learning and improvement. The typology presented by Frank is one that also resonates with stories of experience of care. The kinds of stories of care shared by patients may not be those where patients seek restitution; that is, they may not be looking to repeat the same experience, instead choosing to tell their stories to induce change. The story may indeed entail experiences of chaos in the type of care received (e.g., healthcare errors,

misdiagnosis, or miscommunication), but the act of telling the story may lead the patient out of this chaos. The stories of care shared in this study ultimately may be quest narratives, leading storytellers on a journey; through the act of telling their stories, patients ultimately gain courage and wisdom in the hopes of invoking change. In the process, they are transformed: suffering has led to good, not ongoing bitterness and sorrow. Frank's work is therefore instructive, not just for the typology of stories that he provides, but also for consideration of what happens to storytellers in the process. This typology, as it relates to the stories told within this dissertation, is elucidated in Chapter 5, which examines in greater detail the stories told by patients for learning and improvement; it appears again in Chapter 6, which more closely considers the storytellers—the Patient and Family Advisors who demonstrate altruistic motives in their storytelling acts—and those who are transformed in some way in the process.

Thinking *about* vs. thinking *with* stories

How is it that these restitution, chaos, and quest narratives do their work—and specific to this study—how do they do their work within healthcare organizations, influencing learning and improvement? In his latest book, *Letting Stories Breathe: A Socio-Narratology*, Frank (2010) challenges us to begin to think *with* stories, rather than to think *about* stories. Thinking about stories suggests an analysis of stories as a stable object, fixed narratives that do not necessarily consider the social context and relationships in which they are told. Thinking *with* stories involves mutual engagement: the story is an actor, nested within relationships that remain in process. Thinking *with* stories requires reflection of one's own place in that process, and how stories exist within the relationships that the story itself

works to shape (Frank, 2010). Stories always exist in relationships; thinking with stories allows for the reflexive practice of thinking with our own stories. In this way, stories make life social, connecting people into collectivities, and they coordinate actions among people who share expectations. Socio-narratology examines how stories and humans work together in symbiotic dependency, creating the social milieu that comprises all human relationships, collectivities, mutual dependencies, and exclusions. Thinking with stories requires attending to how a story is used at different times and for different purposes; people will hear and respond to it differently on each telling, and the same story can potentially make a different point to different listeners. If that is the case, then what kind of “truth” is being told? As Frank (2010) says, “stories never resolve the question; their work is to remind us that we have to live with complicated truths” (p. 5).

However, the stories people tell depend on their narrative resources; that is, they are influenced by the narrative templates that provide us with the mental frames of stories that we hear or see in action, and they guide us to construct specific stories of our own. We learn these narrative templates from our culture and our exposure to multiple stories. Narrative resources often depend on social location: which stories are told where we live and work, which stories we take seriously or not, and especially which stories we exchange as members of our groups. The more narrative resources available to tellers, the more they can imagine a different ending to their stories, that some particular future is not only plausible but also compelling (Frank, 2010).

Similarly, David Boje (1991), a scholar of the “storytelling organization,” recognizes the symbiotic relationship between teller and listener that ultimately shapes the stories we tell— stories that are dynamic and varied by context, reinterpreted and revised by listeners as they filter the stories through their own lenses. He suggests that organizations can act as a

collective storytelling system wherein the performance of stories is a key part of members' sensemaking and a way for individual memories to become institutionalized into organizational memory. Storytelling creates (and is imbued within) the social context of the organization: our personal experience mingles with what we hear and then see. As listeners, we are co-producers with the teller of the story performance, and even more so when we begin to prompt the teller with cues, such as head nods, changes in posture, and utterances that direct the performance. Thus, the story becomes a joint performance of teller(s) and listener(s), where subtle utterances negotiate meaning and co-production in this storytelling episode. The words of the story are important, but equally so is the performance of the story, which gives us insight into the complex and varied ways that members use storytelling within their organizations. In this way, the storyteller—and not just the details of the story told—is significant in the performance.

Boje et al. (1999) also attempt to discover how social actors within these storytelling organizations find themselves “constituted as subjects who exercise or submit to power relations” (Foucault, in Boje, Luhman, & Baack, 1999, p.341). The “power to story is hegemonic at the micro level” (Boje et al., 1999, p. 341); that is, having the opportunity to share a story is power, and it makes us question who gets to tell their stories to begin with, and whose voices are silenced. Thus, we need to be attentive to collective issues, such as who owns the right to tell their stories, how are they constructed in their in situ performance, and how are they reconstructed in subsequent tellings. Like Frank (2010), Boje et al.’s (1999) work in storytelling organizations evolves away from thinking *about* stories to thinking *with* stories, collecting stories in situ with greater attention to the issue of polyphony, recognizing the individual voice that has been shaped by a plurality of other voices and the multiple listeners who will hear different things and shape the story differently (Bahktin, 1986). Boje

et al. (1999) suggest that telling a story is always a matter of social choice and selective re-appropriation. Storytellers may or may not be aware of the co-constructive influences of their audiences as they adapt and create their telling in each venue and with each audience, but audiences are co-participants in shaping the story.

Both Frank's and Boje et al.'s work is instructive in examining the social construction of stories. Individual stories do not exist alone: they continue to be revised and negotiated, and thus, the nature of storytelling in organizations is a dynamic unfolding of (re-)negotiated (re-)storying (Boje et al., 1999).

Considerations of organizational learning: using a multi-level model to situate the use of patient stories

Thinking with stories through this constructivist lens provides a theoretical frame for considering patient stories and those who choose to tell them. In this dissertation, I have been particularly concerned with stories that are told in the organizational context, as it is within this context that learning may occur at the individual, team and organizational levels. In doing this, I draw on the work of Chuang et al. (2007) to consider how healthcare organizations learn from patient stories. Chuang and colleagues (2007) have developed a multi-level model of learning from failure in healthcare, drawing from existing theories of organizational learning and organizational behaviour. The stories posed by patients in this study do not necessarily constitute preventable adverse events (the focus of Chuang et al.'s model), although some do; however, they generally *do* represent experiences of care that were not optimal. Unsatisfactory outcomes are often a driver for learning (Miner et al., 1999). In this model, Chuang et al. (2007) focus on factors that influence learning at each

level, which include perceived characteristics of events, group composition and dynamics, and the behavioural and structural arrangements of healthcare organizations.

There is a recognition—particularly in the world of patient safety—of the need to develop a “safety culture,” an environment that supports learning from failure and explores the nature of failure within its context. Similarly, the evolution of theories of organizational learning have recognized knowledge is always enacted and situated, and that learning at work should always be conceived as learning-in-working (Brown & Duguid, 1991), thereby adopting a more socially aware stance toward learning and knowing. Prior to learning being conceptualized as a social process in organizations, it was implicitly conceptualized as individual actors processing information in organizational systems and structures. There has now been a shift to seeing learners as social beings who construct their understanding and learn from social interactions within specific sociocultural settings (Edmondson, 1999), and that knowledge is created mainly through conversations and interactions between people (Brown & Duguid, 1991).

Multilevel organizational learning

Learning at the individual level

Learning is initiated at the individual level, as only individuals are capable of learning. Individual learning is often triggered by practitioners recognizing a gap between current and optimal knowledge, skill, or performance, and it becomes embedded with repetition (Bohmer & Edmondson, 2001). Chuang et al. (2007) bring forward three main factors embedded within the perceived characteristics of preventable adverse events that affect learning at the individual level: the perceived salience, causes, and attribution processes of the event. Similarly, we can consider these same factors related to perceptions of the patient story: how relevant is the story perceived to be, what are the perceived causes, and

why has this experience of care occurred? There is a tendency for humans to attend to some events but not to others, in part due to limited cognitive capacities, famously termed “bounded rationality” by scholar Herbert Simon (1972). Consistent with Frank (2010), individuals situate these stories within their own experiences and frames of reference. Chuang et al. (2007) propose that the more salient the event (i.e., its perceived relevance to the listener), the more learning may occur at the individual level, and as pointed out previously, in cognitive, affective, and experiential domains (Kumagai, 2008). Events (or stories) that are seen to have heterogeneous or multiple causes are richer sources for learning, compared to those that simply put the onus on the individual; therefore, learning may be enhanced at group or organizational levels. Paradoxically, attribution theory suggests that in some instances, individual-level attributions may actually serve to enhance learning, where individuals who attribute negative outcomes to themselves may take actions to improve future performance. However, if an individual attributes negative outcomes to others or to the system, they may be less likely to make changes to their own behaviour. As noted previously, healthcare is a strongly professionalized system where individuals have been socialized in particular patterns and there is a stronger focus on individual, autonomous behaviours. The long-held tradition of individual expertise and autonomy in the highly professionalized healthcare environment indeed may reinforce tendencies to ascribe individual blame for events rather than using a systems approach to learning that engenders collective learning (Tucker & Edmondson, 2003). Also, as noted in the previous chapter, powerful status differences and hierarchies exist in healthcare, and they may inhibit open inquiry and collaborative learning, thereby impeding learning across the organization (Edmondson, 2004).

Group-level learning

Team or group learning is a consequence of the ability and willingness of individual members to share knowledge and experience to promote collective understanding and learning. Group learning refers to a process in which a group takes action, obtains, and reflects upon performance feedback, and makes changes to adapt or improve (Edmondson, 1999). It is at this microsystem level where improvements are instigated (Nelson et al., 2003). According to Crossan et al. (1999), group members interpret and integrate other members' knowledge and experience as a means to promote collective learning. The social interactions required of teams influences how individual knowledge is transferred and routinized at the team level. For example, Bohmer and Edmondson (1999) found that teams facing the same learning task differed significantly in the ways they managed the process of learning, the rates at which they learned, and what specific lessons they learned.

Chuang et al. (2007) suggest that collective learning at the group level may be shaped by contextual and socio-psychological factors, including group diversity, intergroup linkages, group norms, and leadership styles. They suggest that more diverse membership in groups will spur "constructive conflict," thereby raising more issues, perspectives, and potential courses of action. For example, multi-disciplinary healthcare teams have been shown to enhance clinical performance and quality (Mohr & Batalden, 2002). Furthermore, the ability of groups to learn also will depend on social networks created within and external to the group, and the ability to tap into those linkages to promote group learning. The inclusion of the patient as part of the team and the attention given to multiple listening posts for patient feedback may enhance team learning and networks. Examples of patient stories being told to interprofessional teams illustrate this type of learning.

Group norms—the unwritten rules of group behaviour—shape how members may respond to and reflect on potential issues. Structures and processes, such as team debriefing sessions, enable collective learning through which team members can share experiences and jointly reflect on them.

Organizations with staff who feel unable to voice their concerns will fail to identify, investigate, or learn from failures (Edmondson, 2004; Tucker & Edmondson, 2003) or from patient stories. As noted in the previous chapter, Edmondson (1999) refers to such limitations as “psychological safety”—that is, the belief that the team is safe in interpersonal risk-taking. In a psychologically unsafe environment, one would feel at risk if he or she speaks openly, and consequently, less willing to share experiences and knowledge, thus limiting learning. Participative leadership is closely linked with (and helps to foster) a norm of openness and the use of constructive conflict at the group level (Bohmer & Edmondson, 2001). Learning is supported by team leaders who encourage team members to speak freely and openly, and who are willing to support patients to share their stories in a psychologically safe environment. The ability of teams to learn together and engage in productive dialogue will enhance learning (Edmondson, 1999).

Organization-level learning

While individuals learn naturally, teams and organizations do not. Chuang et al. (2007) identify four key factors that promote learning at the organizational level: knowledge management systems, leadership, organizational culture, and network contacts. Knowledge management systems help codify knowledge and store what has been learned in the past, thus helping an organization understand, extend, and codify the knowledge, information, and outcomes associated with its past experience. In the case of patient stories, this may be seen as structured ways in which stories are brought into the organization, such as compliment and

complaint letters, incident reporting mechanisms, and meetings where patient stories are actively sought and told. These systems manifest themselves in the policies and procedures of the organization. For organizations to learn, they require the “absorptive capacity” (coined by Cohen & Levinthal, 1990), which allows the organization to value new information, assimilate it, and apply it (Emmons, Weiner, Fernandez, & Tu, 2012; MacIntosh-Murray, 2001). Thus, in the case of learning from patient stories and other forms of patient feedback, organizations require systematic and deliberate ways to analyze and synthesize information to support learning across teams and the organization. The knowledge presented by patients (via their stories) may be integrated into the learning system through individuals and groups (teams) in which experiences, dialogue, and interactions occur. The group may integrate this knowledge as part of their shared understandings, which then may help to inform routines and processes that occur at the organizational level.

Formal leadership—particularly from “learning leaders” (Sadler, 2001) who promote openness and facilitate others’ learning through mentorship—puts incentives and resources in place to foster a pro-learning culture to integrate and institutionalize learning across the organization. Organizational culture provides the overlay for shared beliefs, attitudes, values, and norms of behaviour. An organizational culture that values the patient voice may be one that values the stories that are told by patients and attempts to learn from them. In particular, these elements create the social milieu in which stories are told and determine how learnings are drawn from them. Lastly, like individuals and groups, organizations will learn from the experiences of other organizations, using their own experiences to guide their actions (Levitt & March, 1988). In particular, the network contacts of key decision-makers will impact on the learning that occurs across organizations. Operating in an open system, organizations

need to look beyond themselves for learning; patients, as both insiders and outsiders, represent the straddling of internal and external boundaries.

Learning across levels

Tensions between exploration and exploitation

Organizational learning theorist James March (1991) highlights the tension between exploration and exploitation in organizations. The essence of exploitation is the refinement and extension of existing competencies, technologies, and ways of thinking and doing; its returns are positive, proximate and predictable. The essence of exploration is experimentation with new alternatives; its returns are uncertain, distant, and often negative. The tradeoff between exploration and exploitation involves conflicts between short-term and long-term concerns, and between gains to individual and collective knowledge. Bohmer and Edmondson (1999) apply this tension in their “practice model” for organizational learning, suggesting that knowledge and practices flow from the individual to the group, and on to organizational levels before returning to the individual level, influencing how individuals act and think. Organizations store knowledge in their procedures, norms, rules, and policies and learning from members that have been accumulated over time. At the same time, individuals in an organization are socialized to the languages, beliefs, and practices that comprise the organizational code, which again adapts to individual beliefs. This feedback is particularly relevant at the individual level, where individuals reflect carefully on feedback offered by their immediate experiences and thereby transform experience into expertise (Schon, 1983).

Crossan et al. (1999) also suggest that learning involves a tension between assimilating new learning in feed forward mechanisms (exploration) from individual to group so they become institutionalized within the organization, and feedback mechanisms (exploitation) to groups of individuals what is learned and institutionalized by the

organization. Tensions exist in maintaining a balance of new learning and exploiting the current knowledge sources used by organizations. While feedback mechanisms (exploiting what is known) may be one way that patient input has traditionally been sought in healthcare organizations, some efforts are more tokenistic than truly explorative as learning opportunities. The influence of patients and their knowledge within EBCD (as presented by Bate & Robert, 2006) may be one way of more fully exploiting the knowledge repository of patient experience that also may be explored in feed forward mechanisms, learning that may move through individuals and teams to organizational levels, becoming embedded within their structures and processes.

Cognitive processes

Like storytelling, learning is a social activity. According to Crossan et al. (1999), it is through the interrelationships of individuals and their social and psychological processes that learning moves between the multi-levels of learning. It is these processes that hold the structure of learning together. Crossan et al. (1999) present the four “I’s”—intuiting, interpreting, integrating, and institutionalizing—as the key processes that occur in sequence and progress through the levels of learning. Not every process occurs at every level. Individuals can intuit and interpret, which spills over into the group level. Groups are able to integrate and interpret, which takes the form of action in groups; they can then integrate these actions into formal rules and procedures, routines that become embedded and institutionalized across the organization. Organizations are thus socially constructed; the routines and rules that make up an enduring organization exist independent of any one individual, but they are influenced by the learning of the individual.

Power and reflection in learning

In recent years, there has been growing recognition of the role of power and politics in organizational learning, in part due to a more social constructivist stance toward learning (Easterly-Smith et al., 2000). Social relations and learning processes do not happen in a vacuum; rather, they take place in a landscape of differential power positions and relations (Lawrence, Mauws, Dyck, & Kleysen, 2005). Lawrence et al. (2005) have extended Crossan et al.'s model (1999) to also consider the power relations within an organization that will influence the ability of organizations to learn. Lawrence et al. suggest two distinct modes of power that influence learning across levels: episodic and systemic power. Episodic power refers to discrete, strategic political acts initiated by self-interested actors, those actors in organizations that are most able to influence organizational decision-making. Lawrence et al. suggest that episodic power occurs most through interpretation and integration processes at individual and group levels. Stories and the act of storytelling may represent a form of episodic power—potentially by non-traditional or outsider actors (e.g., patients and family members)—that is aimed at influencing learning. Systemic forms of power work through the routines and ongoing practices of organizations, diffused throughout the social systems that constitute organizations. Systemic power occurs through institutionalized and intuition processes that shape individual experiences and how they understand themselves in relation to that experience. Structures and processes that organizations have in place may help routinize the use of stories and the inclusion of patient and family advisors in an ongoing manner. Championing a new idea or change will require different skills and resources (and consequently different champions) as an idea passes through different processes of organizational learning.

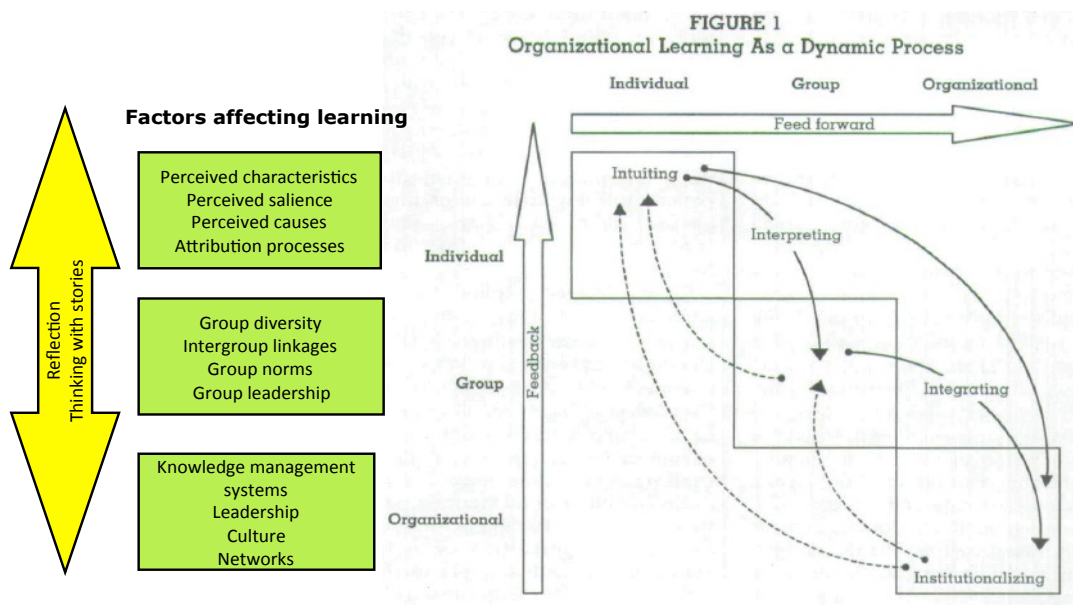
Reflection is key to both action and learning, but reflection is a complex process that is influenced by many characteristics of individuals and organizations. Individual reflection takes discipline, analytical skill and creativity, but collective reflection adds elements of communication skills and social relationships. As noted previously by Kumagai (2008), we see how the use of patient stories may be reflected upon and brought into intentional dialogue to support learning at the individual level. Reflection depends on having the time, social support and skill for reflection, as well as mechanisms for collective feedback and reflection, and a culture that encourages learning from problems rather than defending against blame (Carroll & Edmondson, 2002). Critical reflection is essential to the transformative process because it allows individuals to alter their perspectives and be open to change and personal growth (Henderson, 2002). Without reflection, the cyclical nature of learning through feedback and feed forward mechanisms to exploit and explore would not be possible (Crossan et al., 1999). Critical reflection and action are powerful catalysts for organizational change, and they are the foundation of the increasingly popular approach to learning in organizations: action learning, which demonstrates an explicit link between learning and change (Henderson, 2002).

Argyris and Schon (1978) highlight this ability to reflect as essential to double loop learning. Bohmer and Edmondson (1999) suggest learning is dualistic, requiring both single loop and double loop learning. Based on the seminal work on organizational learning by Argyris and Schon (1978), single loop learning is analogous to maintaining a steady course through the use of a feedback loop, leaving organizational objectives and processes largely unchanged. Double-loop learning challenges fundamental assumptions about the organization that often leads to a redefining of the organization's goals, norms, policies, procedures, or even structures. Double loop learning calls into question the very nature of the course plotted

and the feedback loops used to maintain that course. Development of new and innovative models of service and redesign of service from the ground up represent attempts at this more transformative approach to learning (such as EBCD, where storytelling forms a basis of knowledge sharing and transfer across individuals and teams).

Drawing on the theoretical frames described throughout this chapter, Figure 1 represents how these elements of organizational learning are brought together with the notion of reflection and thinking with stories. Organizational learning is a dynamic and nuanced cognitive and social activity that occurs across individual, group, and organization levels. Learning involves a tension between exploration (feed forward) and exploitation (feedback) mechanisms that moves through the different levels. At each level, consideration needs to be given to a variety of factors that enable or impede learning, particularly as they relate to adverse events in healthcare. Reflective practice is required across levels to enable thinking *with* rather than thinking *about* patient stories.

Figure 1. Model of patient stories for learning (from Chuang et al., 2007; Crossan et al., 1999, p. 532)



Conclusion

Patient stories of their experiences of care may reveal themselves as restitution, chaos, or quest narratives. Regardless of typology, stories—and the act of storytelling—are social, a performative act where the story becomes co-constructed by the teller and listener. Stories are not fixed objects, and thinking with stories acknowledges the social milieu in which they are created, using narrative templates that are culturally and socially bound.

Organizations can use patient stories as a source of learning, exploiting them in feedback mechanisms and exploring them more fully and reflectively in feed forward mechanisms. Individuals may be influenced in their learning depending on the perceived salience and causes of the story, and by the attributions they place upon themselves or others. Collectively, groups may learn from these stories, particularly if the groups are largely heterogeneous and in psychologically safe environments that allow patients to share their experiences and staff to learn. Groups need to be open to such learning, with leaders who encourage and support collective learning. Organizations may learn from patient stories if they have deliberate and structured systems in place to support gathering and hearing patient stories, leaders who model learning and a culture that values the patient voice. Learning does not occur in a vacuum, but rather in an environment that is socially constructed, with overlays of power that will influence learning across levels.

The aim of this chapter has been to elucidate the theoretical underpinnings of this study, using a constructivist lens in order to understand how stories are constructed and co-constructed in their performance. Organizational learning theory provides the backdrop for considering how these stories are used for learning and improvement within the social milieu of healthcare organizations, through multi-levels of learning as individuals intuit and

interpret new knowledge, groups interpret and integrate this learning into group norms, and organizations routinize this knowledge into policies and structures. This learning occurs in constant cycles of feedback and feed forward, and in reflection and action. The methodology chapter that follows provides in-depth detail as to how this study unfolded and the methods that were used within this theoretical frame.

Chapter 4

Methodology

This chapter outlines methodological considerations for the study of patient stories for organizational learning and improvement, highlighting the congruence of methodology with the theoretical framing of organizational learning. I then move to a practical orientation to describe methods used in this study, that is, the research procedures used to gather and analyze data, ethical considerations, and my positionality and subjectivities as a researcher using reflexivity throughout all the phases of research as a commitment to quality in this study.

Methodological and theoretical congruence

Patient stories may be seen as a form of patient engagement to be considered along the ‘continuum of patient influence’ (Bate & Robert, 2006) and as a particular type of knowledge reservoir that creates, retains, and transfers knowledge for organizational learning (Argote, 1999). Stories are inherently subjective; they are constructed within the complex social milieu in which they are told; they are interpreted differently by each listener (Boje et al., 1999; Frank, 2010). Studying stories through any other lens but that of constructivism would create paradigmatic confusion. Thus, this study has taken a constructivist stance using case study methodology. The overall main aim of this study has been to explore the systematic and deliberate use of patient stories within healthcare organizations for learning and improvement. The purpose has been exploratory and developmental, not in search of *a* truth or to be able to make generalizations across all healthcare settings. Rather, this study has aimed to illuminate the ways in which organizations learn and improve their ways of

thinking and doing by better understanding the patient experience through storytelling. Thus, a constructivist approach to this study was warranted. Two prominent authors on case study methodology, Robert Stake (1995, 2000) and Robert Yin (2003) base their approach to case study on a constructivist paradigm. One of the basic tenets of constructivism is the assumption of multiple realities rather than one universal truth (Denzin & Lincoln, 2005).

This research was designed as a qualitative, descriptive single case study, aiming to depict the phenomenon of storytelling within the context of these organizations (Yin, 2003) from the vantage point of patients and leaders. Despite the variation in orientation (i.e., service delivery vs. non-service delivery) of these organizations, all have been identified as those with a strong focus on the patient voice, and as organizations that use patient stories for learning and change. The unifying factor for all of these organizations is the unit of analysis, that is, the ‘patient story’, stories that have been described and shared by patients and leaders within their organizational contexts. In this study, the organization’s use of the patient story is the phenomenon of interest across all case study sites, the common factor across these organizations, and thus forms the basis of this single case study (Aita & McIlvain, 1999).

Several assumptions influenced my choice of using case study methodology. First, stories are a complex social phenomenon – the act of storytelling is a social act (Frank, 2010), performed in some ways (Boje, 1991) where the teller is influenced by the social context in which it is told and interpreted by the listeners in different ways (Greenhalgh & Hurwitz, 1999). I assumed that to study stories as the unit of analysis, I would need to look at collective actions and meanings from the point of view of individuals involved and within their organizational contexts in order to better understand how stories are used purposefully and systematically in the context of healthcare. Therefore, I needed to find organizations that are known to be leaders in this area, organizations that actively search out and utilize stories

in ways that are evident to others, such that they would be identified as leaders. Lastly, following a constructivist approach, I ascribe to Holstein and Gubrium's (1995) view that "meaning is socially constituted; all knowledge is created from the action taken to produce it" (1995, p.3). Thus, this study would require an examination of my own reflexivity and positionality, that is, the mutual creation of knowledge between the researcher and participant, recognizing the effect that context plays in how data were collected and analyzed on research results (Madill, Jordan, & Shirley, 2000).

Based on these assumptions, I approached the research questions through an in-depth case study using qualitative methods, combining methods of in-depth interviews with 38 individuals, observations of meetings where stories were being told, and document review. Three case study site visits were completed over a period of 10-months, as well as telephone interviews during this time.

Study design

Selection of organizations for inclusion in case study

The use of patient stories for learning and improvement has begun to proliferate in many healthcare organizations in North America and around the world. To help identify those healthcare organizations known to be leaders in this area, I first identified, with the assistance of my thesis advisor, a list of potential key informants from across Canada, for a total of eight key informants who had expertise in quality improvement, organizational learning, and/or patient engagement. I then contacted these eight key informants via email with further information regarding my study, and to solicit their assistance to help identify organizations that are known to be leaders in the area of patient engagement and the use of

patient stories for learning and improvement. If agreeable, I then scheduled time for an in-person meeting (if possible) or via telephone. I met with two key informants in person, and conducted 5 discussions over the phone; one key informant did not respond to my emails (initial and follow up emails). In each of these discussions, I prefaced my questions with information regarding my study and the research objectives, and probed regarding their knowledge of organizations that currently use patient stories as a mechanism for learning and improvement. I looked for specific criteria of the organizations that were brought forward, including factors such as: systematic and deliberate use of patient stories within the organization; clear mechanisms by which stories were gathered, shared, and analyzed; evidence of impact; leadership support for the use of stories, and length of time the organization had been deliberately using patient stories for improvement (see Appendix A for key informant letter of introduction and guiding questions). In many cases, the key informants did not have exact details of how stories were used within these organizations. However, intricately tied to these nominations were one or both of these common elements: these organizations were known to be strong proponents of a patient and family centred care philosophy (of which storytelling was one aspect), and/or were known for robust quality improvement structures that tapped into the patient experience. In total, the seven key informants nominated 32 healthcare organizations across North America. One organization was nominated by five different informants; one nominated by three different informants; and six organizations were nominated twice by different key informants. The majority of organizations were noted only once by the key informants. Once nominations were gathered, I sought to obtain more details regarding storytelling within these organizations. I conducted a review of the literature and a brief environmental scan of each of these 32 organizations, primarily through the internet of publicly reported sources and grey literature, related to their

use of stories, patient engagement, and patient-centred care. Based on the information gathered, I then generated a list of four healthcare organizations that potentially could serve as sites within my case study to learn more about their storytelling practices. Together with my thesis committee and based on feasibility considerations, these four organizations were agreed upon as suitable candidates for study, as I detailed the strengths and benefits of each of these organizations, and rationale for not choosing others. Three of these organizations are healthcare service delivery organizations (two in Canada, one in the United States), the fourth organization is a national organization dealing with a broader mandate of safer healthcare across Canada and is not involved directly in patient care.

