Emotions, Significance and Improvement Expectations:
The Personal Matter of a Patient’s Hospital Stay

by

Isabella K S Cheng

A thesis submitted in conformity with the requirements for the degree of Master of Science
Rehabilitation Sciences Institute
University of Toronto

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2017

Abstract

Health systems aim to provide quality healthcare. Patients’ experiences can inform quality improvements. **Background:** Mailed standardized surveys are a way to engage patients about inpatient care experiences. While results from rating-scale questions are regularly reported, no study has analyzed patients’ written responses. **Purpose:** To learn about patients’ perspectives of hospital care, survey comments were examined. **Method:** Inductive content analysis of 1,638 written responses was conducted within a qualitative description study design.

**Findings:** Patients’ comments suggest: Emotions pervade patients’ hospital stay experiences with feelings about perceptions of safety, personhood and preparation for returning to living life; moments in time personalize hospital experiences; and the survey is viewed as an implied contract, where patients provide feedback in exchange for hospital improvements. **Implications:** Findings affirm current understandings about inpatient experiences and extend them. Patients’ comments reveal new insights about the specifics of patient-centered care, patient experience and quality healthcare that merit further study.
Acknowledgments

One early Friday morning this past June, I was awakened by a fantastical dream that remains vivid and holds meaning that I’m still discovering.

Finding myself in a grand room, I note the layers of frames, shelves and textures. The room looks cluttered and feels overwhelming, yet it’s orderly. It’s not my space. And, it’s so familiar. Two people are standing side-by-side in an adjacent smaller and doorless room, both facing the wall. Above me flies a great bird; I know that it is magical. The clouds, dancing in shades of purple, draw my gaze out the window. Then I see the moving swarm of black dots approaching. I feel anxious. Something is changing. And only then do I notice the constant loudness that has always been present. The noise is interrupted by a screech from the bird. It’s coming from outside. I run out the front door to find the bird caged, above my head to my left, too high for me to reach and its magic having no effect . . . Are the floors moving? What’s happening? The noise is deafening! Is everyone safe? I run back inside to find that the two people have not moved. They display no reaction. The walls are lifting, shifting. Is anyone else seeing this, hearing this, noticing this?! . . . Now I have a birds-eye view. That’s me sitting at the great round table, a diminutive presence relative to the vast chaos surrounding me. Someone is stroking my hair. We both face the window. Here together, it’s quiet in the loudness. It’s still in the shifting. Our hearts are beating calmly. I feel safe. It’s all okay.

For me, the dream was a culmination of intense learnings and realizations made while completing my Master’s work. Many people and experiences impressed upon me. Colleagues, professors, students and leaders, as well as changes in roles, policies and legislative directions – all taught me important lessons about quality in healthcare. Patients and family members augmented my understanding about “Nothing about us without us” and “through the eyes of patients”. I thank the woman who replied, “Not so well. My best friend is dying…” when I asked her in the elevator, “How are you today?” I thank the man who replied, “Yes! Please tell me who to talk to about my daughter…” when I asked him in the hallway, “Can I help you?” I thank the couple who shared their accumulated experiences of repeatedly needing hospitalization and the impact on their family. I thank our many patient and family member Partners who invest time, energy, spirit and hope into working together to improve the care received by patients. As a team, in collaborative partnerships and with shared decision-making, we are better and achieve more.
Specific people have impacted the way in which I approach research and live in it. Thank you:

Everything I know about leadership and collaboration began with Molly Verrier’s guidance and mentorship. Her passion for rehabilitation and dedication to bolstering high quality research is limitless. Molly is a constant inspiration.

Authentic relationships, compassion, empathy and a focus on “the person” in healthcare is what Margaret Fitch models and teaches everyone. Marg freely gives her time and expertise to help me grow as a researcher in person-centred care. I am grateful for her dedication and encouragement.

Jane Davis is always generous, always sharing, always there. I appreciate her practical wisdom.

Tracey DasGupta often begins her talks with, “A journey of a thousand miles begins with a single step”. We’ve been on a few journeys together, and in a heartbeat, I would start another one with her.

Moments in time complete my continuing experience of becoming a researcher: When Ciaran expresses pure joy with a squeeze or a kiss; when Beckett shares a new collection of an organized “thing”; when Dale shows caring with a look or with a note; when Sasha laughs at me, makes me laugh, and laughs with me; and when Mommy knows exactly what I need.

For Helene Polatajko, I feel deep love, immense appreciation and great respect. Much has happened for us over the past five years. I am indebted to her for her insights and understandings. And because of Helene, I commit to continuing my research. This is a beginning.
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Chapter 1

1 Introduction

What constitutes ‘quality healthcare’ is ultimately determined by the people who directly experience it. Therefore, the perspectives of patients are important to be understood and to be used toward improving the quality of healthcare services. Worldwide, patients are being asked to provide feedback to the healthcare organizations where they experienced care. In Canada, the government of Ontario leverages legislation in the Excellent Care For All Act (2010) by mandating that every healthcare organization, beginning with hospitals, examines patient experience data and publicly reports an annual plan to improve quality (Government of Ontario, 2010). The Excellent Care For All Act now additionally requires organizations to engage patients and their caregivers in the development of annual quality improvement plans and to report on patient engagement activities (Government of Ontario, 2015). The “Patients first: Action plan for health care” (Ministry of Health and Long-Term Care, 2015) implores that healthcare improvements are “rooted in evidence and patient experience” and that they “put patients first” (p. 2); it builds upon the original “Action plan for health care” (Ministry of Health and Long-Term Care, 2012) and bolsters the Excellent Care For All Act.

Various activities or methods are used by organizations to engage patients to share their perspectives about healthcare services (Carman, et al., 2013; Fooks, Obarski, Hale, & Hylmar, 2015). Among these, mailed surveys have long-standing and widespread use. Patient surveys typically seek overall ratings or scores to defined questions and the resulting data provide organizations with some insights into areas of strength or potential areas for improvement. However, ratings do not provide specific information about why a patient assigned a rating or what type of improvements could make meaningful differences to patients. For example, a patient’s rating of “somewhat” regarding staff having talked with the patient about his/her anxieties or fears, “sometimes” regarding getting answers in an understandable way, and “good” or “7/10” regarding overall hospital performance, does not provide specific information as to how to potentially help staff talk with patients about their anxieties and fears, or how to enhance effective communication by care providers, or how to improve the quality of services. In reality,
ratings provide little direction for actionable improvements that might be important from the perspectives of patients (Berwick, James, & Coye, 2003; Shale, 2013).

While the bulk of patient survey items ask a respondent to assign a rating, surveys often also contain a comment section or an open-ended question. Care recipients (patients) value the opportunity to provide comments and care providers (hospital employees and leaders) value the content of comments (Riiskjær, Ammentorp, & Kofoed, 2012). Open-ended questions allow patients to freely express ideas that may not have been pre-selected as topics for rating and comments may identify issues that are important for patients that are not addressed by survey questions. Within written survey comments, there may be an opportunity to learn about the reality behind the numbers, from the perspectives of patients about what happened. Comments may provide insights into which aspects of care were memorable, what change ideas could make positive quality improvements, and how to prioritize improvements. The purpose of the study reported here was to examine the written comments in a mailed standardized patient survey in order to uncover patients’ understandings about quality inpatient care, from their own words.

1.1 Thesis context

This study was undertaken as part of my graduate studies in the Practice Science Field of the Rehabilitation Sciences Institute at the University of Toronto. Students enrolled in the Practice Science Field work full-time while investigating a practice-based research. The ultimate goal is that the research will contribute new knowledge at large about a current healthcare practice issue, and that when the research question has direct relevance to the student’s place of employment the knowledge gained may offer the organization new insights to influence improvements.

Of the different ways that hospitals engage patients to share their perspectives, the mailed standardized inpatient survey is the longest-standing method. As part of the Ontario Hospital Association’s Hospital Report project, survey data have been collected for over two decades from Ontario hospitals; patients’ ratings are trended within and compared across hospitals (Ontario Hospital Association, 2013), and longitudinal surveying allows for benchmarking against peer groups (Ontario Hospital Association, 2015). Ratings to the global evaluation question about “overall” care impressions are released as a percent positive score, and are the default comparator between hospitals. While quantitative ratings provide some evaluative information, it is the open-text comments that may afford a way to learn more about hospital stay
experiences, specifically about which aspects of care contribute to patients’ experiences of quality healthcare. The purpose of this study was to explore the content of what patients wrote in response to the open-ended survey question of the mailed post-hospitalization survey that Ontario hospitals use to gain feedback about the inpatient stay experience.

At the time of study, the National Research Corporation Canada administered the Ontario Hospital Association-endorsed “Adult Inpatient Survey” (Appendix I), a Picker survey, on behalf of Sunnybrook Health Sciences Centre. As a tertiary care academic health sciences centre, Sunnybrook provides 1.2 million patient visits annually (Sunnybrook Health Sciences Centre, 2016a). The current study used survey data collected about Sunnybrook’s inpatient care.

Improving the quality of care that patients receive at Sunnybrook is an ongoing priority. The content of patients’ survey comments, while regularly reviewed at quarterly intervals at Sunnybrook, has not been previously analyzed using a systematic approach to explore themes based on patients’ perspectives. Further, a search of the literature found no published studies reporting on the analysis of patients’ written comments in standardized mailed patient surveys about inpatient care.

Findings from this study may have significance for hospitals because they must report annual patient engagement activities toward improving quality of care (Government of Ontario, 2015). Further, findings from this study may inform quality improvement work at my place of employment because the hospital strives to use patients’ feedback to improve the quality of services. Commitment to patient engagement and person-centred care increases each year at Sunnybrook, as expressed in annual quality improvement plans. A “focus on increasing patient engagement and on supporting staff to use approaches to care that put the patient first” (Sunnybrook Health Sciences Centre, 2014) progressed into “embedding the voice of the patient in all of our practices and processes” (Sunnybrook Health Sciences Centre, 2015). The most recent quality improvement plan discusses “creating a culture of patient and family engagement to support the delivery of safe, quality and person-centred care” and names several activities in progress that directly engage patients in improvement activities (Sunnybrook Health Sciences Centre, 2016b).

Several study delimitations were set. In order to gain understandings about patients’ care experiences directly from the words of patients, only comments written by patients were selected
for analysis; those written by family members were excluded. Patients’ comments were analyzed within the broad context of “the hospital stay” rather than specific units, clinical care programs or patient age groupings. Analysis was conducted without a priori theoretical assumptions or frameworks to direct the coding. Average scores from the survey’s numerical ratings were not compared with findings interpreted from analysis of patients’ comments.

This study also has limitations because of the nature of a standardized survey instrument that collects voluntary responses from patients about care received during the timeframe corresponding to the data sample. The nature of the sampling is that a subset of patients discharged from hospital are randomly mailed a survey, not all patients who receive a survey complete and return it, and not all patients who complete rating-scale survey questions will elect to write a response to the open-ended question. Therefore, survey responses may not be fully inclusive of the broad-level experiences of the entire population of patients who received inpatient care. Further, there is no option to check the interpretations of patients’ written comments with patients themselves. Correspondingly, a study design that optimized research trustworthiness was chosen.
Chapter 2

2 Background

This research sought to contribute to what is known about patients’ perspectives of inpatient care experiences and was undertaken within the Ontario healthcare context. Patients’ perspectives about healthcare are of concern to all healthcare systems internationally. The delivery of high quality healthcare is a unifying aim. Current understandings about what constitutes quality in healthcare are reviewed in Chapter 2, with a focus on the historical and seminal literature that has contributed to what is known. Quality definitions and frameworks in healthcare are reviewed in this chapter. An overview about the increasing focus on patient experience measurement is provided, with a more detailed examination of the method of a mailed survey to engage patients’ perspectives. As appropriate, knowledge gained and evidence reported from literature around the world are applied to the Ontario context within which this research is situated.

2.1 Quality Healthcare: A Need for Continuous Improvement

In 1977, the World Health Assembly, the decision-making body that governs the World Health Organization (WHO), declared its target of “Health for all by the year 2000” (WHO, 1998). In 2000, the “World health report 2000: Health systems, improving performance” (WHO, 2000) was released and it compared health system performance in countries around the world. This seminal WHO report raised awareness about gaps in how well different health systems were delivering quality healthcare. While originally controversial (Navarro, 2000), the WHO report introduced the potential for public reporting to present evidence that could direct learning toward spreading improvement practices (Walshe, 2003). It was the impetus for new policies and research (McKee, 2010). The Organization for Economic Cooperation and Development (OECD) suggested core elements for a measurement framework to evaluate health systems at national and international levels (OECD, 2002) and today, the OECD regularly reports the performance of health systems in a publicly accessible health statistics database and as publications. In the United States of America (USA), the Commonwealth Fund posts comparative data relative to health system performance across states in the country.
The public reporting practice of comparing, ranking and benchmarking healthcare performance and quality is now commonly used to promote and drive improvements (Arah, Klazinga, Delnoij, Ten Asbroek, & Custers, 2003; Marshall, Shekelle, Leatherman, & Brook, 2000; Schauffler & Mordavsky, 2001; World Health Organization, 2012). Public reporting of quality measurement results, when used with the curiosity and intent for “improvement” through continuous effort rather than to cull organizations by “measurement for judgment” (Berwick, 1996), has the potential to lead to innovative changes.

In Canada, an advisory panel led by David Naylor was commissioned to report on innovations in the Canadian healthcare system. “Unleashing innovation: Excellent healthcare for Canada” (Naylor, et al., 2015), referred to as the Naylor Report, connected the current state of Canadian healthcare quality to recommendations for innovation. Despite increasing total health expenditures, information from the OECD, the Commonwealth Fund and the Canadian Institute for Health Information (CIHI) revealed that Canada is positioned 10th of 11 countries in overall quality of healthcare, better only than the USA, when ranked in relation to peer countries with high-performing health systems (Naylor, et al., 2015, Figure 2.6, p. 15). The Naylor Report outlined some clear opportunities for quality improvement and innovation in Canadian healthcare.

Regardless of reporting country, the quality framework that is prevalent in the literature to review, monitor and measure quality in healthcare is from the seminal report “Crossing the quality chasm: A new health system for the 21st century” by the Institute of Medicine (IOM) (2001a) in the USA. The IOM report names six dimensions of quality that are operationalized as six improvement aims for healthcare systems to adopt in order to deliver high quality care. The IOM dimensions of quality are used in reports commissioned by the government of Canada, such as in the Naylor report, and by the government of Ontario. Health Quality Ontario, an arms-length agency of the Ontario government with a mandate to evaluate and publicly report the effectiveness of the province’s healthcare services, formally adopted the IOM dimensions of quality when it released its “Quality matters: Realizing excellent care for all” report in October, 2015 (Health Quality Ontario, 2015a). The report acknowledged the benefits of using a common set of quality dimensions already used by other jurisdictions, in order to allow for benchmarking.
2.2 The Institute of Medicine Quality Framework

The IOM (2001a) quality framework dimensions are founded upon a practical definition of quality healthcare that seeks to avoid the misuse, underuse and overuse of healthcare services. The six aims for improvement begins first and foremost with healthcare being safe, such that people are not harmed by the misuse of services. Second, healthcare must be effective, such that the use of resources and services are based in evidence and contributes to appropriate care that avoids underuse and overuse. Third, healthcare must be patient-centered, such that people are in control of their care decisions and care is responsive to each individual patient’s needs. The fourth, fifth and sixth aims are goals that healthcare should be timely, efficient and equitable. Each of these dimensions is considered to be necessary for achieving quality healthcare, but on their own each is insufficient. That is, quality in healthcare is understood to consist of the confluence of all of these dimensions.

Based on the IOM definition of quality (IOM, 2001a), safety and effectiveness are the two great pillars of quality that support and is supported by all other dimensions of quality (Berwick 2009; IOM, 2001a). Hence, the study of each of the quality dimensions of safety and effectiveness have been most reported in the literature, usually from the perspective of clinicians, administrators and policy-makers. However, with increasing recognition that patients’ perspectives inform quality improvements, the pervasive importance of patient-centered care is becoming abundantly apparent.

Some authors have suggested the importance of understanding the first three IOM dimensions of quality as interconnected and that current health systems are performing with “particularly substantial deficiencies” in relation to safety, effectiveness and patient-centered care (Scott & Jha, 2014, p. 3). They argue that despite goals to improve healthcare quality, harm to patients continues to occur; and when no harm occurs, care is too often ineffective. Even with consensus about the importance of patient-centered care, patients continue to report not being treated with dignity and respect. In turn, patients’ experiences negatively impact their interactions with care providers and therefore perpetuates an interconnected cycle of unsafe and ineffective care (Scott & Jha, 2014). Further, how safety and effectiveness are linked to patient-centered care has been studied and reported in a systematic review of 55 studies about patient safety and clinical effectiveness outcomes, as they relate to aspects which the authors grouped as “patient
The importance of patient-centeredness to quality healthcare care is endorsed by Don Berwick, who chaired the roundtable that published the landmark “Crossing the quality chasm” report (IOM, 2001a) and founded the Institute for Healthcare Improvement. In his recounting of the roundtable discussions, patient-centeredness was the major topic of debate when participants considered if patients have control or if patients are the source of control of their healthcare (Berwick, 2009). Ultimately, the report stated that quality healthcare is achieved through rules of patient-centered care that ensure “the patient is the source of control” and that care is customized “based on patients’ needs and values” (IOM, 2001a). Berwick advocates that patient-centered care should stand as a foundational pillar of quality alongside safe and effective, expanding the initial definition of quality that was limited to the misuse, underuse and overuse of healthcare (IOM, 2001a), and recognizing that meaningful healthcare system reform will require “disruptive shifts” that move power and control from care providers to care recipients (Berwick, 2009).

2.3 Patient-Centered Care is a Foundational Pillar of Quality

The literature reflects a resounding underlying belief that patients’ experiences of patient-centered healthcare is ultimately the way in which quality is judged (Berwick, 2009; Cleary & McNeil, 1988; Gertais, Edgman-Levitan, Daley, & Delbanco, 1993; Epstein & Street, 2011; Luxford, 2012; Ontario Medical Association, 2010; Patwardhan & Spencer, 2012; Sofaer & Firminger, 2005; Weingart, et al., 2006; Wilde, Starrin, Larsson, & Larsson, 1993), whether it is at the healthcare system level of design or reorganization (Bechtel & Ness, 2010) or at the day-to-day level of hospital interactions between staff and patients and their families (DiGioia, 2008; Meterko, Wright, Lin, & Cleary, 2010). The publicly funded healthcare system of the four United Kingdom (UK) countries, the National Health Service (NHS), declares that same belief in its England Operating Framework: “each patient’s experience is the final arbiter in everything the NHS does” (NHS, 2011, p. 17). In the UK, quality healthcare is simply defined as clinically effective, personal and safe care (NHS, 2008) that ensures that “the patient has the best possible experience of care” (National Institute for Health and Care Excellence, 2012, p. 7). Ultimately, patient-centered care is the dimension of healthcare quality that patients are evaluating when they are asked about their experiences of care (Anhang Price, et al., 2014).
The term “patient-centered” has become commonplace as a description of both the delivery of healthcare (patient-centeredness) and the outcome of it (patient-centred care) (Epstein & Street, 2011; Fook, Obarski, Hale, & Hylmar, 2015), including in Ontario’s action plan for healthcare that describes the current provincial plan for healthcare improvement as “obsessively patient-centred” (Ministry of Health and Long-Term Care, 2012). Similar terms in the literature that interchangeably represent “patient-centered” include descriptions of ‘who’ receives “care”, including “patient-”, “person-”, “client”, “family-”, “individual-”, “user-”, and “consumer-” (Registered Nurses Association of Ontario [RNAO], 2015) and ‘how’ it is delivered, including “-centred”, “-focused”, “-driven”, “-oriented”, and “-directed” care (RNAO, 2015) and “personalized care” (Australian Commission on Safety and Quality in Health Care, 2010).

As an outcome, there is no consensus on a single definition of what constitutes patient-centered “care” (Kitson, Marshall, Bassett, & Zeitz, 2013), however, the key concept of partnership between patients and care providers surfaces when reading the definitions used by system leaders of healthcare quality improvements that have a focus on patient-centered care (see Table 1).

### Table 1. Definitions of patient-centered care

<table>
<thead>
<tr>
<th>Organization</th>
<th>Term for outcome of “-care”</th>
<th>Definition</th>
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<tr>
<td>Institute of Medicine (2001a)</td>
<td>patient-centered care</td>
<td>Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.</td>
</tr>
<tr>
<td>Institute for Patient-and Family-Centered Care (2010)</td>
<td>patient- and family-centered care</td>
<td>An approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.</td>
</tr>
<tr>
<td>Institute for Healthcare Improvement (2016)</td>
<td>person- and family-centered care</td>
<td>Putting the patient and the family at the heart of every decision and empowering them to be genuine partners in their care.</td>
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As an approach or a philosophy about the way care is delivered, patient-centered care is often described in terms of its attributes. The core aspects of what constitutes person-centeredness are reflected in the literature to include shared knowledge, collaboration and teamwork, respect for individual needs and preferences, free flow and accessibility of information, sensitivity to nonmedical and spiritual needs, family involvement (Shaller, 2007), participation and involvement, relationships between the patient and care providers, and the context of care delivery (Kitson, Marshall, Bassett, & Zeitz, 2013). The IOM refers to patient-centeredness as “health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care” (IOM, 2001b, p. 50). Table 2 displays core aspects of patient-centeredness, according to recognized leaders.

**Table 2. Core aspects of patient-centeredness**

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<th>Organization</th>
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<td>Institute for Healthcare Improvement (Balik, Conway, Zipperer, &amp; Watson, 2011)</td>
<td>“Five primary drivers”</td>
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<td></td>
<td>- Leadership</td>
</tr>
<tr>
<td></td>
<td>- Hearts and minds</td>
</tr>
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<td></td>
<td>- Respectful partnership</td>
</tr>
<tr>
<td></td>
<td>- Reliable care</td>
</tr>
<tr>
<td></td>
<td>- Evidence-based care</td>
</tr>
<tr>
<td>Institute for Patient- and Family-Centered Care (n.d.)</td>
<td>“Four core concepts”</td>
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<td>- Dignity and Respect: Health care 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.</td>
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<td>- Information Sharing: Health care 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.</td>
</tr>
<tr>
<td>Picker Institute (Gertais, Edgman-Levitan, Daley, &amp; Delbanco, 1993; Picker Institute, n.d.)</td>
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<td>------------------------------------------------</td>
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<tr>
<td>“Eight dimensions”, known as the Picker principles of patient-centered care:</td>
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<td>- Respect for patients’ values, preferences and expressed needs</td>
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<td>- Coordination and integration of care</td>
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<td>- Information, communication and education</td>
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<td>- Physical comfort</td>
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<td>- Emotional support and alleviation of fear and anxiety</td>
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<td>- Involvement of family and friends</td>
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<td>- Transition and continuity</td>
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<td>- Access to care</td>
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<th>Planetree (as summarized in Shaller, 2007)</th>
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<td>“Nine elements”</td>
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<td>- Explicit recognition of importance of human interaction – personalized care, kindness, being “present” with patients</td>
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<td>- Informing and empowering diverse populations through patient education</td>
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<td>- Integrating partnerships with family and friends in all aspects of care</td>
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<td>- Attending to nurturing aspects of food and nutrition</td>
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<td>- Incorporating spirituality and inner sources for healing into the care of patients</td>
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<td>- Incorporating massage and human touch</td>
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<td>- Incorporating the use of arts (music, visual art) in the healing process</td>
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<td>- Integrating complementary and alternative practices into conventional care</td>
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<td>- Creating healing environments through architecture and design</td>
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The seminal text, “Through the patient’s eyes: Understanding and promoting patient-centered care” (Gertais, Edgman-Levitan, Daley, & Delbanco, 1993) initiated the shift in healthcare to consider the perspectives of patients in quality improvement. It was a product of five years of work by researchers from Harvard Medical School who collaborated with the Picker-Commonwealth Program for Patient-Centered Care to seek extensive feedback from patients through focus groups and telephone interviews. The resulting seven key themes, along with an eighth dimension of access to care, were adopted by the Picker Institute (previously Picker-Commonwealth Program) as the eight Picker principles of patient-centered care (see Table 2).

Patient-centered care literature is diverse and its research is cached under terms including patient satisfaction, patient-reported outcomes, patient experience, and patient engagement. There is also wide-ranging grey literature on the topic of patient-centered care, with examples of guides (Planetree & Picker Institute, 2008), guidelines (Biddy, et al., 2015; RNAO, 2015), reports (Australian Commission on Safety and Quality in Health Care, 2010), statements (Ontario Medical Association, 2010), commentaries (British Medical Journal, 2015) and editorials (Stewart, 2001).

To move the philosophy of patient-centered care and the aspects of patient-centeredness into quality improvement work within hospitals, the Institute for Patient- and Family-Centered Care and the Institute for Healthcare Improvement have an extensive array of educational offerings, including guides for assessing and implementing patient-centered care in organizations, and even on-site organizational assessment, education and services to help healthcare environments effectively deliver patient-centered care (Planetree, 2014). In Canada, Accreditation Canada’s Leadership Standards (2016) state that client- and family-centred care is “an approach that guides all aspects of planning, delivering and evaluating services” and they adopt the four aspects of patient-centeredness outlined by the Institute for Patient- and Family-Centered Care to require organizations to focus on “creating and nurturing mutually beneficial partnerships”...

“working collaboratively with clients and their families to provide care that is respectful, compassionate, culturally safe, and competent, while being responsive to their needs, values, cultural backgrounds and beliefs, and preferences” (Accreditation Canada, 2016, p. 1).

Further, two Ontario-based organizations have made specific implementation recommendations through published guidelines. The Registered Nurses’ Association of Ontario outlines six clinical
best practice guidelines for person- and family-centred care, organized into recommendations for practice (assessment, planning, implementation, evaluation), for education, and for system, organization and policy (RNAO, 2015). And, Cancer Care Ontario makes 65 recommendations in its person-centred care guideline, organized into the categories of knowing the patient as an individual, essential requirements of care to ensure a positive patient experience, tailoring healthcare service for each patient, continuity of care and relationships, and enabling patients to actively participate in their care (Biddy, et al., 2015).

Differing understandings about patient-centered care and patient-centeredness by various stakeholders across the levels of policy, organization and individuals translate into multiple interpretations about what constitutes the range of activities that can improve healthcare quality (Gillespie, Florin, & Gillam, 2004). For example, through 47 interviews with healthcare stakeholders, including managers, educators, professional leaders, regulatory bodies, patient groups and consumer organizations, in which stakeholders were asked, “What is meant by ‘patient-centred care’?”, there was general agreement “about a notion placing the patient at the centre of the care process” and “the importance of health-care relationships as ‘partnerships’” (p. 145), however, different aspects of patient-centeredness were reflected and prioritized depending on the roles and interests of stakeholder groups (Gillespie, Florin, & Gillam, 2004). Health professional groups adopted a more medical view of patient-centred care, viewing patient-centeredness as informing patients and engendering patients’ trust. In contrast, care recipient groups described patient-centered care “in the context of a social or whole person model of health” (Gillespie, Florin, & Gillam, 2004, p. 145). Such differences in definitions and internalized understandings about patient-centered care mean that variations in measurement (Epstein & Street, 2011) continue to be reviewed and debated (Zill, Scholl, Härter, & Dirmaier, 2013) without clear direction about which aspects of patient-centeredness are allotted more weight by different stakeholders (Kitson, Marshall, Bassett, & Zeitz, 2013) and therefore which priorities are most important and relevant for targeted quality improvements.

### 2.4 Patients’ Perspectives in Evaluating Quality Healthcare

A patient is the sole person, as a constant point of reference, who accumulates experiences across the entire continuum of receiving healthcare and therefore is in a key position to evaluate quality and inform improvements. If patients’ experiences are indeed deemed to be the “final arbiter”
(NHS, 2011) of quality healthcare, it behooves healthcare organizations to gain a deep understanding about patients’ perspectives regarding quality. Moreover, when 172 people from six Canadian health and social service centers, including patients, caregivers, public members and healthcare professionals, took part in a cluster randomized trial process to establish healthcare quality improvement priorities, the priorities determined with public involvement were significantly different than the priorities determined solely by health professionals (Boivin, Lehoux, Burgers, & Grol, 2014). The use of information reported by patients holds the potential to improve clinical practice and health systems (Schlesinger, Grob, & Shaller, 2015; Sofaer & Firminger, 2005). And, as patients have greater access to information and increasingly are more knowledgeable about healthcare in general, patients are more often providing their feedback to be used to direct change (CIHI, 2015a; Government of Ontario, 2010; IOM, 2001a; Ministry of Health and Long-Term Care, 2015; Patwardhan & Spencer, 2012; Sofaer & Firminger, 2005).

However, current predominant understandings about patient-centered care and its core aspects impact the measurement of patients’ perspectives about both the delivery of care and its outcomes. The breadth of research labeled as “patient-centered care” and “patient experience of care” is extensive and varied, and depending on definitions used and the design of studies, the relationship between aspects of patient-centeredness and clinical outcomes are reported within a range between significant relationship to no relationship (Rathert, Wyrwich, & Boren, 2012). As health systems in different countries deepen understandings about measurement in patient-centered care, more is understood about how to gather and listen to patients’ perspectives.

In Canada, the measurement of patients’ perspectives about quality healthcare is important, as demonstrated by the organization of the national forum, “Measuring patient-centred care”, (University of Calgary, 2014), which shared and exchanged expertise regarding the collection and utilization of patient-reported information. Further, the Canadian Institute for Health Information reported that its consensus conference in late 2014 determined a new priority area of health system performance measurement to focus on “patient experiences with care services” (CIHI, 2015a).

The segment of the literature that examines patients’ perspectives in evaluating healthcare performance and quality may be considered as falling into two major categories of measurement: patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs).
PROMs measure the impact of an illness or health condition, from a patient’s perspective, and are used to monitor the progress of a health condition or the effectiveness of a treatment over time (CIHI, 2014). PREMs measure a patient’s view of the process of healthcare, and are used to monitor and evaluate service delivery (CIHI, 2014). While PROMs are standardized validated instruments about quality of life (well-being), functional status (disability), and symptoms (impairment) (Coulter, Fitzpatrick, & Cornwell, 2009; Valderas, et al., 2008) which hold potential to help patients and clinicians assess performance to make better decisions (Basch, et al., 2015; Black, 2013; McGrail, Bryan, & Davis, 2012), PREMs constitute a diverse range of instruments that have been less critiqued (Beattie, Lauder, Atheron, & Murphy, 2014). There are numerous examples of new experience measures being developed for specific populations of care (Bobrovitz, Santana, Kine, Kortbeek, & Stelfox, 2015; El Miedany, El Gaafary, Youssef, Ahmed, & Palmer, 2014; Lagha, Noble, Smith, Denvir, & Leslie, 2012; Teale & Young, 2015).

Patient experience may be considered to be “the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care” (Beryl Institute, n.d.) and this definition is predominant in the literature. A synthesis of patient experience literature from the most recent 14 years, led by the President of the Beryl Institute, found three themes that were not explicitly stated in the Beryl Institute definition that help clarify and reinforce applicability. The themes were active patient and family partnership and engagement, the integral need for person-centeredness, and an acknowledgement of the broad and integrated nature of experience overall (Wolf, Niederhauser, Marshburn, & LaVela, 2014). Clarity is important, because like patient-centered care, the term patient experience is understood differently across stakeholder groups.

Shale (2013) found that patient experience is conceptualized differently by patients, clinicians, managers, academics and politicians, resulting in differing understandings about the purposes and uses of patient experience measurement. For example, when politicians and administrators approach patients’ care experiences as “service” or “customer” experiences, measurement limits understanding to consumer choice based on votes and familiarity; Shale labels this type of measurement as a “second-person” approach in which the primary concern of the evaluator is “what do patients think of us?” (p. 287). In contrast, a “first-person” approach to measuring patient experience seeks to understand “how patients experience living with the ‘reality’ of health, illness and medical treatment” (p. 288) and the primary concern is about evidence of quality care.
That is, the evaluation criteria for how to understand, categorize and measure quality is a reflection of the current values and goals of both the healthcare system and members in society, which can be expected to change over time (Donabedian, 2005, re-printed 1966 seminal paper). Evaluating healthcare using patients’ perspectives is weighted with the values of those who are seeking the feedback, such that quality is a “moral, cultural and political issue” rather than a mere technical one (Shale, 2013, p. 286). Hence, how questions are asked of patients about typical hospital encounters, such as with nurses, physicians, care, and the environment, depends on the priorities of the evaluator. Therefore, evaluation of quality healthcare in terms of structure, process and outcome (Donabedian, 2005) may be easily organized, but determining which elements of the patient experience to measure is steeped in values.

What is currently known about patients’ perspectives in evaluating healthcare quality is largely rooted in and laden with the eight Picker principles of patient-centered care (Gertais, Edgman-Levitan, Daley, & Delbanco, 1993; Picker Institute, n.d.), which organizes the aspects of person-centredness into a framework with a common language that may be used across jurisdictions. Using the Picker principles, the Picker Institute introduced and established the use of nationwide scientifically validated patient surveys that became widely used internationally; further, databases of patients’ perspectives in measuring healthcare performance have facilitated organizational performance comparisons and benchmarking (Picker Institute, 2013). While the Picker Institute ceased operations in 2013, its sister organization, the Picker Institute Europe, remains open and engaged in patient-centered care evaluation. The majority of current inquiry into patients’ experiences is framed using the Picker principles.

2.5 The Entangled Measurement of Patient Experience

The clarity provided by separating the complementary measurement of patients’ perspectives into the clinical outcomes of care (i.e., PROMs) and the experiences of the care process (i.e., PREMs) is complicated by the terms “experience”, “satisfaction” and “perception” being misunderstood as the same and its study reported interchangeably (Sofaer & Firminger, 2005). Patients’ experiences may be measured as subjective data or objective data (Monmouth Partners, n.d.). “Satisfaction” is subjective data about how well individual expectations, needs or desires were met and it is evaluative about how positive or “happy” the individual felt about encounters (Coulter, Fitzpatrick, & Cornwell, 2009; Sofaer & Firminger, 2005; Wolf, 2014). “Experience”
is objective data about what happened at points during the care process and is “intended to be factual, rather than evaluative” (Picker Institute Europe, 2007, section 3.8), and it is useful beyond satisfaction because it may provide specific information about quality healthcare (Coulter, Fitzpatrick, & Cornwell, 2009; Sofaer & Firminger, 2005; Wolf, 2014).

“Perception” comes into play in the measurement of both subjective and objective data. Wolf states that “perceptions are the basis of understanding for patients...the foundation of all recollection and at the core of all that will be shared with others...perceptions will vary based on individual characteristics such as beliefs, values, cultural background...” (2012). Furthermore, Wolf (2014) states that “satisfaction is in the moment, but experience is the lasting story”. And by extension, patient experience is “all that is perceived, understood and (perhaps most importantly for healthcare organizations) remembered...one cannot guarantee the ‘same’ experience for anyone...Therefore, the patient perspective must be consistently understood and continuously engaged” (Wolf, 2012).

Clarity in studying and reporting satisfaction versus experience is particularly important when considering quality improvements because patients’ satisfaction is known to be a poor measure of quality healthcare (Coulter, 2006; Sofaer & Firminger, 2005; Williams, Coyle, & Healy, 1998). High overall satisfaction ratings have been provided by patients even when they encountered service incidents (Weingart, et al., 2006). Further, a national prospective cohort study of 51,946 respondents found that high patient satisfaction was correlated with poorer clinical outcomes; that is, there were severe “costs of [higher patient] satisfaction”, namely greater inpatient use, overall drug and healthcare expenditures, and mortality (Fenton, Jerant, Bertakis, & Franks, 2012). Moreover, low satisfaction scores have been correlated with attentive and thorough care, particularly when the care used invasive techniques, caused discomfort or potential embarrassment (such as hygiene or elimination), or requested patients to modify their life style (Eriksen, 1987). Satisfaction ratings are not necessarily correlated with quality of care. Physicians have been particularily concerned about patient satisfaction measures when ratings are used for physician remuneration (Esselman, White, & Chimes, 2013; Labig, 2009).

