Partnering with Patients to Understand and Improve Their Healthcare Experiences

Pilot Study Report - September 2012

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Partnering with Patients to Understand and Improve their Healthcare Experiences

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Executive Overview: Partnering with Patients

Partnering with Patients to Understand and Improve their Healthcare Experiences

“The main thing... the care you’re receiving, that one you will remember forever, because if it's a good care done or people listen to your problem or answer your questions or be pleasant, or just say simply say "hi" to you, it matters, because that you will remember.” (Research Participant)

Toronto’s University Health Network (UHN), with its four world-renowned teaching hospitals, is committed to providing the highest quality of patient-centred care (PCC) through its Declaration of Values including Caring, Respect, Excellence, Teamwork, Innovation, Integrity, and Leadership. UHN holds itself accountable to these values through regular assessments of its performance, including measurements of inpatient satisfaction.

In their April 2012 Briefing, “Integrated Health Care: The Importance of Measuring Patient Experience and Outcomes,” the Conference Board of Canada identifies ways leaders can support the measurement of patient-centred care through new approaches and tools that capture patient experience: “Include the patient’s perspective on integrated care in performance reports,” and “Be prepared to act on what is learned from measuring patient-centred outcomes” (Stonebridge & Godfrey, 2012, p. 12-13). UHN’s primary tool for measuring inpatient satisfaction is an English-only, standardized, mail-in version of the Canada-wide NRC+Picker Group patient satisfaction survey instrument. Between 2002 and 2008, the NRC+Picker survey indicated that Toronto Western Hospital had lower patient satisfaction than UHN’s other hospitals. While survey tools are important, they do not provide sufficient information for UHN to fully understand and address the experiences and unique needs of UHN’s urban, multicultural, and multi-lingual patients.

UHN’s Executive initiated a phenomenographic research study in 2008, to achieve four goals:

1. Acquire new knowledge and greater understanding of UHN patients’ experiences through the patients’ own stories;
2. Include patients with linguistic and cultural differences;
3. Create new models for increased patient engagement and partnerships in research; and,
4. Disseminate and apply the learnings from the patients’ stories to UHN’s practices.

Phenomenography captures the variation in ways that patients themselves understand and make meaning of their inpatient experiences. The pilot study engaged patients as full members of a transprofessional, multi-lingual research team. Five research participants, all former patients at Toronto Western, were interviewed in their own first language (English or Cantonese).

The study’s results represent variation in ways of experiencing patient satisfaction at Toronto Western. Analysis of the patients’ stories produced evidence-based categories of experiences. The prioritized relationships among these categories are represented as five levels of needs in an outcome space that represents patient satisfaction at Toronto Western. The five levels of patient needs in the study’s outcome space represent patient satisfaction at Toronto Western:

- Level of Need 1: Information and knowledge that patients actually understand
- Level of Need 2: Competent, skilled, and respectful care
- Level of Need 3: Culturally appropriate comfort and responsiveness

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- Level of Need 4: Informed and engaged family and friends
- Level of Need 5: Deserve to be treated with respect, as human beings, at all times.

When any of these needs were not met, patients felt that they did not matter to their caregivers. The memory of being disrespected did not diminish over time. Indeed, participants could share stories about the experience as though their hospitalization had taken place the previous day.

While all needs exist throughout a patient’s hospitalization, the pilot study indicates that the importance of each need varies with the phase of hospitalization. Dissatisfaction increases when patients believe that the caregiver ignores this variation. During recovery a patient may need more independence than is possible earlier in the hospitalization.

While the design and preparation for the pilot study extended over two years, interviews and analyses were completed in six months. Multiple UHN staff turnovers, including the co-Principal Investigator and several project coordinators contributed to the initial delays. Forms and transcripts had to be officially translated to support the inclusion of a Cantonese-speaking participant. Each change required re-submission to the UHN REB. These changes were in the context of an action research initiative that could disseminate and apply the findings and recommendations from the study to policy and practice change within UHN.

The Pilot Study met the goals established by UHN’s Executive:

1) Acquire new understanding of UHN patients’ experiences through the patients’ own stories.
   a) Patients identified five levels of needs: Information and knowledge; Skilled care; Culturally appropriate care; Engaged family and friends; and, Respect.

2) Include patients with linguistic and cultural differences
   a) Cantonese speaking participant was interviewed in Cantonese
   b) Results emphasized importance of culturally appropriate care for physical and emotional well-being and overall satisfaction.

3) Create new models for increased patient engagement and partnerships in research
   a) Patients fully engaged as team members from initial design through final analysis
   b) Sustained partnerships among UHN, two universities, and Cantonese community

4) Disseminate and apply the learnings from the study to practices within the healthcare system.
   a) Training and development among UHN staff members in qualitative interviewing, collaborative analysis, transprofessional teams, and understanding variation theory
   b) Final report and options for future publications and presentations.

The pilot study established the foundation for a sustainable and cost-effective phenomenographic research that would complement and add important additional information to the NRC+ Picker survey. This combined knowledge could help UHN continue excel in innovative approaches and tools to measure health outcomes from the patient’s perspective.

The research team recommends that UHN’s leaders utilize the design and new knowledge from this pilot study to implement a twice-yearly phenomenographic study that includes the interviews of a small number of participants (8 to 10), including at least two non-English speakers. The preparatory work has been completed. Sustainable, limited phenomenographic research could be implemented with minimal design modification and limited costs. The value to UHN of subsequent research would be cumulative, expanding the knowledge from this pilot.
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Partnering with Patients: The Pilot Study

I was interested in it listening to our patients and coming to understand the breadth of variability around what mattered to them in the hospital. With such an understanding, we wanted to set an agenda for change to address some of those things. Secondly, I wanted to create a tool that would more effectively measure patient understandings of effectiveness. I also thought it would be an opportunity to move Phenomenography into the Canadian context.

(Mary Ferguson-Paré, Study Initiator, CM, RN (Ret), PhD, CHE; Vice President Professional Affairs & Chief Nurse Executive, (Retired), UHN)

This report describes the pilot study for the Partnering with Patients to Understand and Improve their Healthcare Experiences research project, designed to better understand the variation of patient satisfaction among UHN hospitals. The research was initiated by UHN in partnership with Royal Roads University (Victoria, BC) and Fielding Graduate University (Santa Barbara, California). The objective of this pilot was to test the capacity of the study’s design to acquire and analyze evidence-based data from the patients themselves, to achieve four goals:

1. Acquire new knowledge and greater understanding of UHN patients’ experiences through the patients’ own stories;
2. Include patients with linguistic and cultural differences;
3. Create new models for increased patient engagement and partnerships in research; and,
4. Disseminate and apply the learnings from the patients’ stories to practices within the healthcare system.

Toronto’s University Health Network (UHN) brings together four world-renowned teaching hospitals to achieve its mission of exemplary patient care, research, and education to serve its patients, its community, and the world. UHN’s commitment to patient-centred care (PCC) and partnership with patients is reflected in its Declaration of Values including Caring, Respect, Excellence, Teamwork, Innovation, Integrity, and Leadership. UHN holds itself accountable to these values through regular assessments of its performance, including measurements of inpatient satisfaction.

In their April 2012 Briefing, “Integrated Health Care: The Importance of Measuring Patient Experience and Outcomes,” the Conference Board of Canada identifies ways leaders can support the measurement of patient-centred care through new approaches and tools that capture patient experience: “Include the patient’s perspective on integrated care in performance reports,” and “Be prepared to act on what is learned from measuring patient-centred outcomes” (Stonebridge & Godfrey, 2012, p. 12-13).

UHN’s primary tool for measuring inpatient satisfaction is an English-only, standardized, mail-in version of the Canada-wide NRC+Picker Group patient satisfaction survey instrument. Between 2002 and 2008, the NRC+Picker survey indicated that Toronto Western Hospital had lower patient satisfaction than UHN’s other hospitals. While the survey tools are important, they do not provide sufficient information for UHN to fully understand and address the
experiences and unique needs of UHN’s urban, multicultural, and multi-lingual patients.

This study captures and analyses the experiences of patients from multiple cultural and linguistic backgrounds. Most published research on patient satisfaction (see Appendix B) is based in what medical professionals and researchers believe should satisfy patients and does not account for the patients’ perspectives on their needs or for variations in culture, health care beliefs, and language.

The Transprofessional Research Team included UHN clinical, research, administrative, educational, and multilingual staff; UHN patients; and, academic researchers from Fielding Graduate University and Royal Roads University. The five research participants for the pilot study were English and Cantonese-speaking discharged patients Toronto Western Hospital. The Research Team used a phenomenographic methodology to interview participants and to analyze, prioritize, and graphically represent the most important categories of the patients’ experiences.

These categories were analyzed further into five, interrelated levels of patients’ needs that are presented in the study’s graphical outcome space. This outcome space, with its five levels of patient needs, represents the variation in patient satisfaction at Toronto Western.

Methodology

In our past, we have never done the patient satisfaction especially for a diverse population. This is our first time that we have done the research at this level.... I feel very excited about that. I've worked in the hospital for 10 years, a long time...There are no patient satisfaction questionnaires that are in the top five languages other than English, and that includes Chinese, including Mandarin and Cantonese, Vietnamese, Spanish and Portuguese, the top five most requested languages. Some patients don't know about the existence of the interpretation services. The patient satisfaction research is very important to capture this feedback from the patients themselves. When I started to recruit former patients for the study, I got so many calls from the community from excited people who would have liked to have participated in this project.

(Miu Lin Wong, Team Member, MEd, RSSW, Health Promotion Coordinator, Patient and Family Library, Women’s Health Initiative, Family Health Team, Toronto Western Hospital, UHN)

Phenomenography and Variation Theory

A Phenomenographic research approach was selected, as a collaborative methodology that would capture and analyze the variation in ways that patients themselves understood and made meaning of their hospitalization (see Appendix B). Phenomenography was developed at the University of Göteborg in Sweden to understand the variation in how research participants experience and make sense of a phenomenon, by asking the participants themselves. Its original use was to understand how students in a classroom experienced learning. Phenomenography soon extended into other disciplines, including healthcare, business, psychology, and technology.
Today, researchers in Europe, Australia, New Zealand, and, more recently, in Canada and the United States, use this approach to better understand health care concerns, needs, and experiences. Phenomenography asserts that there is variation in the ways that a phenomenon such as hospitalization is experienced. It is through this variation that the phenomenon is best understood.

This pilot study used a phenomenographic approach to understand the variation in ways that five English and Cantonese participants experienced their hospitalization at Toronto Western, by asking the patients themselves to share stories of their hospitalization.