I then contacted, via email, the senior leader noted on the organizational website to be leading patient and family centred care or patient experience at each of these organizations to explore further the possibility of their involvement as part of this case study. If agreeable, I then scheduled a telephone discussion with senior leaders of the organization (i.e., Chief Executive Officer, leaders in quality improvement, patient engagement/patient and family centred care) to determine their interest and fit for this study. All four organizations agreed to participate in this study, and senior leaders consented to their involvement as an organization. As part of the consent process, these organizations also agreed to be named as participants in this study, as known leaders in the area of patient and family centred care and for their use of patient stories (see Appendix B for information letter and organizational consent form). These organizations also suggested dates that were suitable for a site visit, based on their scheduled activities (e.g., a patient telling their story at a Board meeting). They also assisted with logistics to organize my schedule for a 2-3 day site visit.

Organizational settings

The four organizations that were examined in this study included: Saskatoon Health Region (SHR), Thunder Bay Regional Health Sciences Centre (TBR), Georgia Regents Health Sciences Centre (GRH), and the Canadian Patient Safety Institute (CPSI). The first three organizations are large, academic, healthcare organizations that provide health service delivery. All three organizations provide adult and paediatric inpatient and outpatient services across a spectrum of programs (e.g., emergency, mental health, cancer care) and across the continuum of care (e.g., acute care, rehabilitation), and community clinics. SHR also provides long-term care across its region. The CPSI is a national organization whose mandate is to improve the safety of healthcare systems. While CPSI does not provide service delivery, its work may impact and influence the service provided within health delivery organizations across Canada. CPSI focuses on the safety of patients; storytelling is a key feature of their work in partnership with 'Patients for Patient Safety Canada' and they engage heavily with patients within their own organization on a variety of initiatives related to patient safety. Although a different focus to their work (i.e., not direct service delivery), the use of stories and visibility of their work are notable. Below, I briefly describe each of these healthcare organizations.

Saskatoon Health Region (SHR): SHR is the largest health region in the province of Saskatchewan, servicing approximately 336,000 residents in more than 100 cities, town, villages, and First Nations communities. It is an academic, integrated health delivery agency providing a comprehensive range of services and programs in over 75 facilities, including 10 hospitals (three tertiary hospitals in Saskatoon), 30 long term care facilities, and numerous primary healthcare sites, public health centres, mental health and addictions centres, and community-based settings. SHR is the largest employer in the province, with over 1,000

physicians and approximately 14,000 employees including a wide range of healthcare professionals, support workers, and leaders. Their operating budget is approximately \$1.123 billion. The region services an area of approximately 34,000 sq km (similar to the size of Belgium).

SHR has lead the way in Saskatchewan in the province-wide adoption of a healthcare improvement management system modeled on the Lean Management System, developed initially at Toyota, and introduced and adapted into healthcare. The essence of this Lean Management System is to engage and respect the collective wisdom of patients, families, and healthcare staff. These key stakeholders work together to continuously improve quality and safety of care and services by focusing on efficiency, eliminating waste, and partnering with patients to provide value within healthcare. Currently at SHR, all seniors leaders and one Board member have completed training in Lean Management and are directly involved in a number of quality improvement projects (e.g., weeklong rapid process improvement workshops) and events within the region.

The vision of SHR is: Healthiest People, Healthiest Communities, Exceptional Service, in the pursuit of its strategic directions of better health, better care, better value, and better teams. SHR note the values of respect, compassion, excellence, stewardship, and collaboration in the pursuit of this vision. SHR is dedicated to ‘client and family centred care’, developing a strategic framework in 2010 by which to lead them on this journey. They have developed a robust client and family engagement network of approximately 165 advisors who work together with staff and leaders in program development, implementation and evaluation, policy development and review, facility design, surveying of patient experience, and strategic planning. Advisors are engaged in a number of ways, including the client and family centred care regional steering committee, client and family advisory

councils (at the time of site visit, there were 15 councils active within different programs), on a number of quality improvement events, and on various working groups throughout the organization.

Thunder Bay Regional Health Sciences Centre (TBR): Thunder Bay Regional Health Sciences Centre offers adult and paediatric acute care within a 375-bed regional facility servicing a geographical area of 550,000 sq km (approximately the size of France). It serves approximately 150,000 residents in the city of Thunder Bay as well as a number of small communities and rural areas surrounding. TBR provides service to a large Aboriginal population in north-western Ontario, many of whom live in fly-in communities, or access via ice roads in the winter. TBR employs approximately 2600 staff.

TBR's vision, Healthy Together, is supported by its values of Patients First, Accountability, Respect, and Excellence. Its mission is to advance world class patient and family centred care as an academic research-based acute care environment. TBR is the only hospital in Canada to hold the Leading Practice in Patient and Family Centred Care awarded by Accreditation Canada. TBR is also the only Canadian hospital to be featured by the Institute for Patient and Family Centred Care's "Profiles of Change" for excellence in this area of patient and family centred care which they have actively pursued as their philosophy of care since 2009. There are approximately 100 patient and family advisors who are regularly engaged on organization-wide, program and unit committees, senior management committee, Quality of Care Committee, Board of Directors, Patient and Family Advisor Council, interview panels, and a number of working groups.

Georgia Regents Health System (GRH): Georgia Regents Health System is located in Augusta, Georgia. It is a not-for-profit corporation that manages the clinical operations associated with Georgia Regents University, providing adult and paediatric services. It

includes a 478-bed hospital, numerous outpatient clinics, a 154-bed paediatric hospital, and a cancer centre. GRH provides services to the urban population of Augusta and surrounding areas, as well as satellite practices across the state. They also service a large Medicaid population.

The mission of GRH is to provide leadership and excellence in teaching, discovery, clinical care, and service as it strives toward its vision to be a top-tier university that is a destination of choice for education, health care, discovery, creativity, and innovation. Its values include: collegiality, compassion, excellence, inclusivity, integrity, and leadership. While not explicitly stated in their mission or vision, the principles of patient and family centred care are embedded within their values. GRH (previously known as the Medical College of Georgia) is known as a pioneer in the concept of patient and family centred care. Since 1993, GRH has partnered with patients and families, initially in the planning and architectural design of its Children's Hospital of Georgia, and then into other areas of the adult hospital. In 2006, GRH was featured in a four-part Public Broadcasting System (PBS) series "Remaking American Medicine" as a nationally recognized organization where partnering with patients, families and providers is a guiding vision. The 4th part, "Hand in Hand" showcased the work of GRH. Currently, GRH has approximately 230 trained patient and family advisors who sit on councils across the organization, quality and safety teams, interview panels, and are involved in facility design processes. GRH offers a Learning Lab two to three times per year, to share their learnings regarding the development, implementation, and evaluation of their Patient and Family Centred Care (PFCC) model of care. Healthcare organizations across North America have sent teams of leaders and staff to these Learning Labs as they embark on the journey toward PFCC. Leaders from GRH also act as on-going consultants and mentors to other leaders across North America, including a

number of hospitals in Canada that are working toward developing a culture of PFCC. GRH is also featured by the Institute for Patient and Family Centred Care “Profiles of Change” for their longstanding excellence in this area of PFCC.

Canadian Patient Safety Institute (CPSI): The CPSI is a national patient safety institute that aims to build a culture of patient safety and quality improvement throughout the Canadian healthcare system. It was established in late 2003 following a series of key recommendations in a report, *Building a Safer System: A National Integrated Strategy for Improving Patient Safety In Canadian Health Care* (National Steering Committee on Patient Safety, 2002). It is a non-profit corporation at arm's length from government, promoting best practices, raising awareness and advising on effective strategies to improve patient safety. Patients for Patients Safety Canada (PFPS) is a patient-led program of CPSI that aims to ensure that healthcare organizations and systems include the perspective of patients and their families when making decisions and planning safety and quality improvement initiatives; essentially PFPS is the voice of the patient. PFPS is a Canadian network of patient safety champions, many of whom have had personal stories of patient safety harm. PFPS is part of an international network of patient safety champions through Patients For Patient Safety within the World Health Organization. Members are involved in numerous CPSI working groups that have led to the development of a number of national guidelines and frameworks, and in media events together with CPSI. PFPS members look to inspire and impact policy and practice decisions, and promote transparency of patient safety issues.

The business plan of CPSI is: Ask, Listen, Talk. This plan brings together four key strategies noted under ‘Patient Safety Forward with Four’ to establish a national integrated patient safety strategy, engage stakeholders and build capacity nationally. CPSI has developed a number of patient safety resources provided to healthcare organizations,

including the Canadian Disclosure Guidelines, Critical Incident Analysis Framework, Safety Competency Framework, Effective Governance for Quality and Safety, and the Canadian Framework for Teamwork and Communication, resources that were developed together with patient advisors. CPSI provides training for medical residents, patient safety officers, and for Board members.

In summary, these four organizations collectively form the bounded case study of organizations that are known leaders in the area of PFCC and for engaging with patients through storytelling with impacts on learning and improvement as a result.

Research procedures

Outlined below, I describe in detail the research procedures used to gather data during case study site visits, techniques for data transformation and management, and data analysis. I bring forward ethical considerations regarding the consent process, and anonymity and confidentiality. I conclude this chapter with reflecting on my own subjectivities and positionalities as researcher, and how I sought to ensure rigour and reflexivity throughout the research process.

Data gathering methods

Within the interpretive approach, case studies can build a particularly rich context using data drawn from multiple sources, including direct observations, participant observation, interviews, documentation, archival records, and physical artifacts (Yin, 2003), and as such, help to provide ‘thick description’ of complex social phenomena. In this study, three main techniques were used to gather data: individual interviews, non-participant observations, and retrieval of organizational documents. The majority of data gathering occurred during site visits, with follow up telephone interviews conducted as needed. Site visits were conducted at the three health service delivery organizations for 2-3 days/visit. As

the CPSI is a national organization, the majority of interviews were conducted via telephone. Data gathering occurred over a 10-month period, with site visits and telephone interviews interspersed during this time, allowing for an iterative cycle of data gathering-data analysis to occur, with preliminary analysis helping to inform future rounds of data gathering and line of questioning in interviews. For example, as I began to examine ‘who are the storytellers’, and how it is that this particular group has been invited to share their stories to different audiences, what began to emerge was the inherent “power to story” (i.e., who gets selected to tell their story), and the role and function of an organizational gatekeeper who ensured “the right fit” at “the right time” for patient storytellers. This early analysis during the data gathering phase prompted me to query how organizations perceived (if at all) this “gatekeeping” function, and how this role was framed within their philosophy of patient and family centred care.

Interviews: In-depth individual interviews were the prime data gathering method, a crucial method in which to elicit the opinions and thoughts of participants and their use of stories within these organizations. Interviews lasted 30-90 minutes, depending on the availability of the participant, with the majority of interviews being 60 minutes in length. In total, 38 interviews were conducted, 22 with organizational leaders, 7 with patients, and 9 with family members. The leaders interviewed in this study were those most involved in the area of patient and family centred care, quality and safety, and communications within their organizations, and included senior leaders (i.e., Chief Executive Officer, Vice President, Director level), Board members, and program leaders/managers. All of the patients and family members interviewed in this study also had the role of ‘Patient (or Client) and Family Advisor’ (PFA) within their organizations. In each of these organizations, there was a similar, formalized process by which to become a PFA, an application and an informal

interview to determine the fit and suitability of candidates. In many cases, it was a staff member who recommended a patient or family member to become a PFA. These organizations had suggested timeframes for the involvement of patient and family advisors (usually a term of 2 years), and looked for those patients with recent experience in the organization (i.e., experience within the past 2 years). These timeframes were guidelines only; many of these PFAs have been involved with the organization longer than a 2-year term. Many of these patients and family members have had recent and ongoing experiences within these facilities due to the chronicity of their health issues. Table 1 outlines the number of interviews with participants conducted per case study site.

Table 1. Interviews per case study site

	SHR	TBR	GHR	CPSI
# interviews with leaders	10	6	2	4
# interviews with patients	2	5	0	0
# interviews with family members	5	1	1	2

For interviews with leaders and with patients/family members, I focused on three main areas: the story itself, the learning that occurred through and from stories, and the organizational context in which stories were shared (see Appendix C for semi-structured interview guides). I started the interview asking if the participant could recount a recent story that resonated with them or a recent story that they had told, and probed for details of the story – who told the story and who the audience was, in what context the story was told, and for what purpose, why this particular story resonated with the listener or needed to be told.

Sensitized to the social construction of the story, I made attempts to delve deeper into who was the storyteller, who was the audience, and what they perceived to be the purpose of their story. We then went on to discuss learning from stories, and what may have changed (e.g., personally, professionally, in practice) as a result of the story. Sensitized to concepts of organization learning, I also asked patients and family members about the organizational context that made it comfortable for them (or not) to share their stories, how they prepared to share their stories, and for leaders, about how stories were used in general across the organization, and how people were prepared to tell and hear stories. In some cases, I had the opportunity to hear a patient tell their story first-hand (e.g., in a meeting), watch a videotape of the patient telling their story, or have the patient story recounted to me by a leader, and then had the opportunity to speak with the patient storyteller about this particular story. This enabled me to gain a variety of perspectives about one particular story and to probe more deeply about how it felt to tell/hear the story, and the context in which the storytelling was performed.

Following each interview or block of interviews (depending on the time between interviews), I also created field notes to detail my initial interpretations of and reactions to the interview recently completed, along with the setting where the interview was conducted, length of interview, and any other details that struck me at the time. At the end of each day during my site visits, I also recorded field notes regarding my impressions for the entire day, what I had heard/observed, and any common threads that I was beginning to take note of, consistency of messages from participants, or any questions or comments that I wanted to further explore in future interviews. Thus, these field notes, particularly my end-of-day summaries acted as an early analysis, helping me to make linkages in the day's events, and

with thoughts to pursue in subsequent observations and interactions, and in the more in-depth analysis to come.

Recruitment process: As noted above, most interviews were conducted at the time of a site visit to the organization involved. After the initial discussion with organizational leaders regarding their willingness and suitability to participate in this study, they assigned a liaison to help me coordinate and schedule my visit. I spoke on the phone and/or exchanged numerous emails with this person, to identify the timing of my site visit, usually in conjunction with an activity that would be of interest for my study, for example, when I could observe a Board meeting or a senior leadership meeting where a patient story would be told. The schedule for interviews was then organized around these observational opportunities. In telephone conversations/email exchanges with this organizational liaison, I also outlined the types of individuals that I aimed to interview – a broad range of leaders and staff who have heard patient stories, those involved with using patient stories for learning and improvement, and patients and families who have had opportunities to share their stories within the organization. Based on these directives, this point-person then helped to identify those most appropriate within the organization to participate. I sent the information letter and consent form regarding my study (see Appendix D), to the point-person, who then passed it onto the potential participant. Participants were also informed that they could contact me in advance should they have any questions or concerns regarding their participation. In many cases, the potential participants emailed me the signed consent form in advance of my visit; in some cases, I obtained the signed form at the time of the interview, and answered any questions that they had about the study or their participation prior to the start of the interview. Thus, a schedule of interviews and observational opportunities had been pre-arranged prior to my arrival for my site visit. I also utilized a snowball technique, whereby I asked

interviewees if they had suggestions for other leaders, staff, or patients/family members that I should interview regarding storytelling within their organizations. At the site visits, names provided tended to be on my schedule already. In the case of CPSI, where I conducted all but one interview over the phone (one interview was conducted in person), I utilized a snowball technique and asked interviewees to identify others within the organization that they felt could offer additional insights into how stories have been used within their organization. I then followed up directly with that individual, to provide information regarding the study and to review the consent form. Telephone interviews were then arranged at a time of convenience for the participant.

Table 2. Characteristics of interview participants

Patients (total 7)	Family members (total 9)	Leaders (total = 22)
Men = 3	Men = 1	Men = 6
Women = 4	Women = 8	Women = 16
Employed = 2	Employed = 6	CEO = 2
Not working/Retired = 5	Not working/Retired = 3	VP = 1
		Directors = 10
		Manager (or equivalent) = 9

Non-participant observations: Observation is a common technique used in many qualitative genres, to gain a better understanding of the naturalistic environment and may be a powerful method in which to triangulate results together with other sources (e.g., interviews, texts) (Patton, 2002). Detailed notes were taken at each non-participant observational opportunity, which included a description of the physical environment of the observed activity, if a story was told, details of the story itself, who the teller and audience was and size of audience, verbal and non-verbal reactions to the story, visual cues and perceived reactions to the story, and where possible, the ensuing discussion that was

generated as a result of the story. As well, throughout each of my site visits, I made notes of what I observed in general while walking through these hospitals, in waiting areas, office spaces, and hospital lobbies (e.g., the visibility and types of signage posted, information posted for patients, huddle boards, performance indicators on units), all of which became part of my end-of-day memos that helped formulate overall impressions of the organization, and provide an overall sense of the environment.

Recruitment process: As noted above, the site visits were scheduled at a time that would also provide the opportunity to observe how the organization used patient stories in structured ways. Thus, a variety of non-participant observation opportunities were available during two site visits, including observations at a Board of Directors meeting, Senior Management Council meeting, and at a Patient-Family Advisory Council, all opportunities to observe a patient story being told, and the ensuing reactions and discussions of staff/leaders. In these instances, the consent form was provided to those in attendance prior to the meeting to provide consent (see Appendix E). At the time of the meeting, I was briefly introduced as a student researcher from the University of Toronto, along with the purpose of my study and my attendance at this particular meeting. The audience members had the opportunity to ask questions in advance, prior to the patient story being told. Consent forms were then obtained and the meeting commenced. After the patient story was told, I had the opportunity to stay at one meeting to observe the ensuing conversations following the patient story. In one case, I left the meeting together with the patient/family member, and conducted an interview with them to further discuss their experiences in sharing their story in this particular venue and format. Following the meeting, I had the opportunity to interview two leaders who had heard the patient story that morning, to follow up with their perspectives of this particular patient story and learnings that ensued.

At GRH, observations were made during a 2-day learning lab, offered 2–3 times/year by GRH to share their learnings regarding the development, implementation, and evaluation of their PFCC model of care. As part of a related study, focus group interviews were also conducted at GRH with 14 individuals in 2 groups of leaders, staff and patient advisors. At these focus groups, I acted as a scribe for the proceedings.

I also made observations at a “report out” for a week-long quality improvement event at SHR, in which patients were highly involved as team members throughout the week. Patient stories are not shared at these report-outs, but rather, patients present the work they were involved in throughout the quality improvement process during the week. The report-out events are public events where all staff members and the community are invited to attend to hear what was accomplished during the week-long quality improvement event. At the particular report out that I attended, held within a large hospital auditorium, there were 60+ members in the audience, who appeared to be staff, leaders, and other PFAs from SHR interested in the event. There were multiple teams working on different part of the process; the CEO was a team leader on one aspect of this event. There was one patient involved in this quality improvement event, and received applause when reporting on the work of their team. Table 3 highlights observational opportunities of hearing patient stories told purposefully in meetings during my site visits.

Table 3. Observational opportunities of patient stories

Observation	Details of event
Board of Directors meeting (approx. 30 min observation)	-patient and family member shared some of their experiences of care throughout their journey in the healthcare system (from acute care to rehabilitation and back to community) directly with board members and senior administrators at an 8 am board meeting, chaired by the CEO of the hospital; the patient and family member drove into the city to attend this meeting (they live in a rural setting) as they we were the first item on the agenda

	<ul style="list-style-type: none"> -the patient and family member were warmly introduced by the CEO; they had written notes that they referred to as they stood at the front of the room and shared their experiences; the patient spoke at first, then the family member told the bulk of their experience, as the patient had speech difficulties -the couple expressed sincere gratitude for the care received, but also highlighted feelings of fear and frustration at different points along their journey from acute care to rehabilitation, and back into the community -at the end of their story, the couple sang a song together (a speech therapy goal of the patient), ending a very moving story that highlighted the caring and loving relationship of this couple, and brought tears to the audience -everyone clapped at the end of the story, and the patient and family member were thanked by the chair, and escorted out immediately after -I left the meeting together with the patient and family member to conduct an interview with them; I did not have the opportunity to listen to the debrief at the meeting following the story, although I did interview two leaders later in the afternoon, and they discussed what ensued after the story was told, and the learnings taken
<p>Senior management council meeting (approx. 20 min observation)</p>	<ul style="list-style-type: none"> -two brief stories were shared by a senior leader as the first agenda item of this leadership meeting; these stories were gathered by the senior leader assigned to share a story for this meeting, told to him by other managers -all senior leaders present for this 9 am meeting, including the CEO and a PFA -the first story highlighted issues of transfer of accountability, communication, access to information, and privacy concerns between hospitals in different communities, as outlined in the experience of a patient and family member which was relayed from a manager to this senior leader; this story was concluded with the resolution of this issue, actions taken, and new processes in place -the second story highlighted privacy concerns in relation to police investigations and a patient admitted to hospital; this was an experience of a patient as told by this senior leader, which concluded with actions to be taken/explored, and follow up required
<p>Patient and family advisory council meeting (approx. 1.5 hrs observation)</p>	<ul style="list-style-type: none"> -Council meeting included PFAs from the various programs across the organization; co-chaired by PFA and PFCC leader -meeting took place in the evening and was held in the auditorium at the hospital; buffet dinner was served -a general congeniality was noted amongst PFAs -I was introduced at the start of the meeting and given time to introduce my study -first item on agenda was a patient story (approx. 20 min); a PFA shared a story of an experience in the emergency department; her teenage daughter had a medical emergency, and the PFA felt that her daughter had not been listened to; the doctor ignored the daughter and would only speak to the parent -there was much support and validation given by other PFAs, some discussion about how to improve the “caring attitudes” of doctors and other healthcare professionals -no follow up noted following this story

Document retrieval: Documents retrieved were those that related to the structures and processes created to support the involvement of patients and families, and the use of patient stories, and potentially, the impact of stories at broader levels of the organization (e.g., in performance measurement, policies). Documents gathered from these organizations include: publicly available strategic plans related to PFCC, mission, vision and value statements, organizational policies related to PFCC, framework for PFCC/engagement, the role of patient advisors, templates for agenda/meetings in which stories are used, templates for program/organizational initiatives which require patient and family advisor involvement, interview guides used by patient and family advisors, and templates to capture patient stories and direct learning from these stories. As well, on each of the organizational websites, there are links to video stories of patients and families who have received care in that organization. Many videos highlight patients and family members who have not had positive experiences of care and the lessons learned; other videos highlight how patients, as a result of their experience of care, are now involved in a variety of ways across the organization to help improve care and services. In the case of CPSI, with PFPSC, patient stories are shared on video available through their website, depicting safety issues that often led to tragic outcomes for loved ones.

Retrieval process: Many of these documents are publicly available, which I retrieved from the organizational website. Many documents were given to me (independently without my explicit request) in the course of our interview discussions (e.g., organizational annual reports, background framework documents). During an interview, if a participant referred to a document (e.g., policy, template) that facilitated the use of stories, I then requested a copy of this document for further study. In the case of GHR, I attended a 2-day learning lab where organizational leaders detail their strategies and methods for patient and family centred care

established within their organization. As part of the learning lab, a number of documents (e.g., policies, job descriptions, evaluation tools) were provided for all participants. All of the participants were receptive to being contacted again in the future to obtain further documents if needed.

Data transformation and management

With the exception of two interviews, all interviews were audiotaped and transcribed verbatim with the consent of the participants. Of the two exceptions, one participant declined to be audiorecorded; in the second interview, there were technical failures with the audiorecorder. In both of these instances, participants allowed me to take notes on my laptop computer throughout the discussion. I tried to type as much verbatim as physically possible; however, the length of my notes in relation to the length of the verbatim transcripts were much shorter, and in some areas, details more scant. While I tried to maintain as much accuracy as possible, inherently there is interpretation that occurs simultaneously with writing notes, and hence these notes reflect the overlay of such concurrent interpretation.

A professional transcriber was sent the audiofiles via secure channels, and I immediately deleted the audiofiles from the server once the transcriber had received them. The transcriber then returned the verbatim transcriptions to me as electronic files, again through secure channels. Transcripts were immediately deleted from the server and then stored on my personal, password-protected laptop computer. All identifying information was removed from the transcriptions, and given a code name. Code names and identifying information were stored in a separate file on my computer.

The act of transcription is not a simple one, even though the terminology of ‘transcribed verbatim’ would suggest a rather straightforward act. Inherently, transcriptions are representational and interpretive in nature (Poland, 2002). A professional transcriptionist

completed the initial transcription of audiotape and was instructed to remove any names within transcripts. I provided general instructions to the transcriptionist on how to manage names, pauses, and other speech utterances. Once I received the transcript, I then listened to the audiofile along with the transcription to review the transcript for any errors or to fill in any gaps missed and to ensure consistency for how pauses and stutters or other speech idiosyncrasies were handled. I tried to ensure a faithful representation to what was said, while at times, ‘cleaning the data’ to ensure the meaning could be understood (thereby removing some stutters, involuntary sounds). No transcript can ever be a truly faithful reproduction of what was said (Poland, 2002); however, reviewing the transcript together with listening again to the audiofile helped to ensure consistency in how tapes were transcribed. Lapadat and Lindsay (1999) suggest that “transcription facilitates the close attention and interpretive thinking that’s needed to make sense of the data” (p. 82). Throughout this process, I began to take memos while re-listening to the audiofiles, checking not only accuracy of the transcription (which for the most part, were quite accurate), but listening for other cues (e.g., laughter, repetitions) and intonations and pauses in speech and how any of these elements may provide further depth in understanding and interpreting the written form. Listening to the audiofiles again also helped to formulate early moves in analysis, again through memo-writing, re-visiting the field notes written at the time of the interviews, and hence the beginnings of formulating analysis, which is described in more detail below.

Data analysis

Analysis is not about adhering to any one correct approach or set of right techniques; it is imaginative, artful, flexible, and reflexive. It should also be methodical, scholarly, and intellectually rigorous. (Coffey & Atkinson, 1996, p.10)

The data analysis that I conducted followed some fairly typical “analytic moves” (Eakin, 2013, personal communication) used in many different forms of qualitative research,

as well as specific techniques used to deepen the analysis and interpretation. To enter the data, I first started with ‘open coding’ to sensitize me to concepts and ideas emerging from the data. The process of open coding affixes codes or labels to passages within the data, and is a fairly conventional entry move. I then used two specific analytic techniques that helped me to “open up the data” to interrogate it in fresh ways, and to break through the “analytic paralysis” (Clark, 2005). First, I used situational maps and analysis, a technique described in detail by Adele Clark (2005), a ‘research workout’ that helped to provide clarity to my work, and to evolve my thinking in relation to the data. The second technique that I drew from was conducting layered reads of the data, as described by Mauthner & Doucet (Mauthner & Doucet, 1998)(1998), taking concepts that have emerged from the data and from the situational maps and then returning to the transcripts and reading specifically for that area of awareness.