Patient satisfaction has long been considered inadequate and inappropriate for representing patients’ perspectives (Cleary, 1998). Satisfaction measurement design is argued to reflect the needs of service providers’ research requirements, using topics usually determined by
administrators’ agendas (Coulter, Fitzpatrick, & Cornwell, 2009) and providers’ assumptions about what is important to patients (Picker Institute Europe, 2007). When patients are interviewed about satisfaction, the difference between being satisfied or very satisfied spans a large continuum from “adequate” to “better than average” to “outstanding” (Collins & O’Cathain, 2003). The concern is that the same satisfaction rating may represent “diverse opinions ranging from ‘I’ve evaluated the service and I’m happy with it’, to ‘I don’t really think I have the ability to evaluate, but I do have confidence in the staff’, to ‘the service was appalling but I don’t like to criticize, after all they’re doing their best’” (Williams, 1994, pp. 514-515).

Some researchers argue that the label of “excellent” services should be changed to “most-positive response group” (p. 7), after they found that half of patients who gave the highest overall satisfaction rating also reported some negative experience (Iverson, Bjertnæs, & Skudal, 2014).

Hence, satisfaction measurement is summarized to be “broad and often ill-defined” (Coulter, Fitzpatrick, & Cornwell, 2009, p. 7). Satisfaction ratings reflect patients’ personal characteristics, preferences and expectations (Coulter, Fitzpatrick, & Cornwell, 2009) and results are too generalized (Picker Institute Europe, 2007) to reveal real gaps in quality of care (Patwardhan & Spencer, 2012).

Even when researchers understand the terms satisfaction and experience, the measurement of patient experience is complicated. Existing measures that are labeled patient experience measures may in fact be measuring patient satisfaction, may be poorly validated for what constitutes quality for patients rather than providers, may have limited reliability testing to allow for use in real world practice to obtain reproducible results, and may not be properly selected among a plethora of measures to match an intended purpose when used (Beattie, Lauder, Atheron, & Murphy, 2014). Endeavouring to review existing instruments that claim to measure patient experiences of quality healthcare in hospitals, Beattie and colleagues (2015) published a systematic review of instruments of patient experience of hospital care. They critiqued the utility of each instrument and offered a utility matrix to assist decision-making about which tool to choose for specific hospital quality improvement purposes. Coulter, Fitzpatrick, and Cornwell (2009) argue that while patient experience measurement holds promise for providing solutions to improve the quality of hospital care, it is measurement for the right purpose and of what is relevant to patients that will truly optimize the potential for data to be transformed into useful
and usable improvement information. Only then will data be meaningful to encourage care providers to take account of any problems identified as priorities by their patients.

In order to measure patients’ experiences, patients must be engaged to take part in contributing their perspectives. Patient engagement is a term increasingly seen in the literature, with evidence that patient engagement activities contribute to accelerating improvement efforts and improving care (Baker, 2014). Further, increased patient engagement is recommended as a funding priority to drive healthcare innovation (Naylor, et al., 2015) and as part of building a culture of quality improvement in healthcare (Health Quality Ontario, 2015b). However, “patient engagement” is the most current catch-all term: Between 1995-2010, literature rarely reported on “patient engagement” and a scope-defining study found 15 conceptually similar terms used interchangeably to describe the “patient-” or the “-engagement” process (Gallivan, Kovacs Burns, Bellows, & Eigenseher, 2012). Terms that equated “patient” included “citizen-”, “community-”, “consumer-”, and “public-”, while terms that equated “-engagement” included “-involvement” and “-participation (Gallivan, Kovacs Burns, Bellows, & Eigenseher, 2012).

Frameworks exist to help conceptualize patient engagement. The International Association for Public Participation has the well-established IAP2 Spectrum of Public Participation (International Association for Public Participation, 2007) that frames increasing levels of public impact as public participation goals (inform, consult, involve, collaborate, empower) which are implemented with specific promises to the public. As examples, the participation goal of informing the public provides balanced and objective information and holds a promise to keep the public informed, whereas the goal of empowering places final decision-making into the hands of the public with a promise to implement what the public decides. The IAP2 spectrum has been used to frame research and improvement activities that focus on patient engagement (International Association for Public Participation, 2006). More recently, Carman and colleagues (2013) proposed a multidimensional framework specific for “patient and family engagement” that depends on the level of engagement sought (direct care, organizational design and governance, policy making), the purpose or deepening level of interaction (consultation, involvement, partnership and shared leadership), and the factors that influence engagement (patient, organization, society).
A systematic scoping review of the “patient engagement” literature found numerous practical resources to guide how to solicit information from patients and the authors themed them as tools, education and infrastructure (Kovacs Burns, Bellows, Eigenseher, & Gallivan, 2014). Growing attention is being paid to how to engage patients well (Australian Commission on Safety and Quality in Health Care, 2010; Boivin, Lehoux, Burgers, & Grol, 2014; Coulter, 2012; Coulter & Ellins, 2007; Domecq, et al., 2014; Pomey, et al., 2015).

2.6 The Seminal Work in Patients’ Experiences of Hospital Care

Patients’ experiences with their hospital-based care have been previously studied, with the majority of studies originating from the USA or the UK. In the USA, Cleary and colleagues (1991) conducted telephone interviews with 6,455 patients who had been discharged from 62 hospitals across the country, in order to determine which aspects of inpatient care patients most valued and to document patients’ perceptions of those aspects of hospital-based care. The telephone survey instrument was developed with input from patients, their family and friends, and clinical and nonclinical healthcare staff. Patients were asked about topics they were in the best position to judge, such as their perceptions about patient education and communication with providers, respect for their needs and preferences, emotional support and physical comfort, family involvement, and discharge preparation. Among the findings, the most highly reported problems, in decreasing frequency, included: not being told about daily routines; not having a relationship of trust with any care provider; not receiving discharge instructions regarding food, medication side effects, or danger signs to look for at home; not knowing from whom to request help; not receiving physical comfort from nurses who were too busy; not being told about resuming normal activities after hospital discharge; not having medications explained in an understandable way; no doctor or someone in charge to answer questions; no explanations provided about what to expect regarding tests and pain or discomfort; not having needs met by staff going out of their way to help; not being told what to do to help recover; not being told when to return to work; family not being included; inadequate prompt pain relief; not being “told things patient should have been told” (p. 258); not being a part of decision-making; being prioritized lower than the needs of hospital staff; not receiving answers in an understandable way; and staff talking in front of the patient as if the patient was not there. This seminal research went on to inform the publication of the book “Through the patient’s eyes: Understanding and
promoting patient-centered care” (Gertais, Edgman-Levitan, Daley, & Delbanco, 1993) that then also informed the creation of standardized Picker patient surveys.

In the UK, Bruster and colleagues (1994) wanted to help hospital administrators and doctors identify and solve problems in the hospital and set out to produce data for them that were based on the experiences of patients who had encountered hospital care. After completing 5,150 face-to-face semi-structured interviews with patients from 36 NHS hospitals, they reported that most problems related directly or indirectly to communication. Patients reported having received little information about their daily routine, once admitted to hospital. They were not informed about their condition or treatment. Most patients experienced pain either most or all of the time and received inadequate pain management. And, when patients were discharged from hospital, they had not received information about warning signs or “how they should continue with their lives when they reach home” (p. 1545). The researchers concluded that it is more important to ask patients “what happened” rather than to ask about their satisfaction.

In Canada, Charles and colleagues (1994) used telephone interviews to ask 4,599 patients discharged from 57 hospitals across six provinces about their concerns with care. Public acute hospitals that participated in the study were from provinces that represented the West coast, the prairies, central Canada, francophone Canada, and Atlantic Canada, and each hospital provided the names of 150 patients who had been recently discharged home. Using a standardized survey with 39 process problems, and having the benefit of the Cleary-led research already published, the researchers reported that Canadian patients’ concerns mainly involved communication. In decreasing order of most reported concerns, patients were not told about these things: hospital routines (what to expect), discharge planning (what danger signs to watch for at home, and what normal activities they could do and when), medication side effects and test results (what to look for, explained in ways they could understand), and pain management (how much pain to expect). Additionally, patients reported concerns regarding their relationship with the physician in charge (level of trust and confidence) and family education (receiving needed information to help the patient recover at home).

These seminal studies (Bruster, et al., 1994; Charles, et al., 1994; Cleary, et al., 1991) lay the groundwork for describing the range of hospitalization experiences for patients in the USA, UK and Canada. The findings have informed both our current understandings about patient-centered
care and quality patient experiences in hospitals. In particular, the Cleary-led study informed the now extensively employed measurement methods used in countries around the world.

2.7 The Mailed Survey: A Method to Engage Patients

Patients may be engaged to provide their perspectives through multiple methods, including mailed surveys, telephone interviews, face-to-face interviews, focus groups, patient and family advisory councils, membership on boards and committees, and individualized care planning (Fooks, Obarski, Hale, & Hylmar, 2015). Of the methods available, the mailed survey is the predominant tool used to seek patients’ perspectives because it is a cost-effective way to broadly access a large sample of participants, relative to other methods (Patwardhan & Spencer, 2012). The mailed patient survey has been used at the level of consultation (Fooks, Obarski, Hale, & Hylmar, 2015; Kovacs Burns, Bellows, Eigenseher, & Gallivan, 2014) for decades in many countries (Arah, Klazinga, Delnoij, Ten Asbroek, & Custers, 2003; Castle, Brown, Hepner, & Hays, 2005; Patwardhan & Spencer, 2012; WHO, 2003). Most patient surveys are self-completed questionnaires that ask patients to reflect on their experiences and respond to questions that are separated into specific domains (Beattie, Murphy, Atherton, & Lauder, 2015).

Across the entire care continuum, patient surveys exist to solicit patients’ perspectives, and the most commonly administered and studied mailed surveys ask about adult inpatient experiences. Post-hospital discharge inpatient care surveys are widely used in countries or nations where governments require hospitals to measure and monitor patients’ feedback, such as in the USA and the UK (WHO, 2003). In the USA, where hospital services are not universally funded and are for the most part purchased by the user, the Centers for Medicare and Medicaid Services (CMS) mandate the use of patients’ care experience data in public reporting of quality and pay-for-performance programs. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient surveys are used for these purposes, with the intent to increase transparency so that patients may be more able to make better choices about where to seek and purchase hospital services (Centers for Medicare and Medicaid Services, n.d.). Nationwide Hospital CAHPS (HCAHPS) survey results are publicly reported on the CMS Hospital Compare website. Similarly, in the publicly funded UK healthcare system, where surveying of patient experiences is also mandatory and tied to funding for hospitals, results from national patient surveys are reviewed and monitored by the Care Quality Commission and publicly reported on the
government agency’s website, NHS Choices. In an effort to increase transparency and engagement, patients have been encouraged to post their feedback about hospitals onto NHS Choices since 2007 (Greaves, Millett, & Nuki, 2014).

The dimensions of content collected within inpatient care surveys largely originated from the seminal research by Paul Cleary and colleagues (1991) that was used to create the now commonly used Picker Institute survey instruments that collect numerical data categorized into Picker dimensions (Coulter and Cleary, 2001). Picker surveys have been refined to a core set of 15 standardized survey questions to measure inpatient care experiences (Jenkinson, Coulter, & Bruster, 2002), after undergoing numerous steps to design national patient surveys (Coulter, Fitzpatrick, & Cornwell, 2009). Standardized patient surveys of inpatient care have been widely used in hospitals in the USA, the UK, Germany, Sweden and Switzerland since the 1990s (Coulter and Cleary, 2001) and in Australia, Canada, and across Europe (WHO, 2003).

The administration and collection of national mailed patient surveys used in the USA and the UK are managed under contract by independent third-party companies (WHO, 2003). Currently, while approximately 40 survey vendors are approved to administer the HCAHPS survey in the USA (Hospital Consumer Assessment of Healthcare Providers and Systems, 2016), the nonprofit organization Picker Institute Europe is the major contractor for patient surveys in the NHS of England and Scotland (Picker Institute Europe, 2016). The Picker Institute has had the longest standing traction offering mailed survey service, and continues to operate as Picker Institute Europe (2007) and National Research Corporation Canada. Picker surveys are considered to be well-constructed, standardized and validated to compare performance of healthcare organizations (Patwardhan & Spencer, 2012).

Mailed patient surveys endure the well-recognized limitations of using surveys to collect information about user perspectives. Limitations are largely due to response rates and survey design. In a review of literature on survey instruments used to collect data on hospital patients’ perceptions of care, Castle and colleagues reported that the mailed survey response rate averaged 47 percent, ranging between 17 and 92 percent (Castle, Brown, Hepner, & Hays, 2005). Response rates for mailed patient surveys are lower than those for surveys conducted face-to-face, requiring large numbers of mailings for statistical significance in outcomes or results (Patwardhan & Spencer, 2012). And, for administrators to receive the answers they want and a
return on investment of administering the survey, a breadth of questions are asked in surveys and the resulting increased survey length in turn acts as a deterrent for completion and return (Patwardhan & Spencer, 2012). The timing of post-discharge survey mailings, lagging from one week to six months (Castle, Brown, Hepner, & Hays, 2005), further contributes to lower response rates and accuracy of responses.

Multiple strategies have been studied and may be employed to increase response rates to mailed surveys, including personalizing cover letters, and follow-up contact with non-respondents to receive another survey copy (Edwards, et al., 2002; Nulty, 2008; Sitzia & Wood, 1998). The covering letter holds utmost importance in getting across a sense of urgency and importance (Edwards, et al., 2002; Kelley, Clark, Brown, & Sitzia, 2003). Interestingly, follow-up contact with HCAHPS surveys has provided insight that higher response rates may correlate with patient loyalty, and that a second wave of survey response requests returned lower ratings; therefore, response rates may act as another indicator of quality of the patient relationship (Hayes, 2012).

Additionally, response rates are influenced by how questions are posed, sequenced and positioned with other survey questions so that the effectiveness of the survey instrument depends on appropriate design and application of the right tool in the right situation (Patwardhan & Spencer, 2012). Representative responses from a population are impacted by a survey’s standardization, validation, reliability, responsiveness and discriminatory power (Patwardhan & Spencer, 2012). Further, while responses from people who have lower comprehension levels, cognitive issues or language barriers may be underrepresented, voluntary response bias means that responses from people with strong impressions may be overrepresented (Patwardhan & Spencer, 2012). Additionally, while benchmarking is not possible without a standardized core instrument (Castle, Brown, Hepner, & Hays, 2005; Ontario Hospital Association, 2015) and standardized national surveys preserve the integrity of content for benchmarking, questions often address broad-level issues and may not be customized for local or specific issues (Patwardhan & Spencer, 2012).

2.8 Current Understandings about the Quality of Hospital Care based on Data Collected by Patient Surveys

Current understandings about patients’ experiences with hospital care are predominantly collected through patient surveys mailed to a random sample of adults recently discharged from
hospital. In the USA, the current HCAHPS survey is a 32-item survey that contains a core set of questions that ask patients about their experiences communicating with doctors and nurses, responsiveness of staff to help, pain management, communication about medications, hospital environment (cleanliness and noise), discharge information for recovery at home, transition to post-hospital care, admission through the emergency department, mental and emotional health, and the two standard global hospital ratings of overall performance and willingness to recommend (U.S. Department of Health & Human Services, 2016). Patients are asked to respond to dichotomous questions (yes, no), frequency of experience questions (never, sometimes, usually, always), degree of agreement questions (strongly disagree, disagree, agree, strongly agree), and overall performance rating scales (0-10, representing worst to best) (The Official U.S. Government Site for Medicare, n.d.; U.S. Department of Health & Human Services, 2016).

As a comparison, the current NHS surveys used in the UK include 84 questions that ask about the hospital experience (71), overall questions (5) and patient demographics (8). Topics include questions about experiences with hospital admission, waiting times, privacy, communication of information to specialists, the hospital environment (noise, sharing space, cleanliness), food choice, confidence and trust in health professionals, information and communication, involvement in treatment decisions, availability of staff when needed, staff teamwork, pain, medication, emotional support, informed consent, being treated with dignity and respect, help with leaving hospital, and contact with family. Five questions ask respondents to provide overall ratings about dignity and respect, feeling well looked after, being asked to give views on the quality of care while in hospital, receiving information about how to provide feedback about the hospital, and overall performance. The NHS survey also has a comment section, asking three open-ended questions to solicit information about what was particularly good, what could be improved, and any other comments (National Health Service Surveys, n.d.). Whereas patient participation in patient experience surveys is voluntary in the USA, it is mandatory in the UK.

In 2001, based on patients’ responses to the standardized Picker surveys mailed to patients after hospital discharge, a publication reported on the nature and frequency of problems with hospital care (Coulter & Cleary, 2001). At the time, Angela Coulter was Chief Executive of the Picker Institute Europe and Paul Cleary was the Harvard professor who led the seminal research with over 6,000 patients (Clearly, et al., 1991) to determine the questions that would standardize the Picker instruments. Coulter and Cleary found that across Germany, Sweden, Switzerland, the UK
and the USA in 1998-2000, patients consistently identified similar problems with hospital care (2001). For all five countries, the greatest report of problems were with continuity and transition and were due to lack of information (about medications and side effects, danger signals to watch for at home, resumption of normal activities) and failure to include family and friends in care. Problems with emotional support, information and education, and respect for patients’ preferences were also commonly reported across the five countries (Coulter & Cleary, 2001).

Today, standardized survey information is regularly summarized and accessible on the Internet, organized into their well-established categories. Summary analyses of HCAHPS survey results are publicly posted in the format of star ratings and results tables, and the CMS Hospital Compare website allows the public to compare hospitals in the USA. Reports about key findings informed by NHS inpatient surveys are posted by Picker Institute Europe and the NHS Choices website allows the public to view overall quality of service percentage ratings by patients’ and staff recommendations of hospitals.

Numerical summaries of surveys, typically using the two global patient ratings of overall care and likelihood to recommend the hospital (Health Quality Ontario, 2015b; National Research Corporation Canada, 2014, 2016a; Ontario Hospital Association, 2014; U.S. Department of Health & Human Services, 2016), are used to compare and benchmark organizations. However, despite a plethora of numerical data that is now available to the public, there is still a void in descriptions and literature about how survey results were used to determine what improvements to make and how to prioritize them. A systematic review of articles reporting on the use of patient care performance data to improve quality of care found few quality improvement activities at the hospital level and scant impact on improved patient safety and patient-centeredness (Fung, Lim, Mattke, Damberg, & Shekelle, 2008).

Lack of improvements despite widespread use of national patient surveys thus begs the question about the usefulness of global patient rating comparisons. Robert and Cornwell (2013) argue that “the survey programme may have lulled [hospital management boards] into thinking that they were paying attention to their patients’ experiences” (p. 67) and this type of measurement seems more likely to demonstrate how measurement is used “for judgment” rather than to facilitate improvements in healthcare, as Don Berwick (1996) had long-ago warned. Global ratings are akin to satisfaction ratings. In a fascinating back-and-forth correspondence regarding the
usefulness of surveying patient satisfaction as an outcome measure, White and Chimes debate with Esselman that patient satisfaction measurement is an “easy-to-derive lowest common denominator”, fueled to be “an easily measured metric that has public support”, and is “entrenched by aggressive marketing to both hospital administration and the public by the very companies that make large profits by selling them” and convinces organizations to use the “woefully inept” and “inappropriate tools” (Esselman, White, & Chimes, 2013, pp. 1072-1073).

Bottom-line, global ratings fail to identify gaps and improvement ideas, and may serve marketing and publicity purposes rather than the purpose of discovering why patients are dissatisfied and how to improve services. If patient survey results “cannot translate into a quality-improvement plan”, then time and resources are depleted, and surveying is just “wasteful, unethical and a lost opportunity for improvement” (Patwardhan & Spencer, 2012, pp. 42-43). And, the development of new surveys that result in inadequate measurement encourages healthcare professionals to believe patients are satisfied even when they may not be (Whitfield & Baker, 1992). Moreover, the typical HCAHPS global ratings, as reported in one study of a sample of community-dwelling older adults identified to be vulnerable, were found to not be significantly correlated with quality of care received, particularly the extent to which service standards met the technical aspects of addressing patient needs (Chang, et al., 2006). System-level improvements cannot be made through hospital comparisons and benchmarking; rather, survey results must inform the development, implementation and evaluation of actionable change (Draper, Cohen, & Buchan, 2001).

The skepticism for patient surveys to provide meaningful information that may be effective for improving quality is not new. Some authors have long-argued that surveys are laden with assumptions that patients’ perspectives can be quantified and that surveys can be inclusive of the complexity of what is important and relevant to patients (Williams, 1994). The closed-ended questions that are typical in mailed surveys require one answer to a question, even if the respondent does not completely agree with the answer options (Patwardhan & Spencer, 2012). And, happy leading questions lead to positive responses, which may be used particularly when there are incentives to “rig” results if ratings are used for funding decisions (Patwardhan & Spencer, 2012).
Despite concerns about their limitations, surveys remain the principal method of measuring patients’ perspectives. They are portrayed as if they are “ultimate weapons” by some authors, as reviewed by Patwardhan and Spencer (2012, p. 35). Indeed, a review of the use of patient surveys found a role for them to measure quality healthcare, especially the degree to which care is patient-centered (Anhang Price, et al., 2014). Patient surveys are extensively used as an easy way for organizations to get a large sample of responses that may be numerated. The large-scale and resource-intensive methods previously used, such as face-to-face interviews by Bruster and colleagues (1994), or telephone interviews by Cleary and colleagues (1991) and Charles and colleagues (1994), are simply not sustainable and such elaborate research has not been repeated. Yet, the quest to more deeply understand patients’ healthcare experiences continues (Beattie, Lauder, Atheron, & Murphy, 2014). To gain more meaningful data about patients’ experiences, measurement must include more than quantitative surveys.

Increasingly, attention grows to find alternate ways to gain insight into patients’ perspectives that are cost-effective, regularly solicited and captured, and produces timely and usable information for improvement. The words of patients have been moderated and publicly posted on the NHS Choices website since 2007, with each UK hospital displaying its most recent five comments, unanalyzed (Greaves, Millett, & Nuki, 2014). More recently, the literature is reporting on analysis of unsolicited, patient-generated comments that are posted onto the Internet via online portals and social media, such as Yelp and Twitter, where users may publicly review and rate organizations. Unlike in the UK, the USA patient surveys have no open-text comment option (U.S. Department of Health & Human Services, 2016), and therefore, social media offers an accessible way for patients to take part in reporting their views of care processes and care received (Lagu & Greaves, 2015). Some studies have analyzed online patient reviews of USA hospital care (Bardach, et al., 2015; Hawkins, et al., 2015; Ranard, et al., 2016), extending similar analysis completed in the UK of publicly accessible internet-based reviews by patients (Greaves, et al., 2014). All of these studies compared patients’ online comments to the well-established a priori quality dimensions used in the respective health systems’ national surveys.

The potential for patients’ perspectives to lead to actionable change has been argued to hold value for improving day-to-day interactions between patients and care providers (Epstein & Street, 2011). Further, Riiskjær, Ammentorp and Kofoed (2012) examined patients’ inclination to provide comments and hospital administrators’ perceptions about the usefulness of patients’
comments. Patients were asked to explain their ratings to survey questions. Then, the quantitative results along with patients’ comments were reported to hospital departments. The researchers found that patients were able to articulate their perceptions with words and that over 80% of management teams found the comments useful and also followed up with concrete improvement activities (Riiskjær, Ammentorp, & Kofoed, 2012). Actionable improvements may occur when patients’ perspectives are captured, reviewed and acted upon. While unsolicited online patient comments provide some patients’ perspectives but are unlikely to be representative of the overall patient population (Lagu & Lindenauer, 2010) and more prone to selection bias (Greaves, Millett, & Nuki, 2014), and patients’ experiences summarized into numeric form do not capture the full extent of those experiences (Luxford, Safran, & Delbanco, 2011), there is an untapped source of patient-reported information that has potential to provide representative data with more actionable improvement information. The opportunity lies in patients’ comments in mailed standardized surveys.
Chapter 3

3 Method

To explore and understand patients’ experiences regarding their hospital stays, a qualitative research study was designed to approach an existing source of data that were collected on a survey form. Adult patients’ written responses in a mailed standardized post-hospitalization survey were analysed within an interpretivist paradigm, using qualitative description as a methodology, by means of inductive content analysis as the method.

Qualitative research aims to deepen understanding about a phenomenon and the meaning that people ascribe to it, from the points of views of those who experience it (Green & Thorogood, 2009). Therefore, a qualitative approach was chosen to explore patients’ written responses in order to understand patients’ perspectives regarding the phenomenon of “the hospital stay”.

Patients’ comments reflect the different ways that patients understand or interpret “the hospital stay” that are bound to the time and context of their hospitalization experiences. Multiple truths may exist for the same phenomenon, and in interpretivism, reality is assumed to be relative and multiple (Schwandt, 1994). Further, understandings are assumed to be the intertwined co-creations of what is known and the person who knows it. This study is situated within an interpretivist paradigm. Given the nature of the data, interpretivism according to Schwandt (1994, 2000) guided the research, as it posits that a researcher objectively gains knowledge about the phenomenon by taking an interpretive stance and remains external in the interpretive process. That is, an approach that “objectifies” the data (Schwandt, 2000), was used to interpret patients’ comments that were generated solely by patients themselves.

The nature of mailed-in survey comments is that interpretations cannot be checked with the patients who wrote them. Therefore, the corresponding study design should not require a high degree of transforming the data during interpretation. Qualitative description is a study design that limits the depth and level of abstraction during interpretation (Graneheim & Lundman, 2004), so that findings may remain “closer to the data as given” (Sandelowski, 2010, p. 78). As described by Sandelowski (2000), qualitative description allows approaching the data without pre-existing theoretical frameworks and allows for “straight and largely unadorned…answers to
questions of special relevance” (p. 337) in which a descriptive summary of the data would be the expected outcome of the interpretation. Being able to report rich and straight descriptions of reported experiences is also particularly useful for healthcare research that involves the firsthand experiences of patients (Neergaard, Olesen, Andersen, & Sondergaard, 2009). Therefore, qualitative description was the design chosen for this study.

Consequently, the method of analysis selected for this study derived coding categories directly from the content of patients’ comments rather than beginning with a priori theory or initial codes. The set of procedures described by Thomas (2006) was selected for content analysis of this study’s data, to condense extensive raw text data into categories that are transparently linked to the data, where findings arise directly from analysis of the raw data rather from a priori expectations. Inductive content analysis (Thomas, 2006), described in detail below, was used to categorize the free-text content of what patients wrote in response to the survey’s open-ended question.

3.1 Research Question

The research question for this study was: What do patients’ comments in the National Research Corporation Canada (NRCC) Adult Inpatient survey reveal about patients’ experiences of the hospital stay?

3.2 Ethics

This study was approved by the ethics review boards of both Sunnybrook Research Institute and the University of Toronto (Appendix II) in October, 2014. All hard copies are stored in a locked filing cabinet in a locked private office at Sunnybrook Health Sciences Centre. All data were received de-identified, and electronic data files are encrypted and password protected.

3.3 Data Collection

This research used an existing and available source of patient-reported data, collected through one of the eight NRCC standardized patient surveys used by the hospital at the time of the study. The NRCC Adult Inpatient Survey was selected for study because inpatient care represents the most prevalent type of service provided in the hospital. Also, NRCC Adult Inpatient Survey data are used within the hospital for trending over time and the data are also used for benchmarking with other hospitals in Ontario that participate in administering the same survey.
The NRCC Adult Inpatient Survey is mailed by NRCC, an independent third-party measurement company, to the listed home addresses of three per cent of randomly selected patients. Mailings occur monthly and are associated with a hospital discharge date occurring on the first day of the month. Each survey response is associated with the unit where each patient was discharged. The NRCC Adult Inpatient Survey is a four-page survey with 55 numbered questions (Appendix I). The first 49 questions ask respondents to “fill in the circle” regarding responses to rating-scale questions grouped under the headings: admission, doctors, nurses, hospital staff, pain, going home, overall impression, and amenities. Then, five questions ask about the background of the respondent. Question 55, the final question, is the section in the survey where comments may be written in response to the question, “Is there anything else you would like to tell us about your hospital stay?” Positioned within a box, the question is proceeded by five lines. Responses to question 55 of the NRCC Adult Inpatient Survey were the data source in this study.

Within 24 hours of receipt of a survey, an NRCC employee transcribes any written responses to question 55 and posts them electronically to the eComments website (NRCC, 2016b) where it may be accessible to the hospital’s authorized users. By default, NRCC codes all patients’ responses according to the eight Picker principles of patient-centered care (Gertais, Edgman-Levitan, Daley, & Delbanco, 1993; Picker Institute, n.d.) and also applies a “valence” (positive, negative, neutral or both) to responses.

3.3.1 Custom Report

To analyze comments within this study’s qualitative descriptive design, a custom report was requested from NRCC for all written responses received about hospital care provided on April 1, 2014 through the five previous years. April 1 was chosen because patient survey data are reported quarterly by fiscal year, beginning on this date. April 1, 2014 was also the date when the hospital launched the organization-wide person-centred care initiative, and therefore findings from this study would reflect patients’ experiences prior to the implementation of the initiative. Average survey response rates during this period of time, by fiscal year, were between 41-46%, and 42-45% of returned surveys contained a written response. The custom report excluded any written responses associated with a hospital unit that is currently closed.

A custom report was purchased from NRCC and received in Excel format. The report contained 4,922 written responses and each response was associated with the following information:
response by the “patient” or “someone else”, last “date” of inpatient service received, date of
“posting” (when the transcribed response was posted by NRCC to eComments), patient’s “age”,
and patient’s hospital discharge “unit”. All other default coding was removed.

Filtered to include only comments by patients, the available data set contained 4,236 responses
from patients between the ages of 16 years and 90 years, and hospital discharges from 22 units.
Four hospital units that remain open had ceased participation in the mailed survey by April 2012.
The posting dates by NRCC of patients’ responses ranged from August 12, 2009 through
August 14, 2014, for patients’ discharge dates ranging between April 1, 2009 and April 1, 2014.

3.4 Data Analysis

To gain a general understanding of the overall process, I reviewed several publications that
described the steps for approaching qualitative data analysis (Braun & Clarke, 2006; Down-
Wamboldt, 1992; Elo & Kyngäs, 2007; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005;
Mayring, 2014; Nicholls, 2009; Sandelowski, 1995; Thomas, 2006; White & Marsh, 2006).
Among these, the writings by Elo and Kyngäs (2007) were given prominence as they describe
three distinct phases of content analysis: preparation, organization and reporting. These three
phases were used to organize the presentation of the data analysis procedure reported in this
current study. The inductive coding procedure detailed by Thomas (2006) was used for data
analysis. The process consists of: 1) preparing raw data files into a common format and initial
reading of text data; 2) close readings of the text to identify specific text segments; 3) labeling
and defining text segments to create categories; 4) reducing overlap and redundancy among
categories; and 5) creating a category system that labels and describes the most important
categories, and their links, as the end point of the inductive analysis (Thomas, 2006).

3.4.1 Preparation Phase

The preparation phase of inductive content analysis described by Elo and Kyngäs (2007)
includes deciding on the unit of analysis, gaining a sense of the content covered in all of the data,
and determining how much data to analyze.

The unit of analysis is the amount of data that is large enough to remain whole and small enough
to manage for coding (Downe-Wamboldt, 1992; Graneheim & Lundman, 2004). In this study,
the unit of analysis was chosen to be the entire written response returned in one patient survey.
Preparing files and initial readings of text data (Thomas, 2006)

To prepare the set of written responses in the NRCC custom report for the purposes of analysis, the comments were filtered to include only responses by patients, were separated by fiscal year, and were prepared into a format for coding on hard copy. Of the 4,922 responses received between April 1, 2009 and April 1, 2014 in the original NRCC Excel custom report, 4,236 responses were filtered as written by patients. Separated by fiscal year, 2014/2015 contained 67 patients’ responses associated with the discharge date of April 1, 2014; 2013/2014 contained 769 responses associated with hospital discharge dates between April 1, 2012 and March 31, 2013; 2012/2013 contained 802 responses; 2011/2012 contained 744 responses; 2010/2011 contained 916 responses; and 2009/2010 contained 938 responses. For coding, a hard copy was created with three columns: Unique identifier, written response, and white-space to allow for writing memos.

Inductive coding began with an initial reading of the data to become familiar with the content (Thomas, 2006). Other authors describe this familiarization to be an important step in analysis to gain a sense of the whole (Braun & Clarke, 2006; Elo & Kyngäs, 2007; Hsieh & Shannon, 2005; Sandelowski, 1995). Beginning with the 769 patients’ responses from the fiscal year 2013/2014, I read the comments in its entirety to obtain a general impression of what was being said in the comments before putting pen to paper for coding. Upon repeated readings, I wrote into the left margins my initial thoughts, impressions, and at times, visceral reactions. Line-by-line for each comment, I wrote the key message of each comment into the blank right column, as much as possible using the same words written by patients. The initial readings were the start of the iterative process of inductive content analysis.

Data analysis began with the most recent full fiscal year of written responses and continued by fiscal year until sufficient comments were analyzed to answer the research question. Theoretical sufficiency (Dey, 1999, p. 117), often referred to by many authors as saturation (Mason, 2010), was reached when the addition of new comments into analysis yielded diminishing return without further elaboration or clarification. Theoretical sufficiency was reached after analysis of data from fiscal years 2013/2014, 2014/2015, and 2012/2013, representing 1,638 written responses analyzed. This sample consisted of responses from patients between 16 years and 90 years of age who were discharged from one of 18 hospital units. The posting dates by NRCC of responses in
the sample ranged from October 18, 2012 through August 14, 2014, for patients’ discharge dates ranging between April 1, 2012 and April 1, 2014.

3.4.2 Organization Phase

The organization phase of content analysis (Elo & Kyngäs, 2007) includes the coding of data into categories. Coding steps 2 through 4, as described by Thomas (2006), are organized into this phase.

**Close readings of the text to identify specific text segments** (Thomas, 2006)

After initial readings of the comments, during subsequent readings, I underlined key words or phrases, used different colours to emphasize or highlight text segments that seemed important or significant, and began to separate text segments. I wrote memos in the margins. I made decisions about a coding system for text segments from each patient’s comments by using back-and-forth reading and re-reading to refine coding criteria. Sandelowski (1995) advocates a disciplined approach to coding and I applied coding consistently and systematically to all comments, returning with a new coding system to apply to all of the data when I made decisions to change it. The process of scrutinizing exact words or phrases as units with meaning (Graneheim & Lundman, 2004), and determining what made one text segment different from another text segment even though it may have some same attributes but to a different degree (Downe-Wamboldt, 1992), is how decisions are made about the coding system criteria (Braun & Clarke, 2006; Graneheim & Lundman, 2004; White & Marsh, 2006).

Coded text segments were initially grouped into content headings that were obvious from the data. The obvious headings are likened to what Sandelowski (1995) describes as those elements of the data that are “facts”. These “fact” content headings were preliminary groupings used to manage the large amount of text segments that were being coded from the units of analysis. The headings included: staff members, positive patient report of staff member actions, negative report of staff member actions, family, team communication, evaluative comments, expressions of thanks and appreciation, information sharing, pain, medications, preparing for hospital, preparing to go home, waiting, comments about the survey, hospital environment, food, parking, and sharing space. These content headings were drawn into a visual display, a strategy that Sandelowski (1995) describes as a useful way for a researcher to look at data for suggestive
patterns or relationships and also to see that data is representative of the data set. Text segments that were coded on paper were then moved into the electronic spreadsheet, separated into the content headings.