The Transprofessional Research Team with Patient Engagement

The pilot study benefited from a transprofessional research team that welcomed people from a variety of disciplinary, experiential, linguistic, and cultural backgrounds into a cohesive, collaborative, and effective team (see Appendix C). Members included former patients; UHN healthcare, administration, research, and community-education personnel; and academic researchers. The results reflect the strength of the team’s multi-perspective contributions. Although several of UHN’s team members changed during the project, the other members of the core team, including the patient members, were engaged throughout the pilot study.

The two patient members of the research team, as well as the academic researchers, supported the ongoing continuity of the team, during the transitions of UHN team members.

Throughout the design and development phases of the pilot, the patient team members provided timely comments that brought their critical perspectives into the design. During the analysis phase, a key moment occurred when one patient team member expressed a strong affiliation with the results and the selected quotations – stating that the levels of patient needs in the results reflected his own experiences! He noted differences among caregivers, and saw these differences reflected in the levels of patient needs. During the analysis phase, the patient team members provided key analyses, identified areas that others missed, and helped to fine-tune the important variations in ways of understanding hospitalization.

Pilot Study Development

The development of the pilot study extended well beyond its initial timeline (see Appendix D). The development had seven steps: initial proposal and design; adjustments to staff and design changes; REB approval; interviews and transcription; collaborative analysis; and report writing. While the last four steps (interviews and transcription, analysis, and report writing) were accomplished in less than six months, the initial three steps extended more than two years.

There were multiple UHN staff turnovers, including the co-principal investigator and several project coordinators. Two patients were added as team members. New team members needed training. Forms and transcripts had to be translated into English. The original approach for participant recruitment (focus groups) was revised to individual interviews. Each change required re-submission of the REB application.

Initial attempts to recruit participants while they were still in hospital, proved ineffective. In addition, feedback from potential participants revealed a preference for one-on-one private interviews rather than a focus group approach. As a result, procedural changes were designed to: a) recruit patients after they had been discharged; b) extend the criteria for length of time since hospitalization; and, c) recruit for individual interviews rather than focus groups. In December 2011, REB authorization was obtained to move forward with the new research protocol. The research then proceeded without further delays.

The pilot study included one Cantonese and four English interviews with former inpatients at
Toronto Western (see Appendix E). Each interview was conducted, recorded, and transcribed in the patients’ first language. A bilingual team member conducted the interview in Cantonese. The transcription of the Cantonese interview was then translated into English. Interviews were conducted in January and February 2012, and transcripts were available early in March 2012.

**Collaborative Analysis**

Collaborative analysis is a key attribute of phenomenographic research. The collaborative analysis team included the bi-lingual interviewer the patient members of the team, the academic researchers, and healthcare providers from UHN, in order to understand as fully as possible the variation in ways the study participants made meaning of their hospitalization. The collaborative analysis occurred in March and April and involved several team members. After the completion of one transcript, it was noted that one participant’s experiences were from a hospitalization that was outside of the boundaries of the pilot. This interview was included in the analysis in order to assess if an extension of the time span would have an impact on the results.

The analysis confirmed that the patients’ experiences are easily recalled, even after a period of several years. The key categories of the patients’ experiences remained constant, even after several years. In subsequent studies, the length of time since a participant’s hospitalization should be related to the hospitals structural, procedural, or staffing changes. When these aspects of UHN’s system remain fairly constant, there could be an extension of up to five years in the length of time between inpatient discharge and participation in future phenomenographic studies.

**The Pilot Study Met UHN’s Original Goals**

The pilot study successful met the goals established by UHN’s Executive:

1) **Acquire new knowledge and greater understanding of UHN patients’ experiences through the patients’ own stories;**
   a) Patients identified five categories of needs: Information and knowledge; Skilled caregivers; Culturally appropriate and responsive care; Engaged family and friends; and, Respect as a human being.
   b) The prioritization of these needs vary across phases of hospitalization.

2) **Include patients with linguistic and cultural differences**
   a) Cantonese speaking patient was interviewed in Cantonese.
   b) Results emphasized importance of culturally appropriate care for physical and emotional wellbeing and overall satisfaction.

3) **Create new models for increased patient engagement and partnerships in research**
   a) Patients fully engaged as team members from initial design through final analysis
   b) Sustained partnerships among UHN, two universities, and Cantonese community.

4) **Disseminate and apply the learnings from the patients’ stories to practices within the healthcare system.**
   a) Training and development among UHN staff members in qualitative interviewing, collaborative analysis, transprofessional teams, and understanding variation
   b) Final report and options for future publications and presentations.
The Pilot Study Results

The pilot study analyzed the ways participants made meaning of their inpatient experiences and organized the analysis into five categories that represent different aspects of their hospitalization experience. The relationships among these five categories are illustrated as five, interrelated levels of needs, and presented graphically in a diagram referred to as an outcome space. This outcome space, of five interrelated levels of patient needs, represents the variation in ways of experiencing patient satisfaction at Toronto Western.

Five Levels of Patient Needs

The patient interviews were transcribed in the language of the interview. The Cantonese interview initially conducted in Cantonese, was transcribed and then translated into English. The interviewer, who was also a member of the research team, verified the translation.

Phenomenographic analysis occurred through collaborative analysis with the team members to develop the final levels of needs that best represent the experiences of the participants. These levels of need were validated by the patient representatives on the Study Team as being consistent with their experience as an in-patient.

Analysis of the pilot study transcripts produced five distinct yet interrelated categories of patient needs, based on the experiences described by the participants themselves. The categories are represented in five levels of patient needs:

- Level of Need 1: Information and knowledge of what is taking place and of their medical condition in ways that patients understand;
- Level of Need 2: Competent, skilled, and respectful caregivers, as perceived by patients;
- Level of Need 3: Culturally appropriate responsiveness - providing comfort;
- Level of Need 4: Informed and engaged family members and friends
- Level of Need 5: Above all, deserve to be respected and valued as human beings.

Graphical Representation of Pilot Results as Interrelated Levels of Needs

Phenomenographic research requires analysis that goes beyond that of many other research methods. After the analysis of data into categories, researchers analyze the relationships among the categories and represent the categories in a graphical outcome space. In this pilot, the outcome space represents five, interrelated levels of patient needs, and is based on the variations in the patients’ experiences.

This outcome space may be viewed as a matrix that presents a definition of the concept of patient satisfaction. It is similar to Maslow’s Hierarchy of Needs (1943), where basic safety, food and shelter needs must first be addressed in order for the individual to appreciate higher levels of self-actualization. Each level of patient needs in our pilot study appear to be dependent upon a successful experience in all of the lower levels of need categories.

Level of Need 1 is the basic need for information and knowledge that is understood by the patient. This need may require information presented by trained interpreters for non-English speaking patients.

Level of Need 2, the need for competent and skilled caregiving, requires the first level of need (information and knowledge) is met. Patients need to receive and understand the appropriate
information and knowledge about what will happen and what they can expect.

*Level of Need 3*, the need for culturally appropriate care, requires the first two levels of needs to be met in ways that the patients understand is helpful and is respectful of their cultural understandings.

*Level of Need 4* emphasizes the need for family and friends to be engaged and accompanies the first three levels of need for many patients. Family members or friends may be needed for patients to understand the relevant medical and process information, especially if there are differences in language or culture, or if the patient is incapacitated. Family and friends often provide some of the patient care that may be essential to meet patients’ cultural and linguistic needs.

*Level of Need 5*, the highest-level category of patient needs, represents the deeply held belief by patients that they deserve to be respected and treated as human beings. The “I Matter” category is the overarching level. Meeting this level of patient satisfaction requires that the patient has experienced satisfaction in all of the preceding levels.

**Importance of the Pilot Study Results**

The pilot study’s findings, analyzed directly from the patients’ own words, represent new knowledge that increases understanding of patient satisfaction.

As further validation of the study’s results, the five levels of needs, based in this research, are compatible with those of UHN’s other ways of assessing patient-centred care, including the NRC+ Picker Institute’s eight dimensions of patient-centred care and UHN’s seven values.

This research deepens our actionable knowledge on patient satisfaction as we learn from the specific incidents that patients shared with us. The pilot suggests ways that UHN could improve patient satisfaction, including for patients with limited English or different cultural traditions.

The pilot demonstrates the feasibility of the next phase through a strategy that links a small number of phenomenographic interviews and analysis with recruitment for the NRC+ Picker Group Canada Patient Satisfaction Survey Instrument (Picker survey). The research should be extended into other sites and include other language and culture groups. Funding sources would include community groups, research funders, and organizations that are concerned with patient-centred care, patient engagement, and patient experience, especially among diverse cultural and linguistic groups such as community groups that might support translation costs.

The transprofessional Project Team, including engaged patients, was a resounding success. The team remained cohesive throughout many delays. The two patient members of the team provided leadership, insights, and reality checks throughout the project. As leadership and staff changed within UHN and within the project, there remained a core group of team members who believed in this project, valued the words and experiences of the participants, and never wavered from their commitment to the success of this project.
Five Levels of Patient Needs

<table>
<thead>
<tr>
<th>Level of Need 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Matter!</td>
</tr>
<tr>
<td>I deserve to be respected and valued as a Human Being</td>
</tr>
<tr>
<td>(Level of Needs 1, 2, 3, 4 must be met)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of Need 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Family and Friends to be informed and engaged</td>
</tr>
<tr>
<td>(Parallel to Needs 1, 2, and 3)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of Need 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Culturally appropriate Responsiveness providing comfort</td>
</tr>
<tr>
<td>(Levels 1 and 2 must be met)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of Need 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competent, Skilled, Respectful Caregivers</td>
</tr>
<tr>
<td>(Level 1 must be met)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of Need 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and Knowledge</td>
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</tbody>
</table>

Relationships among Levels of Patient Needs

In this pilot study, the analysis of the patients’ stories revealed five different levels of needs when a person is hospitalized. When patients perceive that their needs are not met in any of the five levels, overall patient satisfaction appears to be diminished. Satisfaction at each level requires the patient needs of the lower levels to be met. See Appendix F for the text from participant interviews that relate to each of the five levels.

Level of Need 1: Need for Information and Knowledge.

The patients’ experiences show how the exchange of knowledge and information, through shared language, are a necessary first step in quality care and for remaining levels of care.

*She had a good sense of humour, which I liked. She was easy to talk to, and we chatted for quite a while. She made if feel personal, opposed to you know someone just going for chest x-rays or submitting for blood work. She made the whole thing seem more personal and I could ah, feel*
more comfortable asking her any questions that I had that day.

Level of Need 2: Need for Competent, Skilled, Respectful Caregivers

Patients notice and assess the skills and competencies of the healthcare providers. The care must meet the hospital’s quality standards—and must be experienced by the informed patients as being respectful and skilled.