Clark (2005) describes three types of situational maps and analyses: (1) situational maps as strategies for articulating the elements in the situation and examining relations among them; (2) social worlds/arenas maps as cartographies of collective commitments, relations, and sites of action; and (3) positional maps as simplification strategies for plotting positions articulated and not articulated in discourses (p.86). Together, these maps help to answer key questions of the project: Where in the world is this project? Why is it important? What is going on in this situation? For this study, I created the first of these three maps, a situational map to describe the situation and its relations, the situation being the locus of analysis, that is, the telling of and learning from patient stories. Once the situation has been identified, Clark suggests asking: “Who and what are in this situation? Who and what matters in this situation? What elements make a difference in this situation?” (p. 87). This situational map included all analytically pertinent human and non-human actors, material and

symbolic/discursive elements of the situation of interest, as framed by those in it, and by the researcher. “Researchers should use their own experiences of doing the research and data for making these maps” (p. 85). Thus, an ongoing reflexivity was required as I engaged with the data to create these maps. Ironically, as I worked through my first map, reviewed and revised over time, I realized that my original map did not include ‘stories’ on it. I had assumed that stories rested with the patient as a human actor. However, returning to the transcripts and reflecting on a recent site visit, I realized the story resides in many places and with many people. Sometimes the story is a ‘patient story’ but at times, it is a story *about* a patient. The goal of this first map was to identify relations – in this case, what are the relations involved in the ‘telling of and learning from patient stories’. Creating the situational map forced me to articulate where these relationships are and why (see Appendix F for the ‘ordered version’ of this situational map). From the ordered version of maps, Clark moves into relational analysis, to isolate one specific element, and to consider each other element, one by one, in relation to this first identified element, and then to repeat this exercise with a second specific element, and so on. I completed two rounds, very purposeful in choosing the elements and their relations from two specific vantage points: the telling of and learning from stories from the patient perspective and from the perspective of leaders (i.e., what are the elements that are drawn out/related to the patient, and those that are related to leaders). Doing so helped to highlight those elements that overlapped, and those that were more important from one vantage point or the other.

Once I had created this first situational map with relational analysis, I drew on the second technique: I conducted layered reads of the data, sensitized to concepts emerging from the data, and then returned to the transcripts and read specifically for that area of awareness. For example, after creating the situational maps and becoming sensitized to the

concept of the patient story as a non-human agent, I began to pay particular attention to different elements of the story on different reads, for example, the type of story told, who told the story, and how stories were framed as ‘patient stories’ by patients and by leaders. These layered reads helped me to deepen the analysis to what eventually formed the three chapters of results – filtering and sorting through the stories themselves, the storytellers, and the organizational context that enabled stories to be told within these organizations. In particular, I was guided by a ‘voice-centred relational method’ of analysis, as described by Mauthner and Doucet (1998). The foundation to this method is based on ‘relational ontology’, where humans are seen as interdependent (rather than independent) within their social contexts. Voice-centred relational methods provides a way of exploring individuals’ narrative accounts in terms of their relations to the people around them and their relationships to the broader social, structural, and cultural contexts within which they live. The technique involves four readings that take different perspectives and foci. As I began to move the codes into larger conceptual thoughts, I then began to trace and look for these elements during specific reads. Mauthner and Doucet (1998) describe this first reading as one that provides an overview for the overall plot and story that is being told by the respondent. The piece most meaningful to me in this reading/re-reading was the reflexive nature of reading for myself in the text, how I place myself, my own experiences, and how I responded intellectually and emotionally to the participant. During this read, I noted my own subjectivities and changing positions emerge. For example, when I reflect on the interviews conducted with patients, and then those conducted with leaders, it is clear that different facets of my knowing come to the fore: with patients and caregivers, I take on a very empathetic tone based on our shared experiences within the healthcare system, and my aim to give them voice to express not only their stories, but also understand their readiness to share their stories, their motivations and intentions – in

essence, it is as if I am ‘one of them’ and looking to learn through their experiences. For example, consider this exchange with a family member:

FAMILY MEMBER 8: My story or my family's story is so much more than that. It's so many, it's circumstances, there's so many situations that it's months of experiences.... there's just so much more that you know, and there's just so much more that is involved....

INTERVIEWER: You're absolutely right cause when I think of my own, the story that I would want to share, that piece is only one piece of it. There are many others.

FAMILY MEMBER 8: Yeah, you see what I mean. Yeah.

INTERVIEWER: When you think of the journey that you've been through, together with your family.

FAMILY MEMBER 8: Exactly that's what it is, it's a journey. Along those ways you have some low points and that was a low point and you have some higher points. (Chuckle). I don't know if you have some high points, but you have some not so low points.

However, when I consider my stance when interviewing leaders, I again have taken an ‘insider’ stance as someone who works within the healthcare system – previously as a clinician, and currently someone who is involved in quality and safety, as a ‘knowing’ professional who understands the challenges and difficulties in doing this work. In some instances, I see how I have taken on the role of ‘cheerleader’, congratulating the leaders for their work, almost encouraging them to tell me more in such a positive light. These are organizations seen to be exemplars in the area of patient engagement, and my assumptions that they are indeed leaders reinforces their positive responses about their work.

This first reading provides an opportunity to reflect on how I, as interviewer, have provided the context in which the interview was conducted, my interpretative moves throughout the interview that has shaped the production of data, and ultimately the interpretation and analysis of these interviews. What is interesting for me to note is how I become a chameleon of sorts, playing up my multiple roles to be seen as an ‘insider’, and

how this shapes data production and the interpretation. “When the readers’ different perspectives on a text are made explicit, the different interpretations should also become comprehensible” (Kvale, 1996, p.212).

The second reading focused on how the respondent experienced, felt, and spoke about him/herself, to recognize the social location of the person interviewed. For this reading, I began to pay specific attention to who the storyteller was, particularly those storytellers who were patients or family members, and how they began to identify with their particular organizations.

The third reading involved a close examination of relationships. Organizations comprise individuals and teams, and it is through their learning that an organization ‘institutionalizes’ learnings (Crossan et al., 1999) in the forms of processes, structures, policies, and cultures. These relationships are foundational to organizational learning, as learning moves through different levels to become institutionalized. Underpinning the use of patient stories are the relationships that patients and families (as individuals) hold with other individuals, teams/programs, and the organization as a whole, that allows their voices to be heard. Reading intentionally for these relationships highlighted issues of power and authority in how these relationships have been formed, with whom, and have evolved over time.

The fourth reading entailed consideration of respondents’ narratives within broader social, political, cultural, and structural contexts. Reflecting on the complex milieu of healthcare, it became evident to me that the organizational learning framework posed for this study (see Chuang et al., 2007) was inadequate to fully capture the essence of my findings. Initially this framework spoke to me for its multi-levels of learning, highlighting the relationships between the various levels and how learning moves from levels of the individual to team to organization. An underlying assumption that I made was in the use of

“patient knowledge reservoirs” (Argote, 1999), an acknowledgement, interest, and value that others may have for the knowledge and experience patients bring. Two issues are raised here: first is the paradox of ‘evidence-based’ medicine, with a highly professionalized workforce that has been trained to view certain forms of ‘evidence’ as legitimate; and second, that of patient stories, experiences of patients that are ‘true’ to patients. Bringing in the work of Lawrence et al. (2005) and considering professionalized forms of power from the literature helped me to consider the inherent power hierarchies that exist and what is seen as legitimate forms of knowledge within this highly professionalized evidence-based workforce, and also who is invited to share their stories within these organizations.

Throughout the analysis, I consistently asked myself: ‘What is this an example of?’ and ‘So what? What is going on here?’. As a result, I created numerous memos as I began to bring together codes and concepts. Memos were used as a way to construct and re-construct my emerging and evolving analysis, helping to elaborate on categories, specify their properties and define relationships, and identify gaps, throughout the time of data gathering-analysis cycle. While the techniques described by Clark (1999), and Mauthner and Doucet (1998) helped me to dig deeper into the data, I did not rigidly adhere to these analytic devices detailed above, but rather used a ‘flexible’ practice for fit within my study.

The analysis described above takes into account the transcripts from individual interviews, and observational notes written at meetings and forum where patient stories were told. The documents obtained from organizations were reviewed, and memos written as they pertained to the issues raised by participants in interviews or in the observations. The documents were used primarily as artifacts to support issues identified by participants, and as demonstrations of how organizations put into place structures (e.g., by way of policies) and

processes (e.g., by way of documentation and templates) that required patient involvement at various levels of the organization.

While I initially used the software program *Hyperresearch* to house the transcripts and to begin coding, I could not resist the urge to move into thinking with the data and conducting linkages and analysis with coloured highlighters and pens, making notes in margins and ongoing memo-writing and note-taking throughout the process. For me, this process created a tactile connection with the data that facilitated my thinking.

The process of writing is also an act of analysis (Hammersley & Atkinson, 2007), and much of my analysis in the later stages became refined as I started to organize my thoughts in the broad buckets, filtering through the memos and notes and codes to create the output in the three results chapters that follow. I have decided what is in the foreground, what becomes background, and how to coherently weave elements of this study together for a particular audience. The act of writing up the research is as much a part of the analysis as the data collection (Hammersley & Atkinson, 2007).

Ethical considerations

This study was approved by the Health Sciences Research Ethics Board at the University of Toronto which sufficiently satisfied ethical review for all of the case study sites except for one. Research ethics approval was requested and obtained from the Thunder Bay Regional Health Sciences Centre. These applications addressed concerns of informed consent, outlined risks and benefits of the study, and detailed processes to ensure anonymity and confidentiality of participants. The participating organizations in this study were those identified by key informants as known leaders in North America in the area of patient and family centred care and for their use of patient stories for learning and improvement. Consistent with other case study reports in the area of quality and safety (see Baker, Denis,

Pomey, & Macintosh-Murray, 2010; Nelson, Batalden, & Godfrey, 2007), organizations have been identified as exemplars in the field, and from whom others may learn from. Thus, in this study, the organizations have been identified with their signed consent and some contextual information regarding their organizations and their journeys toward PFCC has been provided.

All interview participants gave their signed consent and they were offered a copy for their records. Board members and committee members also provided signed consent to allow me to observe the meeting where a patient story was being told. While there may be some assumptions made of the identity of participants in this study based on their position within the organization, the results have been presented in a format that generally does not specify which organization has specific structures or processes in place, nor are quotes attributable to any specific leader, patient, or family member within any one of these organizations.

I also took a number of measures to ensure the confidentiality and safe-keeping of information gathered in the course of this study. All hard copies of transcripts, field notes, and other documents provided were stored in a secured cabinet to which only I had access. I used secured lines of communication to transfer audiofiles and electronic documents to my transcriptionist; these files were immediately deleted upon receipt. As well, any electronic files, including transcripts, audiofiles, field notes, and analysis have been stored on my personal, password-protected laptop, to which only I have access. Identifying information has been removed from all transcripts; each participant was given a code name which was used on the transcripts and any other linked documents. A master list of participants with linked codes has been stored separately from the transcripts and audiofiles.

Researcher reflexivity and positionality

We are telling stories of our participants filtered by our own individuality.
(Mantzoukas, 2004, p.1002)

Taking a social constructivist stance to this research, and understanding my own role in the researched-researcher dynamic, I would be remiss as a researcher to not explore my own positionality and location with respect to this research, and to the actions, decisions, and interpretations I have made throughout this research process. Indeed, a different researcher would have different relationships, respond differently to research decisions, ask different questions, and experience different replies (Finlay, 2002). Reflexivity is a means of interpreting one's own interpretations, looking at one's own perspectives from other perspectives, and turning a self-critical eye onto one's own authority as interpreter and author (Alvesson & Skoldberg, 2000, p.viii). There are many *reflexivities*, rather than just one reflexivity, as there are many “ways of seeing which act back on and reflect existing ways of seeing” (Clegg & Hardy, 1996, in Alvesson & Skoldberg, 2000, p.248).

According to Doucet (2008), there are three sets of relationships through which we construct knowledge whereby we need to consider our own positionality: relationship with oneself; with research participants; and with one's readers, audiences, and epistemological communities. I start with considering my own motivations for my research area of interest. I am a healthcare professional who has worked many years as a front-line clinician in acute care and rehabilitation hospitals. My professional interests evolved, and further education has taken me away from the front-lines and point-of-care clinical problems, to consider healthcare more broadly and the systems in which people work and are cared for. But ultimately, my clinical roots make me gravitate to asking research questions in ways where I hope to impact and provide benefit to those that need the care – ultimately how does this benefit the patient? How does this work acknowledge the patient as a partner in care? Thus, my proposed research area, an exploration of patient stories as a mechanism for

organizational learning—in essence, how do organizations learn from patients?—explicitly values the contributions and knowledge that patients bring to the healthcare encounter.

From an interpersonal perspective, I have experienced first-hand the ‘positionality’ as a healthcare professional, as a patient, and most recently as a family caregiver and advocate, and the power relations inherent within these patient/family-provider interactions, and provider-provider interactions. These experiences have shaped how I listened to the ‘voice’ of the patient, and heightened my awareness of the inherent hierarchies that exist in having this voice heard.

The second relationship Doucet (2008) speaks of is the relationship between the researcher-researched. The oft-cited phrase ‘the researcher as instrument of the research’ is consistent with a constructivist approach that I have taken to my research, understanding that my subjectivity, my positionality has shaped the construction of knowledge with the participants. Implicit in the co-construction of knowledge is how my own subjectivities, including my values, beliefs, and emotions, play into the framing of research objectives, as well as discourses such as age, education, gender and ethnicity that have influenced how data has been gathered and interpreted (Hewitt, 2007). As noted previously, I see how I shift myself to become an insider with both patients/families and with leaders in these organizations and take these into account, particularly as I have moved through the analysis phase.

Lastly, the third relationship expressed by Doucet (2008) in the production of knowledge highlights the relationship between the researcher and one’s readers, audiences, and epistemic (which includes theoretical and epistemological influences) communities that shape our work in subtle and explicit ways. Epistemic community (coined by scholar John Ruggie) refers to the “dominant ways of looking at a social reality, a set of shared symbols

and references, mutual expectations” (Ruggie, 1975, in Doucet, 2008, p.81). Thus, the decisions I have made throughout the research process, what I have chosen to foreground and to background, brings me to the need not only for reflexivity, but also to consider the “logic of justification” (Piantianda & Garman, 2009) as a means to make visible the congruence and interrelationships between epistemology, methodology, and methods and to articulate this logic of justification in a clear and cogent manner, in essence, the extent to which the procedures ‘fit’ with the knowledge generating assumptions that underpin the inquiry. Mismatches between these assumptions and the research procedures create logical inconsistencies or conceptual flaws that compromise the credibility of the study (Piantianda & Garman, 2009).

Writing is “a way of knowing, a method of discovery and analysis” (Richardson, 2000, p.924), and as such, through my consistent memo writing and the use of a reflexive journal, I have made attempts through all phases of the research process to write as a systematic means of searching for my own subjectivity through the use of such a journal. The use of a reflexive journal created an audit trail for the research process, an essential component of ensuring trustworthiness and establishing rigour for the study.

Conclusion

In this chapter, I have articulated the methodological and study design principles adhered to within this study. First, I explicated the use of case study design as congruent with the theoretical and constructivist framing of this study. I have also outlined in detail the study design methods used. The attention to detail was not intended as a means by which others could replicate the study. Rather, it aimed to highlight my own researcher reflexivity

throughout the research process, the theoretical and methodological congruence, and methods used that would allow for assessments in the quality and rigour of this qualitative research (Kitto, Chesters, & Grbich, 2008). Further, I have also provided a brief outline of the organizational settings that constitute this case study, to offer a frame by which to consider the analytical interpretations in the following chapters.

Chapter 5

The Story

We assume we know, but we don't know, we are not the experts. We are the experts in clinical care, best practice, but we are not knowledge holders of experience. (Leader 17)

The focus of my study has been on patient stories that have been shared in organizations for the purposes of learning and improvement. What has emerged in this study through interviews and observations are those stories that describe the *patient experience of care*, that is, the care that patients have received in the healthcare organization, and the impact of this care on their experience as patients. Such stories do not necessarily discuss the outcome of care (i.e., the recovery of patients) or the type of treatment received. In some instances, the patient experience of care describes adverse events that for some have led to devastating consequences, but the majority of stories revealed in this study speak to the experience of being a patient within the healthcare organization, and the impact that this experience had on them.

In this chapter, I will explore in greater depth the type of stories told by these patients and of patients in light of Frank's (1995) typology. These are stories that are "the truth" of their experiences, as seen through the eyes of the patients. Stories are performative acts (Boje et al., 1999), co-constructed by teller and listener in a social context, narrated in ways that are both implicit and explicit, and as found in this study, they are expressed in specific ways to incite learning. As such, I explore how stories act, but also how they are strategic actors, purposefully used as connectors to galvanize action and serve as equalizers. I conclude this

chapter with an examination of these stories in action, taking a look at how stories have led to action and been used in purposeful ways for change.

It is important to note that while I refer to “patient stories” throughout this dissertation, I use this term to encompass stories that have been told not only by patients, but also those told by family members about their perspectives of the care experienced by their loved one or their own experience as a caregiver. While I recognize that there are obvious distinctions between the perceptions of patients and their family members, for the purposes of this study, I have put patient and family stories together because they are generated from the perspective of someone outside (or not employed by) the organization. Also, while I use the term “patient story” for the sake of simplicity, I do differentiate between stories *about* patients told by leaders and stories that are told *by* the patient or family member.

These stories represent “*the patient’s reality and that is true*” (Patient 4). This reality may be quite different than what is perceived by staff or leaders, “*presenting as it is, not as a health practitioner’s thing, or how I would even like it to be, ‘cause that’s not happening yet....but how it really is, and I think that’s what we have to do*” (Family Member 7). But what is truth? Patient and family participants spoke of the “*true stories*” that they told. Some elements of the story were felt to be “*fact*” and therefore verifiable and true (e.g., a test performed or the length of time waiting for an appointment). “*Truth*” was qualified by patients and leaders as “*true in the eyes of the patient*”; that is, as it appears from their perspective, which to some patients, was the perspective that mattered most:

I think it's all about perspective, and when I think when you tell a story, can we be a hundred percent, and say that story's a hundred percent true?The perception, it's a gray areaBut perspective is everything to the patient, and really that's who's important, is the patient...what they feel at that time is the truth. It's the truth, this is what happened to me, right?...that's the patient's reality and that is true. It doesn't matter what your truth as a clinician is, it's what the patient's truth that matters.
(Patient 4)

As Frank (2010) tells us, we live with “complicated truths” and stories do not exist alone; they continue to be (re-)negotiated and (re-)storied (Boje et al., 1999). As noted by a leader,

it's [the patient's perception] not right or wrong, but it's a way that we learn from our patients and families....and if their perception of care is a bad perception, then we need to learn from that....and if their perception is a great perception of care, then we need to build on that. (Leader 2)

A typology of stories

My story, or my family's story, is so much more than that...there's so many situations that it's months of experiences. This is one incident that happened in my story. It's just one that seems to resonate with a lot of people. (Family Member 8)

Patients pointed out that their lives and experiences are not encapsulated in just one story, but that there are many stories of their experiences. Many of the stories shared by patients and families in this study express their sincere gratitude for care received. However, the majority of stories shared by patients and leaders in this study followed a similar arc, depicting details where care was deficient (although not necessarily erroneous), and in some instances, where it led to devastating harm and tragic outcomes. What emerged from many of these stories was how it felt to experience care in this way, and a strong emotive value was tied to these stories. For example, patients recounted experiences where they were not included in the decision-making processes, assumptions were made about them or their family member, they received a lack of care and respect, or they had to deal with poor processes of care. They also described the impact that these situations had on their experience of care (both immediate and long-term) and the “feeling” they had as a result: anger, fear, mistrust, frustration, sorrow, and bewilderment.

These stories are co-constructed between storyteller and audience, based on narrative templates (Frank, 2010) that are socially and culturally determined, both implicitly (i.e., by the norms around patient stories and the types of stories told within these organizations) and potentially explicitly (i.e., through specific storytelling templates created to recount patient stories). Thus, what has emerged in this study are many stories of chaos, stories that describe experiences of sub-optimal care, but which go on to become quest narratives with the specific purpose of learning from such stories. Hence, these stories of patient experiences of care follow a common thread based on Frank's typology. The chaos often describes poor care processes, miscommunication, medical errors or a perceived lack of caring attitudes, much of which is beyond the control of these patients. However, in the telling of their stories, patients and leaders in these organizations move from the chaos that has resulted to make these stories into quest narratives. Patients are not looking for the restitution narrative; they do not want the status quo restored or preserved. Instead, they seek change as a result of their experiences. In the act of telling their stories, these patients may be initiating their own quest to gain wisdom and remove obstacles in imagining a better future or, in this case, better care.

For many of the patients who tell their stories, it is about the process of reflecting and describing this chaos—that something could have been better, something was not quite right—that propels them to tell their stories and hope that through sharing this experience, they may make a difference to others in some way. As one family member describes:

So when I shared that story I didn't know what the problem was, I didn't know how to fix it. I just knew, here's an experience, and so that's where the conversation started with the [organization] and the questions were asked....So I didn't know what could be different; I just knew the challenges, and I just knew the impact and the feeling.
(Family Member 6)

In this example, the family member continues to elaborate on the ensuing discussion that was prompted by leaders who continued to ask “and then what happened?” and “what if...?” as

stories become co-constructed as quests for learning. The quest comes through motivation to share patient stories “*so that it doesn’t happen to anyone else,*” where patients ultimately imagine a different ending than the one endured by them or their families. Patients speak of how they choose which stories to tell, selecting chaos stories that present “*adversity,*” where “*you go by gut,*” and the ones that “*hurt the most.*” As one patient explains, “*I pick the ones that do cause me the most pain, and they’re the hardest ones to tell*” (Patient 2), as those stories will have the biggest “quests”—where learning and change have the greatest potential. These are stories that may also have the greatest salience to the audience, resonating in ways that demand change. The shock value exists in some stories “*because they’re [the stories are] so horrific, that you think this needs to be shared because it should never happen*” (Leader 16). Leaders acknowledge the impact that the most egregious stories of care can have, noting stories that are particularly salient act as a call to action:

I think those stories are really powerful in the moment...we made such a big mistake, we can never afford to do that again, or it was a near miss and it could have been a catastrophe. Those things move you to action. Those stories move you to action because the price of not acting is so high, both ethically, morally, financially....those stories move you to action. (Leader 3)

Leaders ensure that stories told within the organization are those that take a patient’s story from chaos to quest, and in some instances, they guide the audience on this quest by facilitating the learning that can come from a story. For example,

When videos [of patient stories] are shown, they’re usually shown in context, right? So you can frame it around what’s happened after the fact, what improvements have been made, etc. ...and so it’s really how you facilitate that discussion and talk about it that makes a difference. (Leader 16)

Thus, while the story itself may be powerful, it is the opportunity for intentional dialogue and reflection that helps to create the opportunity for learning (Kumagai, 2008). The intent of the story and its trajectory is clear—the process of learning and actions become embedded in this

quest journey. Leaders want to make the learning evident to all; thus stories to be shared may be carefully chosen to fit this purpose. In this way, leaders not only co-construct the patient stories, but they also begin to craft the story of the organization, portraying it as one that listens intently to the patient voice and is responsive in its actions:

And so when we have advisers tell their stories at the board, it's never someone that their issue hasn't been dealt with, and we haven't worked through that issue already, and made improvement efforts. It's someone that we've worked with, we've been working with. They came forward, they told their story and we said, "oh, how we really need to make some improvements in that area." So it's a chance for them to tell their story at the board, and then it's a chance for our administrators at the board meeting to also say, and since this story, this is what we've done about it. So it's a way for the board to see first hand what the patient experience was, and to see as an organization what we've done about that experience. (Leader 22)

As patients and leaders decide on which stories they choose to tell, those with the greatest impact for learning or those that can demonstrate learning are the most appealing.

Table 4 below provides examples of how patients frame their stories, making them into quest narratives as they focus on the learning that results.

Table 4. Examples of stories told by patients: from chaos to quest

The chaos narrative	Feelings evoked	...into the quest narrative
<p><i>Process issue: test results not available at time of appointment (Patient 3)</i></p> <p>“There were a lot of, not mistakes, but there were a lot of things that just should have been done differently, or treated differently....But with this situation that happened with this biopsy report, it got lost...and I was upset, 'cause this had been the umpteenth little mistake that had happened, and I was very tense about it obviously. It was another biopsy. I didn't know if the cancer had come back. The stress amount you're dealing with is off the charts.”</p>	<p>Fear, anxiety and frustration</p>	<p>“This shouldn't be happening to people.” “If things are happening to me, they're happening to other people. It just can't be me falling through the cracks all the time here. I don't want this to happen to anyone else.” “It's not going to be changed if you don't bring it out or talk about it.” “I'm hoping I'm helping other people.” “This is my life I'm talking about. I'm going to the person that can probably correct it.”</p>
<p><i>Communication with family: assumptions made by healthcare professionals regarding causes of accident (Family Member 3)</i></p>	<p>Frustration, helplessness and despair</p>	<p>“It's been a long journey.” “You know, to have that silence, to not</p>

<p>“Our [family member] died of a medical error, and really it was communication: not listening to the family who knew [family member] best, and not hearing what we were saying. They stereotyped him; he was xx-years-old. And, unfortunately, they were biased in their care of him because of that....So I brought my concerns to the nurses, over and over and over again, but they fell on deaf ears. And he deteriorated further....I said something is going terribly wrong, and nobody will listen to me....And then afterwards, you know, the silence. I mean when he crashed, it was like we were totally alone in that bustling, busy, noisy place. The silence was deafening and we had no support whatsoever. The staff did not want to interact with us in any way, shape or form because they knew things had gone wrong....And why wouldn't they listen?....But you know, when your [loved one] has died unexpectedly, you want some arms around you, you want somebody to share in the grief. And unfortunately that did not happen. So that just added to the pain.”</p>		<p>be able to know in my heart of hearts that something had gone wrong and that somebody else might suffer the same thing if improvements weren't made, if it wasn't acknowledged, that was harder.”</p> <p>“I continued to work with them. I wanted to make things better. I wanted them to see that patients and families aren't, you're not to be fearful of them, you're to partner with them. And it's a win-win situation for everybody. So I was always very respectful and I wanted to show them that it could be a good relationship, partnership.”</p> <p>“It's all patients, all families, who experience less than optimal care, that we can learn from and that we do learn from.”</p>
<p><i>Lack of respect for patient and family: assumptions made by healthcare professionals who did not understand mental health issues (Family Member 7)</i></p> <p>“I found great resistance [to be able to ask questions]. I found them [healthcare professionals] impenetrable in their attitudes.”</p> <p>“When [the patient] tried to express concerns, [she] was just looked at as someone very sick and demanding and almost called ‘the princess’....She was so much resented. It came to a point where they started drugging her to keep her silent. And I looked at her one day and I didn't recognize her spirit anymore.”</p>	<p>Anger, frustration and fatigue</p>	<p>“Because I was on the ward so often, I saw so many things...it's not just for my [family member], its everybody.”</p> <p>“So I feel telling my story often enough and in a way that lets them know, that I don't want them fired or removed, I'm not saying that. I'm saying, just take another look. Let's all renew ourselves; it's a good thing. That's why I tell my story, for all of us to take another look.”</p> <p>“People have to hear what patients are saying, or what the [families] are saying, because their needs are being expressed, and there is that hope.”</p>

Organizations also use explicit ways to craft stories as a quest for learning. For example, in one organization, templates for stories have been created that lead tellers (patients and leaders alike) to frame their stories (i.e., the patient story) through a lens of PFCC. This template does not guide storytellers to tell certain types of experiences (i.e., what the experience of care was), but it does explicitly guide the storyteller to consider the story in

light of its emotional value, how the experience may be changed or improved upon, and what has been learned as a result. This is a more structured process to capture stories, and allows the organization to develop a repository of stories:

[It creates] a whole bank of stories. We can see the impact that it [the story] is having on the people who hear the story. So it's giving us a little bit more information about the stories, instead of the sharing the story at a council, and that's where it stays....But this way, I'm hoping, 'cause there's so many really fantastic stories out there that will move people that we're not all hearing. (Leader 2)

Table 5 below provides examples of questions used to guide the storyteller to consider the quest narrative, explicitly set in a framework for learning.

Table 5. Examples of guiding questions for patient stories: from chaos to quest

1. What is the patient/family story/experience?
2. How did hearing this story make you/others feel?
3. What could have made the experience of care better?
4. What made this experience of care positive?
5. What have we learned?
6. How will you/others change your practice?
7. What will you/we do with this knowledge?