**Label and define text segments to create categories** (Thomas, 2006)

Then, I used another activity to continue the inductive coding process. By content heading, I printed onto hard copy all codes collected under one content heading and cut the paper to divide each code into separate strips of paper. On a large empty table, I sorted the strips of paper that each contained a code. This time, for each sorting of the codes, I kept the research question in mind: “What do patients’ comments in the National Research Corporation Canada (NRCC) Adult Inpatient Survey reveal about patients’ experiences of the hospital stay?” By content heading, I continued to print, cut into strips, and sort each code by adding to the groupings that were forming on the table. Being able to physically move codes into different groupings and to shift groupings of coding into closer proximity when they represented an affinity of ideas, led to new insights. I used sticky-notes to assign preliminary labels to categorize these groupings.

Together with Dr. Fitch, my methods mentor who coded in parallel the same 769 responses, grouping by grouping, we read each code within one grouping, discussed the criteria used for placing that code into that grouping, and refined the category system by discussing why one code belonged to one grouping versus another one. We discussed how the groupings were related to one another and what identifiable distinctions kept them separate. The description by Downe-Wamboldt (1992) about moving between the text and the output of content analysis to define a category system, was the strategy I applied to move between a text segment code and the grouping to which I assigned it. I kept notes about the coding system as it was applied to additional data and refined.

I continued to use the coding and category systems to analyze additional patients’ comments from the fiscal years 2014/2015 and 2012/2013. Analysis of the 67 comments from the fiscal year 2014/2015 added two new codes. Analysis of the 802 comments from fiscal year 2012/2013 revealed no new codes. Theoretical sufficiency (Dey, 1991) was considered achieved and no further units of analysis were introduced into the analysis process. The QSR International’s NVivo 10 software was used to manage the data.
Reduce overlap and redundancy among categories (Thomas, 2006)

Categories were continually revised and refined to reduce overlap and redundancy. After working systematically through the data sample, patterns or relationships became apparent amongst categories. I used ongoing communication with my Advisory Committee to help me check how I defined, refined, compared and related categories.

3.4.3 Reporting Phase

The reporting phase of content analysis (Elo & Kyngäs, 2007) is includes reporting of the conceptual system of categories and reporting of clear and sufficient descriptions of analysis so that trustworthiness of the research is increased. Step 5 of inductive analysis is reported here, as described by Thomas (2006), followed by a review of trustworthiness in order to introduce the strategies used in this study.

Create a category system (Thomas, 2006)

A category system that incorporated the categories and their links was determined, using the recommendations described by Thomas (2006). Three figures were created to visually represent the study findings. Figure 1, Figure 2, and Figure 3 respectively summarize the resulting three sets of categories as separate and interrelated findings.

A trustworthy study is one that is rigorous and reported in a way that a reader may evaluate its quality and worth. Elliott, Fischer and Rennie (1999) propose that reporting should address how researchers have met seven guidelines or good practices in qualitative research. First, researchers own their perspective by disclosing their values and assumptions, which helps readers to understand the researcher’s interpretation and decide if alternate interpretations should be considered. Second, researchers situate the sample to persons and situations, which helps readers to judge the range of relevance of the findings. Third, researchers ground findings in examples, which helps readers to consider alternate meanings and understandings. Fourth, researchers provide credibility checks, which helps readers to determine the believability of the interpretation. Fifth, researchers report findings in a coherent and integrated manner, which helps readers to understand how data fits together into a framework or structure. Sixth, researchers report within general versus specific research tasks, which helps readers to limit inappropriate extensions of
the findings. Seventh, researchers write to stimulate resonance in readers, which helps readers to have a clearer understanding or expanded appreciation about the researched topic.

The following sections about trustworthiness and reflexivity report the strategies used to address good practices that I endeavoured to use in this study.

3.5 Trustworthiness

Lincoln & Guba (1985) propose that the trustworthiness, or believability, of a qualitative study depends on several intertwined and interrelated aspects, including credibility, dependability, confirmability, and transferability. Credibility is the extent to which a reader can be confident that the findings are true to the data and it is generally considered the most important aspect of trustworthiness. It is the reader who decides if a study is credible or not. Dependability refers to the extent to which a reader can expect data to be stable so that findings would be consistent if the study was repeated with data from similar participants and the same context. Confirmability is the extent to which a reader can be confident that the findings can be confirmed by the data and reflect a researcher’s neutrality. Transferability refers to the extent to which a reader can be confident to apply findings to another context determined by the reader. There are many strategies reported in the literature to increase trustworthiness (Graneheim & Lundman, 2004; Lincoln & Guba, 1985; Nicolls, 2009; Patton, 1999; Shenton, 2004; Thomas, 2006). The trustworthiness strategies used in this study are reported according to the preparation, organization and reporting phases of data analysis described by Elo and colleagues (2014).

Preparation phase

The data collection method and sampling strategy are important considerations to improve trustworthiness (Elo, et al., 2014). Credibility was increased through the use of data collected by an independent third-party company that uses established data collection methods, including random sampling through the random distribution of standardized NRCC surveys. Confirmability was addressed through the careful preparation of the data for analysis purposes such that NRCC default coding was removed to permit data analysis without bias. The data sample consisted of comments collected during a time period when there were no unusual societal circumstances that impacted typical healthcare service delivery, and thus, the general content and sentiments of patients’ comments are likely to remain consistent for patients in this
hospital, increasing the dependability of the findings. Data came from a standardized survey tool that is used by many comparable hospitals, thereby increasing the transferability of the findings.

**Organization phase**

Categorization and abstraction, interpretation and representativeness are important considerations to improve trustworthiness (Elo, et al., 2014). Credibility was addressed by using established research methods for analyzing patients’ comments, through researcher debriefing sessions with my Advisory Committee that provided a sounding board for developing interpretations, and by checking data through negative case analysis so that exceptions that did not fit patterns were used to refine categories until all codes fit. Dr. Fitch performed independent parallel coding of data, provided coding consistency checks, and provided a check of the category development. Confirmability was addressed through the use of memos and an audit trail to support coding decisions. Comparison of the visual display drawn of the “fact” content headings and the three resulting figures representing the categories were used to check the representativeness of the coding to the entire data sample. A reader may decide transferability through the presentation of examples of patients’ comments and my descriptions of categories.

**Reporting phase**

Reporting the analysis process and reporting results are important considerations to improve trustworthiness (Elo, et al., 2014). Credibility was addressed through detailed descriptions of the analysis process, confirmable through my audit trail and memos which I re-read when preparing this thesis. Examples of patients’ comments were used to illustrate the ways that patients conceived their hospital stay experiences. Researcher credibility was enhanced through my reporting of personal and professional information that may affect my reading of the content and interpretation, including my research experience, training and preparation. In the descriptions reported, a reader would determine if there is sufficient information about contextual factors and descriptive data to judge transferability of any of the findings to another context.

**3.6 Reflexivity**

This study represents both degree completion requirements for my Master’s studies in the Practice Science Field and my contributions to ongoing person-centred care quality improvement
initiatives at my place of employment. When analyzing patients’ comments, I intentionally and consciously created self-awareness of constructing interpretations. Reflexivity strategies, as described by several authors (Finlay, 2002a; Green & Thorogood, 2009; Mays & Pope, 2000), were crucial to help me approach the data because I have prior knowledge about and experiences with existing principles and assumptions about person-centred care, patient experience and patient engagement. During the time of study and thesis preparation, I also personally experienced hospital care, both personally and as a family member. I used the strategies for ongoing self-critique and self-appraisal, as recommended by Koch and Harrington (1998), to remain purposefully open to recognizing and noting any potential assumptions that arose during analysis that could influence the inductive process.

I considered and discussed with my Advisory Committee my own relationship to this research project: in my roles at work, within my family and social relationships, and as a citizen and consumer of health services; in my obligations and responsibilities as an employee, as a student and as a researcher; in my position to influence ongoing dialogue and directions for person-centred care at my place of employment; and in my professional pursuit and personal aspiration to partner with patients in improving quality in healthcare.

I transparently discussed with my Advisory Committee the events in my personal and work life that had the potential to impact analysis. Before beginning data analysis, I reflected on and documented my own values, beliefs and assumptions about patient care, healthcare and relationships with people. Significant life events and potential triggers that might impact data analysis were recorded. I reflected upon all of my professional training as an occupational therapist and understandings about client-centred practice from that education, my 12 years of clinical work as a community-based occupational therapist working with people who have mental illnesses and 3-years as a life skills coach to people who acquired brain injuries, my previous participation in research studies either as a participant or co-investigator, and my role at my place of employment that includes leading person-centred care initiatives and working as an administrator who mainly oversees the quality of hospital-based practice. I have understandings about “the hospital stay” which I acknowledge was a lens that I brought into analysis.

Once data analysis began, there were occurrences that had the potential to influence my interpretations. Again, I recorded my experiences, conversations and insights about events such
as being a patient myself, being the family member or friend of a patient, being a leader responding to staff concerns and patient concerns about patient care events, and being a stakeholder reviewer of the RNAO person-and family-centred care best practice guideline. To support reflexivity, I continually recalled the study question, the chosen paradigm and methodological approach, and why those decisions were made. Strategies to raise awareness of the complex and interweaving commitments owned by qualitative researchers who are the instruments of analysis (Finlay, 2002b) and of the responsibility to report findings in ways that are usable for readers (Sandelowski, 2004; Sandelowski & Leeman, 2012) were used to critically consider how I read and honoured patients’ comments as they were written.
Chapter 4

4 Findings

Chapter 4 reports the findings from analysis of patients’ written responses to the final survey question, “Is there anything else you would like to tell us about your hospital stay?” When considering the entire data sample, patients’ comments varied in length, detail and specificity. Some comments were written as summative or evaluative statements. Other comments elaborated with in-depth descriptions. Comments were usually stated in these three ways: as facts or events, as labeled or implicit emotions, and as suggestions or recommendations.

Patients’ comments often noted the actions of hospital staff that patients personally experienced or observed. The words that patients wrote signaled the sentiment of the comment and suggested the meaning of any reported perceptions. Survey comments were interpreted to be accounts of what patients found to be significant and therefore noteworthy. The emotional sentiment of comments spanned a wide range, from highly positive to highly negative.

Analysis of survey comments yielded findings about the ways in which patients wrote about “the hospital stay”. Chapter 4 reports three separate and interrelated broad-level sets of categories. Chapter 4.1 captures comments related to patients’ hospitalization experiences. Chapter 4.2 captures comments that focused on individual patients’ perceptions, influenced by notable moments in time, which influenced the personal experience of the hospital. Chapter 4.3 captures comments that used the survey as a conduit to express patients’ understandings and expectations about how their comments will be used.

The genders of patients were not included in analysis and therefore descriptions or examples referring to an individual patient’s comment use the gender-neutral singular form of “they” or “their”. Additionally, the term “staff” is used to reference those who represent the hospital, regardless of whether the representative fulfilled a clinical or non-clinical role. Direct comments from patients are reported in italics, to make apparent how they are separated from description and interpretation. All comments were copied directly as they had been received from the electronic NRCC report; as such, abbreviations or short forms, and grammatical, syntax, or
punctuation errors that were present from either the patient’s writing of the comment or the quality of NRCC transcription are marked by [sic] throughout the findings.

4.1 Emotions Pervade Patients’ Comments about ‘Hospital Stay’ Experiences

The content of patients’ comments spanned a range of topics. They included access expectations (to care, to information, to food, to space, to staff, to material resources, to sufficient hospital length of stay), communication (information to the patient, consistent information among different staff, teamwork between staff, the use of language, staff attitudes during, coordinated care between hospital departments), costs of being in hospital (parking, private care by support personnel, lost wages due to cancelled surgeries), discharge or leaving hospital (access to staff, access to supplies, communication and coordination between staff, access to information, enough information, patients having to help themselves, individualized plans, feeling safe for, follow through with the plan), the hospital environment (physical space, appearance, cleanliness, feeling safe in, privacy, signage and directions, access to supplies in, noise, sleeping while in, sharing space), evaluative summaries (of accountability and use of resources, of the entire hospital experience, of staff roles and observed staff actions), religious references (blessings directed at staff), family (being included, being accommodated, receiving information, treatment by staff), and thanks and appreciation.

4.1.1 Thanks and Appreciation

Short statements of “thank you” and appreciation were abundant in the comments to express an overall positive sentiment about the hospital experience, including: “Thanks for everything”, “I really appreciate everyone’s help”, and “Thank you for all the excellent care that I received and my family members.” Staff roles were named in some comments, including clinical and non-clinical roles: “…I owed them many thanks”.

Patients’ perceptions about staff actions were noted in some generalized statements: “…their love & care”, “…nothing was too much trouble for them”, “…all the help, and heart, they put in the job”, “…very friendly and helpful”, and why those actions were important: “…the wonderful care, support and guidance in my time of need”, “…all your support and taking of care me during my treatment physically and mentally”, and “…treated me with respect and dignity”. 
The specific staff actions that received thanks and appreciation provided insight into what patients found helpful. Patients wrote about staff paying attention and being fully present, using active listening skills, interacting in ways that personalized the patient experience, and following through in a timely manner: “…listen, study my file and proceeded in a very methodical & professional way” and “…an interest in my situation and intervened to solve it as soon as possible”. Specific staff actions that were helpful during the hospital stay were also noted together with thanks and appreciation: “…put together a recipe of medications that are working wonders” and “…they made me fell [sic] like I had known them a long time. Like good friends we laughed + joked which took your mind off of everything. It was perfect”.

Sentiments of thanks and appreciation were also linked to statements about how patients were personally impacted by hospitalization, and the long-term effects that they remembered and appreciated: “…returned my health, and my life back to me in the community”, “…assisting me to enjoy life to the fullest”, “…restoring my well being”, “…for saving my life”, “…getting me through a critical time in my life”, “…you made a difference - you extended my life”, “…not only did you save my life, you are still helping me to rebuild it”, “…making my serious illness less stressful”, “…helped me recover”, “…getting back on my feet”, and “When I left the hospital, I had a very positive feeling about my health! Thank you XXXXXXXXXX!”

In addition to thanks and appreciation, the content of what patients wrote about the hospital stay was grouped into three major categories that captured patient’s statements about the emotional experiences of the hospital stay. Patients wrote about feeling safe, secure, comfortable and cared for; about feeling like a person; and about feeling prepared to return to living life. Figure 1 displays the first set of categories as the major categories and sub-categories of patients’ comments regarding their feelings about hospital stay experiences.
4.1.2 About Feeling Safe, Secure, Comfortable and Cared for

In survey comments, patients noted strong emotions experienced by themselves and by their families. Patients wrote responses that described hospitalization as a “very emotional time”, noting feeling “vulnerable” and “struggling”, and labeling moments during hospitalization to be “frightening”, “stressful” and “exhausting”. The actions of staff were often noted, such as when staff made “a very scary + difficult time for me as easy as possible”. At time, specific moments of interaction exchanged between patients and staff were identified as having provided comfort, facilitated quality interactions and communication, and inspired trust and confidence:

*I am totally blessed to have had such a caring experience...the only negative comment I will have throughout my entire time...was the long tiring anxious and fatigued wait.. we found Dr. XXXXXXXX to be very knowledgeable and made us feel totally comfortable... was very caring and kind and made us feel warm and safe and clearly explained my health issue and the remedy to fix the diagnosis...and made us feel*
totally cared and respected in every way...My experience, although frightening and scared, I completely trusted Dr. XXXXXXXXXX and his team in restoring my health... made my family and I feel truly cared for at all times and always check to ensure that we were ok. I guess it would be safe to say that they truly work from the heart.

Sentiments about feeling “safe”, “secure”, “comfortable” and “cared for” were explicit in patients’ comments, expressed in notes about comfort, about how staff interacted and communicated with patients and families, and about how trust and confidence were inspired in patients. Patients’ comments about comfort included topics such as food, sharing space, noise, and pain and some patients recorded why these topics were worthy of note. Patients wrote about the emotional impact from team interactions observed, communication hoped for and not received, and the responses from staff during moments of care that either diminished or strengthened relationships. Patients’ comments suggested that patients “felt safe with care” when staff actions and attitudes were perceived to stem from genuine concern, openness to be “available”, the “willingness” to meet with patients, and encouragement to support patients: “…they tried everything to help me...never gave up trying to help me” and “…were in a great mood, helping relax the atmosphere for everyone waiting to go into surgery. Their manner set the tone.” Patients’ comments made a clear link that when patients “felt safe and comfortable”, they “trusted hospital staff” and “felt confident”. Comments suggested that when staff provided comfort in a caring manner, interacted and communicated with an understanding of patients’ experiences during a difficult time, and inspired trust and confidence, patients experienced respect and dignity. Chapter 4.1.2 presents the three sub-categories of comments about feeling safe, secure, comfortable and cared for.

4.1.2.1 Comforts for Me

Patients often wrote about well-known human comforts. Patients noted having access to comforts in material form such as pillows and blankets, fresh linens, self-care supplies, a phone and a television. Comforting effects on the physical body were noted, such as from access to food, relief from pain, dimmed lights at night and quiet spaces. Comfortable spaces were identified in comments about the hospital environment, such as in observations about how often garbage bins were emptied or washrooms were cleaned. Some comments noted how comfort may be tied to personal experiences, as illustrated in the following entire comment from one
survey: “I particularly missed the pressure of a salt shaker”. Patients wrote about other commonplace things, such as access to “hot water” for “the opportunity to shower on a regular basis”, suggesting that the things tied to people’s typical or daily routines are sources of comfort.

Comments suggested that patients expected access to the familiar comforts that are known to help people take part in regular routines: “The nursing staff were all professional and caring, but no one offered me a basin to clean up. My daughter did that for me. Isn’t that part of the routine morning care?” Further, comments suggested that staff should act according to typical practices that might be expected, such as those during early morning hours: People in the corridor in the early hours should remember where they are and keep their voices down!” While patients commented on basic comforts, they also wrote about not having raised the topic with staff during hospitalization: “I would have liked a face-cloth and a towel, instead of only paper towels. I probably should have asked and would have received them”. Nevertheless, comments suggested that when patients did not experience expected basic comforts, it was understood as disrespect: “I have never been so disgusted with the respect the nurses doctors and other patients have for patients who are trying to sleep. The hospital is supposed to be a quiet place”.

Some comments made explicit connections between access to the things that provide comfort and patients’ feeling safe, secure, comfortable and cared for. There were multiple comments about food, noise levels and pain management and the following examples illustrate how some patients connected those comforts to healing, recovery and relief: “It was a grand thing to have a salad with lunch each day - and fresh fruit! Please continue to improve the food - how else can a patient heal properly”, “Patients need healthy food choices to help recovery”, “Entrance door needs to be addressed. To be there for 48 hrs with no sleep was unbearable. There is constant traffic - never stops - make the design better. No rest keeps people from not healing/recovering”, and “Thankful for relief from pain, felt so much more hopeful when I left for home”. That is, each single brief comment in the survey about “inedible”, “unappetizing and unattractive” or “not nutritionally sound” food, “a lot of noise”, and “a bit painful” or “crying in pain” experiences collectively suggested how much patients felt safe, secure, comfortable and cared for by having access to familiar comforts that brought nourishment, rest or hope while in hospital.

Comments written with labeled or implicit emotions suggested an understanding that the nature of the hospital environment placed limits on the comforts that patients could expect to access,
particularly access to private space: “I understand that there may be a shortage of available beds but being left in the hallway on a gurney for a day and a half while in discomfort was very unpleasant and depressing”. Chance was noted to play a part in access to comfort in physical spaces: “luckily I had good roommate [sic] - neighbors friendly (I felt safe)”. Yet, the desire to want to feel safe, secure, comfortable and cared for remained foundational to expectations during the hospital stay: “The only distressing aspect is they have more control over sick patients so they don’t disturb other very sick patients like myself with outbursts that scared me”.

Simply having access to things that provided comfort did not necessarily make care comforting and patients comfortable. Staff actions made the difference. In the following examples, patients wrote about access to the comforts of blankets and the use of the washroom, but it was the actions of staff that made the difference so that these patients perceived being helped: “very cold [sic] nurses helped with warm blankets” and “Nurse XX help me, after surgery when I need to go to washroom”. Further, comments suggested that it was in the process of staff providing comfort that patients perceived moments of staff being caring or uncaring, and careful or careless. The efforts of staff to provide comfort were perceived as intentional: “…a shout-out to the kitchen & cleaning staff. They were always pleasant & tried their best to oblige” and “…angels with caring arms…knew how scared I am of blood work and always take [sic] extra care and use [sic] the smaller needle”. Staff actions resulted in perceptions of respect also being noted: “Made me feel very comfortable, she was very comforting, treated me with respect - made me feel cared for.”

Comments, seemingly mundane when read as individually, revealed more when analyzed collectively: patients’ comments about ordinary comforts brought order within a chaotic hospital environment and had the potential to help patients to feel safe, secure, comfortable and cared for. The numerous comments by patients about comforts suggested the strong importance of the familiar things that are well-known and understood in terms of patients’ typical routines, particularly during “difficult time[s]” while in hospital.

4.1.2.2 Interact and Communicate with Me

Patients wrote about observing and experiencing interactions and communications with staff that impacted them to feel safe, secure, comfortable and cared for. Different factors were noted to have an effect on patients’ perceptions, including a patient’s state of mind and body, the organizational environment and its processes, staff competencies, staff attitudes, and teamwork.
Furthermore, interactions and communication impressed upon patients’ perceptions of their relationships with staff. Comments that signaled the relationship between patients and staff also suggested the degree to which patients felt safe, secure, comfortable and cared for: “…extremely knowledgeable, caring respectful and a profound doctor in her examination although direct,…She clearly and concisely explained my reason for the sneezing episode” and “Several nurses did not speak English well enough to understand my concerns, or were too busy to listen”.

A patient’s state of mind and body, and the ability for staff to recognize and respond accordingly, were noted to impact effective interactions and communication: “Younger doctors (residents & students) somewhat abrupt with answers to questions & not assessing patients [sic] mental state when providing answers”. Comments suggested an expectation that staff would appreciate that when patients are in the hospital, they experience physical and emotional states that require staff to be supportive and understanding: “Had partner there most of the time, bed staff insisted on telling me info when I was under influence of narcotics” and “…very early morning rounds, it was hard to communicate much with my surgeon, as he’d arrive before visiting hours (so no communication with family members), and I’d be groggy at that time of the morning”. Moreover, these comments suggested that failure to recognize and respond to patients’ states of mind and body lessened patients’ perceptions of feeling safe, secure, comfortable and cared for.

The hospital environment and its processes were also noted by patients to impact interactions and communication. The hospital was described in patients’ comments to be a busy place, with many staff and activities: “Too many staff not [sic] know who’s nurse/orderly/cleaner”. Lack of communication initiated by staff to explain how the hospital works in general, left some patients writing about the experience of feeling insecure, such as in the following examples related to the operations of a teaching hospital and the layers of learners: “Saw a number of drs [sic] and a lot of interns - not sure who in charge” and “Was admitted for surgery. Not once before or after surgery, or during my stay did he bother to come + see me. Only assistants + students had contact with me. That was disappointing, + a little worrisome”. When staff communicated with patients about what to expect in the hospital environment and also adapted processes to help patients feel more safe and secure, patients wrote about those actions. The following comment noted multiple, ongoing discussions between a patient and different staff members in which there was “sharing” about “significant events/incidents” to adjust for being in a semi-private room with a co-patient who was exhibiting responsive behaviours: “…I was taken to my room (semi-
private) close to the nurses' station. I was sharing a room with an older woman...overnight was noticeable [sic] agitated... the nurse shared that…”

An expectation that staff were responsible to recognize how the hospital environment and its processes could contribute to patients’ feeling safe, secure, comfortable and cared for was suggested in comments, such as: “Spouse of patient in next bed stayed at hospital...Once stayed till [sic] 4:00 AM. This was very disrupting + I was unable to sleep. This went undetected by staff”. Further, some comments suggested that the structured hospital environment did not always accommodate the needs of patients as individuals and that the unique needs of individuals should be considered: “I’m a quadriplegic and couldn’t use the call button, there should be a solution for this for severely disabled individuals”. Suggestions were made about changing the way that communication occurs about the hospital environment and its processes, in order to help patients to better feel safe, secure, comfortable and cared for: “I seemed to have a lot of nurses + student nurses taking care of me + I could never remember all their names maybe add a small white board to rooms so they could write them down” and “I shared a room with an elderly woman who seemed disoriented. Sometimes she would come close to my bed and make me feel unsafe. Patient safety/security should be closely monitored”.

Staff competencies were noted by patients. Overwhelmingly, there were two major topic areas related to staff competencies that patients wrote about. First, staff’s knowledge and skills in providing pain management received comments: “…should have professional technicians to take blood - My agony while at XXXXXXXXXX was daily having my blood taken, it was unbelievable. This was my only fear” and “All my care was excellent except that the night nurse was unable to give adequate pain medication during the night...so I suffered severe pain...until a pain specialist was called the next morning”. Second, staff’s ability to provide care in the English language received comments: “The night nurses were somewhat wanting perhaps because their English was limited. I felt a lot of anxiety + somewhat panicky. The nurse couldn’t understand” and “My biggest complaint was being told that I have terminal cancer by a doctor that spoke very broken English. I only understood half of what she said”. Despite the strong sentiment that receiving pain management and care provided in the English language were important for patients to feel safe, secure, comfortable and cared for, comments also suggested that patients did not raise their concerns while in hospital receiving care.
Staff attitudes during interactions and communication also received comments. When patients needed help and they encountered a lack of attention; or attention that was slow, inadequate or inappropriate; or attention was delivered without an attitude of caring, comments suggested that patients did not feel comfortable and cared for: “To [sic] many training nurses - with competitions of all kinds [sic] Too many interns - To [sic] many smiles - Not enough action - my fibromyalgia” and “…not caring and never smiled! I felt very uncomfortable”. Even when comments were written as an event or fact, the sentiment of feeling unsafe or insecure was apparent: “There was one nurse who did not finish anything she started. Forgot to remove IV. Forgot to bring ice for sudden swelling when IV finally removed; forgot to check urine output; forgot to bring medication”, “…extremely slow at responding to go to washroom + for help with meds”, “…Others (not many) answered the call bell but did not offer support - just stood & waited until no help needed”, and “…were rough, throwing stuff on me, pulling me with force out of bed, throwing me back in bed, not taking into consideration pain and wound”.

However, when staff were perceived to approach interactions with an attitude of genuineness, supportive understanding and full presence, patients wrote comments that signaled feeling safe, secure, comfortable and cared for. The following two comments contrasts how perceptions of staff attitudes about being “very busy” led to different patient understandings about feeling cared for: “They were extremely competent and very busy but gave me all the time they thought necessary. The nurses were very respectful, always introduced themselves and tried to preserve my dignity” and “The nurses were always very busy, at least that was what appeared to me. But down in my heart, I was not sure if they were really busy or pretended to be busy”. Patients’ perceptions about staff attitudes also had the potential to influence patient behaviours that possibly placed a patient into an unsafe situation, as described in this comment written about an “unpleasant” interaction:

I never asked her for anything, not did I use the call-button [sic] during her shift, when she took-over [sic] from the night-nurse [sic] in the morning, she came-in [sic] to tell me: [sic] that I am not the only patient she has & therefore not to call her unless it is an emergency such as I need to vomit, etc: [sic] I very seldom called any nurse at all, but I certainly never called this nurse even once!

The topic of teamwork received numerous comments and its importance was indicated in how patients wrote about efforts perceived to be coordinated as a “team” across professions: “The
doctors and nurses all gave the same answer, obviously they confer together” or within the same profession: “RN team on days did not readily support one another [sic] If I wasn’t their patient, very hesitant to help/dismissive. In general I had to actively push for what I needed [sic] IV ran dry, dressing bleeding on sheets” and “The change over from one doctor to another was poorly done”. When staff were not perceived to be working well together as a team in their interactions and communication, patients’ comments suggested they did not feel safe, secure or cared for, such as in this comment: “I couldn’t talk so each time I ran [sic] the call button they responded [sic] what is it? [sic] So I think when you have someone that isn’t verbal. It should be tagged as such so when shifts change they should know”.

Moreover, clarity in communication between staff was noted to influence patients’ feeling safe, secure and cared for. The following two comments contrast experiences of team communication: “Team approach with specialists is efficient + ensures high quality - Everyone knows their role - understands impact on overall process” and “There were many things that didn’t quite work between teams [sic] communication was lacking...Who does what information was not clear”. Inadequate team communication created doubt that the safest care was being received:

There seem [sic] to be a miss communication [sic] amongst physio [sic] therapists re: direction from doctor re: range of motion and whether or not I was allowed to bear weight or bear weight as tolerated. Very frustrating from a patient perspective - it took 3 separate times to get it right.

Additionally, patients wrote about teamwork between and across different teams, such as “Inter departmental communication”. Comments suggested that while patients recognized that the hospital consists of multiple departments, they also assumed that staff worked together across departments as one hospital-wide team that follows the continuum of care of each patient. Comments about the “coordination”, “organization” and “planning” between teams for appointments suggested that when done well, there would be “no endless waiting around” and when poorly executed, a patient might “walk around hospital only to find the area I was sent to closed”. The sentiment that patients expected staff to communicate across teams about care was expressed in comments, such as in this example: “When referred to another surgeon at a different hospital, my images (CAT scan) was [sic] not sent, nor was I told by staff to get it myself. Resulted in wasted appointment”. This example suggested both an expectation that staff were responsible to communicate across teams and a perception that the lack of communication
was experienced as disrespect due to a wasted appointment/ patient time. Coordinated communication and interactions across teams was associated with patients’ overall perception of having experienced dignity and respect: “Staying in the hospital is not easy for me but I was so impressed with the doctors & nurses. They work as a team and it feels we [sic] so important to them” and “They are only the best hospital and every department works so well together. They treat everyone with dignity”.

4.1.2.3 Inspire Trust and Confidence in Me

When patients wrote about how they understood the hospital stay, there was a strong sentiment that feeling safe, secure, comfortable and cared for was “inspired” through staff actions and their responses to patients’ needs: “I look at the doctors as professionals that build my trust and confidence on them”. Trust and confidence were noted by patients to be inspired through the direct experiences with or the observations of staff actions or verbal responses. Comments suggested that trust and confidence were inspired during moments of care and during transitions in care.

During moments of care, patients wrote about timely, attentive and appropriate staff actions that inspired their trust and confidence to feel safe and cared for: “ Immediately on my arrival in the emergency unit, the staff started attending to me, ensuring my safety. They were very enthusiastic...extremely attentive” and “First night I had severe pain. In less than five minutes two nurses questioned me on my pain [sic] They immediately changed my meds & within the hour all was good”. Patients’ comments suggested that staff actions were perceived to be intentional: “…did everything possible for me so that I would not be afraid...I was petrified [sic] referred me to another dr. [sic] to talk to & run tests so I felt more secure...comfortable & calm about having procedure done” and “…caring & knowledgeable [sic] Explaining everything that they were doing & why”. Further, patients noted the actions of staff that inspired their trust and confidence, such as the staff member who everyday “always ensured my meals were correct”, a physician who “…personally responded by phone to deal with a medication and an infection issue - very reassuring!”, and a nurse who:

...was always there when I needed her. She got me a newspaper when I was wondering about the outside world and after waiting for 5 days for surgery, she bought me a coffee + muffin as for the days prior [sic] That was what I wanted as I kept being bumped for surgery.
Staff’s verbal responses were also noted to inspire trust and confidence for patients to feel safe and cared for, such as: “I think the lab techs need more training...and being prepared...when visiting patients [sic] rooms [sic] Eg [sic] bring butterfly needles, do not say to the patient quote [sic] I don’t have any and I’m not going back to get them” and “Hearing from day staff that dressing that had bled to edges on day 2 wouldn’t be replaced since very expensive doesn’t inspire confidence”. Further, verbal responses that did not react to or directly address patients’ expressed concerns diminished trust and confidence, such as when one patient “warned them that what they were going to do would be extremely painful” and to which “They said it would just be for a minute or less”. Patients wrote about times when staff said things that impacted patients' opinions: “…a porter said to me [sic] I’ve been here 20 years + let me give you some advice, if you don’t mess with them, they won’t mess with you [sic] - This scared me + in my opinion was unprofessional”. The things that patients recorded about what staff said to them suggested that patients’ trust and confidence to feel safe and secure was affected by the dialogue or lack thereof: “Re [sic] call button: suggest that nurses + patient discuss the process in order to build common understanding + expectations. Listening to a bell go on + on + on + on does not build patient/caregiver confidence”.

Interestingly, patients’ observations of what staff did and said also inspired trust and confidence. Patients’ comments suggested a recognition that patients were in a position to continuously observe all the hospital occurrences surrounding them: “Nurses...should watch what they are saying someone might be listening”. Patients’ observations of staff actions and verbal responses impacted them to feel safe and comfortable, as suggested in comments by patients who witnessed staff who “fought a lot” or noted differing degrees of willingness for staff to provide care: “…night nurse refused to...They argued back + forth...other nurses had done it previously. This did not affect my care but definitely made me uncomfortable as I heard it all”. Such diminished impressions of confidence levels were contrasted with other comments by patients who witnessed caring and comforting interactions that created positive impressions: “...I had an opportunity to observe. The staff were calm, cool and collected, very efficient, attentive and readily available. The staff had a very calming effect on patients and their families whose anxiety levels were very high” and “The patient in the bed beside me was very confused + fearful [sic] the nurses were amazing, they helped her + stayed with her to be sure she was not scared. She found that very calming and I was very impressed”.

Trust and confidence were also impacted when staff did not act and speak in expected ways. When staff did not follow hospital policies, such as hand hygiene or a fragrance-free environment practices, it made an impact on patients’ feelings of safety: “…no health care provider cleaned or washed their hands in 3 days of observation; not completed and very disappointed” and “I was told that the hospital was fragrance free…One of the night nurses…came on shift reeking of a very strong flowery perfume…so I avoided calling for her. I waited until the shift changed…to call for any help”. Patients’ comments also suggested that their beliefs and hopes informed expectations about how quickly staff should respond, such as waiting “sometimes up to 30 minutes” for an answer to the call bell or having to wait for medication “…to bring my 40 degree C temperature down & I am pregnant (so fever is very bad for the baby)”. Further, “promises” not kept, such as to receive status updates and results, to see staff from a specific profession, and to obtain specific requested information were also noted: “There were promises to come back but it didn't happen...left me with a list of unanswered questions.” That is, putting words into action was crucial for inspiring trust and confidence. Finally, consistency mattered. The following example juxtaposes one patient’s perception about the incongruous priorities of staff and of the patient. It suggested that trust and confidence were not consistently inspired to help the patient constantly feel safe, secure, comfortable and cared for:

2 complications while in hospital taken very seriously + dealt with [sic] When I spilled scalding hot tea on myself (totally my fault) [sic] when asked for help [sic] message not passed on to nurse. No after care (checking burn) done - only bed changed.

Transitions in care across the entire hospital stay experience were noted by patients to be especially important to inspire trust and confidence in patients to feel safe, secure and cared for. Patients wrote about what they observed or experienced staff to do and say when care was transitioned between providers. Examples included continually having received meal trays containing allergens or regular meals after having reported a need for a special diet. Also, patients commented on having to correct medications being incorrectly prescribed or administered by staff, despite documentation of specific medication sensitivities. The transition of accurate information onto patients’ hospital wristbands or their patient care records also received comments. Overall, there was a sentiment that patients felt they had to be diligent when their care was transitioned between care providers and that it was necessary to advocate for themselves in order to feel safe and secure, particularly when “It wasn’t clear that previous
records had been carefully enough reviewed or that team communication was good” and especially when events occurring repeatedly: “Again inaccurate info so again a concern”.