The nurses were very nice overall. Only I feel that - only those with the skills should do the work. You ask her to draw my blood; for sure you would ask someone who knows how to draw blood to do it. That is human flesh - it was pinched and injured all over. That is sin, don't you understand! [Cantonese former patient]

Level of Need 3: Need for Culturally-Appropriate Responsiveness and Comfort

Culture and language add a third layer of complexity, while including information and skill. Patients may suffer if they experience a lack of caring, unresponsiveness, or have their cultural needs and beliefs ignored or discounted.

We used to drink boiled water. It doesn't seem that I have ever tried drinking directly from the tap, and not boiling water to drink. I boil water every day... It was smashed potato every day, and bread, but I could not eat those. I was not used to that. I stayed nine days in the hospital in total and my digestive system had not been well even after I was home. I had ... diarrhea. When I took medicine, he would go straight to the tap to get water but I couldn't drink that water...

[Cantonese former patient]

Level of Need 4: Need for Informed and Engaged Family and Friends

Family and friends are important in all phases of the hospitalization. They may be essential for accurate information and supporting skilled care.

Family and friends are a cultural link, and serve as a lifeline for a patient who is overwhelmed by the foreignness of the hospital as well as illness.

I had a nurse coming from my neurologist’s office. She had permission to be with me for the day (yes) and she said it was very difficult to get permission because she felt like, a bit of an intruder.

Having my husband with me throughout the whole procedure was comforting. He had a good sense of humour so we were able to joke about it a bit. He’s been through a lot with me, so he’s used to these procedures. So he was quite comfortable being there. And he chatted away with the technicians and the staff and so on. We had had the whole procedure explained to us before so he was comfortable with that.

Level of Need 5: Need for Respect and Value as a Human Being

This category supersedes all lower categories, and is the most complex. It is the essence of the patients’ ways of experiencing and understanding hospitalization. Above all, patients deserve to be respected and valued as human beings.

The most important thing is feeling that practitioners and clinicians are not condescending or non-judgmental as far as why you’re there in the first place. I never once felt like I was being looked down upon for having gotten myself into the situation in the first place.

I couldn't sleep at night, and the experience that time, like I said, I had one of this uncertainty and everything was the big thing for me...an encounter with one of nurses. I'm sick, but when I'm coming, the person saw me like, "Oh, you're playing sick." Yeah, it hurt me big time...I said how come a person [talk to] a person like that?

[Cantonese former patient]

The main thing... the care you're receiving, that one you will remember forever, because if it's a good care done, or people listen to your
problem, or answering your questions, or be pleasant, or just say simply say, "hi," to you, it matters, because that you will remember. You won't remember good food or those things sometimes, but to me, honestly, that's more important for me.

Levels of Needs Linked to Hospitalization Phase

While the five levels of patient needs exist in all phases of hospitalization, there is variation in the nature of those needs in each phase.

The five levels of need are represented graphically in the following diagram that is referred to as the outcome space for phenomenographic research. See Appendix G for patients’ words and stories that link levels of needs with phase of hospitalization.
Partnering with Patients to Understand and Improve their Healthcare Experiences

Level of Need 1: I Need Knowledge and Patient Information

I need to give and receive information, to know what to expect, and to understand the “why” of treatments. Language and cultural issues need to be identified early in admissions.

• Admissions – I need to be able to understand and be comfortable asking questions.
• Inpatient – I need to know what is happening and what to expect.
• Recovery – I need support to regain autonomy.
• Discharge – I need full information and may need to have someone with me who understands.

Level of Need 2: I Need Competent, Skilled, Respectful Caregivers

I need to believe that my caregivers are skilled, competent, and respect me:

• Admissions – I need to receive careful attention from staff and providers.
• Inpatient – I need all caregivers to be skilled in their tasks and work to make me well.
• Recovery – I need to understand the ‘why’ of actions – and to leave behind the patient role as soon as possible.
• Discharge – I need to know that the timing is based on my health needs.

Level of Need 3: I Need Culturally Appropriate Responsiveness Providing Comfort

I came to the hospital with deeply engrained cultural beliefs and may have very limited English. The medical culture is strange. I may have different language and cultural beliefs that exacerbate my feelings of foreignness.

• Admissions – I need to be encouraged to share my needs and to be helped to let you when I do not understand.
• Inpatient – I need to have my health beliefs and my dietary needs understood and addressed.
• Recovery – I need to regain my health in ways that match my beliefs and my home life.
• Discharge – I need to know the meaning of the discharge.

Level of Need 4: I Need My Family and Friends to be Informed and Engaged

I need the support of someone from my “real life,” either a family member or friend.

• Admissions – I need support for the admissions process, to understand what is happening, and to be sure the information exchange and expectations are accurate and complete.
• Inpatient – I need my family or friend to support, watch out for me, and help me feel connected to my home life.
• Recovery – I need to regain my health in ways that match my beliefs and my home situation.
• Discharge: I need a friend or family to support me and to ensure that all communication and information is accurate and to understand the needed follow-through.

Level of Need 5: I Matter! I Deserve to be Respected and Valued as a Human Being

I deserve to be respected and valued as a human being through all phases of my hospitalization!
Partnering with Patients to Understand and Improve their Healthcare Experiences

Pilot Results Linked to UHN’s Values and NRC+Picker Survey

The pilot study complements and builds upon the data from the Picker survey. It contributes actionable knowledge by providing authentic data from patients themselves that reflects how the patients understand and make meaning of their hospitalization experiences.

Though these stories and the analysis, UHN can create more effective training modules, promote more inclusive practices, and facilitate meaningful system improvements. The values expressed in UHN’s Declaration of Seven Values and in NRC+Picker’s eight dimensions come alive through the words of patients.
**Actionable Knowledge for Patient Centred Care**

The Pilot Study contributes actionable knowledge for UHN’s conception of patient-centred care.

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**A Good or Bad Inpatient Experience Can Last a Lifetime**

The quality of care, even a single experience, may be remembered forever.

*The main thing... the care you're receiving, that one you will remember forever, because if it's a good care done, or people listen to your problem, or answering your questions, or be pleasant, or just say simply say, "hi," to you, it matters, because that you will remember.*

*I didn't go back to talk to her about it, but it really hurts me as a patient. I didn't expect a nurse talk to me, talk to me as a patient... I'm a patient, so that was a really... I won't forget that experience, which was really... I'm telling [you], I'm not feeling well about it right now, just telling you, because it hurts me big time whenever I remember.* [Cantonese former patient]
Patients Watch and Assess Caregivers

Patients notice and assess the actions and behaviours of the staff and healthcare providers.

Just the whole procedure, there, it, there were two residents, two doctors there, there were no nurses there at the time. So the doctors were quite good at explaining everything. But I didn’t see any nurses around at, at that point. And so I got into the operating room.

Well, I remember the one male nurse who was there and he was very good. He would tell me any time he was leaving the room, if he was going for coffee break, he’d introduce me to someone else who was taking his place. He would tell me when he was back again, so there was good communication with him.

Time Matters to Patients

Unexpected wait times and uncertainty add to the stress. Time seems endless and there is increased stress when patients have to wait for extended periods of time.

I don’t quite remember, seems to have waited for two to three days. I just hoped to take some medicine so that my heart would stop pounding. I was not in any mood when it pounded like that, pounded up and down day in and day out; seems to be really scared of something.

I could see that there was a clock on the wall in front of me, I remember that very, vividly. I was able to keep track of the time. It seemed to be going pretty slowly, I’ll tell you that.

Activity Decreases Stress

Time becomes less noticeable when patients are asked to do things, or are otherwise occupied.

Then they would give me little things to do. Like I had to move one hand or move one leg, or they gave me different little exercises to do. And the male nurse was there and he helped me with those. I found the team in the operating room to be very good. They made me feel quite relaxed.

The Environment Affects Patients.

Patients are aware of time, space, and the presence and activities of others.

I found it to be very chaotic because there was so many people and I guess everybody was a bit nervous and there didn’t seem to be enough nurses going around to, to meet all the people’s needs

Closed spaces increased the sense of impending chaos and light areas brought calmness.

We went to an entirely different pre-surgical room, and it was much more... cheerful and pleasant.

Communication and Activity Decrease Stress

Stress is reduced when waiting stops and activity starts.

There was a lot of sitting and waiting, which to me was difficult because I just wanted to get going and get the whole thing over with. And we were in a very small confined area... I was facing a long, many hours of surgery that day so I was naturally very nervous. But once we got past that, and actually hooked up with the nurse who took me through the procedures of changing my clothes, and that kind of thing. It was just the whole work up that, to the point where they actually got started that seemed to take a long time.

... waiting for a result a little bit longer, but it wasn’t bad. It was good, like, whatever information or anything I will ask, they will consider it...They will ask when I talk to them, they go, “Yeah,” giving me full information, anything I’m asking.
Disregard for Cultural Beliefs and Practices Affects Emotional and Physical Health

Patients’ emotional and physical well-being are at risk when their cultural beliefs are disregarded or their life-long practices are disrupted. A change in diet has an impact on most people. But, a change in a life-long diet, coupled with a belief that the new diet is harmful to their well being, can exacerbate patients’ physical and emotional challenges.

If patients’ stories of their pre-hospitalization experiences are not heard or if the patients are uncomfortable speaking with caretakers, key information for their healthcare may be missed.

Because there was a fire next door, I was scared and also inhaled some smoke. My heart has been pounding for a few days, really pounding. Eh, I just couldn't stand it. It pounded and pounded until the day before, even when my niece from Australia came to see me, I was not in the mood to receive her because my heart pounded to the extent that I couldn't walk or stand.

Language and Understanding Matter

The Cantonese interview reveals the frustrations and challenges faced by patients with limited English and with cultural beliefs and food needs that are not compatible with those who are providing the medical care.

Understood some, sort of. Didn't understand some but never mind even if not understood. Would she have given me poison? Those were all pills meant to cure me. [Cantonese former patient]

The pile of (discharge) papers, that is to say I don’t know what they are, I gave them all to my son. Probably said that I had been examined and nothing was found, like that. I don’t understand. There was a prescription... [Cantonese former patient]
With its lengthy history and outstanding reputation, UHN could further strengthen its leadership role in Patient Centred Care and patient engagement by either expanding this present study, and/or incorporating some of this study’s phenomenographic study elements as a standard part of assessing inpatient satisfaction among all patients, regardless of language or culture. This should include continuing the practice of involving former patients and UHN...
Partnering with Patients to Understand and Improve their Healthcare Experiences

This study complements and adds new insights to the NRC+Picker survey, through in-depth interviews with English and non-English speaking discharged patients and phenomenographic variation analysis of the data. The quarterly mail-in surveys by NRC+Picker provide data to compare and assess patient satisfaction among and across departments, units, hospitals, and with other healthcare systems. However, the survey, by itself, produces an incomplete assessment of the patient experiences and does not assess the satisfaction of patients with limited or no English. The pilot study’s findings add new understandings about the ways both English and non-English speaking patients make meaning of their experiences of hospitalization from admissions through discharge and return home.