As noted previously, a plethora of patient stories can be found on the Internet, connected to various healthcare institutions and health-related organizations. It is no surprise then to find videos of patient stories used for educational and promotional purposes on the websites of each of these organizations. For example, there are video clips of patients who share their experience of care, often highlighting deficiencies, before going on to describe

how they have now become involved with the organization to improve this particular situation and its outcome, thereby demonstrating and promoting a caring institution that not only listens to its patients, but that learns from them and involves them in solution-finding. In other videos, it is a senior leader who briefly describes a patient story, speaking about how the organization has responded by changing a variety of processes related to safety and quality of care based on this story. There are also a series of patient videos that share heart-wrenching stories of care that have led to devastating and often tragic consequences for patients and their families. These stories highlight numerous system-level issues that can have detrimental effects at the individual level of care and to which we should be attentive. These stories offer lessons to learn and hope for change in the future. On another website, rather than videotaped stories, there are patient photos and written vignettes of their stories, each of which focus on patient journeys of illness; this promotes the institution's provision of treatment and care and provide inspiration as stories of recovery. All of these stories serve to humanize care, presenting the patient as a person. Taken together, these stories also are ways for the organization to craft its own story, presenting itself as an organization that is attentive to the patient voice, invoking learning and change in light of these patient stories.

While many organizations are keen to use technology as a means of broadly sharing patient stories on their websites, and available for future use in meetings or other forums, telling a patient story is not a simple process of videotaping a patient telling their story; rather, there is careful construction of these stories before they are immortalized on video. Patients may recount stories in their own words and choose the details and experiences that they deem important to share. However, patients are crafting their stories and choosing their words based on a perceived audience. Leaders also are crafting the story during the editing process; at times, this can be a fairly rigorous edit, involving dramatically reducing lengthy

videos to a final product that is mere minutes long—in essence, a re-storying of the story. Decisions are made about what parts of the story to tell, and ultimately what the message is for each story. In some cases, a professional interviewer is used, and the editing process is left to professionals who re-frame and re-shape the story, taking the chaos of the story and turning it into a quest for learning.

We do try and end every story on a message of hope. And there's a lot of thought why we do that because these [patients] wouldn't even be [part of the organization] unless they wanted hope for the future. And I hear a lot of them say, "I want my [family member's] life to mean something"And so I think that's why we share the stories.
(Leader 6)

Thus, there are many filters on a patient story, even when the patient tells the story directly; it can be reshaped by others and framed for learning: *"It's complete trust and faith that we will do their stories...justice, and present them in the best light....And I've never had a negative experience with that....Everyone's been very, very thrilled with the outcome"* (Leader 6).

Thus, the telling of stories that relay episodes of chaos can be turned into a quest journey of hope, that is, for improvement and learning. In this way, stories become strategic tools for both patients and leaders.

Stories as strategic actors

Stories are told in purposeful ways and often with specific aims in mind. For example, many patients in this study thought very carefully when determining which stories they chose to tell. As noted above, patients described selecting stories that were the most painful to tell because they perceived them as being the most impactful. But in some cases, they also considered who the audience would be and the overall message they wanted to impart to that particular audience in order to tailor the learning to make it relevant to the

audience: *“Sometimes your story changes based on whoever your audience is, so you want to pull what’s most crucial when you want to talk to a doctor or talking to a nurse”* (Family Member 6).

Leaders may also influence what stories patients choose to tell. For example, patients describe ways in which leaders helped them prepare for their story, not *“tell them what to say”* but rather helping them think about their audience and what message they wanted to convey:

That’s been my experience with speaking....at the time I got together with [a leader] before that time, and she kind of laid out the venue, and who the audience was, and talked about my experiences. And we kind of decided what I wanted to share, and what would be good to share, and then in what ways. So then it’s not told what to say, but it was just really purposeful, right? So you know who you’re talking to, you know what you’re going to share, and she kind of helps that way. (Family Member 6)

Both patients and leaders were quick to emphasize that leaders do not tell patients what to say, but rather provide guidance as to what the focus or priority should be for the audience. While subtle, leaders within these organizations ensure that these patient stories are re-crafted in strategic ways to turn stories of chaos into those for learning. Some leaders describe this as *“coaching,”* where they are purposeful in guiding patients to determine what to focus on, depending on the audience:

So coaching them [patients]... ’cause some of the stories, they have so much good information that they just need somebody to help them say what the top priorities are. Because I can tell you another part of my story that’ll address another concern, but maybe that’s for a different group....So what’s in my story, what is the best for me to tell at this point in time? (Leader 2)

Stories as connectors to motivate for change

The power of a story is undeniable. Much has been written about stories and how they can connect at a human level: *“It’s clearly human nature to relate to stories, to relate to*

people, and to relate to people like us....So that's why or how we use it [the story], just to make abstract ideas more tangible" (Leader 13). The stories told by patients act as connectors, linking patient experience to the emotion and empathy of staff and leaders, reinforcing healthcare as a *"touch business"* (Leader 12), emphasizing how the work done within these organizations affects the lives of the patients it serves. There are underlying assumptions that healthcare professionals who are in the *"touch business"* are caring, empathetic people. As such, stories then remind people of their professional roots of empathy:

I think we just kind of get desensitized to that [work in the hospital] and so sometimes I think the purpose of sharing patient and family stories is just to bring staff back to why they probably entered into the profession in the first place and just helping them reconnect with that in a different way, in a way that maybe they haven't for a while. (Leader 16)

In particular, having patients recount their story helps to humanize the situation, giving a face to the issue—in essence creating ‘human data,’ and in doing so, one becomes more connected on a personal level:

Well, a huge strategy is the patients' stories....there's a difference coming to the table and I'm telling you the story and showing you the data. But when I can bring you somebody who's gone through it and what it meant to them, there's a change in attitude and they [leaders and staff] take that seriously. You can't argue with the person sitting at the table. Well, you can, but they don't because it's a real life story that they [the patient] went through and that's the impact it had on their life. It's not just about data, right? It makes a big difference. (Leader 5)

The stories that cause *"the most pain"* and *"hurt the most"* also seem to be stories that resonate with the audience, provoking an emotional reaction and evoking empathy.

I don't know how many hundred people were there, probably four or five hundred people. It was pretty quiet in the room when I was telling it [the story]. And I had a lot of people come up to me after, lots of people...and said, oh wow, that really resonated with me for whatever reason that was. Maybe as a healthcare professional, but...the feedback I got directly from individuals that work in the system that came forward and said, you know what, I work in the system and I still had a similar situation happen to me. (Family Member 8)

Tapping into the empathy of the healthcare providers who “*came to me, not as healthcare professionals, but came to me as sisters and brothers, wives and daughters*” (Family Member 8), helps put people in others’ shoes and “*begins to level the playing field*” (Leader 21). The leaders within these healthcare organizations have recognized the power inherent in the healthcare system, and they see the ability of patients and families to share their experiences with others as a way to give them voice—and in essence, episodic power—to allow others to acknowledge the expertise of patients:

I don't want to miss the fact that there are other sides to some stories. But I think [area of practice] has to really open up and [healthcare] practitioners have to give their stories, but they have to really understand that what they think they're trying to do for the patient may not be what the patient wants or needs, however well intended that may be. And that has been the way it is, we [the professionals] know best. (Family Member 7)

While participants recognize that there are many sides to each story, it is the patient who experiences the entire journey, and it is often this perspective that does not get shared. Hence, hearing patient stories help us better understand this journey from a different perspective:

I think that as a staff person, you think you might have a good understanding of what patients go through in our system. But you only ever see one narrow piece of it, you only ever see the care that their unit has done in terms of pre-op or in the recovery room, whereas the patient is the only person that's there the entire step of the journey. And I think sometimes we forget that. So when they actually get into the emergency room, then they're told they have to wait another eight hours for a bed. Well, they probably have been there twelve hours before. But I think sometimes we miss that, because we're only focusing on one piece of that. (Leader 16)

The sharing of stories looks to support a partnership model, one that does not seek to “even out” power differentials; rather, “it acknowledges that these differentials exist and probably will always exist....the goal of the partnership model is to achieve clarity and insight on

where power is located, assign responsibility, and identify and address what really matters to users” (Greenhalgh, Woodard, & Humphrey, 2011, p.108).

Leaders repeatedly spoke of stories as a way to better understand the patient experience, providing insights that they would not otherwise have as healthcare providers. Insights gained through the sharing of stories and experiences often can have a profound effect that does indeed provide a catalyst for change. Hearing such perspectives also helps healthcare providers reflect on the care they provide, and how the way in which they do so may have considerable impact on the care experienced by patients:

It was a very humbling experience [to hear the stories of patients and families]....And when we heard their stories, there were staff members in tears. And you know, it was a very somber moment....And it was very profound. And so the opinions and the input that staff provided, the tone and the constructive nature of everybody's role on the team, like participation and cooperation was a lot more enhanced [to make improvement]. (Leader 15)

It is through these emotional connections that change and learning are instigated, as people begin to better understand and connect with others’ experiences:

You put people together, you put patients, who have experienced that, with the anesthetist and surgeons and OR nurses. I mean that's basic PFCC, to develop a better way of doing it. But it starts with the story, right? About how awful it was for them, that's how that started. (Patient 3)

Many organizations strategically used patient stories to start board meetings and other senior-level meetings as a way to ensure senior leaders, who are somewhat removed from the day-to-day “*touch business*,” keep patients at the centre of all discussions. Patient stories are a way to “*ground [the leaders] in why they're here....and those human stories putting the face to the purpose [of telling patient stories] is just very grounding*” (Leader 18). They also ensure that “*every patient and their family come first in everything that we do*” (Family Member 8).

Stories that are framed in ways that point out heterogeneous causes (rather than those that “blame the individual”) also act to connect people into a larger whole—in this case, to their workplace and to take pride in what they do. Regardless of where the issue occurred, these types of stories help to remind people that these issues can happen anywhere within the organization, and that they are part of the whole:

It's just an overwhelming, positive response that makes people feel connected to the patient's story, and very interesting how they actually, even though it was a patient who experienced a surgical error, and they work in maternity, they still felt some connection to that....And the other thing I thought was really important was that they felt connected to their organization. So they felt accountable, like they felt part of the problem which was very interesting. (Leader 3)

While stories framed in particular ways may help people feel connected to a larger system, thus promoting learning beyond the individual level, stories that are internalized at the individual level also may provide impetus for staff to consider their work and how it may be improved:

But when you have a story, especially a negative story, we're all proud of our work, right? I don't care who we are. We want to be proud of our work, and if something bad has happened, I think everyone of us wants it to go better next time, right? So I think these stories impact staff that way. (Patient 4)

While the stories emerging from this study tended to be those experiences of care that were suboptimal, learning can also occur from the “good stories,” reinforcing policies, processes, and behaviours, and connecting people to their work. Stories, regardless of genre, have a message to impart and a lesson to learn. Thus, leaders who hear all types of stories may use these positive stories strategically to support changes made and reinforce work done by staff. While it may be the stories of care that connect people to their work, stories can also be used to reaffirm the work people do, also connecting them in this way:

When we hear those stories [positive ones], it actually is very affirming. And so it reminds us that many, many patients come and receive really good care from really dedicated, very talented care providers. So its affirming. (Leader 18)

Stories to action: “take their voice and make some change”

Stories are indeed actors and vital living things: it is the various and inherent capacity of stories that give them their vitality (Frank, 2010). Importantly, as patients tell their stories—and as patients and leaders move many of these chaos narratives to quest journeys—the imagination of these stories make the unseen not only visible but compelling, arousing the emotions of those that hear them. Patients and leaders interviewed in this study could provide examples of patient stories that precipitated change within the organization. As noted above, participants spoke of the emotional impact made with stories, and the value of this emotion for connecting people to their work and the organization. They also spoke of concrete changes and actions made by the organization as a result of stories. When taken together with other sources of data (e.g., compliment and complaint letters, patient satisfaction surveys, incident reports), stories could be the catalyst required to move initiatives forward. To both leaders and patients, these visible changes were explicit representations of how the organization was listening and responding to patients, which then encouraged patients to continue to be involved and share their experiences. Narrative resources are developed as patients hear the stories of others and see action taken, thus imagining different endings to their stories, which then encourage more stories. As noted by one senior leader, *“that’s how it becomes meaningful to the organization as well as to the community and much more than a check on a box....because we do something with it”* (Leader 21). Examples of changes made to policies, processes, building design, and workflow were provided that stemmed from patients sharing their experiences with staff and leaders, and are noted in Table 6.

Table 6. Examples of patient stories (shared by patients and leaders) moved to action

The Story	The Action
<p>A parent relays a story of baby in the neonatal intensive care unit; the baby required urgent attention by medical staff; the parent tried to move quickly out of the way, and in the process, almost tripped over a central line that was inserted, which inadvertently could have been pulled out. The parent perceived that the location of equipment within the room was not ideal, and it created the circumstance where this parent almost tripped over the line.</p>	<p>Parent was involved with the design team to re-design the layout of patient rooms; she recounts this story to the team and her perceptions of poor room design that she felt led to the near-miss. The architect handed her a pencil to draw out a preferred layout; the team agreed with this design, which is how rooms in the new building are currently laid out.</p>
<p>Parents recount an experience of their child heading into surgery; the child was screaming and had to be pried out of their arms, as they were not allowed into the preoperative suite. It was a heart wrenching experience for the parents and the child, creating added fear and anxiety about the operation.</p>	<p>The organization has changed its pre-operative process and now allows parents into the preoperative area until the child is anaesthetized; the child can choose the method of transportation into the pre-operative area, including the use of a Radio Flyer red wagon, a suggestion made by a child to help ease fears of the operating area. Parents and children are also given a tour of the operating area in advance to provide some familiarity and comfort with the area prior to surgery.</p>
<p>“Why do I need to leave when he’s having a bedbath? I am going to leave when he dies.” This story is recounted by a leader who relays a story told to her by a family member who had limited access to her dying husband in the intensive care unit (ICU).</p>	<p>“We flipped ICU on its head” reports a senior leader. Open visiting hours in the ICU are now available to those people most important to the patient.</p>

Leaders also spoke of the evolution of the use of stories beyond board meetings within their organizations, and about the development of processes and structures that facilitate learning from the stories: *“At first, it was kind of sexy to use a patient story because everybody was talking about it”* but now they have progressed to *“doing”* something about it (Leader 3). However, these leaders recognize that how they use stories is part of their *“journey”* toward patient- and family-centred care, where *“we don’t have enough experience yet to say that we have a really structured, solid way of making that happen”* but *“stories are often the ones we probably can learn the most from”* (Leader 21). Thus, while stories can act as catalysts to incite learning, in order for change to happen, structures and processes are

required that allow stories to do their work. The ability of stories to act is explored in more detail in Chapter 7 on “The Organization.”

For these organizations that have clearly embraced principles of PFCC and look to live them in their work, there is no point in telling or sharing stories if action is not taken as a result. Action may take the form of further engagement with patients and families; otherwise, there is a feeling that while “*stories are great, stories can be overused and abused, and I think that you have to find that right balance where you're using stories that are coming out of your engagement efforts that you're doing across your services*” (Leader 22). For all of these organizations, there is an explicit link between patient stories and learning, where the stories themselves are a vehicle for learning: “*So we just have to continue to have folks that want to tell their story, and listen to them and learn from them*” (Leader 2). Leaders were quick to point out that although they use stories strategically as an impetus for change and to garner support for initiatives, the stories are real and authentic: “*So the real stories are not fabricated to fit the situation, but we do use them to make change*” (Leader 5). Stories are not told for the sake of telling—they are not “*roused up because I need to tell a story at today's meeting*” (Leader 5)—but because leaders genuinely see stories for their impact. While stories may not be “*fabricated to fit the situation,*” stories are indeed strategic actors, crafted as vehicles for learning and often stored in the form of videos and written documents, to be used purposefully as needed. Thus, the cycle of exploitation (of current knowledge through the stories crafted and collected in repositories) and exploration (new stories that are gathered) is ongoing.

Conclusion

Many types of stories exist in the healthcare arena. The specific stories that emerged in this study from leaders and patients are those that express patients' experiences of care. These stories are crafted in ways that take stories of chaos and transform them into quest narratives for learning and improvement, and they are co-constructed in subtle ways by patients and leaders. As they are re-framed as quest narratives, they become "authorized stories" to be shared as strategic actors and for particular purposes. Stories also can act as equalizers by creating empathetic connections, seeing and feeling through another person. Stories do act, which leads them to action, but they do not tell themselves; in the next chapter, I explore in greater detail the identity of the storytellers, how they are chosen (or choose themselves), what prompts them to tell their stories, and their performative acts of storytelling.

Chapter 6

The Storytellers

You just hear those moments in people's lives and you feel like you're right there with them. And you just look at these beautiful people, who have so much courage to go on and to share their stories and to try and change the system.” (Leader 6)

In this study, participants pointed to a myriad of ways that patient stories were heard, gathered and shared. There were formal opportunities, where patients and leaders were invited to share their stories. These included conferences or staff/leadership forums (related to PFCC, quality and safety), organizational board meetings, senior management meetings, staff and student education sessions or lectures, hospital orientation and a variety of organizational committees where sharing a patient story starts the agenda. Many patients also were invited to have their experiences videotaped for future use. Informal in-person opportunities also exist to hear patient stories: in everyday conversation between patients and staff, leadership and manager walkabouts, or for PFAs as they participate on committees, working groups, quality improvement events, and in their interactions with staff and leaders. Patients may choose to write compliment or complaint letters (e.g., via online systems, email, or traditional methods), which were a common form of written stories. As noted previously, one organization used a formal template—with direct quotes where possible—to capture the patient story from their perspective (i.e., told by the patient and written down by the patient or someone else). Thus, stories are indeed everywhere. But who shares their experiences of care in these healthcare organizations, and what motivates them to do so? And how do these patients tell their stories to maximize their effect?

This chapter explores the emerging themes related to these storytellers, and how their patient identities are reinforced through their acts of storytelling. I examine patient stories and stories *of* patients, as told by patients and by leaders, and consider what effects this has on the audience. The prime motivation for patients to tell their stories is altruistic, but other positive effects on patients also are also noted. I explore *how* the way in which a story is told can influence the desired change, which demonstrates the strategic and purposeful nature of stories as performative acts. I examine how storytellers are set up for success, through their selection for timing and fit, and how patients self-select to take on this role of storyteller. Lastly, I consider how storytellers feed into a cycle of constructing narrative resources upon which organizations can build.

Who are the storytellers?

In this study, all of the patient and family participants have shared one or more of their stories in some format within their healthcare organizations or other venues. At least 12 of the 16 patient and family participants in this study have been invited to share their stories in formal settings (e.g., at senior leader meetings, large conferences, and education sessions, or in videos and in the media); all of the participants have had the opportunity to share at least one story in informal ways (e.g., as PFAs on committees or working groups, and through interactions with leaders and staff). All of these participants are also PFAs or members of their organizations, and most are highly involved in a variety of committees or specific improvement opportunities. Half of the group is employed but continues to make time to fulfill their roles as PFAs, which may range from 1–2 hours per month to upwards of 10+ hours per week. Many of the PFAs who participated in this study would also be

considered ambassadors for their organizations, as they have accompanied leaders as representatives of their organizations to speak at conferences or other public forums, have been profiled on videos or in media that was used internally or externally, or have participated on broader-based (e.g., provincial or national) committees as a patient representative. Some of the patients and family members in this study have been PFAs within their organizations beyond the two-year term suggested in some organizations; many have had ongoing healthcare service interactions due to chronic health issues.

Because of their extensive involvement with their organizations, patients begin to identify with the organization and its goals: “*It [PFCC] is part of the fabric of who **we** are*” (emphasis added) (Family Member 8). In some ways, the emergence of “*we*” could be construed as a positive sign of how the organization has made concerted efforts to ensure patients and family member feel part of the team, negating an “us and them” attitude. However, this transformation from outsider to insider status may also influence their experiences and perceptions, and what they choose to share. Heterogeneity of teams may provide more opportunity for learning by creating “constructive conflict”; PFAs brought in as part of teams may help to raise a wider range of issues, perspectives, and solutions (Chuang et al., 2007). However, over time, they too may begin to identify with the “we” in the team. Thus, stories and the storytellers are not static; they are dynamic actors that may change over time. The stories told may be altered when people gain more information or awareness of larger issues, or the tone of the teller may change. As one leader notes, patient perceptions (and hence their stories) have changed as they have become more “seasoned patient advisors,” with more understanding of the inner workings of the hospital:

Stories change when people’s perceptions change. So say, for instance, somebody who, when they first became patient advisors, they tell their stories, really heart wrenching, you know. But I think once they learn more about the system, and they

learn more about the intricate parts of being a patient advisor, just when you know more about the system, you're more tolerant to the expectations....So stories change when people know more information. (Leader 9)

As this passage suggests, it may not be that the story changes, but the tolerance or expectations of patients can alter as they learn more about how the system works and other factors. This additional “insider knowledge” may lead to the creation of a different version of the story. One patient recognized a potential shifting of attitudes during this PFA’s more than three-year tenure with the organization, where this PFA was highly involved on a number of committees, and as such, has developed ongoing relationships with staff and leaders and a better understanding of the inner workings of the hospital. Despite this, the patient felt comfortable in the role to represent perspectives of patients, and expressed an awareness of this inherent tension. Even with the “*coaching*” provided to storytellers, patients believed that “*it was always my story...you can’t replicate me, even if you tried*” (Patient 2). In the social milieu created around PFAs and their stories, leaders also raised the need for a “healthy tension” with this group of PFAs to ensure they were getting honest feedback on their care and services.

Despite variations in gender, age, and work status, the patient and family participants in this study appear to be a fairly homogenous group, in that these are patients who have come forward to share their experiences of care, and have chosen to take on roles as PFAs with the goal of remaining involved in the organization and participating in activities that will impact patient care. This group consists of individuals who appear to be educated, articulate, and capable of sharing their stories in clear, concise ways, placing their own stories within a larger context. Are these storytellers—these PFAs—representative of the overall patient population? Some leaders commented on their PFA representation, with the goal of having the PFA group reflect the diverse populations that use their services.

Recruitment of PFAs is ongoing, and while there may not be representative PFAs across all areas, leaders did point to other ways that they had attempted to solicit patient feedback (e.g., surveys, follow-up phone calls, and leader walkabouts). Leaders in organizations that served large First Nations populations spoke of creative ways of seeking to include the voice of these populations (e.g., through a First Nations Advisory Council and outreach into community groups) in ways that resonated with the different communities.

As humans, we are all storytellers. The role of telling patient stories was not limited to patients alone. Leaders and staff tell stories *of* patients, stories that are filtered and told through their own lenses. In one particular organization, all meetings within programs and the organization start with a patient story. These stories were told, for the most part, by staff and leaders, who would recount their interpretations of a story about a patient:

We celebrate the good things that happen. And because that teamwork did so well together, we believe that the patient experience was optimal, right?....At the end of the day, we're celebrating how that impacted the patient, because we worked so well together, right? And so, yes, you're right. It's not through the eyes of the patient, it's really through our eyes. (Leader 20)

As noted in the previous chapter regarding “The Story,” some organizations make attempts to tell the story from the patient perspective by providing a template to capture the patient story. This template serves many functions, framing stories within the principles of PFCC and, as I suggested earlier, as a way to ensure chaos narratives emerge as quest narratives, journeys of learning and change. The template also serves as an attempt to stay true to the patient voice, regardless of who is telling the story:

It's not the same if the patient's telling it or one of us are telling it. But I think we make an effort to do, because we have guidelines. We make an effort to tell a thorough story from beginning to end and usually, always incorporate a quote around, this is what the person said, so we get the real intent of the impact of the story from that individual. (Leader 4)

However, as noted in the previous chapter, the guidelines themselves serve to construct the story in purposeful ways, framing the story as it guides the teller to recount the story, regardless of who is telling it.

While there are many factors that would influence the impact of the story, there is general agreement amongst leaders and patients that having patient share their own stories would have greater impact. Storytelling is a performative act:

[The presence of the patient] would make it more real. It would be real. You wouldn't be removed from it....It would be much more dynamic, much more powerful an experience, for everyone. But the patient or the family member might have difficulty doing that in front of complete strangers, right? (Patient 6)

Particularly when the story is told by the patient, it may evoke a stronger emotional connection—“*the passion is there behind it*” (Leader 2)—connecting staff and leaders to the patient, as well as to their work and the organization overall:

In other situations, when you talk about something that happened to a patient without the patient being there to talk about it, I think people feel disconnected a bit, while that happened over there and that wouldn't happen [here]. So when the patient talked about it, they felt connected to it....And felt that it had a personal impact on how they viewed their work and their organization. (Leader 3)

Importantly, when patients share their own stories, they are able to provide details of the events, but also the feelings associated with the experience, in ways beyond words:

Perhaps what is being lost is not the what happened, but how did it make you feel?....It's really hard to convey that as a third party storyteller. A patient sharing their own experience, even if they don't describe how they felt, they can communicate that through their body language, their facial cues, all sorts of other ways, in addition to this is how it made me feel and using descriptive words. (Leader 21)

It is both the storyteller and the story who can have impact; however, when a story is so egregious, it may not matter *who* has told the story. Connections to the story can still be made, and importantly connections to the problem that the story represents: “*The story belongs to the person, the problem belongs to all of us*” (Leader 10). In this case, the

storyteller may be less important than what the story represents. Stories that are told reflect how organizations live their values,

[that] goes back to the values we believe. We make the decisions we make because its values-based, back to the community, and who we partner with...so sometimes the details of the story don't matter, but rather do we ensure we met the patient's needs while also meeting care needs? (Leader 17).

Thus, the importance is in the message and not necessarily the details. However, messengers remain important because of how they tell the story to ensure the message is heard.

Role of storyteller (and Patient Family Advisor) reinforces the patient identity

When people take on the role of storyteller and a PFA, they continue to perpetuate their identities as patients. For some of these patients, the role of PFA has afforded them an elevated status with respect and interest from others that they did not have previously: *“They just respect me so much, and I feel that respect”* (Patient 2). The development of patients into advisors has given people new opportunities that they would never have thought possible; some PFAs have attended conferences to speak about their roles as advisors and support senior leaders who speak of their organizations’ integration of the philosophy of PFCC. For some PFAs, they have also found a new purpose in life, where they continue on a quest journey to help others:

I am so glad I know about [becoming a PFA], I found out about this [the PFA Program] and got involved with this, because this has given me practically a reason for living too. I feel like every time I go through something, and I can change something to the better, that hopefully it'll help someone else's journey a little easier. That I feel a purpose. I feel excited about it.” (Patient 3)

Their identity becomes cemented as “the patient” well beyond their time as patient within the organization, forming as they travel from the chaos of being injured outsiders (with their

stories of chaos and care) to being welcomed as treasured insiders in their roles as PFAs. For example, when observing meetings where patients were invited to share their stories, and in report-out presentations at the end of week-long quality improvement sessions, audiences were respectful and actively listened to the patient representatives. At each venue, the audience applauded the patient when the story was complete, and comments and thanks were offered to the patient for taking the time to share their experiences. Consider the exchange below:

INTERVIEWER: “So you made a comment...[that] the patient, the PFA, opened [the workshop] with her story and everyone listens.

LEADER 20: Yeah....I think it is the respect we have for patients, who step up to take that leadership role to tell their story. That's what I think it is. Everyone was riveted on what she had to say....she had their undivided attention. And I think it was her message and what she had to say.

Stories told by patients are often used to humanize care, but the stories told by these PFAs may also inadvertently reinforce the role of “the patient” and not “the person,” particularly if patients continue to identify with and embrace this role of patient.

