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On April 1, 2009, AHS brought together 12 formerly separate health entities in the province: nine geographically based health authorities (Chinook Health, Palliser Health Region, Calgary Health Region, David Thompson Health Region, East Central Health, Capital Health, Aspen Regional Health, Peace Country Health and Northern Lights Health Region) and three provincial entities working specifically in the areas of mental health (Alberta Mental Health Board), addiction (Alberta Alcohol and Drug Abuse Commission) and cancer (Alberta Cancer Board).
REPORT ON THE PATIENT JOURNEY STUDY

INVESTIGATORS:

Karen Jackson
Nelly D. Oelke
Daniel Leffelaar
Jeanne Besner
Alexandra Harrison

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REPORT ON THE PATIENT JOURNEY STUDY

INTRODUCTION

Health care systems are complex organizations, which often makes it difficult for patients to navigate their way through the system when accessing services. This can be especially so for patients with chronic conditions who may see multiple providers in the course of multiple visits. Understanding what influences perceived quality of care for these patients and others is an important component in monitoring the efficiency and effectiveness of our health care system. Patients with chronic conditions represent a significant burden of illness in our society (e.g., leading cause of death, significant health care costs for system and individual) and it is important to understand how utilization patterns might be influenced positively or negatively by the way in which services are delivered. In this study, four patients with Chronic Obstructive Pulmonary Disease (COPD) were followed for a three-month period subsequent to hospital discharge, in order to obtain a comprehensive picture of their journey through the system. Data related to patients’ contacts with and experiences of the health care system were augmented with pertinent literature. Findings from this study on the Patient Journey are presented in this report.

BACKGROUND

The Canadian health care system is complex, and many patients, particularly those suffering with a chronic disease, often interact with multiple providers while accessing services in a variety of different health care settings (Haggerty et al., 2003). Measuring health system quality, efficiency and effectiveness is essential to the provision and improvement of health care services. As a result, many organizations have developed methods and theoretical frameworks that attempt to capture and measure important aspects of quality of care. Although understanding of patients’ experiences is critical to the provision of quality care, this aspect of measurement is often not carried out. Little research has been conducted on quality of care from the patient perspective.

Patient satisfaction has consistently been used as a measure of quality of care and to assess patient experience (Bidaut-Russell et al., 2002; Fan, Burman, McDonell & Fihn, 2005). However, a number of inherent issues have been identified with patient satisfaction as a measure of quality. There is no clear understanding of the phenomenon; there is a lack of standardized measurement; and, there is a lack of agreement as to whether it truly measures quality of care (Aharony & Strasser, 1993; Henderson, Caplan & Daniel, 2004). Furthermore, patient satisfaction surveys are often very broad (Scalise, 2003) and provider driven (Henderson et al., 2004) and therefore do not always provide useful data for the improvement of health care service delivery from the patient’s perspective.

Patient experience is seen as an “indispensable” addition to the panoply of performance indicators used for monitoring effectiveness of health services (Coulter & Jenkinson, 2005). Unlike satisfaction surveys, patient experience surveys reveal their concerns about care, as is demonstrated in Table 1 (Scalise, 2003).

Several authors have noted that understanding patient experience is critical to designing patient-centered care (Jenkinson, Coulter, Reeves, Bruster & Richards, 2003; McKeever, 2004; Scalise, 2003). The Planetree Model (Frampton, 2003) of patient-centered care provides a
foundation for the design and implementation of health care services that are sensitive to patients’ expectations. The model includes nine elements - human interaction; education for patients; families and others; participation of family and friends; nutrition; spirituality; human touch; healing arts; integration of complementary and alternative practices; and, healing environments (Frampton, 2003). Similarly, the Picker/Commonwealth Program for Patient-Centered Care (Gerteis, Edgman-Levitan, Delbanco & Daley, 1993; Scalise, 2003) outlines seven dimensions that need to be addressed to achieve patient-centered care: respect for patient preferences; coordination of care; information and education; physical comfort; emotional support; involvement of family and friends; and, transition and continuity (Scalise, 2003).