The next phase of the study could continue in a timely and cost effective manner through a strategy that linked a strategic sampling of phenomenographic interviews and variation analysis with the standard NRC+Picker survey. The study could be extended to other UHN hospitals and include other language and culture groups to further validate the findings and extend the utility of the research. Funding sources for interpreting and translation could include community organizations, federal and provincial grant funders, and other groups concerned with patient-centred care and patient engagement, potentially from among diverse cultural and linguistic groups.

The depth of information from a single Cantonese interview suggests the potential of greater benefits from selective interviews in several language groups. The added costs associated with the interviews, transcriptions, and translations of the non-English speaking participants, could be trimmed through alternate translation options and covered by community, federal, and other sources of grant funding.

Developmental Assessment and Limitations of this Study

The present study has been a pilot of a larger concept for better understanding the variation in the patient hospitalization experience which might lead to differential patient satisfaction rates in different hospital sites, and thereby developing a process to augment the mandated assessment of patient satisfaction at UHN (NRC+Picker survey) in a way which allows for the emergence of actionable knowledge, something currently not possible. The evaluation component of this pilot was necessarily developmental in nature. The ‘Partnering with Patients’ inquiry clearly has far-ranging objectives, only some of which are possible to meet at the conclusion of the pilot phase. These objectives, from the perspective of evaluation, include:

1. Comparing the outcomes of the pilot to the original UHN goals – from the perspective of the members of the Study Team; and

2. Identifying limitations to the utility of the phenomenographic process and the findings of the pilot (validity, reliability, and authenticity) in order to support the fine-tuning of the necessity of hearing from and developing a better understanding of the ways in which former in-patients make sense of their hospitalization experience.
1. The Pilot Study Met the Goals Established by UHN’s Executive:

The completion of pilot study itself represents an assessment of the first four goals. The results of the first four goals are represented by this report. The ways of assessing goals five through eight, and the results of the assessment, are added to the commentary for each goal.

1) Acquire new knowledge and greater understanding of UHN patients’ experiences through the patients’ own stories;
   a) Patients identified five categories of needs in their hospitalization, effectively re-defining their needs with respect to ‘patient satisfaction’: Information and knowledge; Skilled caregivers; Culturally appropriate and responsive care; Engaged family and friends; and, fundamentally, respect as a human being;
   b) The prioritization of these needs vary across phases of hospitalization.

2) Include patients with linguistic and cultural differences
   a) The Cantonese-speaking former patient was interviewed in Cantonese, the interview was then transcribed and translated into English.
   b) Results emphasized importance of culturally appropriate care for both the physical and emotional well-being of the patient to achieve overall satisfaction.

3) Create new opportunities and models to engage patients in the design of new strategies that address the findings of the study;

4) Bring staff and patients together to work on quality improvement projects to further enhance quality of care, while increasing understandings of each other and how to work in closer partnership with our patients; and

5) Explore opportunities for a) increased patient engagement and partnerships with patients and b) with others in research.

How Assessed: in TWH Pilot: The Study Team itself is an example of objectives 3, 4, and 5.

Finding:

a) It is our understanding this project was among the first research initiatives at UHN to include patient representatives on its Study Team. Both of the patient representatives on this Study Team stated they were pleased to have been able to help design the interview questions, and interpret the resulting data and findings. Former patient input was essential in going beyond the clinician perspective to seeing how clinician decisions had an impact on patients. Training and development has taken place among UHN staff members in qualitative interviewing, collaborative analysis, establishing transprofessional teams, and understanding variation and phenomenographic inquiry;

b) This project has involved sustained partnerships among UHN, two external universities, Fielding Graduate University (Santa Barbara, CA), and Royal Roads University (Victoria, BC), and the Cantonese community in Metro Toronto.

6) Utilize the data to investigate the relevance of UHN’s current quantitative survey for patient satisfaction

How Assessed: in TWH Pilot: Study Team dialogue on the Pilot Study Outcome Space findings.
Finding: It was clear that the NRC+Picker survey is the standard tool for assessing patient satisfaction for English speaking patients. However, the tool is inadequate for non-English speaking patients. As per the recommendations, further exploration of strategies to augment the English-only NRC+Picker survey, could include engaging stratified samples of formerly hospitalized non-English-speaking patients in a phenomenographic study, either working with an interpreter or in first language directly, every six months. This would be desirable to gain a more complete perspective of these patients’ hospitalization experiences, particularly in sites with substantial percentages of non-English speaking patients.

7) Disseminate and apply the learnings from the patients’ stories
   a) Create greater awareness of the variation among patients’ experiences and stories through inclusion of patients with linguistic and cultural differences in assessment of patient satisfaction.
   b) Disseminate and apply the learnings from the patients’ stories to practices across the healthcare system.

Assessment: Not possible to fully assess at this stage in the Pilot.

How Assessed: It is a longer-term objective that the Phenomenographic study stories would become useful resources as case studies.

For the TWH Pilot: Potential applications, and study dissemination strategies might still be prospectively discussed through dialogue among the members of the Phenomenographic Study Team once UHN Executive has approved this report and made some decisions on its recommendations. Options for study report dissemination and additional publications and presentations led by the Principal Investigators are being considered.

8) Provide clear direction on priority initiatives across the three hospitals (TWH, TGH, and PMH), and identify areas where specialized initiatives may be required at the different sites.

Assessment: Not possible to assess in the Pilot.
While preliminary indicators have been identified from the Pilot Outcome Space mapping of participant stories, identification of areas in one or more hospitals for specialized initiatives would require a larger, more systematic implementation of this phenomenographic approach across one or more hospital sites.

2. Limitations in the Pilot findings

What may limit or create ambiguity in the findings in the pilot?

1. The findings are limited by a number of factors, including:
   a. Number of participants (N=5, including one Cantonese speaking former patient, and four English-speakers). Despite this limited number, the stories gathered from these participants were rich in detail. The study was aiming for a theoretical range of variables, and not statistical significance. A larger sample size may have allowed for greater refinement in the categories, but the emergent categories would none-the-less all have been included in the Outcome Space.

   b. The originally intended methods for data gathering (focus group) were not successful using the initially planned participant elicitation strategy of approaching patients as they were being discharged. Whether this had to do with a lack of patient awareness of the importance of the study to eventual practice outcomes, patients more interested in their return home, or a lack of persistence or skill on the part of study team members engaged in soliciting participants, the net effect was
that the study switched to an individual interview format for those who agreed to participate.

c. A phenomenographic study involves understanding the variation in how an event is experienced. In the case of hospitalization, there are a tremendous number of potential variables in the patient experience. The Inquiry Team discussed at length the selection criteria for participants. The former patient participants in the pilot were elicited from the General Internal Medicine and the Neurology Units of TWH. It could be argued that hospitalization could be a different experience depending on the presenting physical problem of the patients, and hence the different unit at which the patient experiences hospitalization. Further, additional complexity includes whether the hospitalization was for a chronic or an emergent health problem, the amount of transition required by the patient with respect to the prognosis for recovery – or not – and the degree of support required for effective communication with clinicians. From a methodological perspective the Inquiry Team argued that the UHN hospitalization experience for the purposes of the pilot was a broad construct somewhat independent of medical specificity. This issue would need to be examined in more depth for a broader study.

2. A critical aspect of any pilot study is a reflection on study design and implementation.

a. Some potential interview participants were rejected because their hospitalization had taken place some years earlier than the one-year time limit set for participants. The very first participant, as was discovered only after the interview, had been hospitalized at TWH several years previously, well outside the one-year limit for participation. However, from the standpoint of authenticity, participants recounted their story of hospitalization and a traumatic event associated with this - as though the event had happened the previous day. This was true also for the participant outside of the time-frame initially selected. The inclusion or exclusion of this participant’s comments in the analysis was a major conversation topic within the Team. Because this individual’s comments were consistent with the emerging set of levels of need, the consensus was that the participant selection criterion of having been hospitalized in the last year was more stringent than was necessary for the purposes of determining the Outcome Space for patient needs in their hospitalization experience. From the standpoint of a longitudinal design, however, where changes in policy and practice hopefully would lead to differences in reported hospitalization stories, there is an issue that relaxing this criterion and increasing the acceptable time since hospitalization could potentially reduce the sensitivity of the phenomenographic approach to more recent changes in policy and practice.

b. The above issue with respect to time since hospitalization led to a conversation about validity, reliability and authenticity of the phenomenographic approach. Clearly there was a high degree of validity and authenticity when former in-patients told their story. Stories told reflected clarity of observation, complete with rich contextual details, that in qualitative research are frequently called, thick description (Denzin, 1989; Geertz, 1973). Former patients electing to participate appear to have done so because of a signal traumatic event that has been seared in memory. It remains to be seen in a larger study whether positive events would be remembered with similar clarity. From the perspective
of reliability, it may be necessary to conceptualize an ongoing augmentation study in a slightly different way. That is, to see not only whether the broader categories of needs hold, and whether the degree of how well the levels of need were met, but whether there are additional levels or relationships the pilot did not reveal.

c. One original objective was to conduct the focus group entirely in the original language of former patients, including Cantonese or Mandarin. This was not possible to do when former patients did not volunteer for a focus group. Turning to interviews, the cost of translation for the Cantonese former patient was about $3,000 for the single 60-minute interview. This is an unsustainable amount for any continuation of non-English participants in a larger study. Given the culturally-limited perspective of the NRC+Picker survey, cost obviously cannot be an insurmountable factor in whether the patient satisfaction rates of non-English speaking patients are assessed. Alternate strategies of finding resources for translation and interpreting need to be found, less expensive interpretation/translation strategies determined (with no loss in quality of information), and new funding resources acquired (see recommendations section).

**Design for the Next Phase of Research**

1. **Semi-annual selective interviews linked to NRC+Picker Study**

The next phase could be a three-year project with a selective sample of 8 to 12 interviews twice a year, linked to the NRC+Picker Study. While most participants would be English speaking, at least three of the participants would be non- or limited English speaking. Because of the lower satisfaction ratings at TWH, the initial set of interviews could be with former patients from different clinical areas at TWH. The study would then expand to other UHN sites. In Spring 2013, for example, there could be a set of three or four interviews with English-speaking patients, as well as with two or three patients whose first language was Portuguese, as well as with one or two Cantonese speakers. If translation funds were available, the study could include one or two interviews with former patients from a third language group to validate the initial findings.