Why do patients tell their stories? Motivations of patients for sharing stories

All of the patients interviewed in this study had altruistic motivations for sharing their experiences. Quite simply, “*the reason why I told that story is because I didn’t want it to happen to anyone else....now that I think it through, that’s exactly it*” (Family Member 8). While that is a straightforward response, motivations may run deeper. Many patients choose to come forward; they self-select and choose to share their stories, seeking to turn perceived chaos into a quest journey of learning:

But I think often times, when patients and families write in or phone in with concerns, it's because they have a vested interest in making things better. There's a reason that they've picked up the phone, and sometimes, they just want to vent and get that off their chest, but more often than not, it's because they're frustrated with what they see and the care that's being provided, and they want to really make things better. They want to make sure this doesn't happen to another patient or family member. (Leader 16)

These patients and family members want to ensure that the negative experiences of care never happens to anyone else; thus, sharing their experience and having change result is a way to honour their own experience or that of a loved one, giving meaning to an otherwise meaningless or tragic circumstance. Particularly for those patients or family members who have endured severe consequences to their lives as a result of healthcare, sharing stories and promoting change is a way to make sense out of senseless acts:

The motivation very much stems from the fact that something went wrong. And they want to make sure that what had happened to them or to their loved one never happens to anyone else. And they want to see what steps are going to be taken, or they want to push for specific steps to be taken to make that a reality. They don't want it to happen again. So it's quite an altruistic motivation but it ties into the fact that they want that death or that profound injury to have meaning. And that meaning is found in transforming a tragedy into something extremely positive, which is a good change in the system. (Family Member 1)

Patients also need to believe that they can make a difference, that there will be an organizational response if they do share their experiences. In this way, we can see the dynamic social relations at play between patients and those within organizations, as well as the responses afforded to patient stories. Even small changes help to encourage patients to share their experiences, in the hope that they will make it better for others. In some ways, sharing their stories is a way for patients to reassert their power after an experience that has left them feeling powerless. As one patient explains:

I do it because I really do believe it will make a difference in terms of changing the way that people do their work, or how they approach their work, or somehow it will change the system in some way for the better. Even if it's only a couple a steps. Even if it's only one family that doesn't go through what I've been through. That's why I do it...that's why I do everything that I do. It isn't because I can change the past. I can't

change the past and the things that have happened. And I can't control what happens every day in every unit either. I can't control what nurses say and do...but I can, hopefully, influence even if it's a little way....I wouldn't do any of this if I didn't think I was making a difference. (Family Member 8)

For all patients, their sharing intentions are genuine. But there are also positive effects on patients who share their stories, including building confidence, feeling respected and heard, and “*there's healing in being able to tell your story...healing does start*” (Patient 2):

And that healing experience comes about because they're listened to without interruption. They're believed, they are a product of their courage, they are respected for their truthfulness, they are told that they are motivating for change. So those things actually are like a balm to an injured spirit. (Leader 6)

Thus, patients may find solace in telling their stories: “*People are so shocked and like they do that [she gestures – eyes widened, hand over mouth in shock], that's healing for me, because someone else is feeling my pain....it validates it to me*” (Patient 2). Despite the sense of catharsis patients may feel from sharing their stories, they perceive that their stories and role can only go so far in inducing change: “*We don't have any power to actually make things happen....we can only motivate and influence and inspire*” (Family Member 1).

How do they tell their story? Setting up storytellers for success

What became evident in discussions with participants was that while the story itself was important, *how* the story was told was equally important. How the story is told ultimately affects how it is received and the actions that result. There is a message in every story, and how you tell your story will in part determine how it is perceived, heard, and accepted by others, in essence, storytellers are guided by the narrative templates that create the expectation for what is told and how. As noted by one senior leader:

I think it's how you present the patients' stories is whether that story is listened to or not. Because if you present the story in a way that's non-threatening...in a way that it

doesn't cause that defense mechanism to come, you hear what they're saying. And you can take it to heart. Whereas...if they [staff] feel like they're being attacked or being defensive about it, in their mind they're not hearing the rest of your story. In their mind, they're thinking of all the excuses why that didn't happen...so all of these stories have such a power...if we're asking if something didn't go well, what would have made it better?....And if you just do it like this, it'll improve my experience of care. So it's all about how you present things on how they're received. (Leader 2)

This same leader goes on to provide an example of how a story may be told, and proceeds to re-craft the same story in a way that guides the listener to a favorable response (or at least one that opens up dialogue to resolve the issue):

If I'm a nurse and I hear that somebody comes up to me and tells me in a way that maybe is angry or something, saying why didn't somebody get my mother her lunch? I would have come here had I not known that somebody wasn't going to get my mother lunch. And now she hasn't had it. And that's a story. But if it's presented in a different way: My mom, it's really important that she eats as much as she can because it's hard for her to gain any weight, and she loses it so rapidly. If you're not able to have somebody help her with the lunch, please let me know and I can make sure that I have somebody here. And it all depends—that's not saying that somebody did something wrong? It's saying it in a way that's non-threatening...healthcare professionals...they want to provide the best care possible. And when somebody says something to you that you haven't provided the best care, sometimes your defense mechanisms go up. Well, we're short-staffed, we didn't know, and things like that. So you got to set people up for success, right? So if you set it up so that it is just a solution finding situation. (Leader 2)

In this way, we see how stories purposely continue to be moved from chaos to quest, to be “solution-finding” as ways to learn, and within the realm of what is expected or desired within this social context.

Authenticity is key when telling one's story, words of advice given to storytellers from patients and leaders alike. An authentic storyteller will capture the audience and help the audience hear what they have to say. At their best, authentic storytellers will make the connections with others to inspire and motivate for change. A patient provides this advice for other patients, highlighting the need to consider the purpose of the story and the message, choosing words carefully. These words of advice also highlight how these particular PFAs

attempt to frame their stories in ways that go beyond individual blame and retribution, instead highlighting system change within the larger healthcare context:

I would say, tell your story in your own words. Depending on who you're telling your story to, if you're trying to tell your story to bring about change in the system, then you need to be a little bit careful, avoiding blame, avoiding language like incompetent, negligent...that kind of language is only going to push people away. But that doesn't mean that you can't say what happens, or say how you felt about what happened. It only means that you need to be a little bit mindful that what you're trying to elicit is understanding and motivation to change, and that you're not really trying to punish anybody or make them pay for what happened....Tell the truth, say what happened, do avoid certain kinds of language....but don't hold back on what you feel you need to tell in order to honour your loved one or the experience that you went through....We want to make sure that....they are in a position to inspire and motivate, rather than blame.
(Family Member 1)

Similarly, leaders note that patients who are “genuine” and share their stories in ways that help others to not only relate to the issue, but to own it and be accountable for change, are the most powerful and effective storytellers. Again, we see how storytellers frame their stories as learning opportunities:

I think what really works for a good story, one that makes people ante up and really own that story, even if it's not from here, not from the area, is when the patients are really very genuine. They're not angry or looking for retribution. They very clearly are talking about it because they believe change is possible, and they believe that you can do it as a care provider, like they have faith in you, even though you just did something terrible, not you personally. But I think that's when those stories work. That's when they resonate....When they have a positive reason for being there, and it's because they believe that you can make it better....because they want to prevent it for the next patient. So they're not there because they're angry, because they're blaming. They're there because they have faith, that's what makes them powerful.
(Leader 3)

There is a balance to consider in how to tell a story, and all of these organizations, to some degree, coach their patients to tell their story in order to balance the authenticity of the storyteller and the message that is delivered through the story. In all of these organizations, sessions are offered to PFAs to coach them on storytelling techniques. In one particular organization, the sessions have been developed and are taught by PFAs, and patients also are

peer-mentored. These sessions teach patients to frame their stories to invoke learning and change, and they are taught in two parts:

How to tell your story...its teaching them how to tell their story in a meaningful and impactful way....It's a two-part course and the first course is you outline your story...your current story....You pick up what is truly meaningful within your story. By telling this story, what do you hope people get out of this story? If someone else told your story, what are the most key components of your story that you would want somebody else to tell? So they outline it in their first class, and then in the second class, they partner with another patient advisor and tell their story to the other patient advisor, and they critique each other's story. And tell them what do they think was good about their story, how they can polish the story more. (Leader 9)

Leaders may also coach patients prior to telling their stories, but they are quick to point out that they are not “telling them what to say”; rather, they are helping prepare the patient for the telling of the story to different audiences and identify the salient points to cover. As one senior leader explained:

“Do we coach them? We do coach them in terms of when they go to tell their story to the Board, just to help them figure out what they want to say. We don't coach them in terms of content; they're allowed to say whatever they want to say. But we just coach around, this is the time you have, so you might to make sure that you kind of practice a little bit, and we coach them to support and help prep them, but we certainly don't coach them in terms of what they can say, like really they say whatever they have to say, right? (Leader 22)

While patients may decide on the stories they want to tell, they are guided in their current storytelling situations by cues (most explicitly from the coaches as to how to tell their story), narrative resources that have emerged from these organizations, and cues from other patients and the stories they have told.

The gatekeeper role: right time, right fit and some self-selection

In this study, all of the patients and family members who participated were also PFAs, a role that often entails patients sharing their stories, but one that also involves ongoing

patient engagement beyond storytelling. In each of these organizations, there is a process to become a PFA or member that generally consists of an application and screening process to ensure readiness and fit. Leaders would often meet with former patients or family members to hear more about their experiences of care and interest to become advisors or members. In particular, leaders wanted to ascertain where interested parties were in their healing journey and determine if they were ready to share their story in a productive, “*constructive*” and “*solution-focused way*”—one that indicated that they could see “*beyond their own issue*” and “*did not have an axe to grind.*” Leaders are aware of this gatekeeper role: “*I acknowledge that...but the goal is to be constructive and make positive change*” (Leader 5). Leaders see this screening process as a necessary function that sets up the patient, their stories, and the work they may do within the organization for success:

Sometimes you can tell the emotion is still there. Emotion is not a bad thing, but it's sometimes your experiences are just too fresh or too raw for whatever reason that I actually think it might be causing them more harm to come in and share that again. It's delicate and I don't like the word screening, but I mean essentially that's kind of what it is....I want to set up the patients and family members to be as successful as possible. (Leader 16)

If patients are not “*ready*” to share their stories and are asked to be in that situation too soon, it has the potential to be traumatic. As one leader explained, “*I'm doing a disservice for them if I let someone come in that I don't think is ready...and then they're traumatized even more than they have been*” (Leader 16). Leaders recognize that sharing stories can be a trying, emotional act, and that reliving situations can be difficult to share; thus, they did not want to put patients in this situation if they were not yet ready:

I think it's just a matter though of trying to set everyone up for success. Because if you put a patient that is still really struggling with a lot of their issues in a room full of staff, and you open up that conversation, you're kind of setting everyone up for failure. You're setting the staff up to get offensive, you're setting that patient up to have to deal with that defensive response, whereas those patients that are still in that kind of stage, and want to be involved and want to tell their story, quite often those

are the patients that I'll meet with, and I'm happy just to sit with them and I just hear their story. (Leader 22)

Leaders also expressed concern about when patients may tell their stories, and they generally felt that when patients are still in hospital receiving care, this may not be an ideal time to have patients share their stories, because potential conflicts may ensue with those who are currently providing care:

Typically, we don't encourage people to participate if they're currently receiving care; if they're in hospital currently, we typically don't ask. We encourage them to wait until their current experience is over....I just feel like that's too risky. Because we're going to have the people who are looking after you on this team [hear the story] and then they're going to go back up and look after you....So I just think that's too risky....I think that's something that we'll stick with is, if you're currently receiving care within one of our facilities, it's probably not the right time to do it [share your story]. (Leader 3)

Despite all of these organizations having PFCC as their philosophy of care, leaders recognize that inherent power differentials still exist, and that patients may continue to feel vulnerable.

While all of these organizations had varying ways in which to recruit new membership, one organization had current PFAs/members involved in interviewing potential advisors. In this way, patients look to shape their membership within a partnership model:

There needs to be very careful screening of the membership. That's because our mandate is to work in partnership with healthcare providers. And no one wants to partner with you if you're screaming at them. So we needed to be sure that the people that we took into the group were in fact, in a healthy position to partner. If they were not going to be so overwhelmed by their own grief and anger and hurt, that they could not work in partnership with providers....But we do see it as absolutely essential to have a very good process for taking in new members. So that we can be sure that their compartment is such that they're not going to make things worse...and that's the piece that goes into asking people to do a little self-assessment. (Family Member 1)

Thus, this role of gatekeeper is a strategic one, seen as essential to bring patients successfully into the fold as part of the PFCC philosophy and to demonstrate partnerships rather than adversarial relationships. The application process itself helps patients reflect on why they want to be involved in the organization as an advisor; in essence, it encourages them to

consider their own stories and what they want to offer. However, through this gatekeeping role, organizations continue to hold the power to select who becomes a partner within their organizations.

The screening process was one way that stories were generated, because it was an opportunity for the gatekeeper to hear the patients' experiences. However, organizations mined other sources for stories as well: compliment and complaint letters, discussions with patient representatives and ombudsmen, patient satisfaction surveys and regular walk-about by managers and leaders. But how is it that certain stories (and storytellers) are chosen to share their stories in broader forum (at board-level meetings, quality councils and unit councils)? A senior leader reflects on this by saying,

I don't know. I never actually thought about how I've chosen story. I think, like I'll hear a story and I just think, wow. And I think wow, because the way that they've been able to articulate their experience. Like they've obviously reflected on it and processed it. And that's important, I think. And also, if they can kind of see the system, like the big picture of it, I think is important as well. Though that also doesn't detract from being narrow in scope because both can be powerful. But, I don't know. I guess I've never really thought about that, like how I choose the stories. Sometimes it's just because they're so horrific, that you think this needs to be shared because it should never happen. (Leader 16)

Stories are just one way of engaging patients; their role as PFAs maintains their engagement beyond their stories. Thus, the gatekeeper role becomes justified to choreograph in some ways, the right people to demonstrate early wins and continue the momentum in the direction of PFCC to support organizational goals. As one leader explains:

And I got to tell you, when you first start out [with PFCC], you got to make sure that you have the right patient family adviser working with that team. Because when we first started out, if I would have had somebody that was very opinionated, or had their own viewpoint, or didn't have the qualifications of what we looked for in a patient family adviser, we probably wouldn't be as far ahead with the integration of our patient family advisers in everything we do. Because they really are part of the fabric of our organization. We really, truly look at our patient family advisers as partners.... We want to live our mission. We want to live our vision. (Leader 2)

While the leaders expressed concerns for stories to afford the “*right fit*” at the “*right time*,” patients and family members interviewed in this study expressed similar sentiments. Patients and patient advisors also recognize there needs to be a “right time” to share. Patients comment on timing as critical in terms of patients or family members being ready to share their story:

I think it was easy for me to talk about [the experiences] because I had already come to terms with what had happened. I feel like if it had been closer to when [family member] was a lot sicker that I wouldn't have been able to talk about it. But because I have talked about it with friends and family, it's easy for me to talk about it now. (Family Member 9)

The time from the experience varies with each individual, but it is seen as essential for allowing the person to heal emotionally and articulate the experience in ways that are productive. As one family member notes:

That would be just what I would say: protect yourself first, take care of yourself first, and when you are ready, I think you'll know it. And that's when you're ready to contribute, to really contribute in such a way so that people will hear you. Because they won't hear you if you come in angry or hurt or grieving. They may not hear you as clearly...there's no negotiating when you're in the midst of grieving. And so it's best for everybody if you're there at the right time. (Family Member 8)

Patients themselves choose to come forward with their issues, and for many patients and family members in this study, this led to an invitation to share their experience more broadly, to become a PFA and more involved within organizational committees. As one family member explains: “*I feel like because of our experiences, I have so much I'd like to say and I'm a very positive, happy person so I thought I'd felt like I'd be a good fit*” (Family Member 9). Patients also understand that it is about their experiences, and they think of the bigger picture of the situation beyond their own issues: “*I try very hard not to make it about me or [family member], I try to make it about the experiences...[its about] our experiences to make changes to the hospital*” (Family Member 9).

While these patients are chosen as storytellers because of timing and fit, leaders also recognize that patients will vocalize their issues as they wish. While the story itself is important to launch the discussion in these organizations, the larger role and input of patients extends beyond their stories. This leader comments, *“I think its how you include those patients and how you incorporate them into the event, and that is key, that their voice is still heard...it goes both ways”* (Leader 15). Another leader provided an example of strategies used within the organization to address issues raised, highlighting how ongoing engagement can be effective to create a better fit for partnership, even for those who are not seen as an ideal fit. Such an approach speaks to how these organizations engage with PFAs (beyond their stories) in developing partnerships over time:

Another fellow, my goodness, it's a year-and-a-half-, two-year journey and we engaged him and he had a lot to say that wasn't positive. And it was some work, but again, he had good points and he represented a gap in our system. And at the end of the day, we haven't solved his problem, but we worked with him, right? And we weren't working against him. We recognized the need, we acknowledged it. I think that's what he needed was the acknowledgement. We can't necessarily solve that ourselves, but we can certainly advocate with you, 'cause we recognize it as a gap for many others in our organization. So we've got some good examples of individuals that we work with that certainly were not the best at articulating and were seen as a problem or complainer...from my standpoint, I welcome change, to be able to work with people. I'm always willing to work with people. And I don't label them as complainers and just say, “they just have a different way of getting their point across” and there is a point in there. (Leader 5)

Narrative resources

Patients want to make a difference, and they want their experiences to make a difference. Stories will breed stories—if patients see that action has been taken, it inspires others to tell their stories:

Hearing her [another patient's] story was horrific, and I knew I was doing the right thing [telling my story] because these stories have to be told. People will not learn if

they're not told. And so I had to take that leap of faith and trust that this is for the good. (Patient 2)

Leaders see patients as their best ambassadors: patients will tell others of their experiences, not only their experiences of care, but also their experiences in sharing their stories and the responses and actions that may have resulted:

And that's why patients are so engaged. And that's why they're happy to tell their stories now. So more people will tell their stories, because wow, maybe it'll inspire some change here or here, so I think the two things together are really powerful. (Leader 2)

It is a positive cycle that feeds on itself. Building on the successes of patients and change that is seen creates narrative resources for others to consider their stories. This is particularly the case when it comes to sharing stories, because other patients may be encouraged to share their own story when they see the response to other patients' stories. Patients need to feel that they are heard, that their experiences are respected and considered: *"I may not get my way, but I get my say"* (Family Member 5). As one senior leader describes it:

When they [patients] share their story up on the front stage, the other patient family advisers that were sitting at those tables, that felt that they didn't want, couldn't say their story out loud, stood up and shared some experiences that they had. So it gave them the confidence to be able to share their story. They wanted to, but they were nervous and so, not that they wanted to sit at the front of the room, but they were comfortable sharing their story from the audience. (Leader 2)

Frank (1995) speaks of quest narratives as those that imagine a different ending, and it is because of the narrative resources available that allow this so-called thinking outside of the box to occur. Similarly, stories and the act of sharing the stories on a regular basis help build narrative resources in these organizations, particularly for other patients. By sharing these stories and their impact, organizations not only build repositories of stories, but they also create cadres of patients as PFAs that engage with the organization and act as ambassadors for other patients who want to share their stories. In this way, they begin to build the

narrative resources available to all patients who are willing to share their experiences and imagine different endings to their stories. The quest narrative becomes the predominant arc

for specific stories that have effected change...and because I'm not clinical and most of those changes happen at a clinical level, I tend to use those stories as examples of how PFCC is working and to encourage other people to come forward with their stories, or to become involved as patient and family advisers. (Leader 21)

When patients see the impact that they have had by sharing their experiences, it affirms to the patient that the organization is listening and responsive to their concerns. This encourages them to continue their involvement because they feel that they can make a difference:

There are results that are tangible and they implement the changes....So it's changed. So I think they feel really, really positive....Here's a problem. You have to solve it....So it's action. And they [patients] love that....So I think that's the other piece that keeps people coming back and keeps them engaged and feeling positive about the experience. (Leader 3)

Conclusion

In this study, the group of storytellers that emerged were also those who had extended their involvement with the organization as PFAs or members, choosing to share their experiences in the hopes of improving the experience of care for others. Patients as storytellers continue to take on the identity of patient well beyond their care experience within the organization. While the label of patient (or PFA) affords them a new role and often an elevated status, it may also reinforce the identity of the patient and not the person. How the storyteller relays the story greatly influences how the story may be heard and the actions that may result. Patients and organizations consider timing and fit of storytellers to share their stories, and organizations have a gatekeeper role to screen patients for the “right fit” and “right time,” coaching the storytellers to set “patients up for success”; in essence, these PFAs have become ‘authorized storytellers.’ Storytelling—particularly action as a result of

stories—helps to build narrative resources so that others can imagine different endings to their own stories. The next chapter, “The Organization,” provides insights into the contextual environment in which these storytellers are invited and encouraged to share their stories.

Chapter 7

The Organization

If nobody wanted to hear the story, then we wouldn't be able to tell it. (Family Member 2)

What is it about these organizations that enable stories to be a vehicle for learning?

This chapter explores the organization as the social context that actively seeks stories to serve many purposes, particularly that of learning. According to the model put forth by Chuang et al. (2007), numerous factors influence learning at the group and organizational level, including group norms, heterogeneity of groups, internal and external networks, leadership, and culture. I will highlight these influences throughout this chapter, closely examining how stories are heard and acted upon. I begin with organizational culture and the adoption of patient-centred care as the philosophy of care that has not only factored prominently in setting the stage for patient stories, but also in the broader spectrum of patient engagement activities across these organizations. Stories and the patients who share them are sought after and welcomed into these organizations, in part because of the foundation that a PFCC philosophy provides. To create this culture, leaders have been instrumental in setting expectations as they “walk the talk” to ensure the patient voice is heard, modeling expected behaviours and practices to foster an environment in which patient stories are viewed in the spirit of learning and partnership.

I also highlight the symbiotic relationship of stories with PFCC: PFCC provides the platform that welcomes patient stories, but stories reciprocate as they are strategically used to continually build, reinforce, and support a culture of PFCC and the goals of the organization.

As such, I explore PFCC as a culture change that in essence simultaneously enables a learning culture, demonstrating how stories are used to support PFCC and learning. As noted in earlier chapters, patient stories are framed as quest stories in the hopes that they will lead to learning, as evidenced in actions made by individuals, teams, and the organization. However, I suggest that in many ways, these learnings are ‘authorized’ as a result of how these they are framed as quest narratives for learning.

I then turn to the knowledge management systems that these organizations have put in place within the structures and processes developed to systematically gather, share, and act upon patient stories. These organizations recognize the inherent emotive value that stories bring, but in order for these stories to act, appropriate structures and processes are required to “*give legs to stories,*” enabling them to do their work. The structures and resources for storytelling come in a variety of forms: education of both staff and patients, processes that require patient stories and engagement, accountability structures to ensure staff and leaders adhere to principles of PFCC, and explicit links to quality improvement structures that consider the patient voice.

While much of this section speaks to the experiences of the three service delivery organizations, the experience, values, and attitudes play out in similar ways within CPSI as this organization also actively involves patients and families in its work, most visible through the work of Patients for Patient Safety Canada, which I address at the end of this chapter.

Patient- and family-centred care and patient stories: a symbiotic relationship

“You know, I can’t really talk about storytelling without setting up patient- and family-centred care...because really that’s our philosophy of care.” (Patient 4)

Patient- and family-centred care as a foundation for patient stories: a culture of care

Adopting a philosophy of patient- and family-centred care

Organizations speak of their transformation to a culture of PFCC as a “*journey*,” and one that may “*never end*.” In each of these organizations, the burning platform for adopting a philosophy of PFCC did not emerge from any one specific event. Instead, external reports and influences, feedback, and consultation with patients and families, and other performance measures provided indications that these organizations were “*not putting patients first*” or were not meeting the expectations of their patients. In each organization, the impetus for changing its priorities or focus appeared to initially stem from one senior leader (i.e., CEO or VP) who pursued the PFCC philosophy of care and sought support from other senior leaders and the Board of Directors in forging a path forward:

You can't do it without everybody, right? I would say that it starts from the board and saying this is what we're going to do. We had a strong leader, but it's a corporate strategy and we all needed to buy into it. Cause if just one person around the senior table says, yep, this is what we're doing, and the rest of us don't buy into it, that's not going to work. We've all agreed that this is the model we're going to follow and we all follow it. (Leader 5)

The principles of PFCC were ultimately embedded in various ways across their respective organizations. For example, they were within their mission, vision, and value statements, in strategic plans, job descriptions, organizational performance measures, and in expectations for how patients are involved at all levels of the organization. As one leader explained, these are “*not just words on the wall*,” but “*we live these values everyday*” (Leader 17). Each of the healthcare service delivery organizations has been strongly influenced by the work of the Institute for Patient and Family Centered Care (IPFCC). These organizations have adopted the IPFCC definitions and the principles of PFCC, which include respect and dignity, information sharing, collaboration, and partnership (see Table 7). While

most healthcare service delivery organizations would claim to provide PFCC, it is the degree to which these particular organizations have enacted these principles (discussed in detail throughout this chapter) that make them stand out in this area.

Table 7. Principles of patient- and family-centred care
(from www.ipfcc.org)

Principle	Definition
Respect and dignity	Healthcare practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
Information sharing	Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
Participation	Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
Collaboration	Patients and families are also included on an institution-wide basis. Healthcare leaders collaborate with patients and families in policy and program development, implementation and evaluation; in healthcare facility design; and in professional education, as well as in the delivery of care.

In some organizations, the IPFCC provided training, consultation, and ongoing mentorship as these organizations started on the journey of PFCC; it also linked them to a network of other organizations that have embarked on similar journeys. As a result, these three healthcare service delivery organizations have all taken similar paths toward systematically and strategically developing tools and practices to support PFCC, and the structures and processes to build and sustain this philosophy of care. All of these organizations have developed a cadre of patient and family advisors who are engaged in a number of program and organizational initiatives and committees, to ensure patient perspectives are heard at all levels of the organization. While many of the patient and family

advisors have opportunities to share their stories through the work they do on committees and working groups, their presence at all levels of the organization helps to reinforce PFCC principles of collaboration and partnership. As I noted in the previous chapter, the inclusion of patients on teams and committees increases the heterogeneity of these groups, which in turn can influence learning by creating constructive conflict through varying perspectives and solutions offered by group members.

With the introduction of PFCC in these organizations, common misconceptions emerged, such as the belief that patients and families “*rule the roost*”—that “*there’s no rules now...they [the patients] can do all of this*”—which unsurprisingly resulted in resistance to its adoption, particularly at the point of care. Staff perceived this shift in power “*where the [patient and] family has all the power and the staff feel powerless*” (Leader 3). As one leader explained,

I think at the very beginning when PFCC wasn't really understood, there was a misconception that being patient- and family-centred meant doing whatever the patients and families told you. So if I as the patient said, I want this, that's what I get. That was the belief, as opposed to really coming around to a new way of thinking. And at the beginning, I think there were some who felt that way, that it was going to be a challenge in terms of direct patient care delivery. (Leader 21)

Thus, these organizations made concerted efforts to educate staff and leaders on the principles of PFCC, demonstrating their support for patients and families, but also for staff:

...to make the right thing happen, not only for patients and families, but for our care providers because we need to keep this patient safe...and if you take the patients' rights and responsibilities, they have obligations too. [Staff] also need to feel supported within this model. (Leader 5)

Beyond this initial resistance by some staff and leaders, there is a strong conviction on the part of those leaders that PFCC is undoubtedly the “*right thing to do*,” and that in order to put “*patients first*,” they must be part of the discussions. When starting this journey, these organizations realized that even though “*our patient satisfaction surveys were good*

already...we didn't give patient-centred care before” (Leader 5). The orientation to PFCC has helped them to live their values differently, because PFCC “brings you back to the patient, right?...The change has really made a difference in the way that you think and the way you make decisions” (Leader 5). The principles of PFCC are what form the basis for hearing and seeking the patient voice (often through their stories), respecting different forms of knowledge, and seeing the patient as expert by experience: “You have to look at them as a person, right?...Know where they're coming from, know where their beliefs are, and that's all part of patient- and family-centred care treating people as a person” (Leader 2).