Words expressing emotions, such as “impressed” and “reassured” or “disconcerting and confusing”, signalled the level of trust and confidence that was inspired during transitions in care: “Being out of town…my wife was very impressed that right after my operation doctor called and informed her of my condition and reassured her that all went well” and “I found the constant changing of nursing personnel from one day to another disconcerting and confusing. I did not really know who to ask for what!” Finally, suggestions for improving transitions in care focused on behaviour-based recommendations for staff responses to inspire trust and confidence:

I was there during the time change. Some of the nurses were VERY confused about how to record the next dosage for medication. As a result some patients missed their pain pills. One nurse said [sic] Oh well, this doesn't happen very often [sic] This is NOT the right answer. Do you not have a strategy for time change?? and:

Different people from different teams asked the same questions regarding my many mediations. My wife provided them with a print-out [sic]. I answered the same questions over, & over, & over. Team members did not share info with each other. Wouldn't it be more efficient to ask the questions once, have a competent person be responsible for entering them into a common database & have each doctor or their assistants access the information that in common place?

4.1.3 About Feeling Like a Person

Patients wrote comments about feeling like a person during the hospital stay. Patients noted being seen as a “statistic”, “case”, “number”, “part of a production line”, or “anonymous” rather than as “person”. That sentiment was exemplified in this comment: “The staff and MDs [sic] not only provided excellent care, they cared how I am and showed interest in me as a person and patient”. This comment labelled that a significant contribution to a patient’s experience was in more than staff’s completion of patient care tasks, it was also in the patient’s perception of caring staff attitudes that helped the patient feel like a person.

Feeling like a person was suggested in comments about staff getting to know patients as individual persons, and treating them in humane ways that demonstrated courtesy and
politeness. It was also suggested in patients’ perceptions about being treated as equal to staff and patients’ perceptions about staff behaving as if patients were less valuable people. Further, it was suggested in patients’ comments about having been included in their own care. Privacy was noted by patients to be a key element in helping patients to feel like persons. The underlying sentiments in this category include patients’ perceptions of developing relationships with staff, expecting staff to act with an understanding that being in hospital is difficult for patients, and that the emotional impact of feeling like a person while in hospital forms lasting impressions on patients. Chapter 4.1.3 presents the three sub-categories of comments about feeling like a person.

4.1.3.1 I am a Person

Patients wrote comments that described the experience of being known as a person while being in the role of a patient. The sentiment that a patient is a person was noted in comments written as events: “Quick + good, efficient [sic] Some feeling of being part of a production line” and “…treated me as a number, no real person to person contact. This happened on 6 of the 9 pre-op [sic] stations, one station in admission. I am a person not a statistic, or something to get done before going on break or going home”. It was also expressed with labelled emotions: “…there were no rooms available and I was called hallway - funny, but made me feel a bit anonymous!” and “More than once when I would be being questioned by a nurse or receiving treatment from her she would leave and say before going - I'll be right back. I would never see her again...left me with the feeling that the atmosphere was cold and impersonal and I was more a case than a patient”.

Statements written about staff actions described patients’ perceptions about how well staff recognized each patient as an individual, even for seemingly mundane things: “I liked the fact that I was given a choice of entrees and that I was asked about any food likes/dislikes”. Staff actions helped patients to not feel like they were a “number” or “case”: “From the emerg [sic] personnel to dr's [sic] & nurses, everyone was professional, courteous, respectful and made me feel like I was the prime minister of XXXXXX”. Comments about staff having responded to patients’ fear and anxieties suggested that patients perceived staff to understand that hospitalization is a difficult experience: “extra careful and made this an easy experience”, and staff to recognize the vulnerability and humanity of people needing care in the hospital:
“…everyone responsible for my care extended thoughtfulness, concern, professionalism and kindness with sometimes a gift of humour which was all greatly appreciated. My first experience personally with surgery!”

What patients wrote about privacy strongly indicated experiences of patients feeling like persons. Privacy as a deeply held need and expectation was described in patients’ comments, such as in one comment about being shaved in public by a staff member of the opposite sex who was never introduced to the patient, and in another comment about the exposure of a patient’s body to people in the surrounding area. The following examples further illustrate how patients’ experiences of staff respecting patient privacy impacted perceptions that patients were regarded as persons: “Respect the patient privacy. Consider the patient as the most important person, to give the information about her/his situation”, “Very little concern to privacy - nearly every time I had interaction with nursing staff they paid little attention to closing the privacy curtain”, and “…Asked for a bed pan and she threw it on my bed left the curtain open and walked away. I needed help on it and ended up peeing my bed while my roommate had visitors was very upset and embarrassed”.

Comments about having privacy respected in the hospital were particularly central to patients’ experiences of being treated as persons.

Some patients wrote suggestions for staff to approach each patient with the courtesy, politeness and kindness that would be generally expected in interactions between people. Patients wrote that introductions by staff, a friendly attitude and “genuine smiles and concern” were ways that staff could acknowledge patients as persons: “During change of shift, nurse now on duty should identify self to patient” and “When it is necessary for the patients to empty the TV room to allow the medical staff for a meeting, please be polite to the patients already in the TV room”. Patients’ comments also suggested the importance of staff getting to know the unique experience of each patient and that it could be an intentional choice for staff to make:

My first reaction on receiving this form was to completely disregard, who cares what an old lady has to say. Every individual is special and experiences things differently, more so while ill in hospital. One day bad, the next a little better. This [sic] not a perfect world and as individuals working with people in the medical profession, you sometimes have to put aside your feelings and try to comprehend what your patients are feeling and understanding their concerns.
4.1.3.2 I am as Valuable as You

Some comments suggested that patients wanted and expected to not only be seen as persons, but also to be valued as persons. The sentiment of feeling valued as a person was suggested in comments about staff being considerate of and attending to individual patient needs: “My pants were lost by the ER staff and nobody seemed to care. I was never given a personal belongings bag that would have kept everything secure. I even found my sweater on the floor” and “Nurse or phys. [sic] therapist take me to walk 2nd day with no shoes and pass to washroom with no shoes. Very dirty washrooms I feel dirty to go to bed with my feet dirty”. Protecting personal belongings and wearing footwear in public places may be considered basic conduct by most people. Valuing a person may be demonstrated by such behaviours. These comments, while written as events, implied that while in hospital, patients assumed that they would be treated in considerate ways that valued them as any fellow human being might expect to be valued.

Patients’ comments suggested that patients’ experiences were based on relationships and the bi-directional understandings about patient and staff roles within the context of the hospital environment. The following comment exemplified a patient’s understanding about the pressures on staff to provide care within a teaching hospital: “…when she has too many things going on - she: [sic] has a hair trigger response that is harsh & overly critical when I needed encouragement; & overly focused on promoting her students understanding of my chart (unreadable) my understanding…In the end I am respectful for (unreadable) she is human”. By acknowledging the work environment and recognizing that staff are human beings who work within constraints, this comment suggested that patients have compassion and empathy toward the staff experience.

More often, comments suggested that patients wanted staff to respond to an individual patient’s unique needs, so that they felt valued: “The resident seemed somewhat arrogant, speaking 'down' to someone with an advanced education by saying [sic] You might need a big operation while in ER”. Feeling valued was also suggested in descriptions about being treated humanely, with kindness and compassion, and as a priority: “…ignore calls &...indifferent”, “…not very friendly - seemed mad and grumpy - very cold + didn’t talk. We were not impressed”, and “C/O [sic] nurse - RN then took the time to teach preceptor how to look up drug interactions rather than start the med... I don't believe the priority was on the pt [sic]”. These comments suggested that when patients did not perceive staff to demonstrate recognition of or responsiveness to the
patient as a person, it contributed in a negative way to hospital stay experiences.

The sentiment that patients wanted to be valued as fellow human beings was prevalent in comments about how staff actions were perceived. For example, patients wrote about being disturbed overnight by staff birthday celebrations and by loud staff conversations about their personal lives that made patients feel uncomfortable. Patients wrote that these staff actions took away from the patient role to heal and recover. The following comments suggested that staff actions were perceived by patients to not value and respect them as equal human beings, despite an expectation that staff “should” know and behave in ways that valued patients as persons: “At approx [sic] 6:15AM the doctors had congregated...They were talking & laughing so loud they woke me up [sic] you would think that dr's [sic] with their education would not be so ignorant...It’s not about the patient it is all about them” and:

A scheduled appointment was cancelled due to an emergency situation which is understandable. However, what was unacceptable was arriving on twice for the appointment then being advised of the cancellation - my phone # [sic] is on record - a phone call advising of the cancellation to me & other affected patients should have been made. Our time is as valuable as hospital staff - for me this resulted in a loss of 2.5 hrs [sic] out of my workday.

Feeling respected was further suggested in comments that when patients perceived the actions of staff to intentionally value patients as persons, it made a difference. Particularly in patients’ comments written with labelled or implicit emotions, the sentiment of feeling valued and therefore respected was apparent. Any staff representing the hospital could influence patients’ perceptions of feeling valued: “…staff were busy, and still were able to make me feel well looked after. They always had a smile + took care of me in a timely manor [sic] even though I could see they were running around very busy with many patients”, “…willingness to discuss my concerns without feeling like I was wasting his time. His secretary XXX was absolutely wonderful addressing the many calls she received from me [sic] Top notch!!”, and:

Even the parking department went above and beyond by bringing forms directly to my room when I was unable to go to their office. The staff from top to bottom really seem to understand the emotional stress patients are under and give 100% to ensure this stress is kept to a minimum. Keep up the great work!
The emotional impact of feeling valued while receiving care in the hospital was suggested in patients’ comments that reinforced the recurring sentiment that privacy, consideration for patients’ vulnerability while in hospital, and staff patience to understand the experiences of patients were all important: “I found some nurses (a couple) who treated me like I was a burden on them. Considering the state I was in at the time, this was very demoralizing” and:

...the resident was impatient to view the incision faster than I could arrange my clothing & bedding. He did not express impatient [sic] until he pulled down the bedding himself & exposed my pubic area, pubic hair & all to everyone!!...I’m middle aged think how violated an elderly woman would feel!!

4.1.3.3 I am a Part of My Care

Patients wanted to feel included in their own care, as suggested in their comments. Having access to talking with staff, doctors in particular, and receiving answers to questions were prevalent in the content of comments about feeling included in care: “I still do not know when I will talk to the doctor...several times I have tried, but I was always told that was not possible....”, “...the staff physician who performed a procedure (endoscopy) did not bother to say hi + did not bother to tell me the findings of the endoscopy...It needed or wanted after care, in her leave”, and “...the surgeon should have come around after the surgery to bring me up to date - I was discharged in 3 days & she had 3 days off [sic] The team that took her place were unable to answer my main concern!!” Family inclusion in patient care was also noted: “My family stated to me that they felt much less a part of and informed this stay as compared to my stay in XX”.

Feeling like a person and feeling valued were embedded in the comments about patients feeling a part of care. Comments written as recommendations further suggested that patients felt like persons through how well they perceived they were a part of their own care. The amount of time spent with patients was noted: “Please explain about things [sic] that how when where one going on [sic]. Take some time for them [sic] matters” and “...should spend a little more time with patients, during follow up visits...spend almost (2 hrs [sic] waiting) then to only have a brief chat or none at all with him”. Comments also suggested that patients know their own needs and so “should” be invited to take part in their own care: “Food selections should be double-checked with patient needs”. Specific, timely and directive information for patients to be able to take part in their care was also noted: “Patients need comfort with quick action and right information of actions taken,
the condition of the sickness, the purposed [sic] action and how the patient could cooperate” and:

No information was given re [sic] any tests unless I asked. I wanted to know why the tests were ordered, and the result. The medical staff needs to know that the more knowledge a patient has the more involved that patient is in the treatment program.

Even when written factually or as events, comments relayed a sentiment that feeling a part of care was important to patients: “I learned a lot about this illness and its treatment method from my doctor though English is not my first language”, “I wish I had been told more”, and “Little interaction with any staff except what was absolutely needed. Few check ins… re [sic] recovery plans or actions on my part”. Staff behaviours of asking questions, initiating discussion about patients’ goals, listening, providing encouragement and support, and respecting patients’ wishes and feelings were all ways that patients wrote about feeling a part of their own care: “I was never asked re [sic] - bathing - teeth cleaning - My meal tray came without any input - 5 days”, “No short term goals established”, “Uninformed nurse/ students. Did not ask me questions”, “Little to no encouragement provided by staff/ doctors”, “My experience is diminished by several negative experiences with nurses who would second-guess if my request should be filled, and some who totally disregarded my needs”, and “Ward nurses sometime told me how I felt instead of listening to me!” These comments suggested that patients perceived themselves to be a part of care whether staff put forth efforts to connect with them and understand their needs, or not.

Feeling a part of care made an impact on how patients reported their hospital stay experiences. A positive impression was usually noted when patients perceived staff to purposefully include them in care: “The nurses & doctors involved in my care were knowledgeable & informative as well as caring & cheerful. I was made to feel very comfortable in asking questions as my health problem & they were always willing to discuss”. A more negative sentiment was suggested in comments about not feeling a part of the team or not having worked together in partnership: “I was chastised for failing to perform my exercises to expectation…Excessive, inappropriate, inflexible, demotivating…a totally negative + unnecessary tactic that needs change. Patient definitely does not get considered as a team member”. Furthermore, staff responses when patients took initiative to participate in their own care impacted what patients wrote about:

I did and do have concerns and anxieties re my cardiac condition. I found it sad that no one asked me if I had any, and when I voiced them was told [sic] Oh, you will be fine, don’t worry [sic]. Such a response shuts down any further discussion.
4.1.4 About Feeling Prepared to Return to Living Life

Patients wrote many comments describing experiences outside of their hospital stay, reflecting that hospitalization was only one part of their entire hospital experience. The content of these comments consisted of patients’ thoughts about “return to” “normal life”, and specifically what preparation patients expected during hospitalization to help them to live life again after leaving the hospital.

Patients’ experiences of feeling prepared were written in two ways: through receiving information and through planning. Comments suggested that sufficient preparation was perceived when patients received information and planning in ways that were clear, consistent, accessible, specific and personalized: “…I had several different people with conflicting methods + advice. Was not properly prepared as to what to do at home”. The presence or lack of information and planning impacted patients’ perceptions, as suggested in the following example: “…the procedure I had a week prior, which was a catalyst for this visit being necessary, was not the best. I found that experience lacking in preparation, sharing of information and professionalism…”

This category of patients’ comments about feeling prepared to return to living life integrates and builds upon the categories of patients’ comments about feeling like persons and feeling safe and cared for. The following comment exemplifies how the three major categories are intertwined, suggesting that when patients did not feel valued and a part of their care, trust was not inspired for the patient to feel sufficiently prepared to take part in their recovery:

My displeasure came about because of the arrogance + insensitive behavior of my dr. [sic] is denying my request for rehab post surgery…created ++ anxiety in my recovery. My dr. [sic] did not discuss the matter with me. He (unreadable) came to my bedside, without acknowledging my feelings. Stated [sic] you don’t make the decision re [sic] rehab [sic], you will be discharged shortly [sic] and left the room.

Patients wrote about coming into hospital with understandings and “impression[s]” that staff would provide them with information and help them to plan how to manage their post-hospitalization needs. Comments suggested that patients did not expect to “[have] to” prepare on their own: “I was under impression a nurse would visit my home to help with post operative care”, “Had to rent own equipment + call wheelchair myself”, and “Nobody informed me about
A sentiment of expecting staff to initiate preparation for patients was present in comments: “…follow up regarding next steps was missing”. Comments suggested an expectation for staff to prepare patients across the healing and recovery process, including from patients’ most immediate needs at discharge from hospital: “Nobody helped with the transition home. Incontinent + (unreadable) - very stressful. Had to buy diapers on way home from hospital. Discharge felt very rushed + disjointed”, through to patients’ longer-term needs: “After hip surgery it should be recommended to the patient to go to a rehab facility for another visit if they are on their own at home”.

Patients wrote about feeling prepared for the things they themselves could anticipate and also for things they could not have anticipated but staff “should have”. Patients’ comments described the events and circumstances related to having received preparation while in hospital, and what things made it easy for them to gain information and planning. The personal impacts borne by patients due to the lack of preparation were also noted in comments. Chapter 4.1.4 presents the three sub-categories of comments about feeling prepared to return to living life.

### 4.1.4.1 With Information and Planning

Patients wrote about having received both information and planning that helped to prepare them for returning to living their lives. Some patients wrote about having left hospital after having asked for preparation but receiving little or none, while other patients wrote about having taken it upon themselves to seek some preparation: “Care plan not communicated. My family was left to track down social worker to learn about care plan during and post discharge to rehab [sic]”.

Clear information was noted to be important: “The discharge instructions were not as clean as I would have liked regarding resumption of exercise”. Receiving consistent information between different staff was also noted: “…all physio’s [sic] said something different” and “There was confusion on my departure between doctors on what meds [sic] I would take at home”. Lack of clarity and consistency created unhelpful experiences for patients, as suggested in this example: “…last day was a busy day on the ward and the discharge process was confusing, stressful and got conflicting messages and directions from different staff members”.

Different ways of making it easier for patients to receive information and feel prepared were noted: “The physio [sic] department was more than helpful in my recovery - my routine exercise
was explained and questions answered”. Accessible information, easily retrievable when needed, was appreciated: “Even though the nursing staff did not brief me about side effects, or everything involved with...going home...I did receive a booklet that spoke at length about all the information that I needed when I returned home”. And, when it was lacking, it was noticed:

Support material not readily available for follow-up by family doctor: Following discharge, I was referred to my family physician. My physician has been practicing in Canada for over 25 years and had not had a bi-literal [sic] knee replacement patient in that time...there was a large gap between the support and information from the XXXXXXXXXXXXXX and the approach to pain management that my family doctor was recommending.

Some comments specifically noted the importance of planning to help patients feel prepared. More than solely receiving information, patients wrote about having contact with staff so that they could try out what they had been taught. Patients wrote suggestions for how patients could receive more planning, to help them to feel prepared to return to living their lives: “…had surgery...Was seen by physical therapist once...Did not see Physio [sic] again. Suggest more contact before allowing to go home (direction req'd) [sic]”. Moreover, sufficient preparation was noted to include more than exposure to what to do and that there would be benefit in having patients practice using the information: “I feel strong that we had rehab…they said they would teach us everything we needed. But putting it into practice could really have used support”.

Patients wrote about positive experiences that helped them when staff provided preparation that was perceived to be timely and relevant: “The attention I received near when I was sent home - was absolutely great!” In contrast, other comments described situations in which information was perceived to be provided to patients at the convenience of staff rather than with consideration for the individual patient: “Perhaps due to being on pain meds at discharge. I was not recalling being told the process of receiving meds which caused confusion”. There was strong sentiment suggesting that individual needs had not been addressed in preparing patients to return to living their unique lives: “Everyone is different...More education in this area would be beneficial” and “There is not enough thought given to a patient who is totally on their own regarding aftercare on release from the hospital...”

Moreover, comments recorded a sentiment that preparation should create ease for the patient in
addition to easing the work of staff. Several patients wrote comments using surgery as an example of how they were well-prepared pre-surgery to fit into hospital routines and staff scheduling, however, they were less well-prepared to address their own post-surgery needs: “Pre [sic] op excellent! I felt confident going into procedure but was not prepared for lengthy surgery [sic] what to look for [sic] what could happen [sic] what to do”. Recommendations were made by patients to make it easier to access information and planning about “What to expect recovering – timeline”, to gain explanations about what is “normal” to encounter when regaining functioning, and overall to place emphasis on patients’ needs for return to living life: “One area for improvement - there is a lot of information regarding knee surgery and what to expect but not enough information post surgery...more post surgery info on how to recover would be helpful”.

When patients received information and planning that helped them to return to living their lives again, they noticed: “Communication excellent - during the pre op. [sic] procedures and in the follow up after returning home. Believe that a nurse called the day after discharge to check that all was well + no concerns or problems”. A sentiment of appreciation came across in comments about patients having perceived staff making preparations for them, including planning for services: “…nurses & doctors made sure that I had a therapist travel to my home once a week for 6 weeks”, for functioning and individual needs: “…they arranged my trip from hospital back to my home and to my own apartment. When I was back in my home, they made certain that I have all the necessary equipment, nd [sic] other things, to manage and live alone”, and for unforeseen events: “I was sent home with a bandage that was suppose [sic] to be on for 1 week [sic] We had to arrange for a nurse to come in and change it every day. It started leaking the day after I came home - the hosp [sic] was great in helping to arrange all of this”.

4.1.4.2 For Things Anticipated and Unanticipated

Patients wrote about being prepared to manage the health needs that they themselves could anticipate and also those that they did not anticipate but that staff “could have” or “should have” anticipated for them. Patients wrote about feeling adequately prepared to manage their medications, to function at home, and to being well-connected and transitioned to care and services outside of the hospital; consistently, these were the major topics found in the comments for which patients anticipated preparation. The importance of clear and consistent information and hospital-based planning were also noted regarding being prepared about these topics.
Having to manage medications outside of the hospital was anticipated by patients. Comments noted when preparation regarding managing medications was “…not well managed” and when specific and personalized information and planning was lacking. The idea of receiving individualized preparation as a “life service” so that patients would know what to do when on their own was the sentiment from comments about medications: “…life service to obtain guidance on meds not just a prescription. Ie: [sic] Narcotics & break through pain meds shouldn't be taken together. A specific agenda helps ie. [sic] breakfast take lunch=dinner – bedtime [sic]” and “Did not know how long to use drugs I was sent home with - if I could mix advil [sic] in tylenol [sic] etc.”

Being able to “function” again in “normal life” and in “activities at home” was another topic that patients wrote about, and in general, comments recorded that patients felt inadequately prepared: “More info on care and when I can return to my normal life. Follow up is very poor”. Numerous comments suggested that staff “should have” anticipated that patients would need information and planning for successful return to functioning in life: “There was no information to be had on aftercare and estimated recovery time, particularly regarding how soon afterwards I could function - (ie. [sic] return to work, drive, etc.)” and “I was discharged without any information or cautions about activities at home (driving, stairs, etc.)…”

Comments suggested that patients expected to be asked about and provided with specific information entailing what a patient could anticipate regarding functioning again: “I would recommend stressing the Do's and Don'ts [sic] expanding on time lines, when to start with stairs & different exercises. What to expect…” Preparation for functioning at home again was expected, regardless of the type of procedure a patient needed, and it was noticed when some patients received preparation while others did not: “I should have been more prepared for going home - ie [sic] raised toilet seat, shower bench I had a fusion to my 15-51 vertebrae. Patients who have knee/hip replacements receive info before surgery to recover smoothly”.

Furthermore, even when it was not the first time a patient experienced a particular surgery, patients still expected to receive information about the typical self-care activities and exercises they would need to perform shortly after hospital discharge: “I did not have a shower. If I had not had this surgery before I would have lacked info on how to handle a shower…No one asked me about showering either” and “…my second knee replacement and I was capable of [sic] I had
a better idea of what to do. The first time I found physio [sic] very helpful. This time I felt there was minimal physio [sic] support. I would have appreciated more help with physio [sic] as I was less prepared coming home”.

Being connected with resources and transitioned to care providers outside of the hospital was also a topic noted by patients: “Poor management after discharge was a major issue”. Patients wrote about wanting clear information about next steps, including what resources were planned to be in place for their post-hospitalization needs. Basic contact information was desired so that patients would be bridged to a knowledgeable source for assistance when they had specific questions or concerns: “It is not clear who to contact or how to contact them after discharge if you have concern or need clarification or advice” and:

The only area I have found wanting on both occasions, was the lack of follow up, or ability to be in communication with a doctor who specializes in pain management managing pain especially following knee replacement surgery is CRUCIAL, for an effective recovery.

In addition to writing about anticipated needs related to medication, functioning and support service needs, patients also wrote about the things that they experienced but did not anticipate while in hospital. There was a sentiment in patients’ comments that when patients experienced health concerns, particularly new issues identified while in hospital, it was a responsibility for staff who routinely worked with patients experiencing those health concerns to talk with patients about what to expect. Patients who received new diagnoses or health issues wrote about wanting to be better prepared while in hospital, such as being connected with “support groups” as well as receiving general information about what to do next: “More explanation about TIA what I should do to keep healthy when I leave”.

4.1.4.3 Because of Lasting Impacts

Lack of preparation to help patients return to living life, or its inadequacy, was noted to generate emotional impacts on patients: “…not enough - to cope on discharge”, “…discharged home XXXXX feeling very dubious”, and “I feel I was rushed out prematurely, with no discussion or details of future plans”. Feeling “rushed” and “frustrated” were often noted by patients who commented on not having received specific information and planning: “I felt rushed by the surgeon and not enough direction and explanation, as per injuries sustained”. Feeling alone and
ill-prepared to figure things out was a sentiment in patients’ comments, as seen in this example about managing medications: “I struggled w/ [sic] meds once I got home. Never sure what to take, when and what worked best. Lots of discomfort & anxiety”.

When connections and transitions were not made for patients during their hospitalization, the impact was borne by patients in their own environments. Some patients wrote about the extent to which they went to access services for themselves: “…when I went home. I did spend 1 1/2 days being shunted around emergency dept. [sic] …emergency doc(s) [sic] had poor or non-existent [sic] follow-up charts/systems”. Other patients wrote about the long-term effects of not having information or planning: “Surgery on XXXX - released on XXXXX morning - complication with oral pain meds - nausea - continued for months after surgery”. Still other patients wrote about spending time and effort to obtain help elsewhere because no preparation was set into motion by staff during hospitalization: “…related to the follow-up care…unable to reach my doctor (or the clinical care coordinator) for a medication refill while still waiting for my next follow-up appointment…ended up having to make an emergency visit to my GP (outside of the hospital)…”

Patients who were living on their own wrote about their wishes for rehabilitation or home-based supports because it was “very difficult managing at home by [my]self” and being “alone” made it “very difficult to cope”. Comments relayed a strong sentiment of feeling alone through the toil of having to seek information and determine plans on their own: “…had no clue re [sic] respite. It took me 2 weeks of phoning to find out that only services homes would provide this respite. There is no way I could be safe +/- or comfortable at home” and:

“…I am 80 years old and live alone - no family able to stay with me and help me. I was told it was up to me to find somewhere to go - I would not qualify to go to XXXXXXXX. (unreadable) hospital or my [sic] after I had to spend the next three weeks looking for a place to take me for (unreadable) weeks - then asking for help at home…”

Also, patients who were discharged from hospital without adequate preparation and went home to fulfill a care provider role again especially experienced difficulty, as suggested in this example: “I was sent home with no services. I had to make calls to get a nurse, PSW as my husband is disabled and was unable to care for me…the first week home was very hard on my husband and I”. Moreover, the following two examples of entire comments, despite written as
events, suggested that a single moment overlooked by staff has the potential to lead to significant and lasting impacts, all endured by patients themselves: “The emergency doctor could have warned me what symptoms to look out for should I have a problem - which I did” and:

I was hospitalized XXXXXXXXX with a broken neck & (unreadable). During my stay an incidental find of a tumour in my kidney was present. I would have liked more information at the time on this find [sic] to take home. I was left to research this on my own using the internet.

4.2 A Moment in Time Personalizes the Hospital Experience

Some comments more fully explained the personal experiences of individual patients. These comments suggested that the hospital experience became a personal matter for an individual patient, because of some moments in time that were especially significant. Moments in time that happened during a patient’s hospitalization, moments previously experienced in a patient’s life, and moments that occurred beyond the patient–hospital stay experience all impacted patients’ perceptions of the hospital experience.

A single moment during hospitalization, or the accumulation of many moments, could impact a patient’s hospital stay experience. Moments in time previously experienced in a patient’s life, including work, hospitalizations, or understandings about the healthcare system, could influence a patient’s hospital experience. Events that happened to a patient’s family member or after a patient’s hospital stay also impacted perceptions of the hospital stay or the hospital overall. Figure 2 organizes the second set of categories as the major categories and sub-categories of comments that were written about highly personalized experiences.
4.2.1 Moments During My Hospitalization

Some comments highlighted particular moments that patients experienced while in the hospital. Descriptions of these moments provided fuller and more complete pictures of the personal hospital stay experience for different patients. Some comments noted a single experience that stood out from the overall experience. Other comments recorded a series of experiences that accumulated into an overall impression about the hospital stay.

4.2.1.1 ‘The One Thing…’

Patients’ comments that provided a summary statement along with a more detailed description about “one thing” suggested that a single event often stood out among the entire hospital experience: “I was completely satisfied with my hospital stay in all of its respects. The only thing I would have wished above all the care given would be…” Comments that were written using the general format of ‘the one thing’ usually described a remarkable difference from the overall experience. It spanned topic content presented in Chapter 4.2, including staff actions and responses, individualized attention to patient’s needs, follow-up care, communication, food, pain management, information needs, the discharge experience, access to doctors, the physical
environment, sharing space, observations of how other patients were treated by staff, wait times, and the one staff who made a difference.

Comments about ‘the one thing’ noted something different from what was otherwise observed or experienced, and how it made a particular impact on a patient’s impression: “Overall the care and attention I received at the hospital was beyond reproach. However I do wish to add my one concern…”, “I have to say this hospital was a pleasure to stay in [sic] the only complaint I have is…”, “…only bothering factor was…”, and “…team is wonderful and [sic] consider myself very fortunate to have been under their care. The only thing I found perplexing was…”

Most often, comments about ‘the one thing’ highlighted a negative sentiment about a specific experience. Access to doctors and to medical care were noted: “My only disappointment is that I didn't ever see my surgeon and was followed only (unreadable) doctor…for 5 days in hosp [sic] & after 2 follow ups I never saw real doctor” and “…program is very well run overall [sic] Only difficulty was getting a hold initially of the on-call resident for pain meds…” Staff attitudes were noted: “…the best hospital I've been in. My one reservation – the surgeon…seemed perfunctory in the formal after care meeting…” Communication was noted: “After I was sent home (several days), my doctor received notice I had pneumonia [sic] I was never told this which was the only criticism I could report”. Food and parking were also noted: “From admission to follow-up the care is excellent!! One negative – The food is poor…” and “My hospital stay was wonderful. My only problem is leaving XXXXXXXX for each visit and the cost for parking is very expensive”.

A significant or notable difference in the hospital experience was also signaled through patients’ use of words such as “except”, “but”, “however”, and “otherwise”: “Everything was great, but one nurse…Other than that I was very happy with everything”, “Hospital and staff are fantastic. However the food…”, “…given wrong information…Otherwise everything else was excellent”, “Nursing was excellent – except 1 night…”, and “XXXXXXXXXX is a great hospital, but the problems seem to be with follow up + post op rehab [sic] + lack of communication between hospital staff as to appropriate dates”.

Some comments provided a reason for why a particular experience stood out for a particular patient: “I would however like to single out XXXX my night nurse who gave excellent care…would just pop in to see if there was anything he could get for me + treated my kindly when my pulse rated went to high” and “…Only bad experience was the last day I was wheeled
out of my room a staff member said, [sic] Finally! She's out! [sic] found it rude and made me feel very bad + uncomfortable, worse than I already felt from my condition”.

The comments that identified how overall perceptions were changed because of “one thing” may be interpreted as direct feedback from patients about specific improvement opportunities: “I felt extremely blessed to have had so much caring care. My only suggestion, if at all possible, is to…” and “The only thing that could possibly be improved is communication between nurses and doctors, other than that it was fantastic”.

Comments about ‘the one thing’ may also be viewed as completing patients’ stories about their overall experiences and noting lasting impressions: “I will never forget the way the people was [sic] with me…”, “I never forget her help and attention about my fear, scary [sic] and afraid of surgery. I never forget her kindness, so I appreciate her as long as I am a life [sic]”, and:

At one point in the middle of the night I lost control of my bowels on the way to the bathroom [sic] The nurse was very angry and complained about clean-up [sic] She shoved me roughly into a diaper and told me I'd have to wear it until I learned some control [sic] This one event coloured my entire hospital experience.

Some lasting impressions could not be expressed by patients while in hospital: “As my responses indicate - I was truly impressed with the care I received [sic] I have only one criticism: ....One of the 3 I.V [sic] nurses was dreadful...not patient oriented. I said nothing - but she left me in tears”. These comments suggested that patients’ perceptions about the entire hospital experience may be impacted by one issue or a single experience: “…That moment has left a poor impression with me about my procedure. Otherwise I would have been very pleased with my experience”.

4.2.1.2 The Accumulation of Things

Some patients’ comments suggested that it was a series of occurrences during hospitalization that impacted perceptions. Some patients summarized the accumulation of events into evaluative statements: “It was above my expectation from ambulance to your ER everything ran like clock work [sic]. One of my best experiences renews faith in the medical system”, “Most impressed - 1st time in a hospital [sic] Initial emergency visit -> referral to urology clinic -> decision to do TURP -> XXXXX procedure -> no complications [sic] What more could I ask for?”, and “From the first assessment to leaving after surgery I was pleased with the care and attention”.
Other patients wrote descriptions about what happened during many specific moments during hospitalization and connected the events that impressed upon the unique experience for an individual patient. In longer entries, details were listed about the events that accumulated for an individual patient who continuously experienced the hospital stay. The following comments are contrasting examples of fuller depictions of events that accumulated into differing overall experiences for two patients:

*Admission* - misspelled my name. Diversity training required - assumed I was married & straight - Not enough spinal fluid taken - will never no type of viral meningitis I had - Assumed I did not have herpes simplex one - yet never asked me about it - Took more than 3 hours to get antibiotics when hospital protocols less than 30 min for meningitis [sic] Was given a chest x-ray when I had no respiratory symptoms - never given a choice to opt out - The change over from one doctor to another was poorly done [sic] 2nd doctor could not explain why or how hospital lost 4 vials of blood taken when 1st arrived

and:

…very thorough assessment of my medical condition was conducted...Their approach helped me focus my questions...At no time did I feel rushed or pressured... very well prepared with all my background information, data and x-rays...

Demonstrations were provided...All questions were answered (with humour and in a friendly manner) and handout materials were provided...It was made very clear that it was critical that I commit to undertaking the extensive physiotherapy regime (both at the hospital and on my own) or recovery would not meet my expectations...I was invited to bring my support person (my husband) to all appointments...As a result, my husband and I both felt very prepared...following surgery - I found the care following surgery to be personal and patient centered : - [sic] I felt I had a team of experts who knew my condition exactly, and my expectations regarding recovery...I had access and very quick response by the nursing staff...I was provided with answers to all my questions promptly, and solutions to problems and issues. - [sic] The white board in my rooms [sic] was filled out with the names of each health care provider as the shifts changed - It was explained...no one would be sent home too early or unprepared.
4.2.2 Moments From My Life

Some patients’ comments suggested that life experiences were considered in patients’ ratings about their hospital stay experiences: “Having worked in an XXXXXXXXXXXXXXXXXXX capacity, I may have known more than others what to expect so many of my answers are coloured by that”. Comments that made a connection between patients’ life experiences and their perceptions of the hospital stay specifically named previous hospital-based work, past hospitalizations, or current understandings about the healthcare system.