2. **Engaging with NRC+Picker**

A related strategy would be to engage with NRC+Picker to analyze the cultural content of the current survey and revise the survey instrument to make this more culturally neutral. The revision might need to replace several current questions that rely on specialized western health terminology. Once this had been done, the instrument should be translated into the primary three to five languages of the UHN catchment population. UHN could start the process of validation of the revised survey instrument.

3. **Continue with Core Research Team**

A key learning from the pilot has been the strength of the diverse membership of the transprofessional Core Research Team. The inclusion of a diverse group of clinical leaders, former patients, and researchers from academic institutions has led to new perspectives not usually available to UHN. There would be added benefits because of the learning and training that has already occurred.
4. Expand participant criteria for length of time since hospitalization

As one study participant noted, the important stories of hospitalization “stay with you forever.” The pilot’s criteria for participation in this study required no more that one year since hospitalization. The selection criteria for potential participant at a particular site can be extended to at least two or three years post-hospitalization.

5. Broader use of media and other technologies

Web-Ex videos, social media, and other technologies can be used to support phone interviews, ongoing training of interviewers, team meetings, collaborative analysis, and evaluation.

6. Annual evaluation

The plan for evaluation should be expanded for the next phase of the study, with annual reports on both the current year’s studies and the consolidated group of prior studies.

7. Dissemination of results to UHN, patient support groups, community, and beyond

Interest and participation in the study will grow through increased dissemination of pilot study results to UHN personnel, pilot support groups, and the broader community including ethnic and cultural groups. Such a strategy would signal that UHN was taking its patient-centred care commitment even more seriously as it commits to further improving its relationships with limited-English speaking patients and their ethnocultural communities. Dissemination of the pilot study Report would broaden the awareness of the impact of the phenomenographic approach, and continue to build expertise in all aspects of this research and with variation theory among UHN staff. This would also potentially lead to important new developments in assessing and improving the patient experience.

Reducing the Costs of the Next Phase


Alternate strategies can be developed for REB approved transcription and translation of documents, including transcripts. When the final cost of the pilot study’s document translation from Cantonese to English was known, alternate strategies were proposed for significantly lowering future translations costs.

2. Alternate sources of community-based funding

There are opportunities for specialized funding and community support for non-English speaking participants as well as those with different cultures and healthcare beliefs. One option was an invitation from the Chinese Community to contribute funds to support translation and interpreting for Cantonese participants. It would be useful to follow-up with this community group in the next phases of this study. Opportunities for additional funding, partnerships, and support could come from groups within other, non-English-speaking communities.

3. Acquire additional funding through research grants for the next phase of the study

With the pilot study completed, there is the opportunity for the acquisition of research
funding for the next phase of the study. This research grant proposal could be developed in partnership with Royal Roads University and Fielding Graduate University. Proposals for grant funding could be submitted to provincial, federal, and other sources of healthcare research grants.
**Value to UHN & Beyond: Implications of Study at Different Systemic Levels**

1. **Build an expanding database**

   The results of each set of interviews could be consolidated and analyzed with patient experiences and needs across hospitals, departments, and other UHN research initiatives. The database would support more-informed decision-making, practices, and policies by UHN’s executive, administrative, and healthcare personnel.

2. **Implications of Study at different systemic levels**

   The pilot study has implications for policies and procedures at TWH, as well as for UHN more generally. In addition to the need to consider more carefully what is involved in partnering with patients in a culturally- and linguistically-competent way, there are implications for UHN’s relationships with the ethnocultural and linguistic communities in Toronto, as well as for professional development for clinicians at UHN facilities. Moving outward, the study has implications for how UHN might work with NRC+Picker to lead the province in ensuring that patient satisfaction is assessed in culturally competent ways. Such leadership should also have implications for the Ontario Ministry of Health and Long-Term Care implementation of its Excellent Care for All Act (ECFAA) (2010). There may also be implications for Health Canada’s interests in minority health. Both provincial and federal ministries may have an interest in supporting the expansion of this study.
### Partnering with Patients: The Next Phase-Options

#### A. Design for the Next Phase

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#### B. Reduce Costs

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#### C. Value to UHN & beyond: A Systems View

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September 2012
Appreciation for the Transprofessional Research Team

The research study team remained cohesive throughout many delays. The two patient members of the team provided leadership, insights, and reality checks throughout the project. As leadership and staff changed within UHN and within the project, there remained a core group of team members who believed in this project, valued the words and experiences of the participants, and never wavered from their commitment to the success of this project.

A special thanks to all who participated in this project: The participants, UHN leadership, the team members, and especially the two patient representatives, Lynn and Ted. The collaboration and shared commitment to seeing this drawn-out project move forward contributed to the success of this project.
Appendix A: Patient-Centred Care and UHN’s Assessment of Patient Experience

UNH’s Patient-Centered Care (PCC) philosophy and focus on engagement and partnerships with patients provided the foundation of and conceptual framework for this research project. UHN has a comprehensive PCC strategy focused on the priority of creating an environment that provides exemplary care for patients and families. PCC at UHN is defined as an approach that consciously adopts the patient’s perspective about what matters (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993).

The eight dimensions of PCC are based on the NRC+Picker Group Canada’s patient satisfaction evaluation framework and include: respect for patient’s values, beliefs, and concerns; coordination and integration of care; communication, education, and information; promotion of physical comfort; promotion of emotional/spiritual health; involvement of family and friends; transition and continuity of care; and access to care (NRC Picker, 2011).

To assess inpatient satisfaction, UHN uses an English-only, mail-in version of the NRC+Picker Group Canada patient satisfaction survey instrument (Picker survey). This survey contains 58 questions that ask discharged patients to assess 10 different categories of care, process, and support, which are derived from the eight dimensions of PCC. In the period between 2002 and 2008, these surveys indicated significant differences in patient satisfaction, among UHN’s hospitals. The Picker surveys indicated that Toronto Western Hospital had lower overall patient satisfaction (mean of 71.6) when compared to UHN’s other hospitals (means of 86.7 and 82.7).

<table>
<thead>
<tr>
<th>Site*</th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>Median</th>
<th>SD</th>
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<td>Princess Margaret Hospital</td>
<td>3,106</td>
<td>0</td>
<td>100</td>
<td>81.8</td>
<td>86.7</td>
<td>16.0</td>
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<tr>
<td>Toronto General Hospital</td>
<td>16,552</td>
<td>0</td>
<td>100</td>
<td>78.2</td>
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<td>18.7</td>
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<td>Toronto Western Hospital</td>
<td>7,933</td>
<td>0</td>
<td>100</td>
<td>71.6</td>
<td>76.7</td>
<td>21.9</td>
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*Toronto Rehabilitation Institute is not included; it did not join UHN until 2011

While the Picker survey indicates differences among the hospitals, among those patients who responded to an English-only, written survey, UHN needed additional evidence-based research and analysis to better understand the experiences of UHN patients, as part of their accountability to patients. While there is abundant research literature on patient satisfaction based on criteria established by medical providers and researchers, more research is needed to understand how patients themselves make meaning of their hospitalization.
Appendix B: Literature Review

While patient satisfaction is considered to be a key indicator of hospital and medical provider quality (Woodward, Ostbye, Craighead, Gold, & Wenghofer, 2000), debates continue regarding the most appropriate way to assess, analyze, and improve patient satisfaction. In their April 2012 Briefing, “Integrated Health Care: The Importance of Measuring Patient Experience and Outcomes,” the Conference Board of Canada urged health care leaders to develop new approaches to measure health outcomes from the patient’s perspective and experiences (Stonebridge & Godfrey, 2012).

There is a growing body of literature that recognizes a need to improve understanding of the variation in ways that patients themselves perceive their hospital stays. How do patients make meaning of their hospitalization and what stories do they tell about their experience? How do patients understand the actions and words of the medical staff? What meaning do they make of patient centred care (Mitchell, Bourne, & Hollett, 2006)? What do patients themselves consider acceptable and satisfactory in their healthcare?

Research that analyzes this variation is often linked to demographic factors such as: patient’s age, gender, ethnicity, country of origin (Clark & Redman, 2007; Dayton, Zhan, Sangl, Darby, & Moy, 2006; Mygind, Norredam, Nielson, Bagger, & Krasnik, 2008), language, and culture (Fagerli, Lien, Botten, & Wandel, 2005; Easley, 2010; Saha & Hickam, 2003). Patient satisfaction may improve with the presence of research teams during the hospitalization (Leonard, 2008), trained professional interpreters for patients with Limited English proficiency (Flores, 2005), and with staff satisfaction with their perceived working conditions (Rossberg, 2008). Patient satisfaction is found to be higher when there is a good patient–provider relationship (Platonova, Kennedy, & Shewchuk, 2008; Seago, 2008; Chen & Rocca, 2008) and the patient believes that the provider is empathic (Johnston, Kaplowitz, & Kim, 2004). Patient satisfaction declines when there is perceived racism and mistrust (LaVeist, Nickerson, & Bowie, 2000).

Some studies indicate overall satisfaction is improved by asking the patients themselves about what information they have on procedures and treatments, rather than depending upon the provider’s perceptions of patient understanding, rather than the provider’s perception of patient understanding (Ofoywe & Ofili, 2005; Hagihara, & Tarumi, 2009; Anden, Andersson, & Rudebeck, 2005). Research indicates that practices such as, shared decision making (Chue, 2006; Swanson, Bastani, Rubenstein, Meredith, & Ford, 2007) and asking patients to fill out their own history questionnaire (Hershey & Grant, 2002) improves satisfaction.
While many studies ask medical providers to define the causes of patient satisfaction, there are differences in expectations of quality of care between providers and patients (Lee, & Yom, 2007, Jensen, & Lidell, 2009). Most studies on patient satisfaction occur in western countries, yet research indicates that there are cultural and language differences in ways people understand provider-patient interaction and other factors that may affect patient satisfaction (Ishikawa, Takayama, Yamazaki, Seki, Y. & Katsumata, 2002).

Surveys alone are inadequate to acquire sufficient understanding of variation to successfully address attributes with low or inconsistent dissatisfaction (Otani, Harris, & Tierney, 2003; Jaipaul & Rosenthal, 2003). Biases inherent in surveys designed for English-speaking patients may result in racial and ethnic disparities (Dayton, Zhan, Sangl, Darby, & Moy, 2006). For example, research indicates that the response rate for some groups is improved with advanced notice of the survey, but had no effect in other groups, furthering the disparities in responses (Nápoles-Springer, Fongwa, Stewart, & Pérez-Stable, 2004). With a lack of standardization across North America in patient satisfaction instruments, these surveys remain limited as a primary benchmark for improved care (Dawn & Lee, 2003).