Leaders as key enablers of PFCC

I think what really were the key factors for us, was number one, the leadership. Not just support, the leadership to drive this model of care and the philosophy of care. (Leader 2)

The role of senior leadership in supporting and adopting this philosophy of care cannot be overstated—nor can the ownership that leaders have taken to bring others on this transformational journey: *“I've got some skin in this game, right?” (Leader 7). All of these organizations identified key individuals within their organization who took a leadership role in driving the PFCC agenda within their teams, units, and programs, and across the organization as a whole. Their unrelenting focus on this area and the development of a “vision of where [the leader] wanted the organization to go” (Leader 2) essentially provided a roadmap for the PFCC journey because*

you can only start once, and start well, once, right? So you want to make sure that you have your road map there for you and learn from other people that have gone that way before.....So we had a strategic plan for PFCC. (Leader 2)

Having a clear roadmap also provided shared understanding and a common language regarding PFCC so that

everyone thinks about it in the same way, there's a shared understanding of what it [PFCC] is, and I think that it's permeating the culture. I think that comes from the leadership and goes all the way through the organization. And I think it also comes from the grassroots, from some staff, who really believe that as well. (Family Member 8)

A shared language helps move forward the everyday work of the organization, ensuring everyone is moving toward the same goal:

[PFCC] helps me in that when I go to a meeting now, I'll say to them, okay, is this patient- and family-centred?....So what are the challenges and barriers that we're talking about here? And let's just label them, and let's get to it. And it gets rid of the other artifact, and focuses you on where you should be, right? Before I'd be talking my own language, whereas now it's [PFCC] the corporate expectation. So it makes a big difference. (Leader 5)

Leaders setting expectations through words and actions

If you don't have your leaders modeling that behaviour, you're not going to have the people that are working in the point of care or any area in the hospital behaving that way. (Leader 2)

Leadership has been key in setting the expectations and norms for how PFCC principles of partnership and collaboration are manifested within these organizations. Leaders set the expectations for other leaders and staff to seek out the patient voice, provide ongoing opportunities for engagement of patients and families, and ensure their input is sought in all aspects of service delivery: *"I assumed you engaged on this before you brought this recommendation forth?"* (Leader 21). This expectation for how the patient voice is heard, valued, and acknowledged can be leveraged not only from senior leaders, but also from staff and patients,

so it might be my VP challenging me, have you gotten a patient voicing that? It might be me challenging my managers or physicians I work with, come on you guys, we need to have a patient voice here, right?So it's really setting the expectation at each level and kind of filtering that down. And then the people on the front line also push us as leaders...we need to be pushed by the patients and families and staff as administrators when we're not, maybe making some decisions that are in the best interest to providing the best care possible, right?...and how can we hear from our patients, not just assume we know what they think. (Leader 10)

While senior leaders are essential to setting the strategic vision, local leaders are key to setting the tone within their units by modeling behaviours and actions, and setting group norms for the unit culture. This leader notes that

the staff see me doing it [walkabout on unit talking with patients]. And the staff know as a leader that patient voice is one of my primary focuses. It means a lot, I think that's crucial for any type of culture change. And when I first started doing that, staff would come up to me afterwards and say, "Is there something wrong? Why are you talking to my patient?" First of all, it's our patient, you know, this is my department. It's all of our department, and I want to find out how our patients are doing because they're the reason we're here, right? (Leader 15)

There are other overt demonstrations of the respect these organizations have for patient involvement that also help establish an environment of inclusion and value for patient engagement. These often manifest as the belief that “*the little things that matter,*” which can have a big impact on both patients and staff. For example, as I observed at one general meeting that involved patients, which also was noted by a leader:

Every time a patient steps up to report out, because they're part of the team, so every time they stand up, everybody claps. So you soon start getting the message, if you're a staff member or anybody in the organization, that this is really important. (Leader 3)

As leaders actively seek the patient voice, patients are encouraged to continue to share their comments, feedback and stories. “*I think they made the choice to make sure our voices are important*” (Family Member 9), dispelling any skepticism that these patients and families may have had about their involvement. “*They never for a second made us feel like our opinions weren't important and I never felt like a token flaggy thing to wave in front of the media, which is what I thought was going to happen*” (Family Member 9). Patients also understand that

patients and families can get together and talk about our stories and tell for however often they like, and that if you don't have the right people there listen to us, that it's just talk, right?...People are listening and people with authority to make change is really important. (Family Member 6)

Thus, the presence of senior leaders at meetings demonstrates their explicit support for involving patients, and it sends an overt message to both staff and patients about the importance of patient inclusion *“because it’s worth the Director’s time [to attend the meeting]...outside of work hours...[which] really shows that as an organization, we’re very dedicated to this”* (Leader 22).

A natural human tendency is not only to share stories, but to want others to see and understand things from our point of view. In some ways, the ability to hear different perspectives—and to do so without provoking a defensive reaction—is a learned skill. As one leader explains, *“it’s still hard for them [staff] to separate patient perception from their perception....and the natural tendency is still, ‘let’s convince the patient that it wasn’t like that’”* (Leader 3). However, leaders model the desired responses by demonstrating their willingness to hear patients’ perspectives, and by doing so, they validate these differing points of view and set the tone and expectation for including the patient voice:

What’s helped us to really move forward, is I think that we’ve had a few really key leaders that have that ability to kind of let down those defenses, right?We’ve had those key leadership people that have been able to take a step back and when those clashes happen, they’ve been able to not be on the defensive, right? They’ve been able to say you know what, our patients and our families really bring a very valid perception to the table, and that’s really the perception that we need to listen to, because no matter what’s going on here and the complexities of it, and everything that’s going on, it’s really the feedback from the end user that needs to guide us and tell us where we’re going. (Leader 22)

By responding in this way, leaders demonstrate how they also seek out the patient perspective: *“They look for the stories for real...they want to hear it, they want nothing more than a good story that has to be solved, or that they need to work on”* (Patient 4). Leaders not only acknowledge the patient’s concerns, but also ensure there is a mechanism for closing the loop, creating accountability for action, which again not only validates the experience, but

encourages patients to continue to share. Consider how this leader models behaviour for her own staff in her response to patient feedback:

No matter how rough it is, or how it's presented to you....to always make sure that you at least say I'm sorry for the way you ended up being treated, but thank you so much for telling me. I generally say, if we could change something to make this better for you or the next person, what would you like to see, right?....They just need to be asked, this is really bad what happened to you, what would you like us to do different? And how do you want me to get back to you and tell you what happened? (Leader 10)

In these organizations, there is a conscious coupling of telling stories and a learning culture: *"We tell the stories in the spirit of improvement, for the sake of the patients"* (Leader, 21). Indeed, as noted previously, these patient stories become a quest narrative in how patients are coached to tell their stories, and in how staff and leaders are guided to consider their stories within the principles of PFCC and specific learning that may come from a story framed within these principles. The orientation to learning is evident:

We role modeled [how to tell a story], we taught them how to tell a story, we gave them the guidelines, and then we were asking staff to tell their stories and get use to storytelling. 'Cause you need practice to tell it in a manner that you want to identify the principles [of PFCC], and attach your lessons learned. And how do you go forward from here. Most of the stories that we hear are not so good news stories. But often now we're getting better at it where we can identify the good part of the story, but here's the area of improvement and here's the lesson learned. (Leader 4)

Organizational expectations are also built in to ensure that staff adheres to the values and principles of PFCC. Job descriptions include expected behaviours related to PFCC, and they are the means by which staff and leaders are held accountable for these behaviours,

that's why we went to really gut-level behaviours that we can embed in their job description, and we can say okay, you know what, actually listening empathetically to your co-workers and to patients is actually part of your job description...it starts to give managers more of that ability to actually call out that behaviour, whereas before they didn't have a lot of power to call out that behaviour. (Leader 22)

Leaders developing partnerships

It is building on the knowledge of the patient and family now...traditionally, healthcare providers have always had all the power, all the knowledge...but you want to build on the strength of the patient and the family. You want to look at the partnership, building a partnership; you want to collaborate with them. (Leader 1)

For these organizations that have embraced the principles of PFCC as their foundational philosophy, at the essence of PFCC is the concept of partnership—partnering with the patient and family in their care, and at all levels of the organization. In order to be a partner in care, each partner must have a voice and be respected by the other partners to have their opinions and ideas considered with due thought. As noted by one leader at the point-of-care, it is recognizing

that role between the healthcare provider and the patient, where there's a differential in power, and a hierarchy.... They're not a partner in care if you're a position of power. A partner in care is that you have equality within the healthcare team members, and an ability to have a voice and a say, and that people are listening when you speak. (Leader 4)

Many leaders articulated this perceived power imbalance, linking explicitly the principles of partnership and collaboration as those that would help redistribute power. The use of patient stories was one mechanism to hear the patient voice, along with ongoing patient engagement strategies to develop such partnerships,

that's why I feel like it is so, so important to hear patients' stories. And I think that's one of the reasons why it's really moved to more of a patient engagement piece, 'cause we got to build on all those things to make a better patient relationship with healthcare providers.... The patient knows themselves better and the family knows the patient better than any healthcare provider will ever know. And so they need to go to the patients and families for information. (Leader 1)

Hearing of others' experiences through their stories, and having a better understanding of the situation through the eyes of the patient, is an act of power sharing, as noted by this leader,

they are bringing this power to the table through their stories, the patients', and when the patient is actually at the table.... And so, because I'm thinking about the patient perspective, all of a sudden it's easier for me to put myself in those shoes because I've

heard this story....I'm a human being and I'm a patient, and I'm a family member and I can now think that way. (Leader 21)

The ongoing engagement opportunities afforded to PFAs helps to reinforce principles of partnership and collaboration, where these organizations develop teams whereby patients “really felt like I was there as a member of the team....I felt like everybody was equal and everybody had equal value to the team” (Family Member 9).

While initial misunderstandings about PFCC resulted in staff resistance, it is evident that these initial concerns have yet to be fully resolved. Moving from an expert–lay person model to one framed within the principles of PFCC (that recognizes the patient knowledge and expertise of self), there is a perception among staff about a loss of power and influence. Thus, staff strategize to use PFCC to advance some of their own issues, encouraging patients who have issues to raise them through councils or directly to leaders, as they perceive that the patient voice will be a more effective mechanism for change:

She [the nurse] was the one [who said], if there’s an issue, this is where you need to go [to the patient advisory council], because the administration isn’t necessarily going to listen to other nurses. Because yes, we do need to have primary care but even though we say that, they’re going to listen to the family members more. (Family Member 5)

Reciprocity: patient stories as a mechanism that supports and reinforces patient- and family-centred care

When you look at PFCC, the patient family being at the centre, I think the real anchor to it all is the stories. (Patient 4)

While stories are given a place in these organizations because of the foundation laid through the principles of PFCC, stories also live symbiotically, continuing to build, reinforce, and sustain a culture of PFCC. In this section, I will highlight the use of stories along this journey of developing a PFCC organization.

None of the leaders interviewed make claims to having arrived at the point they hope for in enacting PFCC, but rather see it as a “*journey*” and an evolution: “*It’s a 10 year journey...and you never actually arrive; you just continue to work at it*” (Leader 4). They recognize the hard work to grow and sustain a culture of engagement and PFCC, but it is a journey taken throughout the organization:

The fact that things happen creates the beginning of a cultural change to some extent, and having patients on the team is very powerful because it really does put the ‘patient first’ thinking back in it...so you’ll hear over and over again, well this is about patients, this isn’t about providers...when you hear how we can, instead of, oh, we can’t. (Leader 3)

The first step in this journey is for the patients to feel a sense of belonging: “*I think the patients feel they belong here, that they’re welcomed here....they feel this is their hospital; it’s everybody’s hospital*” (Patient 4).

As noted previously, leaders take a prime role in setting the tone and the expectations for how patients need to be included at all levels of the organization, thus shifting the culture of the organization over time. As noted by one senior administrator:

So the number of times I say, of course, we will have patients and families in the room, because we won’t plan or do stuff without them. The number of times that we turn to whether it’s our advisory councils, or individuals that are part of those councils, or other part of that large network we are now developing. And being able to seek their advice and guidance, and for people to be in a mental frame where they seek out and welcome that input, even though it may not be what we expected to hear. I think it is really truly becoming part of the culture here. (Leader 18)

All of these leaders describe stories as one way to reinforce the values of PFCC, and to ensure that the patient is kept in the forefront of the business at hand, as a daily reminder of “*why we are all here*” (Leader 18). The panels of patients and families that were convened to launch the concept of PFCC were only one form of storytelling. Stories need to be told in many ways, both formally (e.g., presentations) and informally (e.g., in meetings or on

walkabouts) across the organization in order to keep staff and leaders in touch with the core business of patient care on a regular basis because

we can't always have patients and families in every forum, and our intent is to always keep the patient at the forefront of the business that we do. Our business is patient care, so therefore we frame our business in the context of the patient. And I think to make that a daily and frequent and integrated into the work we do, this method of people telling stories has been very successful in framing, okay, now let's start our business discussion. Keeping in mind, this is what we do. And in addition to that, having annual engagements, having other, having PFAs at the tables where they're telling stories, you get that reinforcement and that variety of storytelling. So you could say there're two levels of storytelling but one without the other wouldn't be as effective because you can't incorporate that into your daily work. (Leader 4)

It is this ability to incorporate the voice of the patient in the daily activities of the hospital—and to keep it central to daily work—that will change the culture of the organization and move it toward that of PFCC. There is a positive cycle that gets developed through storytelling, the presence of PFAs throughout the organization, and the underlying philosophy of PFCC that pervades the organization:

Well, I think a lot of it has to do with the sharing of patients' stories, right? We promote that culture through sharing of those stories, and by involving patients in areas where you normally wouldn't have seen them on these councils...and you bring them in and you demonstrate the value. (Leader 21)

Because staff and leaders become attuned to hearing patient stories, they begin to expect to hear them: *"It's gotten a lot better because people are used to hearing patients' stories now"* (Leader 3). You see changes in culture as staff and leaders begin looking for the stories:

"When they [the stories] have impact, then people identify that story. Oh yeah, I did hear that story. No, I didn't. Oh well, you should really, you should hear that story" (Leader 4).

While PFCC is seen as a journey, it is a journey that links with improvement and learning. Many leaders could provide specific examples of how they could see the changes made along this journey. One senior leader provides an example specific to how compliments and complaints, a form of storytelling, help to drive improvements:

I find it [PFCC] changes the conversation now when people are responding to patient concerns, because they know it's important what they have to say and that we're taking that into consideration.... We owe this person a response. They've taken the time to write this down, and they've lived this and this is their perspective.... I feel the pull. It was always a push before, but now it's a pull. I want to make change; I want to do better. Well, tell me where I can make it, a change that's patient- and family-centred. (Leader 5)

This section has attended to ways in which patient stories have helped to develop and sustain a culture of PFCC within these organizations, strongly supported by senior leaders as an overt way to hear the patient voice. The next section examines the structures and processes created by these organizations to support their use of patient stories.

Structures and processes to support patient stories within a philosophy of patient- and family-centred care

I think if you're going to have people tell their stories, you need to have a system that's set up that is doing something about those stories, right? (Leader 22)

In these organizations, the use of stories has been a deliberate strategy to mount the principles of PFCC. They have built the knowledge management systems, and the infrastructures and processes to support the use of stories and the learning that comes from them. The patient voice continues to be integrated, not only through their stories, but also through ongoing opportunities for engagement. In this section, I will outline a number of specific structures and processes that these organizations deliberately and strategically developed to support the use of patient stories as a mechanism for learning. These organizations have begun their journeys of cultural transformation that embrace a PFCC philosophy by ensuring that plans were established in strategic frameworks to allow for the deliberate gathering and telling of stories, and that processes were created to explicitly link the patient voice to improvement infrastructures and performance measurement to provide

some form of accountability. As noted in previous chapters, the organizations help patients frame their stories in ways that promote learning, but they also create a psychologically safe environment for stories to be told and heard by staff as part of that learning process.

Supporting stories through strategic frameworks

All of these organizations speak of the strategic framework of PFCC that underlies their work and their ability to develop the appropriate structures and processes to support a culture of PFCC and how the patient voice is embedded in this work. These frameworks also provide a step-by-step plan for how patients and communities can be engaged within the organization and on certain projects. Without such a strong strategic focus, *“I don't think we would have gotten the results obviously...it [patient and community engagement] wouldn't have been as fully involved and as extensive and as productive as it was, if we didn't have overall strategic focus”* (Leader 7). While patient stories can act as a catalyst for this journey, other structures and processes need to be put into place in order to maximize the effects these stories can have because

it's very challenging. I think patient stories help, but they're not sufficient for real change to occur, unless you give people the skills, tools, time, method to make the change. And if we really want to make the patient first, we got to put them in the room because they're not first without being the room. They can't be. The temptation is too great to put the provider first, even with them [the patient] in the room. (Leader 3)

Stories and storytelling become an integral part of this strategic framework; as noted previously, patients are given a voice because of the foundation of PFCC, but their stories also act to support and reinforce a culture of PFCC. Structures and processes are then built around the ability to use these stories for learning:

We built our strategic plan around it [PFCC], our academic philosophy around it, that's first and foremost. Yes, it was very deliberate. Storytelling became a piece. We launched with patients stories, with forums, with family panels, which influenced our staff and ourselves to know that this was the right way to conduct our business and our care and deliver our care and build their system around. No one can argue with a

patient's story. Like that's their experience, so giving it structure of what can we learn from it. (Leader 4)

Leaders recognized that if supports were not in place to act on these stories, the organization's efforts could be deemed tokenistic, alienating staff and patients alike:

We were getting to a point in the organization where we were using patients' stories all the time, but because we didn't have any meaningful way of acting on them, I almost think they were having a negative effect. So you keep hearing and hearing and hearing and telling patient stories, but it's almost like overkill in a way. So you hear one more heart wrenching patient story but you'll almost start getting a little bit jaded because there's no way to act on it. (Leader 3)

Thus, stories and storytelling are seen as a catalyst to initiate the dialogue and impetus for change, but a “*more deliberate framework*” still is required, one that could explicitly link to “*the principles [of PFCC] and then what are the learnings and how do we share that*” (Leader 4). Structures such as the role of PFA provide an opportunity for the ongoing engagement of patients, who work together with staff on a variety of program and organizational initiatives, including their improvement efforts:

I think the most powerful relationship is not so much the story, it's giving the patient the opportunity to work with you to make it different. So the story gets you thinking that maybe we need to make an improvement here. But it probably isn't going to get the outcome that the patient would desire. The much better partnership is okay, well, let's go fix it there. So I think the [quality improvement processes]....it's giving the legs to the stories....The stories create the thinking about “Wow, we might have an opportunity here”....It's a catalyst, but I don't think it creates different outcomes, really. I think it's taking the patient with you and giving people the skills and tools to improve something. (Leader 3)

What has emerged in all of these organizations are patient stories that are linked directly to quality improvement processes, “‘*cause it's not just about will...I'd love to improve this...like you have to have tools and methods and processes to make it possible for people to be successful*” (Leader 3). Thus, it is through these processes that these organizations are “*giving legs to the stories.*” All of these organizations had numerous committees with patient membership (such as patient advisory councils, steering committees, program/unit councils,

and quality councils), all of which acted as venues for patients to share their experiences, consider opportunities for improvement, and stay strongly connected to patient perspectives that were part of improvement efforts: *“If you're just really listening and acknowledging what they're telling you, and thinking of how it can improve and finding that little piece of improvement within their story, like one story at a time”* (Leader 10). Another leader explains that

if you don't have the tools and the methods and the processes to make a change, it's really hard. It's really hard. So I think [quality improvement processes] have done that. They've done that. They've given talented people a venue and the knowledge and skills and tools and support to make rapid changes. So I think that's what makes a difference. And that's why patients are so engaged. And that's why they're happy to tell their stories now. So more people will tell their stories, because wow, maybe it'll inspire some change here or here or you know, so I think the two things together are really powerful. Separately, neither one is probably as powerful. (Leader 3)

These organizations had varying processes in place to tie real-time stories to patient satisfaction, with immediate links to service recovery and quality improvement. At one particular organization, family support coordinators visit patients upon admission to provide a brief orientation to the organization and what to expect during their stay (e.g., expectations about bedside shift reports, meal vouchers for family members, hourly rounding, and meeting unit managers). Patients and families would then have knowledge of what services they should be receiving on a day-to-day basis and that it should be consistent amongst staff. At the time of speaking with patients, support coordinators may also look to recruit these patients as future patient and family advisors. The support coordinators return to patients on a regular basis to gauge their experience while in hospital. If concerns are raised, patients are triaged into a response system: green (positive experience to date), yellow (some concern has been expressed), and red (more major concern). These flags go directly to the unit manager so that they may be dealt with immediately; the red tickets go directly to quality

improvement. Similarly, positive comments also are sent directly to the staff member and unit manager as “kudos” to recognize and appreciate the work of staff on the units. The flags are themed within the units and are dealt with accordingly. In this way, changes may be made in real time to improve the patient experience without delay:

Traditionally, most organizations use patient satisfaction results as one indicator by which to determine opportunities for improvement...[we aim] to use patient feedback in real-time, and to address issues while the patient is still in hospital....Why don't we be proactive while they're still in the hospital? And try to do a service recovery while the patient is here and better for patients while they're still in house. And so the family support coordinators have quite a role in terms of connecting with patients as they're in hospital, and speaking with them....setting of the expectations but also getting some of their stories or some of their feedback. (Leader 9)

These organizations also made explicit attempts to integrate PFCC with other quality-based metrics, such as patient experience, satisfaction surveys, and complaints. This senior leader explains that

we got tons of indicators built into our scorecards around all of our PFCC engagement...you've got to measure things to know that your change has made a difference. So I think we have tons of indicators that are built into our scorecard that monitor engagement and we added the five questions to our Picker survey around NOD [service excellence standards], and things like that. So I think we do a good job at measuring things and looking at outcomes. So that's how we know a change has made a difference. (Leader 5)

Huddles were also a way for teams to build in accountabilities, as issues are discussed on a daily basis with the opportunity to integrate patient feedback, reinforcing the importance of the patient experience, and a culture of learning:

Again, also as we put it [patient experience data] up on the wall and as we start to talk to it, it also builds that sense of accountability because that's what we're saying is important, right? So as a staff nurse when I see that my manager is speaking to that every day, and asking about it and following up on it, it tells me that that's what's important to that manager. So it's part of that, building that culture, where we value that. (Leader 22)

While structures existed specific for storytelling within the organization, other structures exist to support the philosophy for PFCC more generally. One organization in

particular had developed an ethics framework based on their mission, vision, and values to ensure that decisions were “*patient-centred decisions*” consistent with these values. This framework was implemented within senior teams and at the board level to help guide decision-making, and it will soon be “*embedded on every agenda in the organization*” so that “*you’re living every decision you make, at every meeting...is this the best thing for our patient?*” (Leader 5). Table 8 outlines the guiding questions for the Ethical Decision-Making Framework.

Table 8. Ethical decision-making framework: guiding questions

The following questions should be reviewed for each decision.

- Does the course of action put ‘Patients First’ by responding respectfully to needs and values of patients and families?
- Does the course of action demonstrate ‘accountability’ by advancing quality, safety and patient- and family-centred care and delivering fiscally responsible services?
- Does the course of action demonstrate ‘respect’ by honouring the uniqueness of every individual?
- Does the course of action demonstrate ‘excellence’ by reinforcing that we are recognized leaders in patient- and family-centered care through the alignment of academics and research with clinical services?

Purposeful gathering of patient stories

All of these organizations had structured ways of gathering patient stories: “*We collect stories from our friends, our neighbours, our families...we ask nurses, we ask a variety of individuals if they have stories to share*” (Leader 21). The stories come directly from patients, or as noted previously, from staff who may have stories of patients. All of these organizations made a concerted effort to hear directly from patients. In each of these

organizations, senior leaders were expected to do walkabouts as a means to stay in touch with point-of-care issues:

Each of them [senior leaders] does a monthly walkabout so they're engaging with the front-line staff and patients and families as they do their walkabouts on the units, patient care units...so they gather stories firsthand that way through their walkabout. (Leader 4).

The walkabouts generate stories and feedback; processes also exist to ensure that they are “[shared] at the senior management council....and if we identify a problem area then it's assigned a lead at the senior management council and that person is expected to follow up....and then it's on an action log and we have accountability to follow up on it” (Leader 4).

This ensures accountability to not only gather this information but also to maintain responsibility for action.

Other methods of patient feedback included regular discharge follow-up calls, as well as patient satisfaction and patient experience surveys that also provide a source for patient stories. Together, all of these form a larger picture of the patient experience,

so there's lots of stories in different ways, and it doesn't have to be the patient sitting in front of a group sharing, baring their heart and sharing their story. All of the numbers have a story behind it. And to be able to see the story behind the number, that's the important thing, right? So I think that there's not just one way of looking at something, you got to look at it three hundred and sixty degrees and take a look at it. And one way is not the be all end all. You've got to combine things together for a more fulsome picture. (Leader 2)

Compliment and complaint letters are another source for stories. In each of these healthcare service delivery organizations, compliments and complaints are linked to quality improvement structures, and all of these organizations have robust systems in place to respond them. Some leaders interpret the volume of compliment and complaint letters as a sign of the organization's willingness for change and respond to patient feedback. As a result, increases in the number of letters may be seen “as a good thing”:

“I think that’s [increase in volume of complaints] a sign of an organization that’s trying to be open and transparent...if people feel that they bring a concern forward and you do something about it, they share that with their friends. And then more people will say, well maybe if I called with my concern, they’ll do something about it. Whereas I think that organizations that don’t have that, and aren’t open and transparent about what they’re doing, I think people quit calling after a while, right? Because how many times do you bang your head against that wall. So, I really don’t see it as a bad thing. (Leader 22)

Thus, a certain perverse logic seems to apply: silence may indicate that the organization is unresponsive to concerns, so people do not want to come forward, while greater reporting of experiences (including concerns) may indicate more openness to learning within the organization.

These organizations also looked to develop (or have developed) a repository of stories. For example, organizations have numerous videotaped stories of patients sharing their stories, some available publicly through the Internet or organizational website; some were used for specific educational purposes for staff, accompanied with a facilitated guide for learning. The story templates discussed earlier also provide a written format of a patient’s story that could be accessed at a later time

so when you’re sharing your story, so we are developing now a repository of the stories. So that if you need a story and you want a story to bring to a group to kind of set the stage for something, you have the ability to go through kind of this library of stories that again are real life stories about what has happened to a patient and their family here at the hospital. And it’s not a fictitious story and it’s not picked—hand-picked—for that purpose. This really did happen to this person, before we even decided to do this change idea or have this meeting on this topic. So the real stories are not fabricated to fit the situation but we do use them to make change. (Leader 5)

So while these stories may be “real stories,” the development of such repositories creates the ability of organizations to use stories in ways that suit their purposes when needed. Such repositories also build networks across the organization as a mechanism for sharing stories from one area to another.

Creating a safe environment for staff and patients for learning

If you don't set your staff up for success, then you really have a lot of resistance with trying to hear the patient voice. (Leader 2)

Education of staff forms the basis of understanding the principles of PFCC, and it sets expectations for staff regarding their behaviours and actions, as outlined in their job descriptions. Education, which is often led by PFAs, is embedded into new staff orientation with the goal to help staff “*really appreciate and value the patient experience*” and to help them “*understand what PFCC is all about and help them really start to try to incorporate that into the way that they do their work*” (Leader 22). Education is also reinforced ad hoc by leaders in staff meetings within units or professional groups, which aim to have staff empathize with the patient perspective—to “*put on new glasses,*” as it were—and to step back from their entrenched positions to connect on a human level:

They [managers] prep them [staff] in a way where they want the staff to put themselves in the shoes of the patient. If it was your mother or father, your husband or your wife, your child, or family member or friend, how would you feel? What is it that you would expect if you were coming here? (Leader 1)

These are attempts to create new group norms within the units and across the organization. As noted previously, leaders take on a large role to create these expectations and norms to better understand the patient experience “*because we want to hear different perspectives out there...we know it might not match your [staff] perspective, but it's a patient perspective, and that perception is valid...so we started with that*” (Leader 4).