4.2.2.1 Hospital-based Work Experiences

Hospital-based roles were relayed into some patients’ comments. Personal connections to the healthcare system, because of having served in a role within it, seemed to have influenced patients’ observations: “As a retired physician it was quite interesting. So many procedures now than were available when I was in practice. Nice to see the level of cleanliness and the disinfectant procedures practiced by the staff”. Patients who were previously employed at the hospital wrote about their interactions with staff: “My care was excellent and I joked with some of the doctors that eighteen or so years ago I did fundraising for XXXXXXXXXX...and one of them joked back that well I guess now its [sic] payback time [sic] Thank you”. Also, patients who had previously provided patient care wrote about their perceptions of receiving it:

\[\text{Nursing has really changed, my reward is [sic] nursing over the 39 years has been so rewarding. I would have loved a basin of warm water rather than try to wash in the B/R [sic] with a walker. After several days no shower! A nice wash which I would have given, just to give the PT [sic] a lift, I guess I'm from the old school.}\]

4.2.2.2 Previous Hospitalization Experiences

Some patients wrote about their previous hospitalization experiences and compared them to the current hospital stay. Those comments suggested that patients’ experiences were influenced by what they had previously encountered. The contrast between hospitalization experiences further suggested that patients rated their current hospitalization within the context of their previous understandings: “Compared to my (R) [sic] knee replacement (XXXXXXXXXXXXXX) hospital stay and this one, (L) [sic] knee replacement…” Differences in the hospital environment were noted: “Washroom was dirty all the time/ was [sic] better last year my first surgery 2012” and “...there
has been a great improvement in the quality of the food…” Differences in staffing and in levels of care provision were also noted:

I was last in hospital in XXXX. At this time there was a head nurse for the floor who made rounds every day + engaged with every patient about his or her care. The nurses wore a uniform that looked clean and fresh. The patients were bathed or assisted with bathing every day; beds were changed everyday and the patients knew whether their nurses were RN's [sic] or C.N.A’s [sic], would [sic] that those conditions prevailed today.

4.2.2.3   Healthcare System Experiences

Thoughts about the healthcare system were also written into comments, suggesting that patients’ perceptions about their hospital experiences were tied to those understandings. Funding of the healthcare system was noted in comments: “Patients need to be made aware of costs involved in treatment provided - public awareness about our health system is needed” and “…not enough nursing staff to adequately care for the patients. I don't blame the nurses they are run off their feet. I am also aware & concerned about the stake [sic] of our health care system due to inadequate funding”.

Patients’ perceptions of wastage of public resources, including food, needless tests, and unnecessary days in hospital, were noted in comments: “…the waste of all uneaten (often inedible) food are [sic] alarming - the dark underbelly of socialized medicine all large teaching hospitals face. Hospital should do a food audit on waste”, “I found it very frustrating to stay in hospital... performed numerous unrelated tests and no CAT scan until the morning of my discharge. I felt I was wasting valuable hospital resources for no reason”, and “I was in hospital 4 days and it should have been < 1 day. Helps account for the huge costs!”

And, appreciation was expressed for access to services within a Canadian context, relative to what patients understood about other health service systems:

I was understandably nervous and apprehensive as this was first visit for major surgery and overnighting [sic] in a hospital. With great pleasure and Canadian pride I can say it was a great success, never have I been treated so well by so many people from the moment I arrived at admissions to the charming physiotherapist and trainee who helped me into my car on leaving. With socialized health care under
question south of the border and the examples of Canadian health care not working, let this letter stand as example of how well it works. My arthritic hip was diagnosed in late XXXXXXX and here I am in early XXXX with a replacement. I cannot praise the nurses and staff enough; nothing was too much trouble for them.

4.2.3  Moments Related To My Hospital Stay

The content of some comments was about more than perceptions regarding the hospital stay or about patients’ own experiences. Some patients wrote about events related to their hospital stay that were realized after leaving hospital. Further, some patients wrote entire comments about the experiences of a family member. These comments that were related to a patient’s hospital stay experiences suggested that patients’ experiences with the hospital extended beyond the hospital stay itself.

4.2.3.1  More to My Personal Story

Some patients wrote comments that gave more information about the follow through that was expected after the hospital stay. These comments extended the hospital stay experience beyond dates of hospitalization. The following statements, written as facts or events, were about not experiencing expected follow through actions: “Have been told that I should have had a home visit by a physio [sic] therapist. If this is true, then I did not receive a visit” and “To this day my family dr [sic] has not received any up date [sic] on my stay. It was asked for a month ago [sic] did not know what dr [sic] to contact”. A home visit or an update to a primary care provider, while not directly about the hospital stay, were related to it, and were noteworthy for these patients. These comments suggested that patients’ perceptions of the hospital stay included completion of expected follow through actions that were assured by hospital staff.

Furthermore, some comments were phrased as specific questions, additionally suggesting expected responses regarding personalized experiences: “Why, when complaining of severe and persistent headaches did I wind up in a cancer ward?”, “My rt. [sic] leg gave me about 8 weeks of pain & discomfort which I did not expect. I would like the doctors to tell me what happened? [sic] XXXX Aneurysm?”, and “I was told that I will have a follow up from neurologist, but still now no response from the team. Now while writing this I’m an, [sic] in severe pain…I understand
doctors cannot [sic] identify why?” Again, these patients’ questions arose after the hospital stay but were important to each individual patient.

The following comments suggested both an extension of patients’ personal experiences and an expectation that comments would receive responses by the hospital: “The bad pain that is tormenting me daily are shingles - this torments last 2 years and 4 months. For this, I cannot fine help, if you have somebody please recommend” and:

On XXXXXXXX, I went to see a heart specialist Dr. XXXXXXXXXX, he said to me - XXXXXXXXXXXXXXX should provide a report of my coronary angiography found two blood clots blocked/status and a report of stents to me or Dr. XXXXXXXXXXXXX, (because of the above reports XXXX didn't give me. So I still didn't see) My address: XXXXXXXXXXXXXXXXXXXXXXXXXXXX Dr. XXXXXXXXXXXXX's address: XXXXXXXXXXXXXXXXXXXXXXXXXXXX, XXXXXXXXXXXXXXXXXXXXXXXXXXXXX Tell: XXXXXXXXXXXXX, Fax - XXXXXXXXXX Thanks a lot!

4.2.3.2 My Family Matters

Some patients wrote comments about their family members being a part of the hospital stay, suggesting that family played a critical role in patients’ experiences. Patients who wrote about their family often noted the emotional responses of their family members. The following examples suggested that patients’ concerns regarding their family were typically the result of inadequate or inappropriate communication with staff: “What I remember I am writing...After that what happened at night I cry [sic] so much...Some one [sic] phoned to my daughter [sic] night & made them worry” and “Not informing family of surgical delay + following problems caused my daughter much grief”.

While patients were the direct recipients of hospital care, patients sometimes noted moments in time when the greatest personal impacts were experienced by those on the periphery, by their family members: “My wife is 70 years old and it was too much stress as it was, and the nurse just put more on all of us due to her lack of experience & knowledge...It is not my family's job to endure stress due to incompetence...”. The experience for a family member was at times ‘the one thing’ that was different and most memorable for a patient to note about the hospital experience, as seen in the following comment that was entirely about the experience of a
patient’s wife: “My wife was disappointed... that I had been discharged and taken downstairs... in the main lobby she found me sitting alone on a bench... I'm 71 years old and was obviously weak. This was my only (-) experience at the hospital”.

Furthermore, while the survey asked for the person completing it to indicate if they were the “patient” or “someone else” and this study only analyzed comments from surveys that were marked as completed by the “patient”, some family members used the comment section to add their perspectives: “As the husband of the patient who completed the survey form entirely on her own I would like to say... My wife was exceedingly generous on her comments under the circumstances she filled out this form...”, “This comment is from the patients [sic] spouse: I just want to say that the surgical waiting room for the family is wonderful. The volunteer lady (XXXXXX) was a total delight”, and “My husbands [sic] memory is very poor and he does not remember very much of his stay...” These comments suggested that the hospital stay was as much an experience for family members as it was for patients themselves, and family members also wanted to provide feedback so that responses could be understood within patients’ personal contexts.

4.3 The Survey as an Implied and Inferred Contract

Content analysis of patients’ comments revealed more than patients’ experiences of staying in hospital. Comments also exposed patients’ thoughts about completing a mailed survey about the hospital where patients received care. Some responses to the last survey question, “Is there anything else you would like to tell us about your hospital stay?” suggested that patients provided statements to fulfill their part of an agreement. Chapter 4.3 reports the findings that reflect interpretations of patients’ comments about their understandings and expectations when responding to patient surveys.

The category of an implied and inferred contract was interpreted within the consideration that the open-ended survey question invited patients’ comments as part of an entire survey that was sent with a covering letter that used instructive sentences preceding and following the comment section; therefore, the findings presented in Chapter 4.3 are introduced with a closer look at survey instructions. Comments in this set of categories were interpreted within the context that
patients wrote responses with the understanding they were providing feedback to the hospital and that the hospital would review any feedback provided. That is, survey comments were written in exchange for hospital improvements. Additionally, there were comments by patients that were specifically about the survey itself and its ability to capture feedback for improvement. Figure 3 displays the major categories and sub-categories of analysis of patients’ comments specifically related to the survey as an implied and inferred contract.

4.3.1 My Survey Feedback in Exchange for Hospital Improvements

Some survey comments suggested that patients wrote comments with the understanding that they were taking part in an agreement. The sentiment of an implicit agreement was signaled by the written format of some comments, such as when patients referred to returning the survey: “To whom it may concern: Enclosed please find completed questionnaire...Sincerely XXXXXXXXX”. It was also signaled when comments quoted content from the survey’s cover letter: “P.S. this survey was never sent before as stated in the letter” or when comments referred to the introductory statement preceding the comment section: “I called the above number to ask which hospital stay they would prefer I write about...To date I have not received a reply”. These
comments suggested an inherent cooperation stemming from a mutual understanding that the feedback patients provide will be used in the future for improvements.

The content of the survey’s covering letter may provide insight into why some comments suggested that by completing the survey, a patient had entered into an agreement. Listed here are some instructions from the survey’s covering letter (Appendix I, p. 1): “On behalf of the Board…I ask for your assistance…Your opinions are valuable to us…we want to provide the best possible service to our patients…so, we need to know what we are doing right and what may need improvement. Your feedback will be used to improve how we provide care…Please complete the enclosed questionnaire and return it…as soon as possible…Only a limited number of our patients receive this questionnaire, so your participation is very important…Completion of the survey is voluntary…Please feel free to express your opinions frankly…your personal information will not be provided to the hospital. The hospital will review your comments…Thank you for your time and help. Your effort will help us provide better care to all our patients. Sincerely…President and CEO”. Additionally, the statement preceding the comment section reminds: “The hospital will review your comments…” and the statement following the comment section and ending the survey reads: “Thank you for taking time to complete this questionnaire! Your answers are greatly appreciated…”

The sentiment of an agreement was interpreted as both being implied by the organization’s survey instructions and inferred from the content of some patients’ comments. Furthermore, completion of the survey was interpreted as an agreement in which a patient volunteered their “time and help” and “effort” with the understanding that “the hospital will review [their] comments” and that “feedback” about “what [the hospital is] doing right and what may need improvement” “will be used to improve how [the hospital] provide[s] care”. The comments presented in this category represent the overall sentiment that this agreement was considered to be a mutual understanding between both parties to fulfill a shared purpose to “help” the hospital improve in order to “provide better care to all [the hospital’s] patients,” such as what might be expected in a contract.

4.3.1.1 A Personal Response to a Personal Request

Patients’ comments that began with an apology or with an explanation for a late reply suggested that patients were responding to the request in the cover letter for the completed survey to be
returned as soon as possible, as part of their obligation or duty in the agreement: “Sorry this is so late getting to you…”, “Sorry for the delay but was not feeling myself for a while [sic]” and “…First of all, I am sorry for delay reply, because my language is not good and I was waiting for my lovely kids to help me…” These comments also contained personal information about the patient and at times, they addressed the request in “the letter”.

Moreover, some comments addressed the organization’s “President and CEO”, whose name and signature appears at the end of the cover letter, suggesting that the survey response was a personal response to a personal request: “Meanwhile, I like to thanks [sic] and appreciate for [sic] sender of this questionnaire Dr. XXXXXXXXXXXXXX president and CEO as well. Thanks XXXXXXXXXXXX XXXXXXXXXXXXXXX” and:

To whom it may concern [sic] I return here with the questionnaire sent by Dr [sic] XXXXXXXXXXXX, President + CEO of XXXXXXXXXXXXXXX. My apology for the delay in sending this, as I had to went [sic] for only relative to help me write what I need to say. Due to my age + my limited English language, I hope you will understand if I request you to please exempt me from this kind of questionnaire in the future, if it is voluntary. With my grateful thanks for all that XXXXXXXXXXXXXXX has done for me. Yours sincerely (XXXXXXXXXXX) ENC.

4.3.1.2 Following Up and Following Through

Adding to the interpretation of a contract between two parties, some patients wrote that they were taking up an opportunity to follow up: “I received a survey from XXXXXXXXXXXXXXXXXX. I completed it and mailed it, but felt it important to send additional comments in the form of a letter…” and “I know that I have filled out the survey you sent however, I just felt that I had to make special mention to the amazing doctors, nurses and secretaries, they are truly angels with caring arms…Yours truly, XXXXXXXXXXXXXX XXXXXXXXXXXXXXXX & family”.

Some comments reflected offers to provide additional follow-up: “If you should require any personal feelings concerning it [sic] two nurses mentioned – ie [sic] - One is ICU and one on the floor the last night of my stay at XXXXXXXXXXX - Please call me”, “I would be happy to discuss with hospital if contacted”, and “The hospital is very good but [sic] couple of people at reception
are some what [sic] troublesome. May be [sic] an [sic] Polish nice lady (supervisor) may tell you about this! I may come there & explain this!” Also, delivering thanks was requested by patients in some comments asking the hospital to follow-up and follow through: “... Please ensure this letter finds its way to the people who should be proud of their facility and perhaps help dissipate the constant criticism I am sure they have to endure” and “No complaints - only praise. Please pass my thanks on to the yellow team and the nurses who cared for me on the ward”.

The way that comments were written suggested that patients made serious efforts to help the hospital understand what patients experienced, why their experiences were important, and how improvements could be made. In exchange, there was a sentiment that it was the hospital’s duty and obligation to direct “attention” to improvement ideas. The following comment requested follow through, again suggesting a reference to an inherent agreement that patients’ feedback will be used:

…I would also like to make note that there were a number of other nursing staff working the overnight who were responsive and supportive however circumstances related to ’XXXXX’ made my stay intolerable. I appreciate the challenges within our health-care sector and the demands placed on staff ensuring the care and wellbeing of their patients. Having said this I do feel there were circumstances which staff at XXXXXXXXXXX could have managed in a more efficient, patient focused manner. Your attention to these concerns is greatly appreciated.

And, using comparisons, patients also used the survey comment section as a way to follow up about service intensity or quality standards. The following comment was written with the sentiment that the patient had hope for the survey response to be used by the hospital to follow through with obtaining increased funding: “…Nursing care has changed in last 15 yrs. I recognize this change! Personal care has gone for ever [sic], nurses have not got time to administer hands on [sic] care [sic] I hope this survey will help your level of care [sic] I understand why their [sic] are changes (money & cost)”.

4.3.1.3  Frankly, you...“Should...” and “Could...”

With an invitation on the cover letter for patients to “express [their] opinions frankly”, some comments carried sentiments that patients were providing open and forthright opinions; the words “should” and “could” signaled patients’ perceptions and thoughts about what the hospital
was “supposed to” do or might consider doing to improve patient care experiences. Within an implied and inferred contract, recommendations may be read as a direct method for patients to provide specific improvement ideas about the things that mattered to them while they were in hospital.

The following examples of comments provided improvement recommendations, from patients’ perspectives: “No one should go to the hospital without a dr [sic] who knows the patient’s history & who will be the primary dr. [sic] in charge of your stay”, to be responsive to patients’ needs: “Every time I had a an issue @ [sic] the hospital I was asked to wright [sic] it down... I had some very bad experiences that should have been dealt with immediately, instead of me having to document it”, to decrease financial burden on families: “…maybe you could have a free within one hour parking zone for patient pick up”, to listen to patients reports about pain: “…There can be many improvements if patients pain was taken seriously”, to honour patients’ perspectives: “…Patients should be given a choice”, to help patients feel respected: “Should treat insulin dependent patients with proper care. I should give respect. [sic] When patient is struggling with high sugar endocrinologist should be available & should treat the patient with proper insulin dosages”, and to recognize and celebrate staff who make positive impressions on patients: “My drugs had a negative affect [sic] on my appetite but the dieticians never gave up trying to help me [sic] They were great + should be told!”

Often, the comments with the longest word counts contained the most detailed accounts of patients’ experiences and the most specific recommendations. Moreover, these comments reinforced the interpretation that patients’ comments were provided in exchange for their use toward improvements, as explicitly named in the last sentence of one 384-word comment: “…The expectation is: the next time I get admitted to XX, everything I have addressed will be largely improved as I am taking the time to help you improve it”. The imperative for the hospital to put patients’ suggestions into use was made apparent, as suggested in another comment that named public perceptions of the hospital: “…should exam [sic] the situation on this unit because it is a poor reflection of hospital”.

4.3.2 Using My Survey Feedback for Improvements

The way in which comments were written by patients suggested that efforts were made to provide useful information to the hospital. These following comments suggested that rating-scale
questions insufficiently covered topics that patients wanted to provide feedback about: “As an added note to the survey that I filled out I would like to attach these comments for I feel I did not have a chance to fully express...” and that the comment section was being used to relay additional information: “Although I have answered completely your questionnaire, but I want to write a few more words regarding treatment and management of this vital hospital...”

Some patients wrote about the inability of the survey rating scale to adequately capture the full experience concerning the questions asked. Some statements were written about the timeliness and usefulness of the survey. Overall, some comments suggested that patients perceived there to be limitations to surveying and the nature of a survey to capture the extent of their hospital stay experience. Within the interpretation of the implied and inferred contract, comments written about the survey itself suggested patients’ intent to help the hospital gain the most useable feedback for hospital improvements.

4.3.2.1 Numbers Don’t Tell the Whole Story

Patients commented about the difficulty in assigning numerical ratings to survey questions: “Many of the questions were difficult to give a decent answer to”. Reasons were provided. Patients noted having received care from different staff members: “It is very difficult to assess the nursing staff as you do not see the same person two days running or even again”. Differences in the behaviours between staff were also noticed, influencing the overall impressions made of different staff: “The answers I have given to you [sic] questions did not note that some of the nurses and doctors care was [sic] exemplary while others were less attentive and easily distracted”, “Some nurses excellent, some poor. Nurses changed a lot”, and “It is always difficult to complete such surveys. I saw many different physicians whose performance varied from outstanding to mediocre. This makes it hard to pass an overall impression”.

Some comments suggested that numerical ratings assigned to survey questions were not fully representative of the hospital stay experience: “I answered somewhat - some deserved better or some worse - so I settled for medium”. Patients’ states of mind and body while in hospital also influenced survey ratings: “During my 6 days in hospital, I was under the influence of much medication, incl. [sic] pain killers. That’s why I cannot properly answer some questions”, “#47 food. Hospital food is always difficult. Most of the time I did not feel like eating”, “I do not remember much about my first 4 days. I only remember bits & pieces”, and “As I was unable to
know what was going on most of the time, I cannot answer most of these questions. Sorry!” The ability for the survey to capture the complete experience of events received comment: “The time lines [sic] of events in hospital were not celebrated on this questionnaire. The test schedules were terrible! The waits [sic] outrageous”.

Notably, several comments directed the reader to view additional comment details written beside the numerical ratings assigned to specific questions within the survey, suggesting that some patients understood that their responses would be connected as a whole rather than divided into the numerical and comment components. For example, the following comment referred to “foot notes” made within the survey: “As mentioned in some foot notes, some nurses were excellent and attentive, (though overworked), while others were outright lazy (my observation) and could not be bothered”.

4.3.2.2 Timeliness and Usefulness

Some patients’ comments referred to the timeliness of receiving the survey: “Filled out several months after visit”. Comments suggested that the delay would impact the accuracy of the ratings: “You are giving these forms out too late - hard to remember exactly what happened”. And, some comments made recommendations for how to administer the survey in order to improve the accuracy of responses: “It might be better to do this survey before you leave the hospital” and “If the questionnaire could have been sent promptly after discharge it might have provided a somewhat more accurate picture of my stay at XXXXXXXXXX”. These comments about timeliness of survey administration were again understood within the interpretation that patients provided responses as part of an agreement to help improve the hospital; therefore, patients’ recommendations to solicit feedback sooner suggested patients’ intent to provide the most accurate information.

Patients’ perceptions about the length of the survey and its usefulness also received comments. Opinions varied. Some comments noted excessive length: “No. Too many questions already”. Others comments expressed positivity about the survey: “By the way - this is an excellently-designed and worded questionnaire!” and “Thank you for asking the important questions”. There were also comments about the relevance of the survey: “Many of the questions don’t apply fully as I began in the critical care unit and had little or no input to what was happening - discharged to XXXXXXXXXX”. Some comments made direct recommendations about changing the survey
content or ratings: “I think that this survey of questions was unnecessary [sic] long. One could just say that one was very happy with the care given; [sic] or not. Fewer question [sic] re: [sic] care could have been given” and:

Regarding your survey: You should number grades beside the poor/fair/good/very good/ & excellent options. Then your survey answers would better reflect how we view the service. You rate pain on a scale of 0 to 10, so why not service?

4.3.2.3 Linking This Survey and Other Surveys

Numerous comments made a link to the numbered survey questions, again suggesting that some patients understood that all of their survey responses, including comments and ratings, would be connected: “#26 It happened with one nurse only” and “#17 Not cleared, 26. [sic] I got the help when ever [sic] needed 25. [sic] I was on bed from XXXXXXXXX to XXXXXXXXXX. 31 to 36 [sic] No pain, 37 to 42 [sic] I was shifted to XXXXXXXXXXXXXXXXXXXXXXXX from XXXXXXXXXX, first I was admitted only this time in the hospital. 51 & 52 [sic] After I was shifted from XXXXXXXXX in XXXXXXXXXXXXXXXX on XXXXXXXXX, I was discharged from XXXXXXXXXXXXXXXXXXXXXXXX on XXXXXXXXXX”. These comments suggested that patients made serious efforts to provide clarification or supplemental information to their survey ratings.

Some comments also referred to other surveys that patients previously completed, suggesting an understanding that survey administration would be coordinated and that comments across different surveys would be pooled as improvement information: “I completed surveys in hospital but again, I had 3 exceptional nurses - XXXXXXXXXXXXXXX staff, XXXXX (Agency night) nurse) and another agency night nurse whose name I can no longer recall. However, some nurses were too noisy in the evenings as were visitors during the day. Please check previous surveys”.

4.3.2.4 Ambiguous Comment, Seems Significant

There were some comments from patients that could not be interpreted without ascribing meaning and potentially giving a false impression. These comments were infrequently found, but seemed significant. The nature of a survey is that some comments may not be interpreted without context, such as: “I wish I had the same nurse each shift” and “Showers reminded me of bathrooms in India. (Some of them)”. The following examples of entire comments might be
interpreted as either positive or negative statements, but without additional context they are ambiguous: “It’s been a memorable stay. One I will not forget”, “I am aged 86 year. I have in the course of my life, been a patient one night in many hospitals and clinic. I have never experienced the standard of care and professional attention I have had at XXXXXXXXXX”, “I drove from XXXXXXX as I did not get Emergency care I was satisfied with. I had heart surgery 3 yrs ago there + feel safe with care at XXXXXXXXXX”, and “Thanks? I was in hospital in so; [sic] much pain that; [sic] I am glad to receive help for the treatment from XXXXXXXXXX”.
Chapter 5

5 Discussion

This study sought to explore the research question, “What do patients’ comments in the National Research Corporation Canada (NRCC) Adult Inpatient Survey reveal about patients’ experiences of the hospital stay?” Findings report three overarching and interconnected sets of categories that were analyzed from the content of what patients wrote in response to the open-ended survey question, “Is there anything else you would like to tell us about your hospital stay?” Patients’ observations, insights and experiences about the hospital stay were impacted by how patients felt about their interactions with staff and hospital processes. Events that made patients feel safe, secure, comfortable and cared for; feel like a person; and feel prepared to return to living life all impacted patients’ perceptions that in turn informed impressions about the hospital stay and the hospital overall. Further, for an individual patient, the hospital stay was personalized by perceptions connected to things that happened to them in the hospital, to events from their personal life, and to their reflections occurring after hospitalization and their family member’s experiences. The emotional experiences of receiving inpatient care were intensified by patients’ perceived relationships with staff, in which a single moment of significant interaction could impact the entire hospital experience for a patient and result in dignity and respect being promoted or diminished.

The insights gained from the current study represent the perspectives of patients from one tertiary care, academic hospital in urban Ontario. Patients had thoughts and ideas to share about their hospitalization and their experiences with the hospital, and some chose to use the comment section of the survey accordingly. Specific ways in which patients wrote about their experiences were identified, such that a reviewer may look for them when approaching the comments for patients’ quality improvement ideas. The content of what patients wrote is largely consistent with what is reported in research, theory, and guidelines related to patients’ hospital experiences and patient-centered care. Chapter 5 relates study findings to relevant literature. New insights are also offered that may be relevant to further understandings about patient-centered care and quality improvement in a hospital setting. Chapter 5 puts forth some practical implications for consideration. Limitations and future research directions are also discussed.
5.1 Patients’ Comments Offer Healthcare Quality Improvement Ideas

The content of comments offered insights into what mattered for patients. Patients wrote accounts and impressions of what happened to them, how they felt about events, how the events impacted their lives in hospital and after leaving hospital, and why those events were important to them. Expressions of emotions suggested the significance of what patients chose to account. Patients provided recommendations and suggestions about what they would have liked to have experienced and what they expect to experience the next time they need hospitalization.

The general way in which comments were written provides insight into how comments may be useful and usable. Patients wrote comments as statements of events or facts, as labeled or implicit emotions, and as suggestions or recommendations. Statements of events told the hospital what happened; these comments identified the source of what was done well or potential problems. Labeled or implicit emotions indicated the significance or impact on the patient who remembered the event; comments analyzed to contain emotion may be a guide for prioritization of improvements. For example, the events that were conveyed with emotions of feeling “anxiety”, “worry”, “stress”, “concern”, “confused”, “rushed”, “dismissed”, or “distressed” might be discussed and problem-solved, while the events conveyed with emotions of feeling “appreciation”, “impressed”, “reassured”, “safe”, “prepared”, “comfortable” or “listened to” might be considered for sustaining and strengthening. Finally, suggestions and recommendations provided direct and explicit improvement ideas, from the perspectives of the people who experienced the continuum of services. These ways that patients expressed their perceptions have utility; they help to identify and prioritize improvement ideas and propose solutions.

Survey comments allowed us to learn of instances when patients experienced fear and concern but could not speak up while in hospital; when the impact of inadequate planning during hospitalization left patients unprepared, alone, confused, frustrated and anxious, at times for months; when patients found comfort in the smallest things, such as a smile, a newspaper or a facecloth; when patients felt anxious and concerned by receiving a diagnosis of a terminal illness or receiving care when alone at night from staff who did not speak English well; when patients noticed hospital policies not being followed and how it resulted in diminished feelings of confidence and safety; when patients made recommendations for staff to be mindful about individual’s needs, so that someone who is non-verbal does not receive a call bell response of
“what is it?” during every staff shift; when patients repeatedly made the same observation that hospital processes are set up for the convenience of staff rather than the recovery needs of patients, as seen in comments about being well-readied for surgery but not prepared for return to living life after surgery; when “one thing” said or done influenced the entire hospital experience to be remembered as supportive or as punitive; when patients continuously observed all events surrounding them and were left with positive impressions about how staff calmly cared for and attended to patients in a busy environment; and how patients ‘knew’ when and if staff were intentionally and genuinely caring for them and about them.

Patients’ comments provided insight into a more complete picture of the hospital stay experience than what has previously been reported in the literature. Patients recorded the information that they remembered. What they remembered was likely important to them. Patients wrote about their personal circumstances, their perceptions and impressions, their emotional reactions, and how it all impacted their thoughts, feelings and actions – all human experiences. Within their comments, the ‘real’ person in each patient was allowed to show. Authors who endorse the collection and analysis of patients’ comments applaud the ability for comments to convey more nuance and to raise topics that are not covered in rating-scale questions (Grob, et al., 2016). Patients have reported difficulty in answering survey questions with rating scales because it requires aggregating disparate experiences (Petroz, Kennedy, Webster, & Nowak, 2011). Without structured prompts however, patients may comment on what they value (Bardach, et al., 2015) and what happened. Therefore, patients’ comments have use as a learning tool and change catalyst (Luxford, Safran, & Delbanco, 2011; Riiskjær, Ammentorp, & Kofoed, 2012).

Patients’ comments strongly suggested that patients completed surveys in order to help the organization. That is, the way in which comments were written in mailed standardized surveys about the hospital where patients had recently received care suggested that patients wrote seriously and thoughtfully, with intent to spark and advance improvements. In how patients wrote their comments, an understanding about an agreement between the patient and the hospital was suggested, such that survey completion was done in exchange for improvement ideas to be used by the hospital. The open-ended question in patient surveys holds promise as a space where improvement ideas, from the perspectives of patients, may be found.
Insight about the quality of hospital care, from the perspectives of patients, may be embedded within patients’ comments about feeling safe, secure, comfortable and cared for, feeling like a person, and feeling prepared to return to living life. These categories of comments could serve as a frame for what quality hospital care could aim to strive for in order to facilitate excellent patient-centered experiences for patients. Such a patient-focused frame could complement the quality framework by the Institute of Medicine (2001a) that conceptualizes six aims for providers to avoid the misuse, underuse and overuse of healthcare services. Just as each of the IOM dimensions is considered to be necessary but on their own is insufficient, the proposed elements of quality hospital experiences from patients’ perspectives likely also requires patients to perceive each and all of safety, personhood, and preparation for returning to living life.

5.2 Twenty-five Years Unchanged

Findings from the current study suggest that the general hospital experiences of patients, across countries, have remained unchanged over the past twenty-five years. Written survey comments suggested that patients continue to report similar issues that patients decades ago reported by telephone in the USA (Cleary, et al., 1991) and in Canada (Charles, et al., 1994), and during interviews in the UK (Bruster, et al., 1994).

In particular, study findings about communication, relationships with staff, preparation, and respect and dignity, were similar to the following specific issues identified by Cleary and colleagues (1991): inadequate explanations during hospitalization (information about medications, and what to expect in hospital routines, for tests and with pain and discomfort), issues with care providers (no relationship of trust, no physical comfort from nurses who were too busy, no doctor in charge to answer questions), issues with how care was provided (not being prioritized over needs of hospital staff, not being part of decision-making, not receiving pain relief promptly or adequately, not receiving answers in an understandable way, staff talking in front of the patient as if the patient was not there, not having family included), and issues with discharge planning (no instructions received about food, medication side effect, danger signs to watch for at home, what to do to help recover, how to resume normal activities, when to return to work, and not being “told things patient should have been told”) (p. 258). And study findings were similar to the following concerns reported in the study by Bruster and colleagues: patients expressed that they did not receive information about their daily routines, their condition or
treatment; patients experienced concerns about pain management; and once having left the hospital, patients said they did not know “how they should continue with their lives when they reach home” (p. 1545). Moreover, Charles and colleagues had also found that patients were concerned about the lack of communication regarding hospital routines, discharge planning, medication side effects and test results, and pain management, as well as the lack of relationship between staff and patients and their families.

Study findings also suggest that there has been little change to overall inpatient care experiences since Coulter and Cleary summarized in 2001 the concerns raised in surveys of patients across five countries, namely: problems with continuity and transition (regarding medications and side effects, danger signals to watch for at home, resumption of normal activities); failure to involve family and friends in care; and lack of each of emotional support, information and education, and respect for patients’ preferences. It appears that patients’ broad concerns about communication, emotional support, discharge preparation and continuity of care, education about medication in ways that patients understand, physical comfort, and responsiveness to patients’ individual needs and preferences continues to be expressed by patients today. Additionally, these same concerns are also being reported in unsolicited online reviews by patients today in the UK and the USA. An extensive literature review of all published studies that contained patients’ feedback about their hospital care was conducted and those studies are now reviewed.

**How do patients’ comments about one Ontario hospital collected in mailed standardized surveys compare to unsolicited online reviews about hospitals in the NHS in England?**

In a mixed methods study, part of which conducted qualitative analysis of a random sample of 200 online patient reviews from 20 hospitals posted onto the government website, NHS Choices, Lagu and colleagues (2013) identified five major themes. The following comment examples were coded under the theme “technical care”: “…ended up with total renal failure and had to be transferred elsewhere for life-saving treatment” and “Due to the lack of correct treatment I have been left with an unusable wrist/hand”. Coded under the theme “facility” were: “…tidy and cleaning was carried out on a regular basis” and “…there is a notice asking people to clean their hands…but I counted seven gel holders without gel…” Coded under the theme “wait time” were: “…they forgot about me because nobody came to speak with me. I was invisible maybe for them” and “The clinic was running late (two hours in the end)”. Coded under the theme
“clinicians and staff” were: “…extremely courteous, polite and helpful”, “I was talked over, heard other patients in other bays referred to in extremely derogatory ways by the nursing and ancillary staff”, “…good and not so good members of staff, this department did appear to have an overrepresentation of the latter”, “…gave me my prescription medicine explained how I should take the meds very clearly and it felt like they genuinely cared”, and “Not enough information about what will happen after the operation and no explanations given to someone who finds that they have had extra surgery”. Coded under the theme “communication (other)” were: “…issues and concerns…dealt with sympathetically and promptly”, “Trouble is no one listens, no action is taken…”, and “Communication between hospitals could be improved….” (Lagu, Goff, Hannon, Shatz, & Lindenauer, 2013).

Upon reading these examples of patients’ comments analyzed by Lagu and colleagues (2013), it is apparent that there is similarity between the content of comments posted on the NHS Choices website and those submitted by mail to the open-ended survey question that formed the data source for this current study. However, there were differences in how comments were coded. Comments from patients about cleanliness and hand hygiene, as well as overhearing how staff talked about other patients, may alternately stem from patients’ feeling safe, secure, comfortable and cared for, and may indicate patients’ trust and confidence in staff and their impressions about interactions and communication. Further, comments about being forgotten, disappointment for long waits, courtesy and politeness, and no one listening, may alternately be interpreted as patients’ expressions of wanting to feel like persons who are valued. Additionally, comments about adequacy of information after surgery and clear explanations about medications, may be alternately interpreted as patients’ expressions about feeling prepared to return to living life for things anticipated, through interactions that were made easy. The coding between Lagu and colleagues (2013) and the coding in the current study appears to be differentiated by the attention paid to the labeled or implicit emotions expressed in comments. Further, the current study analyzed 1,638 patient comments, ceasing to code when theoretical sufficiency was reached, and the larger sample may have allowed for deeper analysis of the meaning within the content of patients’ comments.

Similar content in patients’ comments but a difference in coding between the current study and another study is further seen in the investigation by Greaves and colleagues (2014). They set out to determine if patient commentaries captured in the social networking service, Twitter,
contained information about the quality of hospital care. As part of their mixed methods study, the researchers randomly selected 1,000 tweets for directed qualitative content analysis into the three dimensions of quality care used by the NHS, namely patient experience, effectiveness and safety. They found six themes, one of which was “quality”, and the remaining five related to the use of public platforms (fundraising, advertising, seeking/giving health information, organizational information, and messages of support).

Example tweets within the “quality” theme (Greaves, et al., 2014) were similar in content to some of the patients’ comments analyzed for the current study. “Patient experience” tweets were divided into “staff interaction”, “environment/facilities” and “timeliness/access”, including these examples: “…being cared for by such an amazing team…”, “…department is absolutely filthy it makes the hospital visit even more unpleasant” and “…waiting time is ridiculous…” Additional examples about parking, food and cleanliness of facilities were also provided. “Effectiveness” tweets contained content about whether diagnoses were made or treatments were successful and examples included: “…I’m a nurse and would never treat my patients like that…”, “…will ensure transition to home is effective. Makes me very happy!”, and “…Nurse had no respect for me, didn’t speak to me & I’m discharged home with the same thing i came in with!!” “Safety” tweets were all negative and less common than tweets grouped under patient experience or effectiveness, and usually reported perceived medical errors. Examples included: “…needs more training on drugs before serious mistake…”, “…Main concern now is the doctor overprescribing…”, and “…looking at a scan from 2010 when u didn’t get scanned until 2011 not good, wrong person, terrible, disgusting”.