Qualitative methods that are responsive to the fluid nature of the patients' perceptions of their own satisfaction (Collins & Nicolson, 2002) build understanding of the variation in how patients themselves evaluate satisfaction (Owens, & Batchelor, 1996). Qualitative research that explores reveals, combined with existing quantitative measurements, yields a more inclusive, system-wide understanding of patient satisfaction (Merkourisa, Papathanassoglou, & Lemonidou, 2004; Turner & Krizek, 2006).

**Variation and Phenomenography**

Variation matters when the purpose of research is to acquire knowledge that supports effective action and change (Richardson, 1999), such as providing education in social psychology and communication for providers who need to cope with different ways of experiencing patients with medically unexplained situations (Ringsberg & Krantz, 2006). Phenomenography is an evidence-based research approach that discovers, analyzes, and graphically represents the variation in the ways that people perceive and experience a phenomenon (Åkerlind, 2002). Its purpose is to understand this variation and apply this understanding towards practical action (Bowden & Walsh, 2000; Cousin, 2009; Noble, 2009; Riggio, 2005; Schembri & Sandberg, 2002). It originated at the University of Gotenburg in Sweden, as education researchers recognized that students come to the classroom with different ways of experiencing learning and that this variation affects learning outcomes (Marton & Booth, 1997, Uljens, 1996).

Because of its relevance to subsequent action, phenomenography is used in healthcare research designed to increase understanding of both providers and recipients of healthcare (Anden, Andersson, & Rudebeck, 2005; Barnard, McCosker, & Gerber, 1999). Phenomenographic research with caregivers at home with ventilator-dependent children revealed multiple ways that caregivers perceived their experiences and suggested that the health providers’ lack of understanding of the caregivers’ perceptions needed serious attention (Wang & Bernard, 2008).

Another research study highlighted the importance of word selection in understanding (Friedrichsen, Strang, & Carlsson, 2002). Phenomenographic research revealed variation in the ways registered nurses perceive their role with student learners (Brammer, 2006, November), ways student nurses perceive the role of their RN mentors (Brammer, 2006), and nursing students views of their future roles (Holmström & Larsson, 2005).

Phenomenographic research yields understanding of the variation in meaning people ascribe to symptoms and their decisions to seek medical
Partnering with Patients to Understand and Improve their Healthcare Experiences

care (Sjöström-Strand & Fridlund, 2008), the ways they experience emergency care (Wimana, Wikblad, & Idvall, 2007), and the ways family members perceive “good” palliative care to quality of life of their family members (Miettinen, Alaviuhkola, & Pietila, 2001). This approach uncovers ethical dilemmas such as those experienced by nurses who may need to choose between the safety and the integrity of a patient with dementia (Johansson, Backrach-Lindstrom, Struksnes, & Hedelin, 2009) and the multiple roles that the health providers’ perceptions of conscience and guilt may play in the provision of care.

Phenomenographic research supports subsequent participatory action research, a collaborative approach to inquiry that “…provides people with the means to take systematic action to solve specific problems” (Stringer, 2007, p. 8; Tugwell, Santesso, O’Connor, & Wilson, 2007). Action research is an important approach to involving stakeholders in understanding the perspectives of other stakeholders about needed changes in the organization (Stringer, 2007; Coglan and Brannick, 2005; Reason & Bradbury, 2001; Smith, 2007; Whyte, 1989). The action focus is important because the purpose of this research is to provide information that will help UHN design and implement more effective ways to improve patient satisfaction throughout its entire system.

References


Partnering with Patients to Understand and Improve their Healthcare Experiences


**Appendix C: Current and Former Project Team Members**

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Opal Robinson  
Education Coordinator, (Former)  
Nursing Resource Team  
University Health Network, Toronto, ON
## Appendix D: Project Timelines

<table>
<thead>
<tr>
<th>2008 Conceptual Design: Initial Objectives</th>
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<tbody>
<tr>
<td>Project Team Additions/Changes</td>
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<tr>
<td>---</td>
</tr>
<tr>
<td>Initial Project Team: 3 Principal Investigators: -UHN VP &amp; Chief Nurse Exec. -Researcher (Fielding Graduate University) -Researcher (Royal Roads University)</td>
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<table>
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<th>2009 Detail Design &amp; Add Non-English Language Patients</th>
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<td>Add to Project Team: Project Coordinator UHN Director of Nursing Add C-Investigator: UHN Education Coordinator Add Administrative Coordinators: Director, UHN Interpreter Services</td>
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<tr>
<td>2010 Add Patient Engagement Focus and Expand to 3 UHN Hospitals</td>
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<tr>
<td>---------------------------------------------------------------</td>
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<tr>
<td>Project P.I. (VP) retired</td>
</tr>
<tr>
<td>Add: UHN IT, Research Coordinator, Nursing Director TWH; Nursing Director PM; 2 doctoral students; 2 patient representatives; Bi-lingual Community Health Educator; Innovation Mgr.; Advanced Practice Nurse Educator</td>
</tr>
<tr>
<td>Add Focus on Patient Engagement; Project Expansion to all 3 UHN Hospitals; REB Application; Conference Calls; Plan Pilot Focus Groups: English &amp; Cantonese; Evaluation Document; Revised REB; Phenomenography training.</td>
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<tr>
<td>Social networking-IPE Intact, PCC Intact 2010.</td>
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<tr>
<td>Horizontal Violence in Nursing Research Study; Amazing Race; Digital Signage; Ontario Nursing Workforce Alliance; Emergency preparedness for G8.</td>
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<th>2011 Start Implementation: Research Ethics Board &amp; Pilot</th>
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<tr>
<td>Add: Project PI: New VP Exec 2 UHN Health care providers, Research director, PhD student, New Proj Coord. Rsch Coordinator on long term leave</td>
</tr>
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<td>REB approval UHN, RRU, FGU; 5th f2f meeting; Focus on language, culture, interview skills, change to Interviews; Cantonese; IRB Re-submission</td>
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<tr>
<td>Hand-washing campaign-Strategic Plan 2011-2016; Integrate with Toronto Rehab Institute, Nipissing U &amp; UHN form alliance; Accreditation preparation</td>
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</table>

<table>
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<th>2012 Pilot Interviews, Analysis, Report</th>
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</thead>
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<tr>
<td>Nurse Educator leaves; New Project Coordinator; Project team analysts</td>
</tr>
<tr>
<td>English &amp; Cantonese Interviews. Transcriptions; Analysis with f2f meeting; Report preparation and editing</td>
</tr>
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</table>
Appendix E: Interview Protocol

NOTE: TO BE TRANSLATED IN LANGUAGE OF Interviewee GROUP (i.e. Cantonese, Italian etc.)

1. Welcome
   a. General welcome
   b. Brief introduction
   c. Reminder that the interview will be about 60 minutes.
2. Overview of the guidelines
   a. Informed Consent signed
   b. Participant may choose not to answer any of the questions.
   c. Participant may choose to leave at any time
   d. Interview will be confidential
   e. Purpose of the research is to understand the stories and to learn more about how participant experienced being a patient in the hospital.
   f. The interviewer will not discuss medical issues, give medical advice, or cover any of the actual treatments people received.
   g. By sharing stories of your experiences, you will help the hospital improve the experiences of future patients.
   h. We are wanting to learn more about you and your experiences
   i. If you would like, we will send you a copy of the final report
   j. You will be invited to a presentation of the completed study
3. Any Questions?
4. Let’s begin with your Admission to the hospital
   a. What was it like for you to be admitted as a patient in to the hospital?
   b. Encourage conversation and stories
5. What was your day like during your hospital stay?
   a. Encourage stories that cover the full day, from morning until night time.
   b. Encourage stories that discuss the feelings as well as what was pleasing and what was annoying – such as food, light, music, sound
   c. Encourage stories that highlight interactions with people
6. Emphasize the importance of sharing different experiences
   a. Encourage stories about relationships with staff, volunteers, family – that mattered to the participants.
7. How did you learn that you were going to leave the hospital?
8. What was it like for you to leave the hospital?
9. When you arrived home, how did you feel about being home?
10. What is most important to you when you are a patient in the hospital?
11. What else would you like to share about your experiences as a patient?
12. Reminder that participant can request a copy of the research summary and attend a presentation of the findings when the study is completed.
13. Invite participant to fill out a form summarizing her/his hospital experiences (Appendix I)
14. Thank participant for participating and wish them well
Appendix F: Patients’ Words: Experiences Associated with Categories of Needs

Need 1. Knowledge & patient information that is heard, understood, and shared

Patients appreciate knowing what was happening, and what to expect. If information is not given to them, the patients begin to speculate or wonder what might be happening. They assess what is happening and whether or not they are given information. At the lowest level, when the participants need for information was not forthcoming, there appeared to be stress and confusion. A partial lack of information, such as a sudden discharge or unexpected treatments, led to the participants speculating as to why events had changed or were unexpected. The most calmness occurred when there was sufficient information for the participants to know what to expect, to be informed about what healthcare providers were doing, and to be treated in ways that they were comfortable asking questions in a two-way information exchange.

Need to know what to expect, “It was okay...they told me what they were doing”

The patient needs to know what to expect, to be able to ask questions, and to know that they have a correct understanding. Barriers include patients feeling that they are just another number and that the caregiver is too busy to care about them.

They were also very good, telling me what they were going to be doing. It was okay, because they told me what they were doing. They explained it to me.

I felt prepared. This was my second surgery in two years. I kind of knew what to expect from the first time around, not to say that it makes it any easier because surgery is surgery and it’s a life-changing event but yeah, I came prepared, armed with my tools.

Language differences hamper information exchange

Doing without a trained healthcare interpreter is the norm for limited-English speaking patients, despite the existence of a professional interpreter service affiliated with UHN. Limited-English speaking patients typically either bring family members, and accept the accompanying loss of confidentiality, or accept their hospitalization process will involve good will and a lack of understanding. Providers frequently assume patients who can speak a few sentences of English are competent to have a medical conversation in English.

My son was there to talk to her (the nurse).

Understood some, sort of. Didn't understand some but never mind even if not understood. Would she have given me poison? Those were all pills meant to cure me.

Need to be comfortable asking questions and to understand

Many people experience apprehension when they do not understand something but feel intimidated (e.g. “I should know this”) or inhibited because of language, culture, or politeness.