Creating an environment that is open to learning provides an opportunity to open dialogue between all team members, including patients and families. Leaders again set the tone by taking an approach to learning that not only welcomes the patient voice, but that also takes a broader perspective of the situations described. Leaders seek out heterogeneous

causes and take a systems approach to learning, thus freeing up the individual from specific blame so that

staff are not afraid of stories. I don't think they feel centred out....I think we've conditioned over the last four or five years that you know what? We're not going to punish you for doing something wrong; we want you to learn from it. (Patient 4)

A senior leader goes on to describe learning situations from patient incidents, where patients attend meetings with staff to discuss how the failure occurred and opportunities for improvement. The passage below brings together many factors that influence learning at the team and organizational level: development of a culture that embraces learning in a team environment, openness, understanding of heterogeneous causes, leadership that sets expectations, and an environment that is safe for both for staff and patients to learn together:

I think the piece of those meetings that's really important is the work that's done ahead of time. And it's the preparation that you do with the staff and the people that are going to be involved in that meeting. So it's kind of just an overview of what happened, and a discussion of the incident, and what we're really learning to look at is, as we shift from a culture where we blame people for the things that happened, we're really starting to look at how is it that our system actually is set up to make people fail....So, I'm really starting to understand that the way that you frame a situation, and the way you frame what happens allows your staff to go into that situation much better prepared, right? Because if I can go into a situation where something I did led to harm to a patient, but I can understand that there were a lot of factors that affected what happened, and that it wasn't just a decision where I came to work that day and I thought to myself "I'm going to hurt this patient because that's the way I am," right? Then it allows you to really have a more open conversation with the patient, rather than just being defensive right away. (Leader 22)

Patients are attuned to the type of environment where they feel comfortable to share their experiences, and whether they feel their voice is welcomed: *"I think we've encouraged, not only staff but the patients, that there's no punitive notion here: your care is not going to be affected [if you speak up]"* (Patient 4). Despite this, there may be ingrained attitudes prevalent that require continual reinforcement of PFCC principles. Patients feel this

resistance, and they may not feel welcome to express their concerns, fearing retribution for themselves or their loved ones. As one family member describes,

I think for some, I was being an overbearing [family member] and that I was trying to tell people how to do their job. It was never said, but you can tell by people's body language and attitudes, and you know: "Who is she? And she's not in the medical field, how can you tell me what to do? I'm the professional, I know best." So it wasn't from everybody, but from several people, and in interactions, that was kind of the feeling or vibes that were given off. (Family Member 5)

Psychological safety creates an environment where staff and patients feel safe to openly share their concerns; that is, they do not feel they are at risk for expressing concerns (Edmondson, 1999). Leaders at all levels across the organization set the tone for this safe space by encouraging and facilitating patients and staff to share experiences, which helps continue to build narrative resources within the organization. One patient commented on how she felt enabled to share her experiences, and because of the positive experience generated, she felt that she could continue to share:

I remember these two experiences because I felt empowered and I felt "ah, they're listening to me," and it's okay to keep sharing, because if that didn't happen, I don't know if you'd feel comfortable to repeat that, and to speak out.... But it was driven by that person of authority that believed in [PFCC], so to me, I walked away and felt it's okay to keep sharing. Don't worry about what we share because someone will grab it, and I think it's important that they realize when a patient speaks, somebody needs to listen, and really acknowledge that, so that they feel comfortable doing it again. (Family Member 6)

Early on, psychological safety may come in the form of the physical presence of someone with authority, which helps to legitimize the voice of those who feel less capable. As one leader notes: *"And I said I'll tell you what: I'll stand beside you [the patient] the whole time, and you and I will go, and I'll make sure that whatever you have to say, your voice is heard"* (Leader 8).

Living patient- and family-centred care principles in healthcare organizations

Many of the findings relayed in this chapter focus on organizations that deliver care to patients, the implementation of a culture of PFCC, how stories are built into their strategic frameworks to build and to sustain PFCC culture, and the structures required that explicitly link learning and improvement to stories. Healthcare organizations not involved directly with service delivery can also enact principles of partnership and collaboration in the work that they do, using patient stories as a foundation for this work. CPSI has demonstrated this, embedding patients in the work that it does as an organization, featuring patient representatives on numerous committees and working groups that are able to influence and shape the products generated by the organization for use across the nation (e.g., the Incident Analysis Framework and Canadian Disclosure Guidelines). Likewise, CPSI has included indicators for patient involvement—including specific targets and dates for inclusion—within its own performance framework, thereby holding itself accountable for how it engages with patients on a regular basis. As in service delivery organizations, senior leaders at CPSI set the tone and expectations for patient involvement in the work done by their organization, and it is through the membership of PFPSC that many patient representatives are recruited. PFPSC, the patient-led group within CPSI, provides the avenue for patients to share their stories, which they are able to do on a provincial and national level. While the stories shared by patients—the quest narratives—may act more as motivators for change and emotional connectors, these stories are not generally linked directly to the organizations where care was delivered, although many leaders and staff recognize that the chaos described in these stories may happen anywhere, including their own organizations. However, evaluating the impact of their stories has been difficult to determine, but their goal is to partner with decision-makers

and to influence, lead, and collaborate for safe care by sharing lessons learned from their stories. While the main office for CPSI is located in Western Canada, the members of PFPSC are spread across the country, as their work aims to have national influence.

Conclusion

All of these organizations have taken a similar path to providing social contexts that intentionally make space for patient stories to live and breathe. The philosophy of care embedded within PFCC acts symbiotically with patient stories, providing the foundation for patient stories within these organizations, but it also uses the stories to build and sustain its culture. Leaders who have developed strategic frameworks have been instrumental in cultivating a culture of PFCC, as they set expectations for group and organizational norms, modeling behaviours and attitudes of partnership and collaboration by including patients in work across their organizations, thereby creating more heterogeneous teams that can consider a broader range of perspectives and solutions. These organizations create psychologically safe environments for staff and patients to learn together; they have also developed structures and processes that systematically gather and analyze patient stories, linking these stories explicitly with learning and improvement processes, and building in accountability structures to ensure action. Clearly, these organizations have demonstrated intent in hearing the patient voice through their stories, and in developing structures and processes that link the patient experience to improvement and learning. However, as noted in this chapter and the previous two chapters, both the stories (as co-constructions between tellers and listeners) and the storytellers are chosen as the “*right fit*” at the “*right time*,” making them essentially authorized by the organizations. The tensions that are created by authorizing the stories and

storytellers within these organizations are further explored in the next chapter, which brings together the overall learnings of this dissertation.

Chapter 8 Discussion

Stories are the forward movement of description of actions and events making possible the backward action of self-reflection and self-understanding. (Greenhalgh & Hurwitz, 1998, p.4)

Increasingly, healthcare organizations in North America and elsewhere are using patient stories for a myriad of purposes, including (as seen in this study) as a mechanism for patient engagement and for organizational learning and improvement. The stories that emerged in this study have been those that described the patient experience of care and how it felt to receive care in that way. Many stories revealed opportunities to improve the patient experience of care, as well as processes of care themselves. These stories described situations of chaos where patients felt they had little or no control—but in telling their stories, patients were able to impose order on their experiences retrospectively, composing their stories as quest narratives. While this reflects what patients did, we also see how organizations shaped these stories to be “authorized learnings” as they co-construct patient stories and determine the fit of the storytellers. In this chapter, I first will comment on the challenges faced while conducting this study, as these limitations have bearing on the contextualized nature of the results. The nature of the topic has lent itself to specific kinds of stories shared by particular individuals within these organizations. I then explore the tensions emerging from this study, ways that stories have been used that are potentially problematic but remain uncontested. In particular, these tensions raise the following questions: 1. Whose story is it: the patient’s story or the story *of* the patient? 2. In whose interest is the story told? 3. Who tells their story? I reflect on these tensions and their implications for the advancement of practice,

theory, and research in the field of patient engagement and organizational learning and improvement.

Limitations and challenges of this study

I start this chapter with considerations of the limitations of this study, as they provide context for the results and analysis previously shared, and help situate the discussion to follow. In this dissertation, I intentionally sought out healthcare organizations that are known to be leaders in their use of patient stories for learning so that I could better understand the contexts for learning in the interests of disseminating this knowledge to other organizations interested in learning from their patients. Interestingly, the three health service delivery organizations converged on similar paths when it came to using patient stories to establish a philosophy of PFCC and transforming their organizations to create and sustain a culture of PFCC: *“So you want to make sure that you have your road map there for you and learn from other people that have gone that way before”* (Leader 2). For each of the healthcare service delivery organizations, the IPFCC was a major influence in how PFCC has unfolded within their respective organizations, as it had trained and educated their leadership teams to embrace PFCC principles and lead this transformation within their respective organizations. The IPFCC has had ongoing relations with some of these organizations as they have implemented PFCC, and two of these organizations are featured on the IPFCC website. While the enactment of these PFCC strategies may look different in each organization, the strategies themselves are somewhat similar. Storytelling is one piece of the larger engagement strategies implemented, albeit as both an initiator and sustainer of PFCC. Thus, the context for the results emerging from this dissertation lies within these organizations,

firmly rooted within their philosophy of PFCC. Organizations that do not engender a similar philosophy of care may reveal different ways of using (or not using) patient stories and the resulting impact on organizational learning and improvement.

The sampling strategy within each of these organizations has emerged as a prime limitation of this study. Each of my site visits was coordinated and organized by one key leader within the organization who arranged my schedule while I was on site, including participant interviews and opportunities to observe meetings and forums where patient stories were told. My request to these organizations for participants and observations was fairly open: I wanted to interview a broad range of leaders, staff, patients and families who have told or heard a patient story, and I wanted to explore the impact of telling or hearing this story on learning and change. If possible, I also wanted to have the opportunity to observe a patient story being told and interview potential tellers and listeners following the telling of the story. The majority of participants were leaders within these organizations (primarily senior leaders, including directors, vice-presidents, CEOs and board members), patients and family members. No staff at the point-of-care were included in my pre-determined schedule. At the frontlines, staff may experience stories differently; they may hear different kinds of stories from patients on a daily basis, be attuned to these stories in different ways and respond to them differently. However, what did emerge in this study was the important role of leaders in creating the culture for patient stories and supporting the development of structures and processes that ensure these stories influenced organizational learning and improvement; thus, a focus on leaders' perspectives has been appropriate.

Although the group of patients and family members who participated in this study was diverse in terms of age, gender and work status, it was homogeneous in that group members were all PFAs who were highly engaged within their organizations. All of them had

experienced opportunities to share their stories formally or informally (e.g., with local leaders, at committees, or on video) and be involved in presentations that represented the organization as part of media-related activities; some also had served on hospital-wide, provincial or national committees. In essence, many of these patients and family members are leaders within their patient groups, and they could be considered ambassadors for their organizations. The group of patients and families in this study speaks to how these organizations have built up a cadre of PFAs that are committed to the philosophy of PFCC and their role as PFAs in order to build and sustain this culture. However, drawing only from this particular sampling of PFAs has provided me with a particular perspective of the organization, one that comes from those already highly involved.

This study also revealed the homogeneity of the types of stories told: we are told the stories we want to hear (Greenhalgh & Hurwitz, 1998). The focus of this study has been on patient stories for learning and improvement; the stories that emerged were those stories of patients' experiences of care, which had been situated by these organizations for learning and improvement. In hindsight, I reflect on how my preparation for this study, that is, how I positioned this study from the outset in my earliest conversations with organizational leaders to consider fit and opportunities for site visits, and the nature of my documentation regarding information about the study, the consent and the interview guide used, that led me to hearing this specific type of story. In essence, I heard the types of stories that I thought I would. These organizations appeared oriented to not only hearing the patient voice, but also toward learning and improving based on the patient voice, and hence, these are the types of stories that they also seek. The type of story told also may be shaped by the narrative templates that exist in these organizations; this is expressed literally by one organization that has created a

template for use in recounting stories. It also exists figuratively, in Frank's (2010) sense that in the hearing of others' stories, we shape the stories that we will tell.

Lastly, while I speak of the relatively homogeneous types of service-delivery organizations that participated in this study, the inclusion of a non-service delivery organization has highlighted both similarities and differences in how stories may be used and their impact. While the CPSI was unique in this study as a national organization focused on patient safety ("*Safe care...accept no less*"), the way stories were framed and used by the CPSI to shape its work and the products created by working groups reflect the principles and values of PFCC, particularly those of collaboration and partnership. CPSI makes evident the learning they take from patient stories in the end products that they create, demonstrating how partnerships may be enacted across the healthcare spectrum. PFPSC, the patient-led group within CPSI, has a national-based membership of 50+ members, many of whom have shared their stories via video format. However, what differs from CPSI is that it cannot dictate the impact these PFPSC stories can have on specific organizational learning where incidents occurred; rather, the stories provide an emotional catalyst to humanize care and put a face on the safety issue(s) that were identified. The stories told by PFPSC members also identify universal themes of safety (e.g., team communication, medication safety) that help healthcare organizations reflect on their own organizational practices and policies. The inclusion of the CPSI demonstrates that regardless of the organization's mandate and focus, the inclusion of the end user helps shape the work that is done, even for those organizations not directly involved in patient care.

The limitations and challenges noted here require a reflective practice throughout all phases of the research in order to acknowledge these limitations and reflectively consider them in light of the findings revealed. The emergence of these organizations—which have

followed a similar trajectory to transform themselves into PFCC organizations—speaks to a common discourse surrounding PFCC. The PFAs who participated in this study as ambassadors for their organizations points not only to the story that the organizations want to tell of themselves, but also to the shifting roles of patients as partners—and potentially agents—of the organization. The typology of stories that move from chaos to quest narratives also reinforces the overall story of these organizations (i.e., the metanarrative), as organizations that strive to learn from their patients and improve their experience of care through the co-construction and re-crafting of chaotic experiences into quest narratives that promote and enable organizational learning and performance improvement.

Emerging tensions in the use of patient stories for learning and improvement

The organizations in this study have shown leadership in the area of patient engagement. They have demonstrated their commitment to the philosophy of PFCC as their model of care, dedicating resources to PFCC and instituting structures and processes that promote and sustain PFCC. They have created roles for patients and family members at all levels of the organization as a visible way of demonstrating the value they hold for better understanding and responding to the patient experience of care. These are honorable intentions, and in many instances, the experiences shared by patients in their stories have had real impact on policy and practice. However, as noted throughout the results chapters, the act of telling a story is not a simple one. Tensions have surfaced relating to what stories are told, how, by whom, and for what purposes, which I will elucidate below in turn. Specifically, I focus on three tensions related to the story and storytellers that function within their

organizational contexts. I then go on to discuss their implications on practice, theory considerations, and future research directions.

Tension 1: whose story is it? The patient's story or the story of the patient

There is never a “view from nowhere” (Greenhalgh et al., 2011, p.104). Every teller (e.g., the patient) and listener (e.g., other patients, staff, leaders) will bring their own perspective to the story (i.e., their personal interests, schema, priorities, and biases), as well as particular capabilities and limitations shaped by their experiences, culture, religion, class, and gender—in essence the narrative templates that exist within their social context (Frank, 2010). This study has revealed the shifting nature of patient stories: while often told in the words of the patient, these patient stories are crafted in ways to enhance learning, making a chaos narrative into a quest narrative for learning. In their desire to share patient stories, these organizations may overlook ‘whose story is this?’ as they repeat stories *of* patients.

While not all stories are performed, that is, not all can be considered “*baring their [the patient's] heart and soul in front of a room full of people*”—stories are indeed performative acts (Boje, 1991), co-constructed by tellers and listeners, and influenced by the narrative resources and narrative templates available to the tellers (Frank, 2010). Telling any story in any setting is a bridging performance, a complex connection between teller and the audience (Brody, 1998). The act of telling a story to the listener changes the story; the teller cannot ever exactly tell the same narrative again. Each story inevitably has gaps of meaning and significance, and we fill in these gaps as we imagine the world to be and as we imagine the teller intended. Thus, rather than saying we *hear* a story, it is more accurate to say that we construct for ourselves a story about what we *think* we are hearing (Brody, 1998; Frank, 2010).

Narratives do not mirror past events in a straightforward way. Because, as Kirkegaard reminds us, we live our lives forward but understand them backwards, our narrative understandings are not fixed in stone. They are fluid, ever-changing entities in which the present and the past and the individual narrator and their culture are in a perpetual state of interplay. (Skultans, 1998, p.232)

The organizations studied in this dissertation have created—and continue to build—narrative resources with a cadre of PFAs involved across their organizations, providing multiple opportunities to share patient experiences in formal and informal ways. The social contexts in which patients share their stories create the milieu in which narrative templates emerge, based on the social location of tellers and their audiences, which lead to the extraction of particular aspects of the story and the likely suppression or omission of other aspects (Frank, 2010). Patients and leaders alike claim that these are patient stories, despite the coaching and guidance provided for key messages and how to tell their story. Videotapes of patient stories also are represented as the patient story, told by the patients “in their own words.” However, the reality is that patients and leaders give thought to what the essence of the story is, what message should be imparted, and importantly, what learning should be taken from the story, thereby becoming ‘authorized stories’.

It is about being able to turn [the patient’s] experiential knowledge into something else; a translation process where [the patient’s] knowledge is transformed, in their own mind, and in discussion with others (who may be fellow service users, professions, or a person such as service user facilitator), into something generalisable; something that can be acted upon. (Cotterell & Morris, 2012, p.68)

Often this translated knowledge is used to maximize the potential of the story within these organizations to support their own agenda; this leads to the next tension.

Tension 2: in whose interests are these stories told?

What also has emerged from this study is the question of whose purpose does the story serve? As noted in previous chapters, there is some level of catharsis for patients and family members who can share their stories: “*It was harder **not** to tell his story*” (emphasis

added) (Family Member 3). Patients note a sense of “*healing*” and “*validation*” of their experiences, as well as an altruistic satisfaction in “*doing good by others*” and that “*something good can come out of something tragic*” (Family Member 1).

For organizations, the use of patient stories serves many purposes, and specific to this study, they were notably seen to build and sustain a culture of PFCC, and to act as a catalyst for improvement and learning. As noted above, these stories may be crafted in particular ways to become “authorized stories” that are purposefully chosen for their value in facilitating learning, told by “authorized storytellers” who were chosen to share their story. These stories thus become “authorized learnings”; that is, authorized by the organization as ones from which to learn and improve. For example, stories recounted to the Board of Directors generally will be those stories that demonstrate an opportunity for improvement and an instance where action has been taken. The organization controls the agenda, and in many cases, it also chooses which story is told, when, and for what purpose. In this way, as Costa et al. (2012) have pointed out, stories become a “commodity” used for others’ purposes.

More broadly, within patient involvement efforts—even though a genuine commitment to engage patients in the design, delivery and evaluation of services may exist—evaluation of engagement efforts shows how the input of patients can be used instrumentally by clinicians, managers, and policy-makers to achieve what amounts to their own agenda. Work by Rutter et al. (2004) evaluated user involvement in the United Kingdom and found that organizational leaders held power in terms of decision-making, determining the role of users and deciding how their experiences shaped the initiative. In some cases, user involvement was used to legitimize decisions made by other stakeholders, where

we found that user involvement remained in the gift of provider managers: providers retained control over decision making, and expected users to address Trust agendas and conform to Trust management practices. Users also wanted to achieve concrete changes to policies and services, but had broader aspirations to improve the status and condition of people with mental health problems. (Rutter et al., 2004, p. 1973)

Similarly, Harrison and Mort (1998) note that patients may act as a “lever for change,” supported by clinicians and managers who, at the same time, employed strategies to dismiss or denigrate certain patient perspectives, while legitimizing others by drawing selectively and strategically on those patient perspectives that they themselves deemed worthwhile.

The use of stories by the organizations noted in my study served many seemingly well-intentioned purposes, such as improving understanding of the patient experience of care, acting as connectors for empathy and understanding, and serving as a tool for learning. The patients and their stories were afforded episodic power (Lawrence et al., 2005) as stories were re-crafted in particular ways and chosen for particular purposes. Leaders spoke of developing a repository of stories to allow them to be shared more broadly across the organization—and potentially to be used at a later time to serve organizational purposes. Thus, while there was a genuine commitment to using stories as a vehicle to hear the patient voice, the stories themselves may be transformed in ways that serve particular interests beyond the intentions of the patient storytellers.

Tension 3: who gets to tell their story? The hegemonic power to story

Another tension that has surfaced is the issue of who is invited to tell their story. What has emerged from this study is how the selection of storytellers (and PFAs) occurs at multiple levels. First, patients themselves self-select: they choose whether or not they will share their experience through a compliments and complaints process, by completing a survey and providing further qualitative responses, or by speaking directly with organizational ombudsmen, managers or care providers about their experiences. The

organizations discussed here have created processes to respond to these patient stories and link them specifically to quality improvement processes. As one leader explains, “*they have taken the time to write this letter; we owe them a response*” (Leader 5). As noted in the “The Storytellers” chapter, there are leaders within each of these organizations who choose patients to tell their stories (e.g., in person or via videotape), or who choose to tell a story of a patient. There is a “right fit” and a “right time,” both for the “authorized storytellers” who tell stories and the settings where organizations choose to share them. This gatekeeper—a leader who hears the patients’ experiences through the application process as a PFA—is seen as essential to the success of engaging with patients. However, it also points to the “hegemonic power to story” (Boje et al., 1999); that is, it underscores the selective functions that organizations still possess in determining who is invited to share their stories, with whom and when in order to serve specific purposes of the organization.

Policies set by provincial and national bodies (or within organizations that require engagement of patients at various levels) help to set expectations for patient involvement beyond storytelling, but they also may lead to tokenistic forms of engagement or involvement of the so-called usual suspects. For example, Costa et al. (2012) note that in the mental health community, the involvement of people with lived experience became a requirement for those organizations who reported themselves to be community-based or community-involved service providers. However, the methods by which organizations sought participation remained rooted in conservative and paternalistic values, with those “consumers” who were more appeased by services received being chosen first as representatives on various boards, panels, and consultations (Costa et al., 2012). Hogg and Williamson (2001) found that lay people (i.e., healthcare users) tended to assume one of three types of interest: 1. dominant interests (aligning with doctors and other healthcare professionals); 2. challenging interests

(aligning with the executive or management perspectives); and 3. supporting repressed patient interests. Each of these interests may be considered when organizations choose patients who are the “*right fit*” and at the “*right time.*”

Greenhalgh et al. (2011) speak of two tensions here: of “representation versus representativeness,” and of “staying naïve versus going native.” Both of these speak to the tensions noted in the storytellers and PFAs identified in my study. While all of these patients and family members have had care within the organizations studied, many (or all) of their experiences may have occurred some time ago. While some patients do have recurring chronic conditions—and therefore have regular or frequent contact with the organization—for some, their sole contact with the organization is through their roles as PFAs. Thus, their ability to represent the patient experience may not be fresh, and it may not represent current experiences.

When patients are fresh, their stories and experiences of care can help staff to reconsider their assumptions, reframe their view of what the service is about, and explain and question their jargon. Over time, however, that may change as the PFA potentially becomes more of an “agent of the organization,” supporting—as Hogg and Williamson (2001) have pointed out—dominant or challenging interests. However, the longer and more closely the patient is involved, the greater the risk that freshness and “naïveté” will be lost, and that they will unconsciously take on the assumptions and worldview of the staff and the organization (Greenhalgh et al., 2011). Some patients expressed awareness of this inherent danger and spoke of ways in which they reach out to other patients to obtain feedback in order to represent a broader patient perspective.

Implications for practice

The organizations in this study are known exemplars for their engagement of patients at all levels within their organizations, and for using patient experiences to learn and improve. In these organizations, the systematic and deliberate use of patient stories represents one method they use to better understand the patient experience and recognize the expertise the patient holds of their illness and care. Stories are not stand-alone vehicles for engagement; rather, these organizations have made purposeful linkages of stories and other data that together feed into their quality improvement processes. These organizations also have demonstrated how they “*give legs to stories*” through their structures and processes, which in turn allow them to act on these stories.

While their intentions for learning are commendable, what has been apparent in this study is the need for reflexive practice when engaging with patients and using their stories as a mechanism for learning. Organizations that look to use patient stories need to consider why they are using stories, for what purpose, and in whose interests. Leaders and staff also need to reflexively consider their role in how stories are co-constructed: while they aim to see through the “*eyes of the patients,*” this may not necessarily be the case, because patient stories are crafted, edited and coached in different ways to elicit “authorized learnings” from “authorized stories.” Thus, despite their best intentions to engage with patients, organizations must recognize the power they continue to hold in not only determining what story is told, by whom and when, but also who is represented in telling the story and to what end. Similarly, as Costa et al. (2012) suggest, patients as storytellers need to consider who profits from them telling their story, what purpose is served by sharing their story and how this organization (or another) will use the story to make material change.

Some leaders viewed patient stories as a way to “*equalize the playing field*”; the dominant model portrayed by these organizations was that of partnership, as they built and sustained ongoing relationships with patients and family members in their roles as PFAs. As noted by Barnes and colleagues (2000), a partnership model does not seek to even out power differentials between patients and the institutions that provide care to them; in fact, it acknowledges that these differentials exist and probably always will exist. The goal of the partnership model is therefore to achieve clarity and insight about where power is located, assign responsibility, and identify and address what really matters to patients:

Empowerment may be an outcome of partnership with service users, but is not its primary aim. What is important is that the users’ voice is heard, their perspective is valued, and their views have influence. (Barnes et al., 2000, p. 191)

Thus, organizations seeking to use patient stories need to ensure that they have the structures and processes to support these stories, and they must take a reflexive stance in their use, aware of the power differentials that exist and supportive of a partnership model for ongoing patient involvement.

Implications for theory

In this dissertation, I used a theoretical frame to consider stories in the context of organizational learning, one that considered the co-construction of stories and their performance as a dynamic process that is not only dependent on the teller and their audience, but that is also set within the social milieu of the organization. First, in light of Frank’s (2010) urging to think *with*, rather than *about*, stories, I elaborate on how these organizations do both. I then consider these findings in light of organizational learning theory.

Organizational leaders spoke of stories happening at two levels within their organizations; both were needed in order to build and sustain a culture of PFCC. At one level, stories are used to remind staff, leaders and board members of their “*business*” and to re-orient them to “*patients first*” at the start of their meetings. The use of stories in this way suggests organizations are thinking *about* stories, which is somewhat akin to “spectating stories,” those stories that emotionally move the listener or reader, but potentially leave their actions unchanged (Boler, 1999). At another level, sharing a patient story allows individuals and teams to “bear witness” to the story (Kumagai, 2008). Instead of passively receiving stories as spectators, readers and listeners more fully engage in intentional dialogue, an opportunity to reflect on one’s own values, beliefs and assumptions, to gain awareness of others’, and to consider and take responsibility for change. Bearing witness in this way represents thinking *with* stories. Many examples emerged throughout this study that demonstrate how organizations aimed to think with stories (e.g., through facilitated discussion to debrief an incident with team and patient, or watching a videotaped patient story followed by a facilitated discussion with guiding questions). The explicit structures in place to support ongoing engagement activities of PFAs and “*to give legs to stories*” are ways that these organizations begin to think with stories and build their narrative resources to do so. While some evidence exists for thinking with stories, patients and leaders also appeared to lack insight into the co-constructed nature of their storytelling efforts, with both groups insisting that patients “*say what they want to say*” as it is the “*patient story*.” The templates used to guide story recollection, the coaching of storytellers, and video stories that are (heavily) edited, are all ways that stories are actively crafted and co-constructed.

This study focused on the use of patient stories in healthcare organizations as a mechanism for learning and improvement, and in doing so, it highlighted multiple levels

where learning occurs within organizations and a variety of factors that influence learning at each of those levels. The stories that have emerged in this study from patients, family members, and leaders alike were those stories of so-called failures in care that have impacted patient experiences and, in some cases, patient outcomes. Chuang et al.'s model (2007) of multi-level learning from failure has been instructive for considering salient elements through which organizations may learn from patient stories. It also has been useful for highlighting how they have used stories to explore new knowledge, feed forward from individual to group to organizational levels, and exploit learning by institutionalizing what has been learned. In fact, the structures and processes put into place by these organizations demonstrate how they have routinized the practice of storytelling within their organizations. At the individual level, staff and leaders consider the relevance of the patient experience in relation to their own experience, cognition, and affect. When shared across teams, a psychologically safe space provides the opportunity for the team to engage in dialogue. The role of PFAs that has been established in these organizations provides opportunities for ongoing engagement of patients and family members in helping to problem solve together with teams. At the organizational level, learning may be institutionalized into new expectations for practice and policies, with the use of stories routinized in organizational processes. Chuang et al. (2007) note the importance of culture, particularly a psychologically safe culture, for learning from preventable adverse events. Leaders who demonstrate a participatory style of leadership help to create such an environment.

However, the model presented by Chuang et al. (2007) does not explicitly address issues of power as a function of organizational culture or a factor in creating psychologically safe environments in which groups can learn. Power revealed itself in many ways throughout this study: in consideration of stories themselves and the value they are given as a legitimate

form of knowledge, in recognition of the inherent expertise that patients bring of their illness and care, in team dynamics (teams that include patients) and professional hierarchies that have traditionally existed, and in the ways that the organization and its leaders determine “authorized stories” and storytellers. Chuang et al.’s model could be extended to consider the workings of power and its influence on learning at the different levels, and as power relates to the cultural norms of teams and organizations, in developing psychologically safe spaces in which they can engage in dialogue and learning. Considering the professionalized hierarchies that exist within health care, power will have bearing on the inclusion of patients as a part of the team, and how their voice is heard. Lawrence et al. (2005) raise the concept of power to extend the model of Crossan et al. (1999), focusing on episodic and systemic power that works through the cognitive processes of intuiting, interpreting, integrating and institutionalizing. In this model, stories and the storytellers are afforded episodic power through the telling of their stories and in their inclusion as PFAs. Systemic power may potentially come in the form of structures and routines (e.g. an agenda that starts every meeting with a patient story or the inclusion of PFAs on all organizational committees). This represents one way in which power may be conceptualized for learning, but further exploration of organizational learning models and the implications of power relations specific to learning would be worthy contributions to the learning literature.