A closer look at the content of the tweets (Greaves, et al., 2014) may suggest that being cared for, being in clean spaces, receiving care from trained staff, and matching test results to the correct patient, may alternately be expressions by patients about feeling safe and secure, through caring interactions, the comfort of clean spaces, and the competence of staff that inspire trust. The tweets about the treatment of the patient who is trained as a nurse and the disrespect reported by another patient may alternately be expressions of not feeling like persons or valued as equal to staff. And, the tweet about elation to have an effective transition home planned, may alternately be an expression about the patient feeling prepared to return to living life. Again, the differences in coding appear to stem from the extent to which labeled or implicit emotions were incorporated into analysis.
While the current study found that patients’ emotions were ever-present in the content of comments and analysis was conducted accordingly, the content analysis of both the Lagu-led study (2013) and the Greaves-led study (2014) appeared to not code the emotions that were embedded into virtually every comment or tweet. Furthermore, findings from the current study were coded without using any a priori quality dimension categories, which allowed for open coding to interpret the meaning that patients may have been attempting to convey.

How do patients’ comments about one Ontario hospital collected in mailed standardized surveys compare to unsolicited online reviews about hospitals in the USA?

In the USA, where the national standardized patient survey contains no comment section (U.S. Department of Health & Human Services, 2016), researchers who see value in patients’ narratives have begun to analyze the unsolicited online postings volunteered by patients and others on social media sites, such as Yelp and Twitter. Three publications have examined online comments about hospital-base care (Bardach, et al., 2015; Hawkins, et al., 2015; Ranard, et al., 2016) and findings in the current study will be discussed in relation to each of these articles.

Hawkins and colleagues (2015) used computer software processing to analyze the sentiment of 34,725 social media posts captured on Twitter that were identified as being about the hospital experiences in 1,726 hospitals across the USA. Patients’ tweets, in decreasing order of counts, were organized into the following ten categories: general satisfaction/dissatisfaction, time management, money concerns, communication with staff, room condition, pain management, food, medication instructions, treatment side effects, and discharge instructions. For each category, an example tweet was provided in the article. There are similarities between some of the tweets (Hawkins, et al., 2015) and the written comments analyzed in the current study, except that tweets were pithy. Given that a tweet allows up to 140 characters of text, pithiness may be expected.

However, again, what was dissimilar was the coding of content. Here are example tweets from Hawkins, et al. (2015) to illustrate differences. The tweet "I’m thankful...treated as a person, not just a patient" was classified as “general satisfaction with procedure and/or staff”, when it may be an example of the importance of feeling like a person while in hospital. And, "waiting 3.5h...a little much" was analyzed to be about “communication with staff”, when it may be an example about feeling valued as a person, or feeling safe and cared for. Similarly, the tweets "[hospital] gave my mom a prescription for discontinued medications. #Silly hospital" and "hold off on
the collection...until my bill is actually due...keep it classy” were analyzed respectively as “medication instructions” and “money concerns”, when they may both be examples of patients feeling safe through interactions and hospital processes that inspired trust and confidence. Further, the truncated tweet "...epic fail on my TKA discharge" was analyzed to be about “discharge instructions”, when the entire tweet could possibly hold meaning about feeling prepared to return to living life.

The recognition of human emotions and patients’ emotional experiences related to interactions with the hospital staff make a significant difference in content analysis of patients’ comments. For example, again from Hawkins et al. (2015), “…12 hrs...not good...just now getting a room”, “...blood clott found...will this affect my heart??”, and “sucks!...nurses in the back having coffee while there is a sick child in pain in empty ER” may be about more than just “time management”, “treatment side effects” and “pain management”; they may be expressions of human emotion and reactions to not feeling safe, secure, comfortable and cared for while in hospital due to inadequate communication and interactions that did not include patients or make things easy for them.

In a more recent study, Ranard and colleagues (2016) used fully computer-automated natural language processing to analyze 16,862 Yelp reviews collected about 1,352 hospitals in the USA and found topic correlation to the HCAHPS domains as well as 12 new domain topics not covered by the HCAHPS domains. The new topics generated by computer related to finances (cost of hospital visit, insurance and billing), ancillary testing, hospital environment and processes (facilities, amenities, scheduling), quality (of nursing, of staff, of technical aspects of care), specific type of medical care, and compassion of staff (Ranard, et al., 2016). The topic domain of compassion, potentially encompasses more of the emotional aspects of patients’ experiences that were consistently and heartily represented within the comments analyzed in the current study. Specifically, an example comment was provided for each of staff being comforting, caring, wonderful and friendly (Ranard, et al., 2016, Appendix Exhibit A2, p. 2). The research team identified topic gaps in the HCAHPS survey and concluded that Yelp reviews can supplement data from the HCAHPS surveys (Ranard, et al., 2016). The study was publicized in the Washington Post daily newspaper (Cha, 2016) and the following day, the Yelp website posted a blog with the headline “Study finds Yelp reviews more helpful than government data” (Walker, 2016). However, despite the claim that Yelp reviews of hospitals can “provide
actionable feedback for hospitals” (Ranard, et al., 2016, p. 697), and the publicity that the study has garnered, clear recommendations for what to look for in an online review that can direct quality improvements were not provided. Again, what appears to be missing in analysis that may help to direct actionable improvements was coding of emotion that was labeled or implicit in every example presented in the article’s appendix.

What computer-based analysis can perform, specifically, to process large amounts of data in a short amount of time, is tempered by the results that computer analysis cannot supply and only human analysis can achieve. Human analysis of patients’ online comments has been performed and the difference in depth of analysis between computers and humans may be gleaned from considering the interpretations. Bardach and colleagues (2015) reviewed 244 comments about hospitals in the USA that were publicly posted via social media Yelp.com, plus.Google.com and local.Yahoo.com, looking at the two most recent comments posted for each of 193 hospitals that received comments. Interestingly, over 38% of postings were put forward by family or friends. The researchers’ objective was to compare the content of the online postings to the standardized HCAHPS domains and assess whether there was congruence. Their thematic analysis revealed that while 57% of online reviews mentioned content that may be captured in one of the eight HCAHPS domains, over 51% of the reviews contained new content. The additional content was categorized as financing (11.5%), system-centred care (rather than patient-centered care) (7.8%), and perceptions of safety (41%). Safety was sub-categorized into trust in providers, unsafe practices or outcomes, and observations of missed or incorrect care. Further, comments about pain control, communication about medications, and discharge instructions – which compose three of the eight HCAPHPS domains – were present in only less than 10% of the online reviews.

The posts selected for publication (Bardach, et al., 2015) were again similar in content to the comments analyzed in the current study. Consistent with findings in the current study were references by Bardach and colleagues to “poor communication”, “inflexibility in system policies”, “disempowering” experiences, and staff actions that conveyed “a message to patients that their time is less important than the overall functioning of the system” and that a patient’s needs are “secondary to the system needs” (p.4). There was closeness in the coding of posts such as, “...I felt like the most important person there. No waiting...” into the theme “system-centred care” (Bardach, et al., 2015) and the current study’s category of “feeling like a person”. Both reflected similar patient-reported content, however, findings in the current study were phrased in
the perspectives of patients. The theme of “financing” (Bardach, et al., 2015), a considerable issue in the USA where most patients pay for their healthcare, was similar to the “money concerns” category found by computer analysis of tweets by the Hawkins-led study (2015). However, human analysis also captured the emotional aspect in patients’ hospital experiences within the theme of “financing”, such that “confusion”, “stress” of the “unexpected”, and “a call for greater price transparency” “from a desire to avoid unplanned costs” (Bardach, et al., 2015, p. 4) were revealed.

Not consistent with findings in the current study was that Bardach and colleagues (2015) suggested that pain control, communication about medicines and discharge may not be as important to patients as assumed. Alternatively, perhaps analysis of only 244 reviews, with only 50% identified as being posted by patients themselves, may explain why these topics that are largely directly experienced by patients rather than by family and friends, were less frequently found online. It may be reasonable to expect that patients themselves might be more concerned about pain control, specific medication instructions, and discharge instructions than those not experiencing direct care. Findings from the current study, which reports only patients’ comments, certainly did identify many concerns from patients about inadequately receiving information and planning related to medication and return to living life. This illustration may be a practical example of the advantage of representative sampling achieved through the formal administration of a mailed standardized survey rather than extracting available data from voluntary online posts. Voluntary responses may lead to inaccurate frequency representations (Patwardhan & Spencer, 2012).

Table 3 summarizes the published studies that report narratives by patients about their inpatient care experiences. Articles are listed in chronological order of publication.
Table 3. Comparison of studies that report the verbatim comments of patients about inpatient care

<table>
<thead>
<tr>
<th>Authors</th>
<th>Country: hospital inclusion</th>
<th>Data source</th>
<th>Data</th>
<th>Data analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Lagu, Goff, Hannon, Shatz, &amp; Lindenauer, 2013)</td>
<td>England: 20 hospitals randomly selected from all hospitals registered on the government agency website, NHS Choices, as of August 25, 2010 and that received at least 10 online reviews.</td>
<td>Publically accessible information from NHS Choices: Patients’ responses to five rating-scale questions and to an open-ended narrative feedback response section that contained three prompts.</td>
<td>2,640 online responses to quantitative questions and 200 online narrative reviews.</td>
<td>Mixed methods: 1) Directed qualitative content analysis of the open-ended narrative feedback, using a previously developed a priori codebook; and 2) frequency of select codes and themes.</td>
</tr>
<tr>
<td>(Greaves, et al., 2014)</td>
<td>England: 75 acute trusts (hospital organizations) that were on Twitter, as identified in April 2012.</td>
<td>Publically accessible tweets, prospectively collected over a 365-day period between April 17, 2012 and June 26, 2013.</td>
<td>198,499 tweets directed at the included trusts.</td>
<td>Mixed methods: 1) Directed qualitative content analysis of 1,000 random tweets into quality components of patient experience, effectiveness and safety; and 2) quantitative analysis of all 198,499 tweets (i) using simple descriptive analysis to measure volume and frequency and (ii) using automated sentiment analysis by commercially available software, TheySay Ltd., to calculate the average sentiment of tweets per trust and in order to compare the sentiment score with that hospital’s average overall rating of experience question from the 2012 national inpatient survey.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Number of Hospitals</td>
<td>Number of Online Reviews</td>
<td>Tweets Included</td>
</tr>
<tr>
<td>-------------------------------</td>
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<td>-----------------</td>
</tr>
<tr>
<td>(Hawkins, et al., 2015)</td>
<td>USA</td>
<td>2,136</td>
<td>34,725</td>
<td>9.4%</td>
</tr>
<tr>
<td>(Bardach, et al., 2015)</td>
<td>USA</td>
<td>193</td>
<td>244</td>
<td>122</td>
</tr>
<tr>
<td>(Ranard, et al., 2016)</td>
<td>USA</td>
<td>1,352</td>
<td>16,862</td>
<td></td>
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</tbody>
</table>
In summary of the comparison between findings from the current study and findings from other research that has analyzed the content of what patients have reported, several remarks are made. First, across countries and over recent decades, there is similarity in what is reported by patients about their hospitalization experiences. Next, multiple methods have been employed to gain a better understanding about the perspectives of patients. The method of analysis of patients’ comments, whether by human or computer, serves different purposes. To analyze a large amount of information, computer analysis is logical. Recognizing that automated and machine based sentiment analysis “does not perform as well as human curation” (Hawkins, et al., 2015, p. 8), human resources are required to get at a deeper analysis of the richness and potential meanings of patients’ comments. Further, regardless of how content is categorized, studies that investigate the perspectives of patients all contribute to advancing and deepening knowledge about what is important to patients.

Lastly, findings from the current study were identified without beginning with a priori quality dimension codes, and the open content analysis seems to have better allowed for patients’ emotions to be coded. The result was that there are some additional insights that this study contributes to what is currently known about patients’ hospital stay experiences. Specifically, Chapters 5.3 and 5.4 review some new insights about the hospital experience as an emotional experience in which a single moment of significant interaction could impact a patient’s perception of their relationship with a staff member, and the resulting overall perception of dignity and respect being experienced at the hospital.

5.3 Hospital Experience, Human Experience, Emotional Experience

Being in the hospital was, in the words of a patient, a “very emotional time”. Patients’ comments revealed a range of emotions. In their writings, patients specifically named their feelings or implied them, often connecting their feelings to a statement of fact or an event. Feeling is defined in the Oxford dictionary in four ways: (1) An emotional state or reaction; (2) An idea or belief, especially a vague or irrational one; (3) The capacity to experience the sense of touch; and (4) A sensitivity to or intuitive of (Oxford Dictionaries, n.d.). For the purposes of understanding how patients wrote about their hospital stay, the definitions of emotional states, ideas or beliefs, and a sensitivity or intuitive understanding are all helpful.
That people link feelings to events is well-documented in the literature. Kensinger (2009) reviewed research dating back to 1977 about the strength and permanence of emotional memories, or memories that link an event with an emotional response at the time it happened. There is extensive evidence that an event is more likely to be remembered when it arouses emotion, and that while a positively experienced event is recalled as having occurred, it is the negatively experienced event that is remembered with more accurate details (Kensinger, 2009). Within patients’ survey comments, there were indeed more details written in the ones with largely negative sentiment.

Within patients’ comments, emotions were attached to patients’ descriptions about the relational aspects of their care experiences. This too has been reported in the literature. For over a decade, the NHS has used the Experience Based Design (EBD) approach to (re)design healthcare based on the experiences of patients (NHS, 2013). Specifically, patients’ emotions are mapped along the care pathway to pinpoint areas for quality improvement. The tools and techniques in the EBD process actively engages patients to tell the stories of their care experiences, to identify the “touchpoints” along the pathway of care that most influenced their experience, and to map their emotions to the touchpoints (Health Quality Ontario, 2013; NHS, 2013). In essence, by capturing patients’ high and low emotions, attention is directed to understanding which touchpoints require improvement. The NHS has used EBD as part of improving patients’ experiences for over a decade (NHS, 2013). Recognizing that the NHS now builds EBD into all its services and programs, Health Quality Ontario encourages the use of EBD to capture patients’ voices and target the crucial parts of care most important to patients when engaging in quality improvement initiatives (Health Quality Ontario, 2013). In this way, the “relational aspects of care which impact thoughts, feeling and experiences” become the focus over “simple patient satisfaction measurement” (Health Quality Ontario, 2013, p. 7). A focus on patients’ emotions is therefore critical to decision-making in quality improvement initiatives.

Across the categories of comments about feeling safe, secure, comfortable and cared for; feeling like a person; and feeling prepared to return to living life, there was a cross-cutting theme of patients’ perceived relationships with staff. Each category, particularly in relation to perceived relationships, is now discussed.
About Feeling Safe, Secure, Comfortable and Cared For

The current study found that patients wrote about feelings of safety and security that were impacted by their perceptions of comfort, of interactions and communication, and of inspired trust and confidence. Safe patient care, a dimension of quality healthcare (Health Quality Ontario, 2015a; Institute of Medicine, 2001a; NHS, 2008), has been heavily studied and there are numerous publications on the topic. Therefore, it is useful to begin the discussion about the current study’s findings in relation to the literature on safety. However, the concept of patients feeling safe has been relatively less studied. What is known has been reviewed by Mollon (2013). Identifying 31 articles that referenced feeling safe, Mollon conducted a concept analysis and found four main characteristics that were consistently expressed by healthcare providers or by patients themselves: trust, cared for, presence, and knowledge. Similarly, findings from the current study suggest that feeling safe, secure, comfortable and care for are all linked. Findings are consistent with Mollon’s findings in that the competent actions of staff and the attitudes of staff that signaled full presence impacted patients to feel cared for and also inspired their trust and confidence.

The link between patients’ trust and confidence in providers and their feeling safe has been seen in patients’ verbatim online comments reported in other studies, such as: “I felt really safe and confident in his care” (Kilaru, et al., 2016, p. 17), although the comment was coded into the HCAHPS survey domain of “communication with doctors”. Coding makes a difference to allow the aspect of feeling safe within perceived relationships to become apparent. When Bardach and colleagues (2015) identified a theme of “perceptions of safety”, from their analysis of patients’, family and friends’ online reviews of hospitals, they provided examples of comments about family having to advocate for a patient and to convince staff to act (sub-themed “trust in specific providers”), observations of staff not following sanitary procedures (sub-themed as “unsafe practices or outcomes”), and a family member receiving a meal tray six times despite her fasting for a test (sub-themed “observations of missed or incorrect care”) (p.5). These findings were consistent with the current study’s findings that patients’ sense of safety and security were impacted by trust in care providers, staff competencies and attitudes, and organizational processes. Small things, such as a nurse wearing perfume, could impact trust and confidence such that a patient would not use the call bell while that staff was responsible to care for the patient.

Communication was also found to be strongly linked to patients’ perceptions of safety, as suggested in what patients wrote. The association between perceptions of safety and
communication has been studied by Burroughs and colleagues (2007) who conducted telephone interviews with patients seven to ten days post-hospitalization. They found that patients defined medical errors to include ineffective communication by staff, lack of listening by staff, and lack of attentiveness or responsiveness by staff. While patients often could not specify details about medical errors, they described situations that “didn’t feel right”, including when a nurse did not “appear confident” (p. 9) in their performance. Further, when Solberg and colleagues (2008) examined patients’ reports about medical errors in surveys and compared them to patient records, staff behaviours and communication were identified among patients’ safety concerns. Further, waiting times, staff rudeness, inadequate explanations, not appearing competent during tasks such as drawing blood, and the belief that pain was inadequately addressed were all considered safety concerns to patients (Solberg, et al., 2008).

Communication has been discussed to compose a large component of how well patients feel able to participate in preventing safety errors (Sahlström, Partanen, & Turunen, 2014). Also, there is evidence that when patients take part in their hospital care, such as seeking information and being involved in decisions, fewer adverse events occur (Weingart, et al., 2011). However, patient factors (including health literacy level, socioeconomic level, age, and seeing participation as a patient role) and healthcare worker factors (including the desire to maintain control over patients, unwillingness to share decision-making power, lack of training about patient participation, time required to education patients, and personal beliefs) have been reviewed to present obstacles to patient participation in safety (Longtin, et al., 2010). Further, in another study, patients who had experienced safety problems were interviewed and they said that their inclination and ability to speak up about safety events was fundamentally determined by the quality of relationships forged by how healthcare providers behaved with and responded to them; even patients who were healthcare professionals themselves and “quite able to recognise potential problems” were “sometimes led to doubt their grounds for concern” (Entwistle, et al., 2010, p. 4). Despite serious concerns about their safety, many patients do not ask staff about or disclose safety-related events in hospital (Schwappach, 2008). The current study also found a link between patients’ feeling safe and patients’ perceptions of trust, confidence, communication and interactions. That is, the perception of relationships between staff and patients had effects on patients feeling safe and taking part in their own care. There were also instances in which patients wrote about feeling unsafe or witnessing unsafe events, but did not speak up during hospitalization.
Further exploration about what patient safety means to patients and how it impacts patients’ hospitalization experiences is warranted.

Comfort

Feeling safe, secure, comfortable and cared for was described to be facilitated when patients experienced access to comforts that were well-known and familiar. These comforts were present in different ways. Physical comforts, such as pillows and hot water, helped patients to feel more comfortable. Emotional supports, such as supportive and caring gestures, were perceived as comforting. And, being able to participate in routines, such as engaging in self-care activities, eating familiar foods, and experiencing dimmed light and lowered voices, contribute to patients’ healing and recovery. Findings in the current study suggest the importance of familiar comforts to help patients feel safe and secure while hospitalized. The literature related to physical comfort, emotional supports and routines are now discussed.

Access to physical comforts has been reported to be significant in helping patients to feel a sense of personal control and emotional comfort while in hospital (Lauck, 2009). Patient interviews and observations have revealed three conditions that augment hospitalized patients’ feelings of control and emotional comfort: access to staff when help was needed, so that they felt secure; access to information, so that they had knowledge about what to expect; and access to environments that felt like home (including furniture, food, TV), so that they felt a level of personal value or personhood (Lauck, 2009). Findings from the current study are consistent with these findings. When considering that patients may be emotionally comforted through access to physical comforts, there may be a practical implication to direct more attention to ensuring patients have familiar things readily accessible to them. Having a pillow, a phone, or a facecloth, all things that patients wrote about in the survey, may provide emotional comfort as well as boost a person’s sense of self and value. Perhaps then, a comment about missing the pressure of a salt shaker, a statement that if read on its own may be wholly dismissed, actually provides insight into how familiar physical comforts can help patients to feel safe, secure, comfortable and cared for while they are in hospital.

The physical comfort of pain control was noted in patients’ comments. Historically, pain control has been repeatedly reported to be of concern to patients (Bruster, et al., 1994; Charles, et al., 1994; Cleary, et al., 1991; Coulter & Cleary, 2001). Findings from the current study suggest that
the perceived relationship between a patient and staff made a difference between a patient expressing feeling “hopeful” or “in agony” about pain control. In another study that surveyed patients about their experiences of pain control, higher ratings of overall satisfaction were provided by patients when they perceived that doctors and nurses were courteous and respectful, and that staff did everything possible to control pain; these factors were more predictive of higher satisfaction ratings than when pain was actually always controlled (Hanna, González-Fernández, Barrett, Williams, & Pronovost, 2012). The experiences of physical comfort and emotional support appear to be highly associated.

Emotional support has been a long-time priority to improve patient experiences, and an Ontario-based study by Adamson and colleagues (2012) endorsed it to be the factor that is most highly correlated with global ratings in patient surveys. In the study, patients in hospital were interviewed about which behaviours by healthcare providers conveyed emotional support. Responses indicated that emotional support occurred for a patient when staff adapted their actions and verbal communication to the illness needs and surrounding environment of the patient. Specifically, eight strategies employed by staff were experienced to convey emotional support: empathy, informative communication, being present and available, inspiration and hope, personalization, supportive gestures, humour, and an ambient (friendly) environment (Adamson, et al., 2012). Each of these strategies are essentially ways in which staff build relationships with patients. Consistent with findings in the current study, these strategies were all found in the content of patients’ survey comments.

In addition to physical comfort and emotional support, patients also wrote about being able to take part in routine activities, such as showering or face-washing. They also wrote about being able to take part in their typical meal and sleep routines, and that comfort was increased when staff checked that meals were delivered as ordered or when lights were dimmed at night. When analyzed together, the numerous comments written about daily activities revealed the importance of continued engagement in known and familiar routines despite hospitalization, and suggested that routines may be linked to patients’ feelings of safety and security. There is extensive literature from occupational therapy research and theory, some of which have been reviewed by Townsend and Polatajko (2007), that connects the importance of people being able to take part and engage in doing the things that are meaningful to them. Findings from the current study may encourage care providers to help patients in hospital to maintain or re-engage in occupying their
time, minds and actions with the routines that bring structure to their lives. Given that patients noted that hospitalization was a difficult and emotional time, there may be merit in further exploring how current ideas of patient-centered care may be extended by supporting patients to take part in known and familiar routines may promote their health and well-being.

Interact and Communicate

Most prevalent in comments were observations and perceptions about interactions and communication with staff that either promoted or diminished patients’ feelings of safety, security, comfort and sense of being cared for while in hospital. Patients’ perceptions about interactions and communication were impacted by a patient’s state of mind and body, the organizational environment and its processes, staff competencies, staff attitudes, and teamwork.

There is extensive literature about communication and interactions in healthcare. Interpersonal interactions that support a patient’s sense of personal control has been found to be a key component of hospitalized patients’ feelings of emotional comfort (Williams & Irurita, 2006), which aligns with the current study’s categorization of interactions and emotional comfort as part of feeling safe. Further, higher overall ratings about care have been found to be provided by patients when healthcare providers are perceived to use active listening skills and patient-centred communication (Wanzer & Booth-Butterfield, 2004), and when medication information is communicated between providers (Péyfoyo & Wodchis, 2013).

Effective communication for diverse populations has been identified to consist of the use of clear, simple and sensitive language that is humanizing and inclusive (McAlister, VanderBent, & MacLeod, 2015). Findings from the current study echo multiple examples in the literature that demonstrate how staff’s active listening and consistent teamwork lead patients to perceive quality interactions and communication with staff (Merlino & Raman, 2013; Pinto, et al., 2012; Platt, et al., 2001; Politi, Dizon, Frosch, Kuzemchak, & Stiggelbout, 2013; Weber & Swendiman, 2014), which in turn helps patients to feel safe and secure. With all that is known about the importance of communication between care providers and patients, those who truly are committed to improving healthcare quality are encouraged to consistently use the guidelines that are already published (Biddy, et al., 2015; RNAO, 2015). The experiences of patients described in the current study’s findings may provide reasons for why it is important to patients that care providers do so.
Comments about teamwork were abundant. Many patients wrote about their perceptions of team, and how they thought the team purposefully worked together. Team was understood by patients to be more than the immediate care team. Patients expected that departments within the hospital were working together. Strong emotions were attached to comments about care not being coordinated or organized, and when communication was lacking between teams. Findings in the current study suggest that relationships between the patient and staff, and also between staff, were important to patients.

Patients wrote about communication and interactions when they noted teamwork between care providers working within and across professions. The importance of communication in teamwork is found in the literature, and a framework for team collaboration is found in the National Interprofessional Competency Framework (Canadian Interprofessional Health Collaborative, 2010). The framework focuses on the practice competencies of healthcare providers to integrate the knowledge, skills, attitudes and values of working together and collaborating as a team. Two competency domains in the framework, interprofessional communication and patient/client/family/community-centered care, influences and supports all other domains of interprofessional collaboration and are relevant in all practice situations.

Other authors have offered protocols for the complex implementation of patient-centred care as part of interprofessional work, so that all members of the team provide holistic, collaborative, and responsive care (Sidani & Fox, 2014). Findings from the current study suggest that patients notice when communication among team members works well or breaks down, when care considers the whole person and is responsive to individual needs, and when the patient is included in care planning. Interestingly, the two complex constructs of interprofessional collaboration and patient-centered care may have strongly embedded social, political, and economic dynamics that influence power relations between professionals and patients (Fox & Reeves, 2015). Patients did write about feeling a part of making care decisions, or in other words, how they felt a part of their team. And, findings suggest that power, authority and professional hierarchies may indeed have been experienced by patients who wrote about how they felt included in care, how staff talked to them, and how staff were observed to interact with each other or with other patients. The interplay between interprofessional collaboration and patient-centered care, from patients’ perspectives, is worth future study.
Inspire Trust and Confidence

Findings from this study suggest that inspired trust and confidence are essential to helping patients to feel safe and secure while in hospital. Furthermore, the actions and responses of staff that were observed or directly experienced by patients could inspire or dampen those feelings. Timely responses to requests for assistance, attentiveness, reassurance, caring behaviours, competence and knowledge, and a willingness to help were examples of how trust and confidence were inspired. Arguing in front of patients, not promptly responding to patients needs, not performing hand hygiene, repeatedly exchanging inaccurate information, and speaking aloud comments that were inappropriate or not meant for patients to overhear, were examples of how trust and confidence were diminished.

A search of the literature about trust and confidence yielded commentaries and research about patients’ perspectives regarding doctors. In 1997, Thom and Campbell engaged 29 patients in focus groups and identified nine categories of physician behaviours that promoted the trust experience for patients. Five categories were of interpersonal behaviours toward the patient (understanding the individual patient’s experience; building partnership and power-sharing; expressions of caring, communicating clearly and completely; and demonstrating honesty and respect) and two categories were of technical competence (thoroughly evaluating problems, and providing appropriate and effective treatment). Organizational structures and staffing, and predisposing factors about the doctor, also impacted trust experiences (Thom & Campbell, 1997).

Trust between patients and doctors has been theorized to be central to the therapeutic relationship, but it has not been often studied (Croker, et al., 2013). From secondary analysis of numerical survey data, patients have been found to more highly rated their trust and confidence in doctors when patients had a sense of being taken seriously and being involved in care decisions (Croker, et al., 2013). Further, patients who report trusting and good interpersonal relationships with their primary care doctor have been found to more likely remain seeing and to recommend their doctor (Platonova, Kennedy, & Shewchuk, 2008).

The majority of the many theories about patients’ trust in doctors emphasize the behaviours and interpersonal skills of physicians (Pearson & Raeke, 2000), which may also be applicable to other staff who interact with patients. Findings in this current study are consistent with those found in the research about doctors by Thom and Campbell (1997), and further suggest that any
staff representing the hospital may make an impression on a patient’s trust and confidence, such as in the courtesy of office administrative staff or attentiveness of staff delivering a meal tray. Other staff behaviours and interpersonal skills that were reported in the current study’s findings that align with the literature included demonstrating concern for patients’ comfort, expressing compassion and empathy, providing reassurance, instilling hope, demonstrating active listening, answering questions, using a sensitive approach, acting with a calm and relaxed manner, treating patients as equal human beings, honouring commitments, thoroughly reviewing a patient’s history, putting forth best efforts, responding to patients’ needs, taking into account family perspectives, treating patients as unique individuals, considering the ‘whole person’, and being respectful.

The Cleveland Clinic is an example of one healthcare organization that has embraced the notion that the behaviours and interpersonal skills of any and all staff can impact patients’ experiences. After every staff member at the Cleveland Clinic took part in education about how to deliver a new model of care that emphasized communication and collaboration between staff and patients, patients’ experience ratings improved by almost 40% in four years (Merlino & Raman, 2013). All staff were asked to deeply understand the needs of patients and to collectively change behaviours, toward a mutual goal of ensuring that patients have positive experiences. The fundamental change rested in shifting the mindset of every representative of the organization, from doctors to administrators to janitors, to all see themselves as “caregivers” (Merlino & Raman, 2013).

**About Feeling Like a Person**

Patients are people. While in hospital, comments suggested that patients wanted to feel like they are people. Patients wrote about feeling like they were part of a production line or anonymous, and asserted that being treated solely as a patient was impersonal. Patients used words such as “statistic”, “case” and “number” to describe how they felt. Other studies have reported the words of patients, including feeling “invisible” (Lagu, Goff, Hannon, Shatz, & Lindenauer, 2013, p. 11) and being treated as “less than human”, “an object” and “like a slab of meat” (Rowland, McMillan, McGillicuddy, & Richards, 2016, p. 9). Findings from the current study support the use of language that acknowledges the “person first” in patient interactions. “Person first” language is endorsed for how to talk about people with disabilities (National Center on Birth Defects and Developmental Disabilities, n.d.), people with dementia (Alzheimer Society, 2011),
and people with cancer (Biddy, et al., 2015). While in hospital, “person first” language could be a step towards helping patients feel like persons.

I am a Person

Study findings support the use of practice guidelines, such as the Cancer Care Ontario person-centred care guideline, which asks care providers to develop an understanding about the patient as an individual, without making assumptions, and considering the values, lived experience and needs of the person (Biddy, et al., 2015). Patients wrote about the things that staff did to help them feel like persons, such as when staff introduced themselves, took time to explain information, reassured patients who were scared, validated patients, provided their full attention, demonstrated warmth and kindness, behaved politely and with courtesy, and acted as a resource. Patients also wrote about things not as helpful, such as being rushed or judged, and not having information about who was caring for them and for what reason. These reported experiences align with the person- and family-centred care best practice guideline published by the Registered Nurses Association of Ontario (2015) that recommend verbal and non-verbal communication strategies to help build “genuine, trusting, and respectful partnership(s)” (p. 23) with patients. Study findings encourage the implementation of existing practice guidelines and they provide insight into the reasons why following the practice guidelines could be important to patients.

I am as Valuable as You

Leaders in patient-centered care have asked healthcare providers to recognize the values of patients, as part of honouring the individuality of each patient (Gertais, Edgman-Levitan, Daley, & Delbanco, 1993; Institute for Patient-and Family-Centered Care, n.d.). This study’s findings support that request and further suggest that helping patients to feel as valuable as hospital staff is also important to patients. Comments about showing up to a cancelled appointment that was not communicated and being awoken by loud voices during typical sleeping hours were more obvious examples of patients’ expressions of not feeling as valuable as staff. However, the implicit emotions within statements about being walked to the washroom without shoes and then returned to bed with dirty feet, or about finding a sweater on the floor after not receiving a personal belongings bag, conjure up images about the ways in which patients are made to feel valued as equal human beings, or not. Recommendations to use humane actions, such as being
polite when asking patients to vacate a shared space, also indicate that patients wanted to feel like persons of value and worth while in hospital.

Considering previous studies, it is possible to identify the idea of patients not feeling as valuable as staff. For example, findings from a telephone survey summarized that patients’ needs and preferences were not met: 19.9% of patients reported staff did not go out of their way to meet their needs, 16.3% reported a doctor or nurse talked in from of them as if they were not present, 11.4% thought something was not done that should been done, 9.9% thought staff put their own needs first, and 9.7% thought something was done to them that should not have happened (Cleary, et al., 1991). Further, patients’ verbatim comments in other studies suggest the importance of patients feeling valuable. For instance, coded as the “demeanor” of clinicians and staff, a patient reported being “talked over” and “referred to in extremely derogatory ways” by staff (Lagu, Goff, Hannon, Shatz, & Lindenauer, 2013). These studies did not discuss the potential underlying concern that patients did not feel valuable. Findings from the current study extend understandings about patient-centred care by asking care providers to not only consider the values of patients, but to also value people in the role of patients as human beings with equal worth. Not feeling valued while in hospital has been identified to have dehumanizing, objectifying, disempowering and devaluing effects (Coyle & Williams, 2001). Therefore, this finding may warrant further examination to explore the relationship between how valuable patients feel while in hospital and current understandings about patient-centered care.

I am a Part of My Care

Patients wrote about how they were included as part of their own care. They wanted to know how to “cooperate” and they wanted to be included in decisions about the things that concerned them, including food selections, teeth brushing, and treatment program decisions. Clear explanations initiated by staff, check-ins, enough time spent with staff, and staff asking questions of patients contributed to patients feeling a part of care. Staff attitudes also either encouraged patients to be active participants or to “shut down” participation. Some authors have cautioned that shared decision-making is markedly hampered by some care providers’ belief (that is based on assumptions about a patient’s age, education, health literacy skills, values and preferences) that certain patients are unable to or do not want to participate in making decisions about their healthcare (Politi, Dizon, Frosch, Kuzemchak, & Stiggelbout, 2013).
Study findings are widely consistent with recommendations found in the literature, including guidelines (Biddy, et al., 2015; RNAO, 2015), standards (Accreditation Canada, 2016) and statements from patient-centered care organizations (Balik, Conway, Zipperer, & Watson, 2011; Gertais, Edgman-Levitan, Daley, & Delbanco, 1993; Picker Institute, n.d.; Institute for Patient-and Family-Centered Care, n.d.). Some specific strategies have been offered to foster patients’ involvement and engagement in order to improve health literacy, treatment decision-making, and self-management of chronic conditions (Coulter, Parsons, & Askham, 2008). Again, findings offer reasons for why staff should enact published recommendations. Further, some researchers stress the importance of listening to patients, answering questions and providing clear explanations for treatment, and including patients in decision-making because patients who experience effective communication perceive that their care providers know them as persons (Tabler, Scammon, Kim, Farrell, & Tomoaia-Cotisel, 2014).