Umm, well she had a good sense of humour, which I liked. She was very easy to talk to, and we chatted for quite a while. She made if feel personal, opposed to you know someone just going for chest x-rays or submitting for blood work. She made the whole thing seem more personal and I could ah, feel more comfortable asking her any questions that I had that day.
Well, I remember the one male nurse who was there and he was very good. He would tell me any time he was leaving the room, if he was going for coffee break, he’d introduce to someone else who was taking his place. He would tell me when he was back again, so there was good communication with him.

I don’t know what they were doing. I think she didn't know the reason why I was there.

Need 2. Competent, skilled, and respectful caregivers

Patients have lots of time to observe and ‘assess’ or invent a story about the skill and competencies of the caregivers. As healthcare providers assess patients, the patients likewise assess the skills and competencies of the caregivers.

For sure you must make good use of those who are skilful.

I asked, "Nurse, just right now, so many tubes of blood were drawn, how come that you are drawing it again?" She said, "the people downstairs said they lost the blood just drawn." I said, "Oh my God, how come it could get lost?" So after they drew my blood again and took it downstairs, then they told me they found the blood drawn earlier.

That is human flesh. It hurts. Perceptions of lack or regard for skills

A perception that the healthcare provider lacks skills, may lead to anger and a sense of abuse, where the morality of the institution itself is questioned.

Find someone who knows how to do IV the right way. Caused people to suffer repeatedly, my God, that is human flesh. It hurts.

The nurses were very nice overall. Only I feel that - only those with the skills should do the work. You ask her to draw my blood; for sure you would ask someone who knows how to draw blood to do it. That is human flesh - it was pinched and injured all over. That is sin, don't you understand!

Not speaking out about perceived poor care

There may be a fear to share knowledge for reasons such as intimidation by power or not wanting to seem disrespectful or potentially insulting, to the caregivers.

I dare not [speak to the nurses] because when they failed to draw my blood they looked very disappointed. What was I going to say? Can I say, why can't you draw blood? Such poor skills - can I say so? They were apologetic in taking away the basket and the needle and all that. I don't know what to do as well. No blood to draw, then after a while they swapped and another person would come to draw.

Need 3. Comfort & responsiveness to my needs, in culturally appropriate ways

Patients are strangers in a foreign environment. They are outsiders who are forced into an environment controlled by insiders (the healthcare providers). As visitors to this foreign environment, participants often expected responsiveness and attentiveness from the insiders, those who were there to meet the patients’ medical and personal needs.

When the patients’ cultural expectations were met, there was a sense of order, of having their needs met, and of calmness. When the participants experienced a lack of responsiveness or attentiveness, especially when they expected it, there was greater dissatisfaction with those who were providing the care.

The most important... little things really matter, like when you're in pain, or the way the cue or the behaviour or anything. As a patient, because you're sick, your expectation of your nurses or any other personnel is more because you're a
sick patient, a sick person. You need more attention.

But she did give me a blanket because I was feeling very cold...

She was just very prompt and polite and nice and caring at the same time. She was just fantastic. When you needed them, they were there without fail. I never had to wait. If I called them, they were right there and ready to do whatever I needed.

**Being a stranger in a foreign environment – alone and uprooted**

Outrage and anger emerged when they perceived themselves to be foreigners in the strange environment of the hospital, and their deeply rooted needs for the nature of their lifestyle's food was disregarded. An eastern belief in yin and yang, warmth and cold, can conflict with western medicine.

Staying overnight, like I say, it's not like home. You're in different environment completely, so if they make it a little bit more pleasant...

The environment... it's not my own bed.

Oh, staying overnight... it's not like home, of course. Honestly, I be honest, I sleep maybe only maybe three hours that night. The environment... it's not my own bed. It's not... of course, I have a neighbour just beside me.

Being able to eat accustomed foods is an important aspect of patient satisfaction. In Canada’s most diverse city, with food court vendors offering hospital visitors a diversity of meal choices, it seems strange to patients that culturally-appropriate food is not available, but this seems like one more indignity to be suffered.

To me, most important - what I wanted most was to help manage my heart beats, also ... perhaps I am Chinese, I hope to be able to eat congee or rice. There was not one single meal in rice, and it was smashed potato every day, and bread. May be I am not used to these. But it's all right, I was thinking, of course, you are in hospital. Can it be that you cook a 9-course meal at home and people will still do the same for you? It doesn't matter. That's how I let everyday go by...

I wanted to go home soon to drink some tea. To drink boiled water at home. To boil water and to cook some congee.

The food...they bring lunch for me. I didn't like it at all, because I wanted something soup or something soft. But, that's why I go get downstairs some soup. I didn't eat hospital food.

**Need for Culturally Appropriate Food and Care:**

Patients experienced a lack of awareness of or respect for their cultural beliefs about what they consider to be healthy food and environments. A perceived disregard for the patients’ beliefs on food needs and healthcare, adds stress for the patient. Disruption in familiar food may have a physical impact on the patient that is exacerbated when the patient is urged to continue with the hospital’s food or drink.

Because we are old-fashioned, we used to drink boiled water. It doesn't seem that I have ever tried drinking directly from the tap, and not boiling water to drink. I boil water every day.

It was smashed potato every day, and bread, but I could not eat those. I was not used to that. I stayed nine days in the hospital in total and my digestive system had not been well even after I was home. I had ... diarrhea. When I took medicine, he would go straight to the tap to get water but I couldn't drink that water...And every day the food was like that. Afterwards I told the doctor and the nurses I had diarrhea, I could not drink milk and that stuff. Then she switched to 1% for me, but I could not drink even 1%. I simply could not drink milk. I said I am full, but when you see that the stuff lying there untouched, isn't it a waste? It's been delivered anyway, so even when I didn't want to eat; I still would eat a few spoonful of smashed potato or the small bun.
But my body couldn't stand it, even if I didn't eat it. Originally I didn't have much expectations regarding food, but for nine days like this, that's how it's like.

This is Chinatown and many Chinese would go to the hospital. You prepare some food catered to the Chinese taste, simple ones, so that they find it more comfy to eat. We're not used to eating mashed potato, drinking milk and juice, and the butter and jam and the like, all of them are not suitable for old people like us.

Uncertain diagnoses, procedures, and outcomes lead to stress and nervousness

Uncertainty increases stress. Patients need to have emotional support for reducing fear and anxiety as well as physical support for their medical needs.

“Why I'm like this... why I'm sick like that”, so that was really important and worried about it, too, because it's unknown to you. I know somehow that what's going on, but still unknown, like why it's continuous something like this is happening to you, which is main thing is stress, they're telling me, "Lessen your stress."

The doctor came and I asked the doctor, ‘what's my illness?’ He said he had performed whatever tests for me, took X-ray here and there, but he could not diagnose what illness I had. He said he didn't know how to treat me. If you don't know how to treat me, then I don't even know. That's how it was.

Need 4. Family and Friends to be Informed and Engaged

Patients need family and friends to be present, informed, and engaged even when patients are not able to inform them directly.

Informed and engaged family member or friend

Having a friend or family member present and engaged comforted patients. Patients often depended upon the family member to ask questions and be informed.

[Having my husband with me throughout the whole procedure] was comforting. He had a good sense of humour so we were able to joke about it a bit. He's been through a lot with me with the Parkinson's so he's used to these procedures. So he was quite comfortable being there. And he chatted away with the technicians and the staff and so on. We had had the whole procedure explained to us before so he was comfortable with that.

When I got sick, I called my husband, I say..... I couldn't be walking around, so I have to go lie down, and I asked somebody to cover me. Then I called my husband, also. I say, "I'm really... I might leave, go to Emerge or come home because I'm in lots of pain." He came by. My husband came by at the Emerge.

Concern arose when a friend had difficulty getting permission to be with a patient during the day of major treatment.

I had a nurse coming from my neurologist’s office. She had permission to be with me for the day (yes) and she said it was very difficult to get permission because ah it was like, she felt like, a bit of an intruder

Patients need social connections. They like having others within sight, as loneliness could be a problem. The social connections extended to others outside the hospital. The family and friends remain vital to the participants’ experiences. Being in the hospital was temporary and did not negate the importance of connections beyond the hospital. Patients continued to care for the well-being of family or friends, even while they were hospitalized.
I didn’t know whether they (nurses) would be able to go out and talk to my husband. It seemed to be quite a while before anybody was going out to tell him anything and I knew he would be sitting out there so I asked (the nurse) to go out and speak to him and so she did. They went down and had coffee at one point. I found the communication to be very good.

When no one comes to see you, it can be lonely.

That's it. No one came to see me. Just like a nurse said, why others - I stayed in a ward by the entrance and it was for two people.... No one came to see me. Only in the evening when my son was off from work, he would sleep in the hospital at night to keep me company. He would not be in the hospital during the day

Social connections can problematic

Troublesome noises from other patients or staff can be unsettling.

I say night-time is not as noisy as day-time. Usually day-time could be more noisier, but it depends, like I say, it depend on... if the floor is... how is the floor is busy, noisy... we have lots of patients sick, or the one who's calling constantly, so of course it's disturbing the others. To somehow to decrease that noise...

Another time when social connections were problematic were when the participants needed to rest and to have quiet surroundings as part of the recovery—and family, friends, or others in the hospital intruded with noise or interruptions.

They stayed for about ten minutes and I told them that they had to leave just because the medication was making me really nauseous and I just couldn’t sit up and try and be a person when I was under the influence of so much narcotics. It was very difficult and yeah, I absolutely still kind of regret that fact that I had to send them home just because they came out at night.

Connecting with other patients

Being in a room with other patients can add additional social connections that can be alternately comforting or unsettling.

I didn’t find it intrusive or bothersome or anything but I would kind of act as a go-between to get their attention to come to look for her because she wasn’t doing very well. If anything, it was more of a comfort to know that there was somebody else in the room and that I wasn’t completely isolated and going through this by myself.

[It was] rather quiet. At times the person in the other bed ... during the time that I stayed, there seemed to have changed two or three people. If they were discharged or there was any transfer, I don't know. Never asked. Anyway, two or three people have changed. Everyone was ill - they were pushed out - I was also feeling dizzy. Sometimes when I met them I would say hi. It's all right.

The one on the other side - her daughters often came to see her - this one calling her Mammy, that one calling her Mommy. So she asked, "Do you have any daughters?" I have several daughters but every one of them needs to work. No one came to visit. My daughter's work requires her to fly here and there and fly to other places.

Need 5. I Matter! I Deserve to be Respected and Valued as a Human Being

Listening and communication is critical

Patients are keenly aware of what others (caregivers and fellow patients) were doing. Patients observe and assess the others. Chaos with too many others was unsettling. Friendliness and “small talk” was often appreciated. Kindness from others led to a sense
of appreciation and calmness. The social connections were important within the hospital and beyond. Participants appreciated those who took the time to speak respectfully and kindly to them.