Implications for future research

The area of patient engagement is relatively new in North America, and it is rich for ongoing discovery to better understand what works, for whom, and in what context, to improve the patient experience of care and patient outcomes. Storytelling represents one way

to engage with patients, and as revealed in the results of this study, there are numerous avenues ripe for future exploration. For example, further study could focus on the storytellers, their characteristics, motivations, and identities, particularly in groups that are under-represented as PFAs. Similarly, more in-depth study could examine the perspectives of point-of-care staff and how stories may be used (or not) to shape their practices and behaviours. Future research could also explore different types of healthcare organizations—such as other non-service delivery organizations that seek to include patients as part of their mandates or organizations that have not explicitly identified PFCC as their philosophy of care—and how patient stories are used in these organizations. This is just a sample of future research directions brought to light by this study. For this purposes of this discussion, however, I will limit myself to a program of research that I think would extend the work of this dissertation in four key areas, as the potential next steps that I could undertake as a researcher in this area of patient stories for organizational learning.

First, this study took an interpretive approach to understanding and exploring the use of stories within the organizations that were studied, and strongly tied to the use of stories were concepts of empowerment and partnership. A critical discourse analysis of patient stories would provide a different lens for further consideration of issues of power and the hegemonic discourses that exist within healthcare as they relate to hearing the patient voice, developing mechanisms for patient engagement, and creating models of partnership and empowerment. Such a perspective would help to provide a more thorough understanding of issues of co-optation and appropriation of stories, but also insight into the stories and storytellers that are silenced or not invited, enabled, or supported to share their stories. For example, in a study by Elwyn and Gwyn (1998), discourse analysis was used at the level of doctor–patient interactions, examining the exchange and narrative of those communications.

This analysis revealed intricate communication strategies and how patients construct their roles within consultations. Their study revealed how healthcare professionals can better learn to open up a new way of ‘listening’ to the signals that so often pass unnoticed:

By being aware of certain signaling practices and discourse markers in the patient’s talk, general practitioners might also be able to listen more constructively to their patients’ stories, and allow a more ‘democratic arrangement of voices’. Added to which, lest we forget, for countless patients, it is the telling of their stories that helps to make them well. (Elwyn & Gwyn, 1998, p. 173).

Discourse analysis would extend beyond the individual level to consider team and organizational practices that inhibit and enable thinking *with* patient stories, examining the power structures within teams and the organization, and the patient’s place within these structures.

Second, the stories that emerged in this study represent one type of story—stories for learning and improvement. Thus, it was those stories of care experienced by patients and the learning that came from them that were apparent, primarily as stories of chaos that turned into quest narratives. However, a myriad of patient stories exist, and future research could further explore the spectrum of storytelling in healthcare, delineating a broad typology of stories, their format (e.g., verbal, face-to-face, written or videotaped), their purpose, and their impact. Such a study could take a number of lines of inquiry. For example, a systematic review of patient stories in the healthcare literature could be conducted to create a typology of stories (beyond stories of illness). For example, Reader et al. (2014) conducted a systematic review of patient complaints and developed a typology of patient complaints to improve understanding of issues raised by patients, with the potential to guide areas of improvement. Alternatively, in-depth case studies of healthcare organizations could also uncover the multitude of patient stories (beyond the focus of this study) that are used within organizations, similarly resulting in a typology of patient stories.

Third, and of particular interest to me, is the use of technology and how the proliferation of video stories of patients has the potential to impact the wider patient engagement movement. The explosion of patient stories on the Internet provides a far-reaching vehicle for patients to share their experiences to audiences worldwide. Of specific interest are those stories that have gone viral, which could be explored in-depth to determine why certain stories become widely viewed and the potential influence they have more broadly on patient engagement (at the individual, organizational, and policy levels). For example, at a conference that I recently attended, the Chief Executive Officer of a provincial quality organization featured a YouTube video of a 15 year-old patient named Morgan; in a span of two and a half minutes, Morgan was able to articulate three key quality improvement opportunities based on her experiences of care. This video now has 65,000 views, and it has the potential to influence not only the organization that provided her care, but also how patients engage in the system and are empowered to be involved at different levels of their care (and within the system as a whole). This same video was picked up by e-Patient Dave, a prolific patient advocate on social media, who wrote an article about this video for Forbes. Thus, the use of technology and the far-reaching audiences reached by these video stories has the potential to further move patient stories from episodic power to more systemic forms of power, beyond the individual and organizations for larger systems change.

Lastly, while the prime concern of this thesis has been on exploring and understanding patient stories for organizational learning and improvement, this work could be extended further to examine how learning from patient experiences may be linked more broadly to organizational performance. In particular, this study has pointed to the role of organizational leaders who have strategically positioned patient and family centred care as the philosophy of care, and through their leadership, visioning, and role modeling, have

looked to create a culture of care that enables the patient voice to be heard at all levels within the organization. Garcia-Morales and colleagues (2012) point to the role of leadership – particularly transformational leadership – as influential in organizational performance through organizational learning and innovation, with organizational learning having a positive influence on performance improvements (Fiol and Lyles, 1985; Senge, 1990). Firms that show a greater breadth, depth, and speed of organizational learning have higher performance levels. A management style of transformational leadership through organizational learning and innovation simultaneously influences organizational performance (García-Morales et al., 2012). Thus, further research could explore how leaders that embrace this philosophy of patient and family centred care fuel learning within their organizations, using tools such as patient stories as a lever for learning, to improve performance, particularly in this area of patient-centred care.

Conclusions

The prime objective of this dissertation was to better understand how healthcare organizations use patient stories for learning and improvement. I engaged with this subject matter through a constructivist perspective, examining leading organizations in a case study design using qualitative methods to explore their use of patient stories. Stories indeed can act as a powerful catalyst for change and learning, but as these organizations demonstrate, stories do not act alone. The use of patient stories is part of a larger engagement strategy that has helped to build and sustain a culture of PFCC and set the stage for ongoing partnerships, and they have been supported by structures explicitly linked to quality improvement and learning. The patient stories were transformed from chaos to quest narratives for learning, co-

constructed by tellers and listeners within the social context of narrative resources available to them. The storytellers themselves were consistently altruistic in their motives to share such stories, which in their telling afforded them an elevated status within their patient identities. These storytellers were patient and family advisors within their organizations or members of patient groups. While diverse in their backgrounds and issues, they were similar in that they chose to come forward to share their stories, and they were capable of clearly articulating their experiences.

The organizations were grounded by their philosophical orientation toward PFCC, which patient stories helped to develop and sustain. These organizations created the structures and processes required to not only gather and share patient stories, but to use them in purposeful ways linked with quality improvement and learning. Organizations aimed to create psychologically safe spaces by which to share stories, preparing both patients and staff members to tell and listen to stories. Importantly, leaders were visible in their expectations and role modeling of behaviours that spoke to the value of the patient voice. Thus, in many ways, these organizations demonstrated ways in which they were thinking *with* stories and learning from them occurred at individual, team, and organizational levels. What also emerged, however, was the hegemonic power to story, as leaders and organizations retained control over which patient stories would be shared, in what forum, and for what purposes. So while patient stories were one way that these organizations felt they could create partnerships with patients, affording them episodic power in their roles as storytellers and as PFAs, there simultaneously exists an underlying current of control that organizations continue to hold in “authorized stories” and “authorized storytellers.” Leaders need to engage in a reflective practice to better understand the power and privilege that exists in all interactions, and of the power they continue to hold, despite their best intentions to hear the patient voice. This area

of power and privilege is one to explore further in theory development for organizational learning.

Epilogue

Grace's story

I had the opportunity to watch Grace's story (described in the prologue) on video prior to my interview with her. In the video, Grace sits in front of the camera, and over a period of about eight minutes, she recounts this story. The camera frames her close-up, and you can see the emotion in her face as she tells this story. Tears well up as she speaks. She later recounted parts of the story to me, particularly regarding the emotional impact of that story itself—both on her as she told it, but also on the audience.

The story shared by Grace highlights how one particular organization aimed to think *with* stories. In conversation with the manager of the ICU where her father was hospitalized, Grace shared the experiences of her family regarding the care of her mother at a different facility. She was then invited to share these experiences of care as part of a patient panel at a large quality and safety forum with over 400 healthcare providers and leaders in attendance. The forum (and the panel) helped to launch the organization's foray into developing a culture of PFCC, and to systematically use the patient voice to guide their improvement efforts.

Interestingly, the experience shared by Grace was one that occurred at a different healthcare institution, but because it resonated so loudly with leaders and staff alike, it became a story that this organization has used to work on their own improvement efforts; Grace has been a part of the team working on the improvement initiative. After the response to the story at the forum, the organization felt that it was a story that should be videotaped and used for learning purposes. Together with Grace, they created a facilitated learning guide to be used by healthcare teams to prompt self-reflection of cognitive, affective, and experiential learning.

While she reflected on many stories that she could tell of her experiences as a family caregiver to her loved ones, she chose this particular story to share at the forum as it was an experience that “*hurt the most.*” As an initial foray into storytelling efforts, Grace and the other panelists have begun to create narrative templates for this organization and ongoing narrative resources for future storytellers. Grace also speaks of the experience of telling her story: she recalls that “*there was silence*” as she spoke, and felt that there was a psychologically safe space to share her experiences, together with other patient storytellers.

From an organizational learning perspective, this particular story appeared to have relevance to its audience, clearly drawing on its affective and emotive powers, as well as tapping into both the cognition and experience of the audience members. This was a story where staff and leaders alike were able to bear witness “*as sisters and brothers, wives and daughters.*” At a team level, this story continues to resonate, as Grace works together with the team to change policies related to family presence, particularly in the ICU. While changes have not yet been institutionalized into practice (via policy),⁷ this story and the ongoing involvement of Grace have created the dialogue necessary for ongoing reflection and improvement. Leaders in this organization have created the necessary conditions to support not only sharing this particular story in ongoing ways (e.g., by videotaping the storyteller), but also by ensuring that the reception to the story is active (not passive), creating a space for intentional dialogue that can be used to learn and reflect on this story for change (e.g., through the development of a facilitated learning guide that accompanies the use of this story). Grace speaks of PFCC as “*part of the fabric of who we are,*” [emphasis added]

⁷ At the time of the organizational site visit, Grace shared with me that she continues to work with the clinical team to share experiences in the hopes of changing attitudes and practices toward family presence in the ICU. The policy has not yet been changed, but the ultimate goal was to bring a family presence policy forward that would enable family members (or other care givers identified by the patient) to be welcomed into the ICU whenever they choose to be in attendance with their loved one.

indicating she feels embraced by the organization in her role as a PFA and by a partnership model that she feels includes and empowers her. Grace comes across as someone of the “right fit” (i.e., articulate, educated, and able to see beyond her own issues) at the “right time” (i.e., at least a year had passed from the time of the experience to when she told her story)—thus, she is an “authorized storyteller” with an “authorized story.”

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Appendices

Appendix A:

Key informant letter of introduction and guiding questions

Dear

Re: Research study entitled: ***'Letting stories breathe': Using patient stories for organizational learning and improvement***

We are conducting a research study to examine how patient stories are used for learning and improvement within healthcare organizations. This study is part of a larger research study that is examining healthcare organizations that have had success in engaging patients and families in developing processes and systems of care. This particular part of the study will involve a series of case studies of organizations that have successfully used patient stories as a mechanism for patient and staff engagement and have learned from these stories to improve the care and processes of care for their patients. We want to learn from those organizations that are exemplars in the use of patient stories, to examine their strategic plans and organizational priorities, the mechanisms in which stories are gathered, and to understand the organizational context that supports or hinders the use of patient stories. Results of this study will provide guidance for other healthcare organizations that seek to improve their organizational learning and person-centredness through storytelling methods.

You are a noted expert in the area of [quality improvement/organizational learning/patient engagement/ person-centred care]. As such, we are contacting you for your insights on healthcare organizations that you feel exemplify the use of patient stories within their organization. These will be organizations that have systematic and deliberate ways to gather patient stories and use these stories for learning and improvement.

We ask that you nominate up to FIVE (5) organizations in Canada or the United States that you feel best exemplify the use of patient stories for learning and improvement. Please consider the following when providing information for your nomination:

1. Name of healthcare organization
2. Are patient stories deliberately gathered within the organization? How?
3. What avenues are available to tell patient stories? For what purposes?
4. How long has this organization been using patient stories?
5. What change has occurred as a result of a patient story (or stories)? What is the evidence of this impact?
6. What is the leadership support for the use of patient stories?
7. Why do you feel this organization has had success in using patient stories?

A response with nominations implies consent to participate in this study. Your nominations will remain confidential; your role as a nominator will be anonymous. For more information about this study, please contact Carol Fancott, principal investigator, at carol.fancott@utoronto.ca or Dr. G. Ross Baker (thesis supervisor) at ross.baker@utoronto.ca (416-978-7804).

Thank you for your insights in helping us identify those organizations who have had success in the use of patient stories for learning and improvement.

Sincerely,

Carol Fancott
Principal Investigator
PhD candidate, Institute of Health Policy, Management and Evaluation
University of Toronto

Research Team (from the University of Toronto):

Dr. G. Ross Baker, PhD, Institute of Health Policy, Management, and Evaluation
(Thesis supervisor)
Dr. Whitney Berta, PhD, Institute of Health Policy, Management, and Evaluation
Dr. Ayelet Kuper, MD, PhD, Department of Medicine

Appendix B:

Information letter and organization consent form



Study title: ‘Letting stories breathe’: Using patient stories for organizational learning and improvement

Research team from the University of Toronto:

Carol Fancott, PhD candidate, Institute of Health Policy, Management and Evaluation
Dr. G. Ross Baker, PhD, Professor, Institute of Health Policy, Management and Evaluation
Dr. Whitney Berta, PhD, Associate Professor, Institute of Health Policy, Management and Evaluation
Dr. Ayelet Kuper, MD, DPhil, Assistant Professor, Department of Medicine

We are inviting your organization to serve as a case study site as an exemplar in the use of patient stories for learning and improvement.

Study topic and purpose:

The purpose of this study is to learn from those healthcare organizations that have had success in using patient stories for organizational learning and improvement. Our goal is to understand what structures and processes exist within the organization to systematically gather, analyze, and act upon patient stories, the contextual factors that facilitate or inhibit the use of patient stories, and the impact of stories on learning and improvement. We hope to provide guidance to other healthcare organizations that look to effectively and successfully use patient stories to enhance the patient experience of care.

What is involved in participation for this study?

As a case study site, we will be collecting information about your organization in three different ways:

Interviews: We will conduct individual interviews with leaders, staff, former patients, and board members involved in the telling-listening dyad of patient stories within your organization. Interviews will focus on exploring the mechanisms you have in place to gather, analyze, and use patient stories, the purposes for which stories are gathered and used, who has told and re-told these stories, factors that have facilitated or hindered the use of patient stories, and the impact that stories have had on your organization. The interview will take approximately 60 minutes and will be scheduled at a time and place of convenience for the participants.

Document retrieval: Including relevant minutes of meetings related to patient stories, organizational mission/vision/value statements, organizational strategic plans, performance measurement reports, results of patient and staff surveys, hospital annual reports and newsletters, compliment and complaint letters.

Observations: If feasible, we would like to observe venues in which patient stories are told within the organization (e.g. Board meetings, staff townhalls, team

meetings). The researcher will take notes of what has been observed during this time

Potential risks and benefits:

Participation as a case study site is voluntary. We do not anticipate any risk to your participation in this study. Apart from the inconvenience of the time involved, the main risk is breach of confidentiality and we have listed the steps we will take to protect against that in the next section. By participating in this study, you will have the opportunity to showcase your organization as a leader in the area of patient engagement and the use of patient stories for learning and improvement, and will contribute to the development of new knowledge in this area.

Confidentiality:

As a case study site, the name of your organization will be used in the findings of this study. However, information collected by the means described above will remain confidential.

1. For interviews:

- Participants will be identified by code number for follow-up purposes and the code list will be kept in a secure office. The list will be destroyed when the study is complete.
- Transcripts and field notes will be kept in a secure office, and only study investigators will have access to it.
- Interview recordings will be securely stored during the study and then will be destroyed.
- The transcripts and data will be analyzed on a personal computer, which is password protected.
- We will not use personal identifiers or attributable quotes in any reports or publications without consent.

2. For documents:

- Documents retrieved will be stored securely during the study and then will be destroyed.
- Any identifying information on the documents will be removed.

3. For observations:

- Notes made by the researcher will not contain any identifying information of participants.
- We will not use personal identifiers or attributable quotes in any reports or publications without consent.

Withdrawal from the study:

Participation as a case study site is voluntary; if you choose to participate, you may withdraw your organization within 72 hours of the case site visit. There are no negative effects of withdrawal from this study and any information collected from your organization will not be used in this study.

Contact information:

If you have any questions about this study, please feel free to contact Carol Fancott, principal investigator at (416) 536-8458 or by email: carol.fancott@utoronto.ca or Dr. G. Ross Baker (thesis supervisor) at ross.baker@utoronto.ca (416-978-7804).

CONSENT

- I have read this information letter and have had the opportunity to have my questions answered to my satisfaction.
- I agree, on behalf of this organization, to participate as a case study site. I understand that I may withdraw this organization from the study within 72 hours of the case site visit.
- I have been given a copy of this information letter and consent for my personal records.

If you have any questions or concerns about your rights as a research participant, please contact Daniel Gyewu, Research Ethics Board Manager, Health Sciences, at d.gyewu@utoronto.ca or 416-946-5606.

(Signature of organizational leader)

(Signature of researcher)

(Please print name)

(Please print name)

(Date)
Version date: 15/11/12

Appendix C:

Interview Guides
For staff/leaders
For patients/families

Semi-structured Interview Guide for Staff and Leaders

A. Introductions and background:

As per information sheet/consent form, the principal investigator will provide a brief background to the study and purpose of the interview.

In this interview, we want to learn more about patient stories you have heard and the impact they have had on you and the organization. Do you have any questions before we begin?

B. About the story

1. I have heard about a patient story related to xxx (as identified by senior leader). Can you tell me more about this patient story?

Probes: Who told the story? Who else was there when the story was told? Tell me more about the story.

2. Stories are everywhere. What was it about this particular story that made you remember it? What made this one stand out?

Probes: storyteller, details of story, circumstances, their own situation at the time

3. How did you feel when you heard this story?

Probes: emotional context (happy, sad, angry)

C. Learning from stories

4. What did you learn from that story? What did you do after you heard the story? Have you done anything differently in your everyday practice since hearing that story?

Probes: timeline for actions, timelines for telling story again? Action as a result? Changes in behavior? Changes in processes? Learning to action?

5. Have you re-told this story to others? What made you decide to tell this story?

Probes: When? Why?

D. Organizational context

6. Within your unit, do you often share patient stories? Tell me more about these stories.

Probes: for what purpose, when, to whom, by whom, leadership for stories, context for stories

7. Within the organization, do you often hear stories about patients? Tell me more about these stories.

Probes: for what purpose, when, to whom, by whom, leadership for stories, context for stories, sharing of stories across units/across organization

E: In closing

8. This was one story that seemed to resonate with some. Have there been other stories that have been meaningful to you? How did they affect you and your learning?

9. Is there anything else that you would like to add?

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Semi-structured Interview Guide for Patients and Families

A. Introductions and background:

As per information sheet/consent form, the principal investigator will provide a brief background to the study and purpose of the interview.

In this interview, we want to learn more about stories that you may have told about your care at this hospital and how it felt to tell the story. Do you have any questions before we begin?

B. About the story

1. I have heard about this story that seems to have resonated with people who work here at this hospital (as identified by senior leader). Can you tell me more about this story?

Probes: What happened? Who did you tell this story to? How did you tell the story (e.g. written or face to face, on the telephone)? What happened when you told the story?

2. What compelled you to tell this story?

3. How did you feel when you told your story?

Probes: emotional context (happy, sad, angry, relieved, frustrated)

C. Learning from stories

4. What impact do you think you had by telling this story?

Probes: impact on self, impact on others, impact on actions/learning

5. Have you told this story again to others?

Probes: To whom? When? Why?

D. Organizational context

6. What enabled you to tell your story?

Probes: specific person, clear process to tell story/provide feedback, listening/caring environment

E: In closing

7. What advice would you give to other patients who want to share their stories about the care they have received at this hospital?

8. Is there anything else you would like to add?

Version Date: 15/11/12

Appendix D:
Information Letter and Informed Consent Form
Interviews



Information Letter and Consent to Participate in a Research Study

Study title: 'Letting stories breathe': Using patient stories for organizational learning and improvement

Research team from the University of Toronto:

Carol Fancott, PhD candidate, Institute of Health Policy, Management and Evaluation
Dr. G. Ross Baker, PhD, Professor, Institute of Health Policy, Management and Evaluation
Dr. Whitney Berta, PhD, Associate Professor, Institute of Health Policy, Management and Evaluation
Dr. Ayelet Kuper, MD, DPhil, Assistant Professor, Department of Medicine

We are inviting you to participate in a research study to learn more about how patient stories are used within your organization.

Study topic and purpose:

The purpose of this study is to learn from those healthcare organizations that have had success in using patient stories for organizational learning and improvement. Our goal is to understand what structures and processes exist within the organization to systematically gather, analyze, and act upon patient stories, the contextual factors that facilitate or inhibit the use of patient stories, and the impact of stories on learning and improvement. We hope to provide guidance to other healthcare organizations that look to effectively and successfully use patient stories to enhance the patient experience of care.

What is involved in participation for this study?

We are inviting you to participate in an individual interview to learn more about the patient story that you heard/told, your reactions (and subsequently your actions) to the story, your thoughts on the impact of this story, what helps you hear/tell stories within the context that you work, and the support you feel that stories have within your organization. The interview will take approximately 60 minutes and will be scheduled at a time and place of your convenience.

Potential risks and benefits:

Participation in this study is voluntary. If you experience any distress as a result of recounting a patient story or your experiences, we will provide counseling services if required. Another risk is breach of confidentiality and we have listed the steps we will take to protect against that in the next section. However, by participating in this study, you will have the opportunity to showcase your organization as a leader in the area of patient engagement and the use of patient stories for learning and improvement, and will contribute to the development of new knowledge in this area.

Confidentiality:

Information collected in the interview will remain confidential.

- Participants will be identified by code number for follow-up purposes and the code list will be kept in a secure office. The list will be destroyed when the study is complete.
- Transcripts and field notes from the study sites will be kept in a secure office, and only study investigators will have access to it.
- Interview recordings will be securely stored during the study and then will be destroyed.
- The transcripts and data will be analyzed on a personal computer, which is password protected.
- We will not use personal identifiers or attributable quotes in any reports or publications without consent.

Withdrawal from the study:

Participation is completely voluntary and if you choose to participate, you can withdraw from the study within 72 hours of the interview without consequence to your current or future employment or care at this organization. Should you choose to withdraw, information gathered from you at the interview will be destroyed and not used in the overall analysis for the case study.

Contact information:

If you have any questions about this study, please feel free to contact Carol Fancott, principal investigator at (416) 536-8458 or by email: carol.fancott@utoronto.ca

CONSENT

1. I have read this information letter and have had the opportunity to have my questions answered to my satisfaction.
2. I agree to participate in the interview and I understand that I may withdraw from the study at any time I choose.
3. (Please initial one of the following options)
 - ____ I give my permission to have the interview recorded. I understand that I may request to have the recorder turned off at any point during the interview.
 - OR
 - ____ I do not give my permission to have the interview recorded.
4. I have been given a copy of this information letter and consent for my personal records.

If you have any questions or concerns about your rights as a research participant, please contact Daniel Gyewu, Research Ethics Board Manager, Health Sciences, at d.gyewu@utoronto.ca or 416-946-5606.

(Signature of participant)

(Signature of researcher)

(Please print name)

(Please print name)

(Date)

Version date: 15/11/12

Appendix E:
Information Letter and Informed Consent Form
Observations



Information Letter and Consent to Participate in a Research Study

Study title: ‘Letting stories breathe’: Using patient stories for organizational learning and improvement

Research team from the University of Toronto:

Carol Fancott, PhD candidate, Institute of Health Policy, Management and Evaluation

Dr. G. Ross Baker, PhD, Professor, Institute of Health Policy, Management and Evaluation

Dr. Whitney Berta, PhD, Associate Professor, Institute of Health Policy, Management and Evaluation

Dr. Ayelet Kuper, MD, DPhil, Assistant Professor, Department of Medicine

We are inviting you to participate in a research study to learn more about how patient stories are used within your organization.

Study topic and purpose:

The purpose of this study is to learn from those healthcare organizations that have had success in using patient stories for organizational learning and improvement. Our goal is to understand what structures and processes exist within the organization to systematically gather, analyze, and act upon patient stories, the contextual factors that facilitate or inhibit the use of patient stories, and the impact of stories on learning and improvement. We hope to provide guidance to other healthcare organizations that look to effectively and successfully use patient stories to enhance the patient experience of care.

What is involved in participation for this study?

We will be observing a committee meeting where a patient story will be told. The principal investigator will be taking notes regarding the story itself, the observations of reactions to the story, types of questions asked, and the ensuing discussion. You do not need to do anything different than you normally would as a member of this committee. If you do not wish to be observed, the principal investigator will not take any notes or make comments regarding what you say or what you do within this meeting.

Potential risks and benefits:

We do not anticipate any risks to you by attending this meeting as a regular member.

Confidentiality:

No names will be attributed to any information gathered within the meeting that is observed.

Contact information:

If you have any questions about this study, please feel free to contact Carol Fancott, principal investigator at (416) 536-8458 or by email: carol.fancott@utoronto.ca or Dr. G. Ross Baker (thesis supervisor) at ross.baker@utoronto.ca (416-978-7804).

CONSENT

I have read this information letter and have had the opportunity to have my questions answered to my satisfaction.

I agree to be observed in the regularly scheduled meeting.

I have been given a copy of this information letter and consent for my personal records.

If you have any questions or concerns about your rights as a research participant or if you wish to speak to someone other than a research team member about this research project, you are welcome to contact:
Daniel Gyewu, Research Ethics Board Manager, Health Sciences, University of Toronto at d.gyewu@utoronto.ca or 416-946-5606 or Chair, Research Ethics Board,
Thunder Bay Regional Health Sciences Centre at ResearchEthics_Chair@tbh.net or 807-684-6422 (fax: 807 684-5904; 980 Oliver Road, Thunder Bay, Ontario P7B 6V4).

(Signature of participant)

(Signature of researcher)

(Please print name)

(Please print name)

(Date)

Version date: 15/11/12

Appendix F:

Situational Maps - Ordered Version

Situational Maps: Telling of and learning from patients stories

Individual human elements/actors

Patients
Families
Staff
Leaders
Patient ombudsman/advocate
Board members
PFCC leader(s) - gatekeepers

Collective human elements/actors

Patient advisory councils
Unit councils
Quality councils
Board committees
Communities beyond hospital

Discursive constructions of individual and/or collective human actors

Patients with “an axe to grind”
Patients want to “take home the store”
Staff as defensive
“Remembering why we came into healthcare to begin with” – healthcare professionals as caring

Political/economic elements

Excellent quality of care legislation
Added resources needed to be PFCC

Temporal elements

Takes more time to be patient-centred
Takes more time to involve patients in organizational-level work

Major issues/debates (usually contested)

Its “just one story” – representation of a story
Power hierarchies in healthcare – doing to, doing for, doing with patients

Other key elements

PFCC as emotional work

Non human Elements Actants

Mission, Vision, Value statements
Organizational strategic plans
Patient satisfaction/experience goals
Technology to share stories
Structures and processes to support PFCC
Stories

Implicated/silent actors

Patients
Families
Organizational culture
Norms/expectations

Discursive constructions of non-human actants

PFCC is the ‘right thing to do’
PFCC as ‘transformation culture change’
Learning culture as open, non-blaming

Sociocultural/symbolic elements

Healthcare as a “touch business”
The ‘patient voice’
Partnerships and building relationships

Spatial elements

Patient and family-centred design – welcoming spaces

Related discourses (historical, narrative, and/or visual)

Healthcare advocacy in some sectors prominent (e.g. paediatric care, cancer care, mental health)

Situational analysis (Clark, 2005)

1. Situational maps as strategies for articulating the elements in the situation and examining relations among them
2. Social worlds/arenas maps as cartographies of collective commitments, relations, and sites of action
3. Positional maps as simplification strategies for plotting positions articulated and not articulated in discourses