An illuminating example of the impact of staff actions on a patient’s perceptions and the resulting impact on the patient’s ability to take part in care may be seen in an article written jointly by “Ann”, a patient, and “Robert”, a medical student (Weber & Swendiman, 2014). In their brief article with a powerful message, Ann, who is a narrative psychologist and retired professor, wrote about the ways in which Robert helped her to regain confidence, control and competence in the hospital environment while Robert wrote about his reflections and realizations. The simple actions of Robert having knocked on the door, introduced himself, addressed Ann by name, sat down beside her rather than hover over her, invited her to “talk”, and then listened, all helped Ann to gradually shed the “unnaturally passive” and “good patient” role she was increasingly assuming after having “lay supine, self-conscious, and vulnerable”, feeling “frightened and in pain” (Weber & Swendiman, 2014, p.1005). The impact of a strong and positive perceived relationship by Ann, facilitated by the humaneness of Robert’s behaviours and attitude, are similar to findings from the current study, in that Ann appeared to feel able to tell her personal story, to feel equally valued to Robert, and therefore to be optimally able to take part in her own care.

**About Feeling Prepared to Return to Living Life**

Patients wrote about their “normal life” and wanting to be prepared to “return to” it. While there is a wide range of existing literature related to ‘discharge planning’, findings from the current study highlight that patients were more apt to write about being “at home” and returning home
rather than discharge planning. Further, patients wrote about how well they had been “prepared” for a return to living their everyday lives, describing preparation as including both information and planning. These two findings that patients focus on return to normal life, and that adequate preparation includes information and planning, provide some new insights about what is important to patients and may inform how to better enact what is currently known about patient-centered care.

The concept of discharge planning comes from a care provider perspective: patients must be discharged from the hospital and the plan therefore, is to make that happen. However, findings in the current study suggest that patients desired a different plan. Patients wanted to know what to do at home, what plans were in place to support them at home, how to manage their medications within their home routines, and what connections existed for them to obtain continued care. Patients had questions about being able to take part in rehabilitation programs, what exercises to complete, how to shower, and when they could drive again or return to work. Patients wanted to know how to function again. They did not want to know how to leave the hospital.

With Information and Planning

To feel prepared to return to living life, patients commented about their experiences in two ways: as having received information and as having had planning arranged. When receiving information, patients described wanting it relayed in ways that were clear, consistent, specific, personalized, accessible and easily retrievable when needed. ‘Patient education’ is a highly prevalent topic in healthcare literature, and it is founded on the principles of ‘information sharing’ that are endorsed by patient-centered care leaders (Accreditation Canada, 2016; Institute for Patient-and Family-Centered Care n.d.; Picker Institute, n.d.). Healthcare providers would likely agree that educating patients and sharing information are important to help prepare patients for hospital discharge, however, findings from the current study offer that patients also strongly desired planning in order to feel prepared to return to living their lives.

Planning was described in comments to include the coordination of rehabilitation or home care follow-up, specific agendas that fit into patients’ individual home routines, adaptive equipment put into place, connections to support groups and aftercare, coordinated and personalized care plans determined, and instructions for what to do if something goes wrong. Further, patients wrote about being able to “practice” while in hospital using the information and strategies demonstrated or taught by staff. Practice may also be understood as an important part of planning.
to patients. Sidani and Fox (2014) argue that the implementation of patient-centered care must include collaboration that supports patients to apply treatment options into daily life, in addition to instructions for chosen treatment options.

To feel prepared to return to living their lives, findings suggest that patients wanted both information and planning. This insight may provide new directions for research that improves the experiences of discharge planning for patients. A focus on preparing patients that considers the individual needs and circumstances of patients, the spaces where patients will reside, and the integration of care providers’ recommendations into the routines of patients may lead to ways of helping patients to return to living their lives that is different than the current discharge planning processes that are typically used in hospitals. The topics that patients most often noted wanting more preparation for related to medications, functioning, and services at home. Further investigation into how to best incorporate these topics into discharge planning, to better meet the preparation needs of patients, has the potential to improve patients’ experiences.

**For Things Anticipated and Unanticipated**

Considering that patients wrote descriptions about feeling prepared to return to “normal life”, the current predominant healthcare approaches of discharge planning and patient education/information sharing may be considered provider-centric rather than patient-centric. A provider-centric approach limits preparation to what patients themselves can anticipate, by addressing only the topics that patients raise themselves or that are typical for a patient’s current phase of illness or diagnosis. It does not allow for patients to be also be prepared with what staff could anticipate for individual patients. Some authors emphasize the importance of staff-initiated conversations with patients about the things that would be commonly known by staff because they work with many patients, but might not necessarily be known by patients who are experiencing new concerns for the first time (Hargraves, LeBlanc, Shah, & Montori, 2016). Indeed, in the current study, some patients identified in their comments that it was their “first experience” with a procedure or a diagnosis.

The finding that patients want to be prepared for things that they can anticipate themselves as well as for the things that staff “should have” known to prepare them for is an insight that may hold potential to advance understandings about patient-centered care. A clear example of a provider-centric model of delivering healthcare was highlighted in multiple comments from
different patients about having been well-prepared before a scheduled surgery, with information and plans in place, but not being well-prepared for what to expect at home after surgery. Other examples provided by patients may also be interpreted as provider-centric care, such as information being provided to patients during early morning hours when patients were not fully aware, when family members were not present, or while patients were under the influence of sedation. Further, an example of incongruent priorities was noted by a patient who commented on having received prompt life-saving care but minimal attention to care for wounds caused by spilled hot tea. That comment suggested that the patient viewed care that saves lives and care that treats wounds to be equally important, but perceived that staff responded as if they were not. Greaves and Jha (2014) speculated that there is a “disconnect” between the care that healthcare providers and patients regard as appropriate, and that “when lives are saved, comfort comes second” (p. 525). If accurately speculated, the narrowness of providing healthcare based on the work-flow priorities and assumptions of staff rather than based on the needs and experiences of patients, limits the realization of quality healthcare at its fullest extent. These examples illustrate opportunities for improving quality by truly considering care from the perspectives of patients.

**Because of Lasting Personal Impacts**

When care is not truly patient-centered, patients themselves incur the costs. Findings provide real examples of how inadequate preparation affected patients after they left the hospital. Patients wrote about times when preparation failed to be helpful and created stress. Patients cited the time they spent arranging their own services and the burden they experienced when there were personal circumstances at home (such as living alone or being in the role of a caregiver). Patients also wrote about their increased use of healthcare resources when they had to follow up in the emergency department or with their family doctor. Strong emotions were expressed when patients did not feel properly prepared, particularly with planning, and these findings suggest that improved planning to prepare patients to return to living their lives may be an area of priority because inadequate planning may lead to consequences for patients, their families and the healthcare system.

Findings also suggest that improvement ideas may be found in patients’ comments that hold implicit emotions, and that it is a staff responsibility to prepare patients for what they may not anticipate themselves. For example, during hospitalization for a broken neck, one patient did not
receive any information or planning regarding an incidental find of a tumour and was left to research it at home, alone. Such experiences by patients beckon hospital-based care providers to thoughtfully consider the patient as a ‘whole person’ who will return to live in their own environments.

A value of survey comments is that it is a space where patients may extend their story about how hospital-based interactions helped or hindered their longer-term recovery and well-being. And, survey comments provide information about patients’ experiences of transitions in care and where there are gaps along the continuum of care, such as communication or coordination between care providers and between teams in different care settings. While the survey’s comment question asked for feedback regarding the hospital stay itself, the content of patients’ comments often included experiences encountered after it.

5.3.1 Perceived Relationships

In 2013, MacLeod and Sharkey, the respective presidents and chief executive officers of the Canadian Institute for Patient Safety and the national healthcare organization Saint Elizabeth, wrote that “healthcare is a human service business, delivered by people, to people. Healthy relationships and an active and engaged workforce are prerequisites for excellence in quality, safety and patient satisfaction”. They argue that it is in networking “people’s needs and interactions” and “engaging the hearts and minds” of people that enable health systems to change and transformations to emerge.

Signaled by patients’ notes about their emotions, perceived relationships were apparent across all categories of findings. Perceived relationships strongly influenced how patients interacted with staff. For example, being told by a nurse only to use the call bell for emergencies led one patient to report not considering using the call bell at all when that nurse was working. Comments were expressed as a sense of connection that was formed when staff were perceived to have made an effort to know the patient as a person, to have adapted their actions to help patients feel safe and secure, and to have followed through to help prepare patients. Any staff representing the hospital could influence patients’ perceptions of relationships, such as in interactions noted about cleaning, parking or administrative staff.
Patients’ perceptions of their relationships with staff have been previously reported in studies that identified communication to be of crucial importance (Charles, et al., 1994; Cleary, et al., 1991). Further, analysis of numerical survey data has demonstrated that overall satisfaction of care is most highly correlated with survey questions that ask about being treated with dignity and respect, and good communication with staff and between staff (Doyle, Reed, Woodcock, & Bell, 2010). These questions may be understood as essentially asking about perceived relationships.

Furthermore, a sense of relationship may be understood to be a foundational factor for developing “mutually beneficial partnerships”, which is a part of the definition of patient-centred care by the Institute for Patient- and Family-Centered Care (n.d.) that Accreditation Canada (2016) has adopted. Patients wrote about their desires to take part in their care, such that the partnership between care providers and the patient would be mutually beneficial: “The medical staff needs to know that the more knowledge a patient has the more involved that patient is in the treatment program”. Moreover, patients’ comments suggested that perceived relationships are central to developing such mutually beneficial partnerships. Interestingly, Beattie, Shepherd and Howieson (2012) conducted an integrative review of articles published about quality of care and found that the Institute of Medicine’s widely adopted six dimensions of quality (IOM, 2001a) insufficiently addressed two recurring topics in the literature, namely caring and navigating the system. Both caring and navigating the system largely depend on perceived relationships. And, other authors stress the need for a national policy that supports staff to gain and maintain skills in delivering patient-centered care, which is ultimately determined by the quality of interactions between staff and patients (Epstein, Fiscella, Lesser, & Stange, 2010).

**Intentionality**

Patients noted the importance of “real person to person contact” and described the ways in which they knew when relationships were purposefully being cultivated and when they felt they were treated as “a priority”. Within staff attitudes, patients noted their perceptions of staff caring about and for them, with intention. The comment that staff “not only provided excellent care, they cared how I am and showed interest in me as a person and patient”, suggested that showing interest was observable. Patients noticed when staff listened attentively, were methodical, never gave up, asked questions, offered alternatives, stayed with patients who were scared, ensured meals were correct, and were extra careful. Conversely, patients also noted slow responses to calls for
assistance, chastising or speaking rudely, not finishing tasks or keeping promises, pretending to be busy, carelessness, not bothering to see the patient, not being gentle, and not taking time to cover patients’ bodies or close the privacy curtain. All of these actions and attitudes were perceived to be intentional. Furthermore, patients noticed when staff cultivated relationships with each other, describing times when staff “fought a lot” or “obviously...confer together”. The “manner” of staff set the tone and these examples from patients provide insight into the kinds of attitudes and actions that can make a difference in how patients perceive their relationships with staff.

Findings give reason to support the literature that promotes relationship-centered care (Beach, Inui, & Relationship-Centered Research Network, 2006; Safran, Miller, & Beckman, 2006; Tresolini & Pew-Fetzer Task Force, 2000), which stresses partnerships, attention to relationship processes, shared decision-making, and self-awareness (Suchman, 2006). Dewar (2013) extends the premises of relationship-centered care and argues that compassion is expressed through the interpersonal processes that build relationships between people in a healthcare organization. In order to promote and support a culture of compassionate relationship-centred are, Dewar also provides strategies for the cultivation of compassion through deliberate relationship-building with oneself, patients and their families, health care professional colleagues, and the organization. An example of a healthcare organization that transformed the way in which its employees provide care is the Cleveland Clinic, through its program that all staff receive, so that they approach patients and their families with the intention to cultivate positive relationships and provide compassion (Merlino & Raman, 2013).

**Staff Responsibility**

Findings suggest that patients perceived positive relationships with staff who took responsibility to help patients heal and recover. Patients’ comments suggested that patients expected access to familiar comforts, to be seen by their doctor, to be kept safe from other patients, to be told about hospital processes and what to expect, for communication about them to occur across teams, for hospital policies to be followed, and for privacy to be respected. These expectations were for staff to bear in mind, and to act and speak accordingly. When staff acted to ensure these expectations were met, patients’ comments suggested positively perceived relationships. Patients noted when staff did everything possible, immediately attended to them, explained everything done and why, were present when needed, and they wrote about what staff did to make them feel safe and
secure, like a person, and prepared. A sense of relationship was perceived by patients when staff displayed ownership of their roles by using small gestures such as smiling, being willing to discuss concerns without making the patient feel like time was being wasted, and choosing a smaller needle for a patient who was afraid of blood work.

Helping healthcare providers to recognize and own their responsibilities in developing relationships with patients is the focus of some healthcare literature. Professional development activities that target behaviour change are argued to have most success (Légaré, et al., 2015) and there is evidence that such activities improve the experiences of patients (Merlino & Raman, 2013). Further, mindfulness has been advocated as a strategy to help staff improve interpersonal relationships (Moll, Frolic, & Key, 2015), to increase the use of positive care practices (Dewar, Pullin, & Rocheris, 2011), and to enhance patient- and relationship-centered interactions (Frankel, Eddins-Folensbee, & Inui, 2011).

“Life Service”

When healthcare providers take responsibility to partner with patients in ways that facilitate healing and recovery, they may be seen as intentionally providing a “life service”. Ultimately, the aim of healthcare is for patients to be able to live their lives in their own environments, and therefore a strong relationship focused on serving the life needs of individual patients is more likely to help patients achieve their post-hospitalization goals. The idea of a “life service” expressed in one patient’s comment may be viewed as encapsulating the purpose of the relationship between a patient and hospital staff. While the idea of a “life service” was discussed in relation to being prepared for using medications at home, it may be extended to other topics often noted in patients’ comments, such as for pain management and for functioning at home. Findings from the current study offer insights into what actions by staff may be considered as providing a “life service” that helps prepare patients to return to living life. As examples, when staff listened, intervened promptly, problem-solved, tailored solutions for individual needs, offered detailed information, and set forth personalized action plans, patients wrote about being better able to cope and feel safe at home.

Findings from the current study suggest that patients in hospital often experienced a lack of “life service” being provided by staff. In order to improve the quality of patient care, the argument has been made that healthcare providers must learn to truly engage patients as consumers of service
rather than solely providing treatment; even when a patient’s individuality is honoured, solely treating a patient is not enough (English, 2016). Further, Hargraves, LeBlanc, Shah and Montori (2016) argue that when care providers stop short at providing evidence-based information and an array of treatment choices, it insufficiently supports the individual patient to determine the decision that best suits their unique circumstances. They further advocate that it is in the conversation between a care provider and a patient that uncovers patient’s values and preferences so that the care provider, who is the “instrument of care”, may lead the patient to decisions that make the most “intellectual, practical, and emotional sense for each patient” (p. 628). Achieving shared decisions in this way may require patients to positively perceived relationships with staff and require staff to approach care with a mindset of providing a “life service” for the patient.

Lastly, the idea of a “life service” may also be relevant when considering the processes of ‘transitional care’ between the hospital and patients’ post-hospital environments. Patients wrote about their experiences with care transitions and many comments related to the presence or absence of information and planning to help patients transition back to their own environments. In a systematic review of research on transitions from hospital to home for people aged 60 years and over, gaps were identified in transitions from pre-hospital care through to post-hospital follow-up and in the integration of care across episodes (Allen, Hutchinson, Brown, & Livingston, 2014). Findings from that study and findings from the current study both advocate for patients to be involved in making decisions about the transitions that impact their lives.

5.4 Moments of Significance

In addition to noting emotional experiences during hospitalization, some patients’ comments identified experiences from specific moments in time. Those experiences could influence how patients perceived their hospital stay or change patients’ overall impressions of the hospital in its entirety. Patients wrote about moments in time that they personally experienced while in hospital, prior to or after hospitalization. Patients also wrote about moments in time that they did not directly experience themselves, but were still significant in shaping their impressions of the hospital. What patients described as an event, memory, response, or series of actions bound to a notable experience, was interpreted to be a moment in time that was significant. Chapter 5.4 discusses patients’ comments about moments of significance.
Moments During My Hospitalization

Understanding which events were mentioned most by patients may help direct quality improvement considerations because patients’ comments revealed that not all events in the hospital were equally important or significant to patients. Some particularly significant events occurred during patient hospitalization. Comments allowed patients to identify and integrate a series of events into overall perceptions, with each event contributing positively or negatively. Comments about series’ of events provided insight that some overall impressions formed as the accumulation of significant events.

Comments that identified the most significant “one thing” were especially interesting, because those comments may hold utility, particularly for quality improvement. For example, the action of a staff member during any moment in time could strongly influence a patient’s perceptions, such as a porter’s off-the-cuff comment that was viewed as unprofessional or a resident speaking “‘down to’ someone with a high level of education that was viewed as disrespectful. Moreover, the memory of specific interactions, observed or overheard, between staff and other patients, the consistency of information among team members, and the way that family members were included into the care team, were also noted by patients to be significant. These moments of significance made lasting impressions on patients and were sometimes the distinguishing features of the hospital stay that became a lasting “reflection of hospital”.

‘the one thing’

Survey comments provide insight that patients often noted one thing that particularly stood out for them. A general statement followed by a declaration about “one thing” that was outstanding was consistently found across comments that spanned different topic content. Comments expressed in the format of ‘the one thing’ or the format of “…except” have been seen in patient narratives reported in other studies. For example, “The only thing that worries me about this place is that a lot of people seem to come back with c-diff and or infections” (Bardach, et al., 2015, p. 5) and “the staff was generally polite and respectful, but I found one physician was rude and dismissive” (Lagu, Goff, Hannon, Shatz, & Lindenauer, 2013, p. 13). Recognizing that patients write about a single impactful occurrence is useful because it identifies improvement ideas. From the current study, one comment noted how one critical remark by a nurse brought a patient to tears, and another comment noted how one nurse who would “just pop in” to check on
a patient contributed to a perception of excellent care. Comments using the format of ‘the one thing’ provide guidance on improving patients’ experiences by emphasizing everyday practice behaviours that might be discouraged or encouraged.

Some authors propose that “some things that happen to only a few people can be very important... If they occur – even on only one occasion – they must be investigated…and action taken to prevent a recurrence” (Coulter, Fitzpatrick, & Cornwell, 2009, p. 12). In practice, a “single concern” from one event, even if the concern was not linked to an actual medical error, has been found to significantly reduce the likelihood that a patient would return to or recommend the hospital where the event occurred (Burroughs et al., 2007, p. 10). Findings from the current study suggest that comments using the format of ‘the one thing’ may have utility for identifying and prioritizing patient-reported improvement ideas. When there is something that stands out in the minds of patients, so much so that it is remembered and documented in a patient survey, it behooves healthcare providers to consider that content for improvement ideas.

A recent CBC News article recorded an example of how one moment in time could influence the overall perceptions about an entire hospital while also impacting the reputation of the hospital. When 99-year-old Sophia Nemis was admitted to Seven Oaks General Hospital in Winnipeg after twisting her ankle, her son Dan received a phone call on his cell phone. A nurse told Dan that his mother had died, insisting twice when Dan questioned what happened. When the nurse realized the error, the response to Dan was “Oops, wrong person”. Dan said that the experience was “painful” and that he will “never forget it” (Rutherford, 2016). This news article highlights how one moment in time can be especially significant and impactful on impressions. Similarly, findings from the current study suggest that one significant moment in time can change entire perceptions, as seen in this comment: “This one event coloured my entire hospital experience”.

**Moments From My Life**

Hospital stay events described in patients’ comments were written implicitly to be understood within the context of their life experiences. Patients wrote comments about life experiences gained prior to their hospital stays and how they viewed their hospital experiences with those understandings in mind. The individual and personal characteristics of a person influences perceptions (Wolf, 2012) and findings from the current study suggest that survey comments offer deeper understandings about the types of life experiences that influence patients’ perceptions.
most. Patients who had worked in a hospital, been previously hospitalized, or had knowledge about the healthcare system wrote about how their understandings influenced their expectations. Patients’ comments reported in other studies have also identified patients’ personal characteristics that influence perceptions. For instance, the study by Greaves and colleagues (2014) contained verbatim comments by a patient who commented about the hospital experience in relation to their nursing role.

Findings in the current study may introduce an area for further investigation, about how to best integrate the life experiences of patients to better deliver patient-centered care. Perhaps knowing that a patient has worked as a doctor or a nurse could lead a care provider to initiate conversations that engages shared decision-making differently than for a patient without healthcare training. Or, perhaps knowing that a patient has had previous hospitalizations could lead a care provider to ask more specific questions about coping needs experienced since the last hospitalization, in order optimize preparing the patient’s return to living life. Understanding patients’ life experiences may direct care providers to have more individualized conversations with patients. How to incorporate the life experiences of patients into healthcare delivery may be a topic for further study.

**Moments Related to My Hospitalization**

While the survey asked for comments concerning the “hospital stay”, patients often commented on more than the hospital stay itself. Patients wrote about realizations they made after the hospital stay and any resulting questions. Patients also wrote about the experiences of their loved ones rather than, or in addition to, their own experiences.

**More to My Personal Story**

Currently, surveys ask patients about performance in a single episode of care, which provides little information about health system performance and does not address the continuum of care that patients care about (Mountford & Shojania, 2012). The current study found survey comments contain information about patients’ experiences related to the hospital episode of care, including their experiences in the past with the hospital, connections across hospital teams, and their concerns with transitions of care. Some authors argue that patients’ entire experiences need to be measured more often, because a focus on continuity and coordination more meaningfully
provides information about what is important to patients and what improvement gaps exist (Robert & Cornwell, 2013). Findings from the current study suggest that analysis of comments can provide information about the long-term, lasting impact on patients’ health and well-being.

My Family Matters

Family were impacted by patients’ hospital stays. Some patients wrote comments about the interactions between staff and their family member. Some entire comments were about the impact of a moment in time experienced by a family member. While the current study did not review comments written by family, findings did suggest that some patients perceived the hospital experience to be as significant for their family members as it was for them.

An example of the impact of significant moments exchanged between staff and family members may be seen in “Joan’s Family Bill of Rights” (Lewis, 2014). Patients’ bills of rights are often posted on hospital walls. Barbara Lewis, Joan’s sister, wrote a corollary to a patient’s bill of rights, specific to family members, to document the rights of family members when their loved one is in hospital. Direct staff actions were identified, such as announcing and introducing selves to family and making eye contact with them, communicating with family because everything done “to the patient is felt by family”, and matching and mimicking energy levels to “be in tune with” the patient and family. Contributing actions were identified, such as collaborating with colleagues so as not to “burst [family’s] confidence”, avoiding complaining because being in hospital is stressful enough, and limiting noise that “upsets the family who has been keeping vigil”. Staff attitudes were also identified, such as valuing family as people who are a part of care rather than treating family as meddlers, understanding that every word said matters and that others are listening and observing, providing comfort “like a loving family member” would, and using kindness to ease the “devastating pain” and “breaking heart[s]” of families (Lewis, 2014). There is similarity in the content of “Joan’s Family Bill of Rights” and the moments of significance suggested in patients’ comments in the current study. Analysis of comments identified as being written by family members may be another avenue for future research.

5.4.1 Respect and Dignity

“Respect” and “dignity” were explicitly noted by patients. Findings in the current study suggest that individualized moments of significance contributed to patients’ feelings of respect and
dignity. Findings also suggest that the times when an individual patient felt like they were known as a person, more than “a patient”, were memorable moments for patients to write about. Responding to the individuality of each patient was suggested to be expected: “Every individual is special and experiences things differently, more so while ill in hospital... you sometimes have to put aside your feelings and try to comprehend what your patients are feeling and understanding their concerns”. Patients wrote about having “full respect” for the hospital and that they “[felt] ... respected in every way” through how staff approached them “as the most important person”.

Respect and dignity are complex constructs. Respect has been explored through semi-structured interviews with patients and found to be associated with attention to patients’ needs, recognition of their individuality, empathy, care, autonomy, information provision, and dignity (Dickert & Kass, 2009). Dignity has been explored through interviews and found to be comprised mainly of patients’ feelings of being comfortable, in control, and valued while in hospital (Baillie, 2009). Further, dignity has been found to be promoted when patients feel cared for, when patients have access to privacy, and when staff upheld patients’ privacy, particularly by paying attention to patients’ physical presentation (Baillie, 2009). Merlino and Raman (2013) argue that a truly patient-centered healthcare organization will focus quality improvement activities on patient experiences, rather than medical excellence, because patients already assume that they will receive excellent clinical care when they go to hospital. Findings from the current study indeed support that argument. Patients wrote about their emotional experiences and the significant moments that led to them feeling respect and dignity; comments rarely contained clinical content.

The close connection between respect, dignity and privacy are suggested in findings from the current study. Further, patients commented on professionalism when they wrote about experiencing dignity and respect. Findings from the current study suggest that patients’ overall experiences of professionalism in staff, or their overall experiences of privacy, respect and dignity, strongly informed patients’ overall impressions of their hospital stay and the hospital. Ultimately, patient-centered care and excellent patient experiences are created during moments of significance that result in overall perceptions of respect and dignity.
5.5 Fulfilling the Contract

Patients wrote comments about purposefully responding to the survey to enable improvements at the hospital where they had received care. This finding in the current study contributes new knowledge about how patients approach responding to a survey and introduces new questions about how survey comments are used by the hospital. Comments revealed that patients undertook responding to a patient survey as a serious endeavour. The words and phrasing written by patients signaled that comments were thoughtful and deliberate. Comments contained specific information about what happened as well as patients’ recommendations for improvement. Comments also referred to information on the covering letter accompanying the survey, suggesting that responses were provided as part of an agreement where two parties, the patient and the hospital, were each fulfilling their parts towards a mutual goal of quality care for patients.

Patients are regularly surveyed and in general, the purpose of measurement is to identify issues or to monitor trends. After decades of monitoring trends using standardized patient surveys and reporting results numerically, few improvements have been demonstrated (DeCourcy, West, & Barron, 2012; Robert & Cornwell, 2013). Even if comments are coded for review into established frameworks, such as when an NRCC employee applies a code based on the eight Picker principles of patient-centered care (Gertais, Edgman-Levitan, Daley, & Delbanco, 1993; Picker Institute, n.d.) during transcription of comments collected in the NRCC Adult Inpatient Survey (NRCC, 2016b), it is not enough. Only through understanding what happened to a patient may potential improvements ideas be identified. For example, one study that compared 50 random comments associated with extreme positive ratings (“excellent services”) and 50 random comments associated with extreme negative ratings (“services have clear improvement needs”) grouped all comments into similar themes (Iverson, Bjertnæs, & Skudal, 2014). However, very different descriptions about experiences were found, including instances of extensive surgical wound infections leading to lost confidence in doctors, and receiving incorrect diagnoses or incorrect medications that could have killed a patient (Iverson, Bjertnæs, & Skudal, 2014). While these comments might have been coded as physical comfort, or information and communication, it is in the the details of the comments that specific improvement ideas are found.

To effectively implement patient engagement, new approaches to evaluate and share learnings from existing strategies, such as surveys, is necessary (Tepper & MacLeod, 2015). Perhaps it is
time to return to patients’ narratives about their hospital experiences, particularly because today’s narratives remain strikingly similar to the narratives recorded in seminal investigations (Bruster, et al., 1994; Charles, et al., 1994; Cleary, et al., 1991), and take a different direction with what patients have reported to be important to them.

Findings suggest that patients took seriously the endeavour of completing a survey. Comments provided useful information that may be usable and should be used. One survey comment echoed that sentiment: “Your attention to these concerns is greatly appreciated”. An ethical imperative therefore exists to honour the efforts of patients who may have engaged in survey completion with the understanding that their comments would be reviewed and considered for making quality improvements. The promise of improvement made to patients in the covering letter of a patient survey implores organizations to review and use patients’ feedback. The following section discusses how patients’ comments may be used, as a way to fulfill the contract.

5.6 Practice Implications

Several practice implications stem from findings of the current study. Chapter 5.6 begins with broad considerations for why survey comments should be regularly reviewed, by whom, and how best to present them. More specific practice implications are then proposed for what process could be used to review patients’ comments within the context of the hospital where the study was completed.

Why review, analyze and use patients’ comments?

Across participating Ontario and Canadian hospitals, comments have been collected in NRCC (previously Picker Institute) surveys since the surveys have been implemented. The collection of responses to patient surveys is a costly responsibility of hospitals. Fiscal accountability and restraint in hospital spending dictate that any information that may improve quality healthcare must be considered. Comments are readily accessible to hospital administrators. Regular analysis of patients’ comments is likely feasible and achievable. It therefore behooves organizations to examine all of the data gathered by measurement tools already deployed and to consider using relevant information toward innovating improvements.
Further, patient engagement is increasingly becoming a priority and patient surveys are a type of patient engagement tool. While the collection of numerical data from patient surveys have resulted in few quality improvements (Boiko, et al., 2015; DeCourcy, West, & Barron, 2012; Reeves & Seccombe, 2008), the use of quantitative survey results together with patient comments has been demonstrated to increase the application of survey results into quality improvements (Cuthbertson, 2014; Riiskjær, Ammentorp, & Kofoed, 2012; Sawatzky & Cuthbertson, 2013).

Therefore, patients’ comments in patient surveys are a viable patient engagement method to fill the paucity of innovation that some authors argue needs to be supplied through increased patient engagement (Bate & Robert, 2006; Health Quality Ontario, 2015a; Naylor, et al., 2015) and disrupting the status quo (Ball, 2010). Moreover, the use of patients’ comments presents an opportunity to empower patients, moving patient engagement further away from the basic level of consultation, as described by Carman and colleagues (2013), and closer to a shared decision-making level. Fostering a culture of continually learning from patients’ experiences and promoting collective engagement with patients’ perspectives is important (Schlesinger, Grob, & Shaller, 2015) and it is the right thing to do. There is also the opportunity to report the analysis of patients’ comments as a patient engagement activity in mandatory annual quality improvement reports.

**Who is responsible for reviewing patients’ survey comments?**

Patients’ comments may be of interest to different healthcare stakeholders. Comments, once analyzed and prepared for reporting, could be considered by patients themselves, their families, healthcare providers (including specific groups, such as doctors and nurses), hospital administrators, policy makers, and government agencies. Different stakeholders will likely have different intended purposes for reviewing the comments.

While high quality patient experiences are viewed as important by hospital chief executives and boards, less than one-third of hospital nurses and doctors support hospital-dictated efforts to improve the patient experience (Manary, Staelin, Kosel, Schulman, & Glickman, 2015). Results from standardized patient surveys have had little influence on engaging clinicians to use the results in local areas (Mountford & Shojania, 2012; Reeves & Seccombe, 2008). One study reported that hospital employees found it “difficult to trust surveys to reflect ‘reality’” (p. 1985) and that staff believed that only patients with strong views completed surveys (Boiko, et al., 2015). Further, staff saw surveys as only able to provide a snapshot, they had concerns about the
design of surveys and the weaknesses of surveying, and they doubted that patient experiences could be quantified into results that could be relevant for local areas and individual practitioners to use (Boiko, et al., 2015). There is evidence that targeting care providers working at the local level to review and use survey data is crucial to yielding any changes at the level of direct care experienced by patients (Rozenblum, et al., 2013). However, the content and presentation of survey data must be acceptable to care providers (Boiko, et al., 2015).

Mountford and Shojania (2012) advocate for local ownership of quality measurement to encourage professional responsibility for monitoring performance and to counter the current “defect-focused” (p.519) and “minimum standards approach” (p. 520) to track “easily measurable elements of care, often on what is being done ‘wrong’ rather than what is being done ‘right’”(p. 519). Local ownership and accountability is further warranted when considering the study by Rozenblum and colleagues (2013) that surveyed 1,004 clinicians from four teaching hospitals in four countries and found that despite over 90% of clinicians declaring a belief that improving the hospitalization experience was important and achievable, only 34% of clinicians recalled ever having received patient feedback, and only 9.2% of clinicians were aware of any structured plan for improvements. Unit-level culture has also been found to vary widely within a hospital, particularly regarding pain control practices, and interventions to improve quality of care should thus be directed at the unit (Hanna, González-Fernández, Barrett, Williams, & Pronovost, 2012).

Therefore, the current evidence suggests that the most critical group to review patients’ comments consists of staff with direct contact with patients. Furthermore, leaders from the Institute for Healthcare Improvement note that it is the “collective energy of staff members” that generates organization-wide actions toward improved patient experiences (Balik, 2011, p. 78), and that a major “indication of an organization’s level of patient centeredness is staff members’ level of engagement in improvement” because any improvement processes that are not absorbed into the activities of frontline staff would be considered siloed, separate and an add-on to their everyday work (Bisognano, 2012, p. 70). And, the exchange of information between an organization and its staff may help to create what O’Toole and Bennis (2009) describe as a culture of candor, in which transparent communication is key to innovating improved performance.
How should patients’ comments be presented?

Worldwide, to date, the results of patient surveys have been reported and shared as trend data, comparison data and summary scores, and prepared for “everyone” rather than for specific audiences (Teleki, et al., 2007). Associations between numerical data from patient surveys have also been reported (Jha, Orav, Zheng, & Epstein, 2008). However, the inpatient survey tool by itself is not a quality improvement tool (DeCourcy, West, & Barron, 2012) and survey results themselves do not lead to actionable improvements (Boiko, et al., 2015; Mountford & Shojania, 2012; Reeves & Seccombe, 2008). Take for instance in England, where the NHS has administered the adult inpatient survey since 2001, survey results remained stable for nearly a decade, and while survey results had been linked to some reports, they did not translate to improved experiences of care; further, only when government incentives and penalties were applied were improvements shown (DeCourcy, West, & Barron, 2012). Further, Robert and Cornwell (2013) reflected that national surveys have “contributed to a tick box or compliance mentality on the part of management boards” (p. 67). The original purpose of surveying patients in order to improve patients’ experiences is seemingly not being advanced. If this is indeed the situation, then surveying has arrived at the place of measurement for “judgment” that Berwick (1996) decades ago warned about.

While numerical survey data alone do not motivate healthcare providers to make improvements, the use of patients’ comments alongside numerical patient ratings has been shown to increase the use of survey results (Cuthbertson, 2014; Riiskjær, Ammentorp, & Kofoed, 2012; Sawatzky & Cuthbertson, 2013). “Rich details of patient experiences” are found in patients’ stories (Robert & Cornwell, 2013) and patients’ narratives of their experiences are argued to have the potential to improve standardized patient surveys (Schlesinger, et al., 2015) as well as foster greater accountability and push forward quality improvement efforts by hospitals (Lagu & Lindenauer, 2010). Therefore, the presentation of patients’ narratives complemented with systematically collected standardized survey results is an ideal way to present feedback from patients’ perspectives (Lagu, Goff, Hannon, Shatz, & Lindenauer, 2013) and it has the potential to help plan change processes to improve services (Robert & Cornwell, 2013). However, staff must be supported to reflect on the meaning of the data in order to drive change where it matters most (Boiko, et al., 2015) as well as training to develop skill in delivering patient-centered care (Balbale, Turcios, & LaVela, 2015).
What should be included as information about patients’ experiences of the hospital stay?

The current study is the first known content analysis of patients’ comments in mailed standardized inpatient care surveys. A framework and process is proposed for how to incorporate the study’s findings into the presentation of information about patients’ experiences of the hospital stay. As a proposal, it will require testing and refinement, and is meant to assist local teams to become familiar with handling data and presenting data as information.

Figure 1 displays the categories of patients’ comments about 1) feeling safe, secure, comfortable and cared for, 2) feeling like a person, and 3) feeling prepared to return to living life, which represent the gamut of hospital stay experiences reported across the entire hospital. Therefore, these categories form a useful organizing structure to frame selected patients’ comments for presentation. Survey comments may be reviewed every annual quarter, coinciding with existing organizational processes such as the quarterly preparation of quality reports to the hospital quality committee of the board.