The main thing... the care you're receiving, that one you will remember forever, because if it's a good care done or people listen to your problem or answer your questions or be pleasant, or just say simply say "hi" to you, it matters, because that you will remember. You won't remember good food or those things sometimes, but to me, honestly, that's more important for me.

(The most important thing), it wasn’t the pain. I knew they had that under control. And it wasn’t the after-surgical procedure, because I had a lot of confidence in my doctors. But it was being able to talk to the staff and communicate with them.

I am a human being – I matter

Patients expect and need to be treated and respected as an individual, not as one case among hundreds. Communication can be stressful and incomplete because of the felt power differential, the perception that the caregiver is too busy to take time with the patient, only partial understanding of the health issue or prognosis, frequently due to a lack of English language skill, or feeling intimidated, or embarrassed about not understanding the care provider.

But they don’t listen and again, as I said my big thing is communication. And when you get the team that doesn’t listen right, it makes me very frustrated; it makes me very angry actually because it’s not necessary.

Communication fails when information is given in a rushed way, without time for shared understanding with the patient, and the patient’s friends and family if necessary.

The participants in this study shared stories of events prior to admissions that may have been relevant to their symptoms and their care. With no one to listen, these important stories are not heard.

Because there was a fire next door, I was scared and also inhaled some smoke. My heart has been pounding for a few days, really pounding. Eh, I just couldn't stand it. It pounded and pounded until the day before, even when my niece from Australia came to see me, I was not in the mood to receive her because my heart pounded to the extent that I couldn't walk or stand. In the end my son came home from work and said it shouldn't be so,

Not feeling judged or looked down upon

Patients assess whether the clinicians are condescending or judgmental. They can experience intimidation if they believe they are being judged. For some, the most important aspect of hospitalization is the sense that they are not being punished or looked down upon.

The most important thing is feeling that practitioners and clinicians are not condescending or non-judgmental as far as why you're there in the first place. I never once felt like I was being looked down upon for having gotten myself into the situation in the first place.

Poor communication affects care

Lack of understanding due to language barriers can affect care. Even when patients are able to speak some English, they might not be able to fully understand or communicate effectively.

Understood some, sort of. Didn't understand some but never mind even if not understood. Would she have given me poison? Those were all pills meant to cure me.

I would understand some of (what they said). There was nothing I couldn't understand... It's OK. It's all right.

The doctor said, "we didn't know what's wrong with you, we couldn't find the source of your illness, there is no need to occupy the hospital
bed." I think, that is asking me to leave, then I should leave.

**A Patient who is not believed may feel abused**

When patients experience staff as not believing them, patients feel abused.

I couldn't sleep at night, and the experience that time, like I said, I had one of this uncertainty and everything was the big thing for me... an encounter with one of nurses. I'm sick, but when I'm coming, the person saw me like, "Oh, you're playing sick." Yeah, it hurt me big time... I said how come a person tell a person like that.

I said, "Oh, do you think so?" Because it doesn't matter. I was sick in the unit. Sick, but I got really lonely and everything. I don't want to stay in the room, so I'm coming the nursing station sitting there. She saw me at that time and she said that. I didn't go back to talk to her about it, but it really hurts me as a patient. I didn't expect a nurse talk to me, talk to me as a patient.... I'm a patient, so that was a really... I won't forget that experience, which was really... I'm telling, I'm not feeling well about it right now just telling you because it hurts me big time whenever I remember. I don't want to. Sorry. “Oh so-and-so, now you're playing, playing sick?” or something like that. It was really hurting me. I, myself sick, and on top of it, to have a person talking to you like that, it's hurtful. Sorry.

**Grateful for being valued**

Patients are grateful when they receive good care and when they perceive that they are valued and respected.

The main thing... the care you're receiving, that one you will remember forever, because if it's a good care done, or people listen to your problem, or answering your questions, or be pleasant, or just say simply say, "hi," to you, it matters, because that you will remember. You won't remember good food or those things sometimes, but to me, honestly, that's more important for me.

I'll just reiterate. Just what a great care team Toronto Western and University Health Network has.
Appendix G – Patients’ Words: Experiences & Needs Connected to Hospitalization Phases

1. Admissions: Expectations, Asking Questions, Sharing Information

Patients need to know what to expect. They need to be encouraged to ask questions and share relevant information, including recent experiences, in culturally appropriate ways.

I just showed up the morning of, couple of hours prior to my surgery and staff were very helpful in doing what they had to do and were very clear and concise as to the process of admitting and who I was going to be meeting with and when and so forth. And then I was taken in for my surgery. It was very simple.

Misinformation or misunderstood directions at the time of admissions add to the patients’ stress and anxiety.

We were supposed to be there by six o’clock in the morning but they had the wrong entrance doors for us to come in so it was six o’clock and we were wandering around outside trying to find the entrance that we should go in. So that part of it wasn’t good.

There may be missed opportunities for care when sufficient information is not obtained early in the hospitalization.

Also you check out the patients and find out what their background are and provide them food catered to their taste. That would be better, isn’t it? You don’t have to provide me with good stuff. Simply give me a bowl of rice, hot and steamy, some veggies or fish. [Cantonese former patient]

When the admissions process is predictable and understood, the patient finds it simple, not chaotic.

2. Treatment Period: Engaged Participant or Complacent Victim

During the treatment period of the hospitalization, patients experience satisfaction when they are respected, informed, able to ask questions comfortably, and are engaged as partners in their own healthcare.

So in the morning I go for an ultrasound for one and a half hour when I come back, so waiting for the result. Meanwhile, when I see the surgeon, ... waiting for a result a little bit longer, but it wasn’t bad. It was good, like, whatever information or anything I will ask, and they answer. I consider it a very nice thing. They will ask when I talk to them, they go, "Yeah," giving me full information, anything like I’m asking.

They were asking if "Are you okay with a wheelchair?" I said, "Better stretcher, because when I’m moving, I’m having more pain," Yeah, I go with stretcher.

When they do not understand, and do not feel comfortable asking about what is happening during treatment, their experience is that of a victim not a participant

I don't know what they were doing; anyway when I was told they need to draw blood, I would offer my arm for them to draw. But I have never asked, ‘what do you draw my blood for? For what tests?’ I didn't ask. Some nurses wouldn't even know
anyhow. The doctor asked them to draw and they would do it. Therefore I didn’t ask. I don’t know what they were doing. I think she didn’t know the reason why I was there. [Cantonese former patient]

3. Recovery: Regain Independence and Not Feel Like a Patient

As patients emerge from the intense treatment phase, they need to become independent and to regain a sense of self, autonomy, and their own identity as persons. They do not want to “feel like a patient.”

They also gave me leeway which was kind of nice because I’m the kind of person, I’m relatively independent so I like to do things when I feel like I’m ready to do them.

He would tell me, “Just buzz. You shouldn’t be doing this on your own.” I kind of didn’t like that only because of the fact that I know myself well enough that I can handle what I can handle and what I can’t. If I need help, I’m always going to ask for it. That was probably the only thing that kind of made me feel a little like a patient. Everybody else was great.

On the other hand, the transition from patient to independence can also take more time than the patient may have initially thought. As a patient begins to leave the “patient” phase, the transition to independence may be slower than anticipated.

I’m in as a patient, I’m in the hospital and I’m still surrounded by calmness and to eat when I was here was no problem but when my friend came with coffee and something to eat...I think I asked her to bring me a sandwich...I couldn’t, I think, because I was becoming too awake and my system wasn’t ready for the overload of the food and the senses and the smells and everything.

4. Discharge: Uncertainty, Abruptness, Surprises, and Lack of Information

The discharge process may be filled with uncertainty. It was often abrupt, sometimes unexpected. Patients experienced discharge as being released with insufficient understanding about their healthcare situation or insufficient information about their next steps. Once at home, there was a sense of loss. The experiences of patients upon discharge were often confusing. They often felt unprepared to leave.

We didn’t know what’s wrong with you; we couldn't find the source of your illness; there is no need to occupy the hospital bed. I think, that is asking me to leave; then I should leave. After I returned home, I still felt unwell.... They said they need my son to come... My son said, "OK, OK, I'll come after work." The doctor was waiting for him. After having waited for a while and my son still hadn't come, he (the doctor) was gone and left me a pile of papers that were for prescription, for the arrangement of when to do what, that stuff. [Cantonese former patient]

The pile of (discharge) papers, that is to say I don’t know what they are, I gave them all to my son. Probably said that I had been examined and nothing was found, like that. I don’t understand. There was a prescription...

The discharge experience was often an abrupt break from the hospital environment that was experienced as being disconnected from any treatment plans that care providers may have developed, and potentially even without the knowledge of the healthcare providers.

Nobody else came to say anything to me, not even my surgeon. Apparently, my surgeon didn’t even know that I was being discharged until when I went to my follow-up, he’s like, “I came to see you the following day,” he goes, “and you were gone.

The moment I got into the room, the physio came back and said, ‘How would you like to go home?’ That was it. He said, ‘The hospital would greatly appreciate it because we need the
space and you’re free to go.’ I was surprised. It’s not that I thought that I wasn’t ready. I just didn’t...from what I had heard and read it would be up to a four-day stay. I was here for two days. Then, ‘How would you like to go home?’ Then I went home and that was it and it was just a strange...it’s like I got sucked up in a vacuum all of a sudden. It was just this strange going through the motions of packing my things and having my friend there who’s a social worker and just having this surreal feeling of, I guess, maybe disbelief and awe of what I had just gone through and that I was going home already.

I think there might have been a moment of, just like a slight moment of...I don’t know if apprehension’s the right word but maybe a slight moment of ‘What?’ of Then I just dismissed it very fast because I wanted to go home and I didn’t see the need for me to stay any longer anyways and if they need the space, they need the space.

I asked my nurse that if the doctor is allowing me to go because I was a little bit tired because I couldn't sleep last night and I wanted to go home. She said, ‘yeah,’ she'll find out from the doctors. I saw them. They say, yeah, so they gave me discharge summary and I discharge myself.

5. Post-Discharge: Transition Period

Once at home, after the discharge, there is a transition period, which can involve sadness and loneliness.

I started the (support) group a week after I was discharged from the hospital so that week in between was a week of sadness; it was just sad and lonely.

Yeah, it was kind of lonely in that even though I had a lot of help and people looking in on me, I didn’t really...you go through something like that and I didn’t really have any...I talked about it but I didn’t talk about it at the same time. There was, yeah, I just felt kind of lonely and sad.
Authors of the Pilot Report

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