Comments received about a local area may be reviewed by local team members, including doctors, nurses, occupational therapists, pharmacists, physiotherapists, social workers, other clinical team members who work in the local area, together with managers and team leaders. Ideally, non-clinical staff should also be included, as patients often comment about their interactions with non-clinical staff. Given the breadth of comments that made up the data analyzed in the current study, the presence of comments that could be coded into each of the three categories is expected. Further, studies with smaller samples (Greaves, et al., 2014; Lagu, Goff, Hannon, Shatz, & Lindenauer, 2013) have all reported verbatim patients’ comments that could be coded into each of the three categories. Sub-categories may help to prompt staff to consider the things that matter to patients. Per annual quarter, team members may read and code comments into the categories. Then, by consensus, local team members may select the top two comments per category to be presented.

The process of regularly reviewing all comments facilitates a team discipline to recurrently read patients’ comments about the care provided on the unit, and it trains staff to become aware of trends occurring over time in the unit. In this way, staff are engaged to learn about the ‘real’ experiences of patients who received care from them, and to look out for improvement ideas. Monthly unit council meeting times may provide an existing meeting time to review comments.
To select the most impactful comments for presentation, each comment should meet at least one of the following criteria: describes what happened to the patient, contains labeled or implicit emotion about the patient’s experience, states why the event was important to the patient, and offers insight into the effects or impacts on the patient. Usually, a comment that could be effective in offering improvement ideas will note a moment of significance and/or a perceived relationship with staff.

There are words to look for that may help in the selection of comments: 1) words containing emotions, labeled or implicit; 2) statements in the format of “...the one thing” or “...except”; 3) specific recommendations or suggestions; 4) statements containing “should have...”, “could have...”, “expected...” or “anticipated...”; 5) observations and experiences about staff actions and responses to patients’ individual needs; and 6) statements linked with words of “thanks” or appreciation. Comments that contain these types of leading words have the potential to highlight the human connections that matter to patients, the outstanding events that made impressions on patients, and the events that created lasting memories or lasting impact.

The final group of comments that span patients’ experiences of feeling safe and secure, feeling like a person, and feeling prepared to return to living life should represent a complete and balanced set of information that is coherent and relevant, so that the information will have meaning for staff. Completeness, balance, coherence and relevance are endorsed for any public posting of patients’ comments (Grob, et al., 2016). The presentation of survey ratings alongside selected patients’ comments may be organized onto a single sheet. Displaying the data on the unit may open opportunities for discussion, particularly if unit managers and leaders make space for the discussions about how the information may apply to the care of patients on their unit.

Time should be reserved for team discussion about the positive patients’ experiences reported (that the team can celebrate and commit to continuing to perform), the experiences reported with concern (that they can discuss improvement opportunities), and the plan for what staff will do over the next three months that will improve the quality of patient-centered care. Bohmer (2016) describes that lasting improvements can only come about from the prolonged hard work of staff who are empowered to repetitively and incrementally change local processes such that their work is operationalized at the local level to meet the objectives set by the organization.
What might come of regular review and use of patients' survey comments?

Browne and colleagues (2010) argued in a commentary that there is benefit to reporting standardized survey information about patients’ perspectives to different stakeholders, in order to achieve different goals. At the organization level, patient’s perspectives about topics such as coordination of care and access to information may identify hospital-wide issues. At the provider level, recurring issues at the local level may be identified. At the patient level, patients may be empowered to discuss survey topics with their healthcare providers. While the commentary (Browne, Roseman, Shaller, & Edgman-Levitan, 2010) was specific to the numerical data collected and analyzed in the CAHPS surveys about primary care practices, the same proposal may be extended to the presentation of complementary numerical and commentary data within hospitals.

Regular review and reporting of patients’ survey comments alongside numerical survey ratings have potential benefits for staff, for patients and their families, and for hospitals. For staff, being able to see hospital and/or unit-level numerical survey data together with unit-level patients’ comments may help staff to learn about patients’ perceptions about what happened to them, what specific things staff should continue to do, and what aspects of care are important for patients that staff may consider improving. For patients and families, seeing patients’ perspectives displayed at the unit or hospital level may motivate and empower more patients to provide additional feedback. Further, patients may see how the unit is indeed reviewing their comments, and potentially using them. Such transparency and ‘looping back’ to patients is part of patient engagement. For hospitals, the reporting of patients’ comments alongside numerical ratings may tell government agencies and the public that the organization is actively engaging the improvement ideas of patients. There is potential for other hospitals to learn as well.

Finally, a commitment to the responsibility of reviewing and using patients’ survey comments holds great opportunity. What information is gathered about experiences has the potential to improve future experiences. In the words of a patient, the following statement is a reminder of that sentiment: “The expectation is: the next time I get admitted to XX, everything I have addressed will be largely improved as I am taking the time to help you improve it”.

5.7 Strengths and Limitations

This study has strengths and limitations. Among the strengths, as the first known content analysis of comments in mailed standardized patient surveys, this study contributes new information to current understandings about quality healthcare, person-centred care and hospital care experiences. The collection of comments through a standardized measure that is randomly sent to patients has the benefit of accessing more representative populations than comments that are volunteered by self-selected participants. Comments do not restrict patients to limited topics and patients wrote about topics not covered in the structured survey questions that were likely important to them. Analysis was completed in a systematic manner without a priori domains to guide category development, which led to new insights not previously identified in the literature by research that is directed by assumptions or established quality dimensions. Relative to other recent studies (Bardach, et al., 2015; Lagu, Goff, Hannon, Shatz, & Lindenauer, 2013) that analyzed relatively small sample sizes of volunteered and publicly accessible patients’ comments (244 and 200 comments, respectively), the data source used for the current study was adequately large and theoretical sufficiency was reached before coding ceased at 1,638 written responses. This large data sample helped to identify more details about patients’ hospital experiences and to allow more associations to become apparent than some other studies have reported. Patients’ comments in the current study addressed topics that have been raised by patients in other studies; there were no surprises in patients’ verbatim comments reported in the other studies, suggesting that the overall hospital experiences of patients in different parts of the world are largely similar.

This study’s limitations relate to the nature of a standardized survey instrument, specifically to issues of sampling. As this was a qualitative study, issues of sampling do not relate to representativeness of the sample, a major issue discussed with regards to surveys. Rather, the issue is one of inclusiveness, theoretical sufficiency and transferability. The nature of the sampling for the survey data used in the current study is that only a subset of patients discharged from hospital received the mailed survey and that response rates to mailed surveys tend to be low in general. Further, not all patients who complete survey question ratings write a response to the open-ended question from which the data for this study were drawn. Therefore, survey responses may not be fully inclusive of the entire broad-level experiences of the patients. Further, because the study objective was to understand patients’ experiences of the hospital stay, in general, all inpatient stay comments were analyzed together. While there may be cultures within hospital
programs or units that are unique to those areas, this study was not intended to compare and contrast hospital stay experiences across patient groupings. Accordingly, no subanalysis of patient groupings was undertaken.

Timing of the survey administration may impact the breadth of responses. It may be argued that there is no time limit on the things people remember to be important or significant. On the other hand, others may argue that information that relies on human memories, which may change over time and with new experiences and understandings, may not be reliable. Furthermore, answering an open-ended question after having completed the survey’s rating-scale questions may have influenced or prompted the topics raised by patients in their comments. Also, written comments could not be clarified and the interpretations of patients’ written comments could not be checked with patients themselves. Analysis conducted without a priori theoretical assumptions or frameworks to guide the coding also means that these findings are not directly comparable to research that is framed within established standardized survey domains. Comments analyzed were not compared with quantitative survey results and no associations or comparisons were made because this was not the purpose of the research, although alternate insights may be gained by doing so.

Finally, regarding breadth of patients’ reported experiences and transferability of findings, this research was conducted using data from a single, academic, tertiary care centre in Ontario. Comments were collected about patients’ hospital stays between April 1, 2012 and April 1, 2014 and perspectives are bound to hospital and societal events and trends during that time. It is the reader of the current study who decides which aspects, and to what extent, findings may be relate to their contexts. Readings of the details in descriptions of the sample, study design, and examples of patients’ comments in the findings will help a reader determine whether the study covers a breadth of inpatient care experiences that may in turn be transferred to the reader’s own situations.

5.8 Future Research Directions

There are numerous opportunities to continue expanding our knowledge about patients’ experiences of hospital-based care in Ontario and Canada. In the past year, the landscape of patient surveying has changed in Canada. A new national, non-proprietary standardized inpatient care survey instrument by the Canadian Institute for Health Information, the Canadian Patient
Experiences Survey-Inpatient Care (CPES-IC) (CIHI, 2016a), is available. The new CPES-IC tool for measuring and monitoring patients’ experiences consists of structured rating-scale questions and one final open-ended question that is virtually identical to the NRCC patient survey question that was investigated for the current study. With 23 of 49 questions adapted from the USA HCAHPS survey (CIHI, 2016a), international benchmarking is now possible in addition to national benchmarking of hospitals. Beginning in the 2016/2017 fiscal year, the Ontario Hospital Association endorsed the use of the CPES-IC while CIHI has been accepting data into its Canadian Patient Experiences Reporting System (CIHI, 2016b). The National Research Corporation Canada continues to hold the contract for administering patient surveys in Ontario (Ontario Hospital Association, 2016) and to post verbatim CPES-IC comments for access by hospital administrators (National Research Corporation Canada, 2016b). Continued analysis of comments collected in the CPES-IC may serve to generate additional categories of patient-reported experiences, or they may be compared to the categories reported in the current study.

The content of patients’ comments in the current study were similar to the content of verbatim comments reported in recent studies from other parts of the world (Bardach, et al., 2015; Hawkins, et al., 2015; Lagu, Goff, Hannon, Shatz, & Lindauer, 2013; Ranard, et al., 2016). They were also like reports by patients made throughout the 1990s (Bruster, et al., 1994; Cleary, et al., 1991; Coulter & Cleary, 2001). A dedicated focus on implementing changes based on patients’ perspectives, rather than solely measuring and monitoring them, will be an important next step for patient surveying. Findings from this study propose more attention should be paid to patients’ survey comments. Descriptions of events that link to patients’ emotions or their accounts of long-term impacts, as well as comments that make direct recommendations or suggestions, are found in survey comments. A potential next step is studying how those comments may contribute to quality improvement, particularly at the local level where there is evidence to support that direct care providers should review data and be accountable for identifying and implementing change (Boiko, et al., 2015; Rozenblum, et al., 2013).

New research directions are also identified from the current study’s findings related to patients’ understandings and perspectives about safety. This topic has not been well-explored, as other researchers have noted (Bardach, et al., 2015). Immersive research of patient-centered care will prompt researchers to constantly question and scrutinize the historical circumstances that have contributed to our knowledge about what is important to patients. It is possible, and likely, that
the bulk of our current understanding about patient safety has its origins in ideas from administrators, clinicians and scientists (much like our understandings about patient satisfaction and patient experience, until more recently). Findings from the current study suggest that patients’ perceptions about feeling safe in hospital were influenced by their observations of and experiences with comfort, communication, staff interactions that inspired trust and confidence, organizational processes, staff attitudes and competencies, and teamwork. There are opportunities to further explore patients’ perspectives about feeling safe in hospital.

The importance and value of familiar comforts and routines were suggested in patients’ comments. Not having been told about daily routines was a highly reported problem about UK- and USA-based hospital care in the 1990s (Bruster, et al., 1994; Cleary, et al., 1991). During that same time in Canada, the most frequently reported concern by patients (41% of patients asked) was not having been told about in-hospital daily routines (Charles, et al., 1994). Yet, it has not been studied. Findings from the current study suggest that helping patients to engage in and perform the routines that are familiar to them may help patients to feel safe, secure, comfortable and cared for. Investigating how patients’ experiences might change when patients are supported to take part in routines that they know and value, therefore, may be a research opportunity.

Some topics that were raised within patients’ comments hold potential to help innovate quality healthcare, particularly patient-centered care. The idea of a “life service” for patients, in which care is truly centered around patients’ individual needs and delivered with the post-hospitalization goals of patients, rather than the convenience of staff, is compelling. There are opportunities to research the idea of moving away from ‘discharge planning’ and toward ‘return to living life’. Further, there are opportunities to investigate how ‘preparation’ that is inclusive of information and planning/practice, rather than solely ‘patient education’ or ‘information sharing’, might lead to improved patient experiences and potentially improve outcomes for patients. There may also be more directed research that asks patients what they want to know about their post-surgical needs, so that the focus is on helping patients with their long-term recovery and living needs, rather than only helping hospital staff with pre-surgical and day of surgery preparation to ensure hospital processes run smoothly. Another opportunity is to explore what healthcare providers think patients need to know and to ensure that patients are adequately prepared during hospitalization for both what they might and might not anticipate upon returning home. Such research may lean heavily on theoretical and philosophical stances about patient-centered care.
and require the implementation of patient-centered care guidelines. There is the potential to improve patients’ engagement in their own care and empower them.

The use of patients’ comments as part of reporting numerical ratings, whether at the local unit or hospital level, or publicly as part of accounting for annual quality improvement activities, may be studied. One objective might be determining if complementary data consistently leads to improvements, as has been demonstrated by some researchers (Cuthbertson, 2014; Riiskjær, Ammentorp, & Kofoed, 2012; Sawatzky & Cuthbertson, 2013).

Reviewing the language and message used in covering letters of surveys may be warranted. The procedure manual for the new Canadian Patient Experiences Survey-Inpatient Care (CPES-IC) (CIHI, 2016a) specifies content requirements for the survey’s cover letter (CIHI, 2015b). It requires the patient to be addressed by name, rather than sending a generic letter. It also requires that the CEO’s signature be on the letter. The intent and purpose of the survey must be stated, such as for quality improvement and a national initiative. There is leeway for how a hospital might choose to word the cover letter. Findings from the current study might offer insights into how to be transparent about how survey results are collated and used.

Further, designing studies to analyze comments based on different factors may have utility for quality improvement. As examples, analysis of all survey comments filtered by professional group (such as doctors and/or nurses), by unit or clinical care area, by patient or by “someone else”, by patient groupings (such as age or gender), or by valence (positive, negative, neutral) may each lead to deepening understandings about patients’ experiences with hospital care.

Patients’ perspectives about care by doctors has already been studied, including from open-ended questions in patient satisfaction surveys in Poland (Marcinowicz, Chlabicz, & Grebowski, 2007), and from online posts in the USA (Detz, López, & Sarkar, 2013; Gao, McCullough, Agarwal, & Jha, 2012; López, Detz, Ratanowongs, & Sarkar, 2010). Also, while valence in patients’ comments has been analyzed (Iverson, Bjertnæs, & Skudal, 2014), further exploration into valence may have merit based on research into the effects of emotions on memories. Specifically, Kensinger’s (2009) extensive review reported research that found that events that aroused positive or negative emotions are more likely to be remembered than non-arousing events, and that events with negative experiences are remembered with more detail and accuracy than
positive experiences. The richness of descriptions found in patients’ comments hold opportunities for healthcare quality improvements.

Finally, as a new researcher and a student in the Practice Science Field, my next steps will be to publish the findings of this study and to bring the findings back to my place of employment, to honour the patients who dedicated their efforts toward improving quality of care, and to encourage and stimulate healthcare innovation.
Chapter 6

6 Conclusions

Some patients who have stayed in hospital are invited to comment on “the hospital stay”. Comments from each patient comment reflect that person. Each comment contains the memories, impressions and perceptions of an experience. Patients’ comments hold information about what happened to them, what they observed and experienced, how they perceived staff actions and responses, and why or what impacts were borne by them and their families. Patients’ comments are written as events or statements, as labeled or implicit emotions, and as suggestions or recommendations. These comments often describe perceived relationships and moments that were significant or memorable. Patients’ comments indicate what is important to patients and what they value most about hospital-based care.

Using an existing source of data containing patients’ comments collected through a mailed standardized patient survey, the content of 1,638 comments was analyzed using a systematic approach. The written perspectives of patients suggest the hospital stay is a highly emotional and human experience, during which patients want to: feel safe, secure, comfortable and cared for; feel like a person; and feel prepared for return to living life. Further, the hospital experience is personalized through especially significant, specific moments in time. Comments also suggested that patients respond to surveys with serious intent, offering information to the hospital to be used for improvement activities. The wording of some comments suggested that patients entered a voluntary partnership with the hospital, to fulfill their part in an agreement, in which their efforts were offered with the understanding that their feedback will inform hospital improvements.

This study offers insights about patients’ experiences of hospital care that may inform quality improvement ideas and guide prioritization of change. Expressed through written comments in a survey, patients may identify and describe the source of excellence or insufficiency. Comments written in the format of “the one thing” may cue reviewers of survey comments to the events that make strong impressions on patients, as they signal moments of significance. Human emotions articulated as part of comments may help direct attention to patients’ most important considerations during hospitalization. Often, those aspects were written about perceived
relationships between staff and patients. Finally, patients’ specific recommendations or general suggestions may provide direct improvement ideas. Strong emotions expressed by patients, as well as specific recommendations, signal moments of significance and may serve to help prioritize improvement activities that bolster excellent hospital experiences and minimize poor ones.

Findings suggest that during hospitalization, patients wanted to feel safe, secure, comfortable and cared for. Several factors influenced these feelings, including access to physical, emotional and routine comforts known to people. Interactions and communication with staff were influenced by patient’s state of mind and body, the organizational environment and its processes, staff competencies, staff attitudes and teamwork. Trust and confidence were inspired in patients during moments of care and during transitions in care, and influenced by what staff did and said, and whether staff responded in expected ways to patient’s individual needs. Findings offer new research opportunities to explore what might help patients feel safe in hospital and how helping patients maintain their participation and engagement in their routines may contribute to improved patient experiences.

Findings also suggest that patients wanted to feel like persons while in hospital. The perceptions of caring and compassionate behaviours and attitudes by staff contributed to patients being able to assert themselves as persons, to feel as valuable as staff, and to take part in their own care. Patients’ comments advance what is known about patient-centered care, with specific details about what helps and what hinders. Findings reinforce that published guidelines be used.

Findings further suggest that during hospitalization, patients wanted to feel prepared to return to living life. Feeling prepared was described as both receiving information and having planning in place. Comments suggested that patients expect to be prepared for the needs they could have anticipated, such as medications, functioning at home, and the transition to care services outside of the hospital. Comments also reflected an expectation that patients would be prepared for needs they could not anticipate, but which might be reasonably anticipated by healthcare providers, particularly when a new diagnosis is received.

Specific opportunities were identified to improve patient-centered care so that preparation is also made easy for the patient rather than just for care providers; numerous comments about being well-prepared for the day of surgery but not well-prepared for what to do and expect after
surgery were provided. Further, a focus on tailoring an individual’s ‘return to living life’ rather than a focus on ‘discharge planning’ of patients from the hospital may be an opportunity for further research. Findings suggest that providing ‘patient education’ and ‘information sharing’ are not enough, and that incorporating more patient-focused ‘planning’ and ‘practice’ may better serve patients’ return to living life needs. The ability for the survey tool to capture the lasting impacts that are borne by patients at home when inadequate preparation was provided during hospitalization, provides an opportunity to better understand how important it is for patients to receive clear, consistent, accessible, specific and personalized preparation while they are in hospital. It further contributes to knowledge about patients’ experiences with coordinated care along their care continuum.

The findings that patients want to feel safe, secure, comfortable and cared for, that patients want to feel like a person, and that patients want to feel prepared to return to living are inextricably linked. It is likely that all components must be present for patients to experience high quality patient-centered care, and while each is probably necessary for excellent hospital stay experiences, the presence of only one aspect would be insufficient. Further, the culmination of hospital events that did help patients to feel safe, like persons, and prepared made impressions upon patients’ overall experiences of respect and dignity.

There is richness of information contained in patients’ comments, such that the ‘real’ experience of patients helps to explain what happened and why it was significant for patients to remember. The open-ended question in the patient survey tool serves as a viable patient engagement activity and findings may be used to complement numerical survey results. Survey comments, reviewed and used at the local level by the healthcare providers who provide direct care to patients, present opportunities to guide improvement ideas and direct care to leading the improvement of relationships with patients. Findings inform a proposed framework and process for how to approach reading and interpreting individual patients’ comments so they may be discussed by local level teams.

Because this study used survey comments from patients, a final note is made about respect for patients’ time and efforts in completing a survey. Findings suggest that patients endeavoured to provide comments that were practical and could be used. At times, specific recommendations about changes that could improve the hospital stay experience were made. Regular review of
patients’ survey comments to assess the utility of them, and then to prioritize a plan to use any that are practicable, may be a next level of respecting patients’ engagement. The new Canadian Patient Experiences Survey-Inpatient Care (CPES-IC) (CIHI, 2016a) is now collecting patients’ survey data, including comments, into a national database (CIHI, 2016b). While the patient survey remains the predominant method of patient engagement, all efforts should be made to use the information collected therein. It is time to regularly review, organize and present, formally discuss, and prioritize the recommendations that come from patients’ experiences, including those that are already collected and available in patient surveys. The task is likely feasible and achievable. The process will require an investment of hard work by direct care providers to incrementally change and sustain local improvement processes (Bohmer, 2016). The high hopes that exist for patients’ perspectives to guide new innovations toward higher quality healthcare (Naylor, et al., 2015) may only be realized if we increase meaningful patient engagement activities.

The imperative to do something different is growing. It is time now to use the information we gather. The use of patients’ survey comments could add to what is already happening, and help to meet and surpass financial, ethical, patient engagement and quality improvement goals and accountability. Patients’ survey comments provide useful patient-reported data about patients’ observations, insights and experiences for quality improvement, and they suggest what could be possible for excellent patient experiences.
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Appendix I

NRCC Adult Inpatient Survey

Sunnybrook
HEALTH SCIENCES CENTRE

Please use the enclosed postage-paid envelope and mail the completed survey to:
National Research Corporation
Canada
7100 Woodbine Ave Suite 411
Markham ON L3R 5J2

[ Name of patient ]

[ Mailing address of patient ]

Dear [ Name of patient ]:

Recently you were mailed a questionnaire regarding the inpatient services you received at Sunnybrook Health Sciences Centre. If you have already returned your questionnaire, thank you and please disregard this note. If you have not yet had a chance to complete the questionnaire, or if you no longer have the copy sent to you, please take a moment to complete the extra copy enclosed.

Your opinions are valuable to us. At Sunnybrook Health Sciences Centre we want to provide the best possible service to our patients. In order to do so, we need to know what we are doing right and what may need improvement. Your feedback will be used to improve how we provide care.

Please complete the enclosed questionnaire and return it in the envelope provided as soon as possible. If you choose to have a friend or relative assist you in completing the survey, please make sure that the answers represent your own feelings. If you require accommodation to participate in this survey due to a disability, an accessible format can be made available upon request by calling NRCC at 1-866-771-8231. Only a limited number of our patients receive this questionnaire, so your participation is very important.

Completion of the survey is voluntary. Your responses will be kept confidential. Please feel free to express your opinions frankly and be assured that your future care at our hospital will not be negatively impacted. An independent research company will receive your response and analyze the results. To protect your privacy, your personal information will not be provided to the hospital. The hospital will review your comments, however you will not be contacted directly regarding any comments or concerns. Should you wish to speak with someone directly regarding your care experience, please contact our Patient Advocate at (416) 480-4940.

If this questionnaire has reached you in error, please contact us to have your name removed. Every effort is made to ensure that this questionnaire is not sent to families of patients who have passed away. If a grieving family member receives this letter, please accept our heartfelt condolences and our sincere apology. It is certainly not our intention to add pain to your sorrow and grief. If you wish, you may respond to this questionnaire on behalf of your loved one. If your wish is not to respond, we will respect your wishes.

If you have any questions or concerns or wish to be removed from the survey, please contact our Patient Advocate at (416) 480-4940. When leaving a voice message, please provide the ID # that is above your address.

Thank you for your time and help. Your effort will help us provide better care to all our patients.

Sincerely

[Signature and name]

President and CEO
Your Hospital/Facility Stay...

Please fill in the circle that best describes your experience during your hospital/facility stay ending on March 3, 2013. Thank You!

ADMISSION...

1. Were you:
   ☐ Admitted through the Emergency Department
   ☐ Admitted through a planned admission by your doctor
   ☐ Admitted unexpectedly after a day procedure or test
   ☐ Transferred from another facility
   ☐ Other

2. How organized was the admission process?
   ☐ Not at all organized
   ☐ Somewhat organized
   ☐ Very organized

3. Do you feel you had to wait an unnecessarily long time to go to your room?
   ☐ Yes, definitely
   ☐ Yes, somewhat
   ☐ No

4. If you had to wait to go to your room, did someone from the hospital explain the reason for the delay?
   ☐ Yes
   ☐ No
   ☐ Did not have to wait

5. How would you rate the courtesy of the staff who admitted you?
   ☐ Poor
   ☐ Fair
   ☐ Good
   ☐ Very Good
   ☐ Excellent

DOCTORS...

6. Was there one particular doctor in charge of your care in the hospital?
   ☐ Yes
   ☐ No
   ☐ Not sure

7. When you had important questions to ask a doctor, did you get answers you could understand?
   ☐ Yes, always
   ☐ Yes, sometimes
   ☐ No
   ☐ Did not have questions

8. If you had any anxieties or fears about your condition or treatment, did a doctor discuss them with you?
   ☐ Yes, completely
   ☐ Yes, somewhat
   ☐ No
   ☐ Did not have anxieties or fears

9. Did you have confidence and trust in the doctors treating you?
   ☐ Yes, always
   ☐ Yes, sometimes
   ☐ No

10. Did doctors talk in front of you as if you weren’t there?
    ☐ Yes, often
    ☐ Yes, sometimes
    ☐ No

11. How would you rate the courtesy of your doctors?
    ☐ Poor
    ☐ Fair
    ☐ Good
    ☐ Very Good
    ☐ Excellent

12. How would you rate the availability of your doctors?
    ☐ Poor
    ☐ Fair
    ☐ Good
    ☐ Very Good
    ☐ Excellent

13. Overall, how would you rate the care you received from your doctors?
    ☐ Poor
    ☐ Fair
    ☐ Good
    ☐ Very Good
    ☐ Excellent

NURSES...

14. When you had important questions to ask a nurse, did you get answers you could understand?
   ☐ Yes, always
   ☐ Yes, sometimes
   ☐ No
   ☐ Did not have questions
15. If you had any anxieties or fears about your condition or treatment, did a nurse discuss them with you?
   - Yes, completely
   - Yes, somewhat
   - No
   - Did not have anxieties or fears

16. Did you have confidence and trust in the nurses treating you?
   - Yes, always
   - Yes, sometimes
   - No

17. Did nurses talk in front of you as if you weren’t there?
   - Yes, often
   - Yes, sometimes
   - No

18. How would you rate the courtesy of your nurses?
   - Poor
   - Fair
   - Good
   - Very Good
   - Excellent

19. How would you rate the availability of your nurses?
   - Poor
   - Fair
   - Good
   - Very Good
   - Excellent

HOSPITAL STAFF...

20. Sometimes in the hospital, one doctor or nurse will say one thing and another will say something quite different. Did this happen to you?
   - Yes, always
   - Yes, sometimes
   - No

21. Did you have enough say about your treatment?
   - Yes, definitely
   - Yes, somewhat
   - No

22. Did your family or someone close to you have enough opportunity to talk to your doctor?
   - Yes, definitely
   - No
   - Family did not want or need to talk
   - Yes, somewhat
   - No family or friends were involved

23. How much information about your condition or treatment was given to your family or someone close to you?
   - Not enough
   - Too much
   - Family did not want or need information
   - Right amount
   - No family or friends involved

24. Was it easy for you to find someone on the hospital staff to talk to about your concerns?
   - Yes, definitely
   - Yes, somewhat
   - No
   - Did not want to talk/no concerns

25. When you needed help getting to the bathroom, did you get the help in time?
   - Yes, always
   - Yes, sometimes
   - No
   - Did not need help

26. How many minutes after you used the call button did it usually take before you got the help you needed?
   - 0 minutes/right away
   - 6-10 minutes
   - 10-15 minutes
   - More than 10 minutes
   - Never got help

27. In general, after you used the call button, was the time you waited for help reasonable?
   - Yes, completely
   - Yes, somewhat
   - No
   - Didn’t use call button

28. Did a doctor or nurse explain the results of tests in a way you could understand?
   - Yes, completely
   - Yes, somewhat
   - No
   - No tests were done

29. Were your scheduled tests and procedures performed on time?
   - Yes, always
   - Yes, sometimes
   - No
   - No tests/procedures

30. Did you feel like you were treated with respect and dignity while you were in the hospital?
   - Yes, always
   - Yes, sometimes
   - No

PAIN...

31. Were you ever in any pain? If no, go to #37.
   - Yes
   - No (Go to #37)

32. When you had pain, was it usually severe, moderate, or mild?
   - Severe
   - Moderate
   - Mild
33. Did you ever request pain medicine? If no, go to #35.
   ○ Yes    ○ No (Go to #35)

34. How many minutes after you requested pain medicine did it usually take before you got it?
   ○ 0 minutes/right away  ○ 6-10 minutes  ○ 16-30 minutes  ○ Never got medicine
   ○ 1-5 minutes           ○ 11-15 minutes  ○ More than 30 minutes

35. Do you think that the hospital staff did everything they could to help control your pain?
   ○ Yes, definitely  ○ Yes, somewhat  ○ No

36. Overall, how much pain medicine did you get?
   ○ Not enough  ○ Right amount  ○ Too much

GOING HOME...

37. Did someone on the hospital staff explain the purpose of the medicines you were to take at home in a way you could understand?
   ○ Yes, completely  ○ No  ○ No medicines at home
   ○ Yes, somewhat  ○ Did not need explanation

38. Did someone tell you about medication side effects to watch for when you went home?
   ○ Yes, completely  ○ No  ○ No medicines at home
   ○ Yes, somewhat  ○ Did not need explanation

39. Did they tell you what danger signals about your illness or operation to watch for after you went home?
   ○ Yes, completely  ○ Yes, somewhat  ○ No

40. Did they tell you when you could resume your usual activities, such as when to go back to work or drive a car?
   ○ Yes, completely  ○ Yes, somewhat  ○ No

41. Did the doctors and nurses give your family or someone close to you all the information they needed to help you recover?
   ○ Yes, definitely  ○ No  ○ Family did not want or need information
   ○ Yes, somewhat  ○ No family or friends involved

42. Did you know who to call if you needed help or had more questions after you left the hospital?
   ○ Yes  ○ No  ○ Not sure

OVERALL IMPRESSION...

43. While you were in the hospital, were you able to get all the services you needed?
   ○ Yes, completely  ○ Yes, somewhat  ○ No

44. Overall, how would you rate the care you received at the hospital?
   ○ Poor  ○ Fair  ○ Good  ○ Very Good  ○ Excellent

45. How would you rate how well the doctors and nurses worked together?
   ○ Poor  ○ Fair  ○ Good  ○ Very Good  ○ Excellent

46. Would you recommend this hospital to your friends and family?
   ○ Yes, definitely  ○ Yes, probably  ○ No

AMENITIES...

47. How would you rate the quality of the food (how it tasted, serving temperature, variety)?
   ○ Poor  ○ Fair  ○ Good  ○ Very Good  ○ Excellent

48. How would you rate the condition of your room and hospital environment (cleanliness, comfort, lighting, temperature)?
   ○ Poor  ○ Fair  ○ Good  ○ Very Good  ○ Excellent
ADDITIONAL QUESTION...

49. How would you rate how well the team members on your unit worked together?
   ○ Poor  ○ Fair  ○ Good  ○ Very Good  ○ Excellent

YOUR BACKGROUND...

In order to be sure we have survey responses from a variety of people, we are asking you to provide some information about your background. Remember, your individual responses will not be shared with anyone.

50. In general, how would you rate your health?
   ○ Poor  ○ Fair  ○ Good  ○ Very Good  ○ Excellent

51. During the past month, how many days did illness or injury keep you in bed all or part of the day?
   ○ None  ○ Two Days  ○ Four Days  ○ Eight-to-Ten Days
   ○ One Day  ○ Three Days  ○ Five-to-Seventy Days  ○ More than Ten Days

52. Including this hospital stay, how many times in the last six months have you been in a hospital overnight or longer?
   ○ Only this time  ○ This time and one other time  ○ This time and more than one other time

53. What is the highest grade or level of school that you have completed?
   ○ Public school  ○ College, trade, or technical school  ○ Post university/graduate education
   ○ High school  ○ University undergraduate degree

54. Who completed this survey?
   ○ Patient  ○ Someone else

The hospital will review your comments, however you will not be contacted directly regarding any comments or concerns. Should you wish to speak with someone directly regarding your care experience, please contact our Patient Advocate at (416) 485-4940.

55. Is there anything else you would like to tell us about your hospital stay?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thank you for taking the time to complete this questionnaire. Your answers are greatly appreciated. When you are done, please use the enclosed pre-paid envelope to return this questionnaire to National Research Corporation Canada, 7100 Woodbine Ave, Suite 411, Markham ON L3R 5J2.

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Appendix II

Research Ethics Board approvals

To: Isabella Cheng
Professional Practice
Room DG11b

From: Dr. Brian J. Murray

Date: October 2, 2014

Subject: Going Beyond the Numbers: Hearing the Voices of Patients

Project Identification Number: 390-2014
Approval Date: October 2, 2014
Expiry Date: October 2, 2015

The Research Ethics Board of Sunnybrook Health Sciences Centre has conducted a Delegated Board review of the research study referenced above and approved the involvement of human participants. Quorum for approval did not involve a member associated with this study.

The approval of this study includes the following documents:

- Protocol dated August 15, 2014

☐ The Sunnybrook REB has determined that an Informed Consent Form (ICF) is not required for this study; consent requirements, if applicable, have been otherwise dealt with in accordance with Article 3.7 and/or 3.12 and/or 5.5 of TCPS2.

As Principal Investigator you are responsible for the ethical conduct of this study which may be subject to review by the Quality Assurance and Education Program. The study must comply with current legislation outlined in the Ontario Personal Health Information Protection Act (PHIPA) and all acts, regulations, guidelines and policies that govern this research. The REB requires immediate notification of internal serious adverse events and significant deviations, submission of a renewal form prior to the approval expiry date, and notification of study closure.

The REB and Research Ethics Office are in support of facilitating the progress of ethical research and thank you in advance for your efforts to protect research participants. Best wishes for a successful project.

Brian J. Murray, MD FRCP(C) D, ABSM
Chair, Research Ethics Board

Philip C. Hébert, MD PhD FCFPC
Vice-Chair, Research Ethics Board
PROTOCOL REFERENCE # 30880

October 28, 2014

Dr. Helene Polatajko
DEPT OF OCCUPATIONAL THERAPY
FACULTY OF MEDICINE

Ms. Isabella Cheng
DEPT OF OCCUPATIONAL THERAPY
FACULTY OF MEDICINE

Dear Dr. Polatajko and Ms. Isabella Cheng,

Re: Administrative Approval of your research protocol entitled, "Going beyond numbers in patient satisfaction surveys: Hearing the voices of patients"

We are writing to advise you that the Office of Research Ethics (ORE) has granted administrative approval to the above-named research protocol. The level of approval is based on the following role(s) of the University of Toronto (University), as you have identified with your submission and administered under the terms and conditions of the affiliation agreement between the University and the associated TAHSN hospital:

- Graduate Student research - hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board (REB). Please note that you do not need to submit Annual Renewals, Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University's involvement requires ethics review.

Best wishes for the successful completion of your research.

Yours sincerely,

[Signature]

Dario Kuzmanovic
REB Manager