Table 1. Patient Satisfaction vs. Patient Experience

<table>
<thead>
<tr>
<th>Satisfaction</th>
<th>Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient evaluates whether he/she is satisfied with care</td>
<td>Patient reports how/when events occurred</td>
</tr>
<tr>
<td>Uses word like “excellent,” “good,” “fair”</td>
<td>Uses words like “sometimes,” “never,” “always”</td>
</tr>
<tr>
<td>Uses cumulative scoring: higher scores are better</td>
<td>Uses “Problem Scores”: lower scores are better</td>
</tr>
<tr>
<td>Typical questions may include: How well did your physicians keep you informed? Excellent, Very Good, Good, Fair, Poor</td>
<td>Typical questions may include: During your hospital stay, how often did doctors explain things in a way you could understand? Never, Sometimes, Usually, Always</td>
</tr>
</tbody>
</table>

From Scalise, 2003

Beyond the concept of patient-centered care, a variety of domains that capture the experience of patients (Scalise, 2003; Jenkinson, Coulter, & Bruster, 2002) are outlined in the literature. The Scalise (2003) model encompasses most domains mentioned in the literature (see Figure 1).

Figure 1. Domains of the Patient Experience

From Scalise, 2003

Our review of the literature found very little primary research directly focusing on
these specific domains of patient experience. It is difficult to know whether patients explicitly consider these elements when they discuss their experiences of the health care system. Experts who study patient experience and patient-centered care suggest that “we need to develop systematic, appropriate and effective ways to ask patients what they need, expect and experience” (Gerteis et al., 1993, pp. 299-300) in managing their health. This information is critical in planning and implementing improvements in health care delivery (Gerteis et al., 1993; McKeever, 2004), not only in acute care but across the continuum of care delivery. There is a need to understand patients’ experiences from their perspective if we are to identify factors that they associate with quality care.

Clearly, there is a need for research to further our understanding of the patient experience. This will contribute to the identification and validation of indicators of quality as perceived by the recipients of care. The purpose in this study was to better understand quality of care from the patient perspective. The elaboration of patient journeys is one way to gather information about patient experience and begin the identification of patient derived domains and indicators of quality of care.

RESEARCH OBJECTIVES

- To understand the patient experience, through the studying of comprehensive patient journeys.
- To identify domains and sub-domains reflecting patient experiences.
- To determine the feasibility of collecting various types of data (interviews, patient journal, corporate data and primary care data) and using process mapping as tools for describing a patient journey.

APPROACH

Methods

Case study methodology was used to address the research objectives in this study (Bryman & Teevan, 2005; Merriam, 1998; Yin, 2003). Case study methodology provides an opportunity to conduct an in-depth analysis of a “case” through a rich, thick description including contextual information of the case. Both qualitative and quantitative approaches are used to collect data and multiple data sources are often utilized in case study research to best answer the research questions and provide a detailed description and analysis of the case (Yin, 2003). This study used both mixed methods and multiple data sources to uncover the important aspects of patients’ health encounters and experiences. Each patient and his/her journey through the health care system were treated as a separate case. Cases were then compared one to another throughout data collection and analysis. Ethical approval was obtained through the Conjoint Research Ethics Board at the University of Calgary.

Sample

Four participants from one acute care medical unit in the Calgary Health Region were recruited with assistance from the Patient Care Manager. To obtain desired gender variation, both men and women were recruited prior to discharge from hospital. Selection criteria included a diagnosis of Chronic Obstructive Pulmonary Disease (COPD); discharge to home
or seniors’ housing; and fluency in English. Patient recruitment began July 2006 and ended November 2006. Informed consent was obtained from each of the participants prior to enrolment in the study (Appendix A).

Patients with COPD were selected for participation, since patients with a chronic illness often require substantial amounts of care during their hospital stay and subsequent to discharge, and many have frequent encounters with the health care system over the course of their illness. It was felt the experience of this chronic disease population would provide researchers with a beginning sense of the scope of the issues these patients face in managing their health.

**Data Sources**

Semi-structured interviews and participant journals were used to collect in-depth data on the experiences of patients. Utilization data abstracted from administrative databases augmented self-report data collected in participant journals. Data from interviews and participant journals were used to construct process maps which served as a visual representation of each patient’s journey.

**Participant Interviews**

Semi-structured interviews provided information related to interviewees’ experiences and understanding of their journey through the health care system (Bryman et al., 2005). Interviews were guided by five open-ended questions and several probing sub-questions that explored the patients’ journeys (Appendix B). Questions focused on patients’ experiences in managing their health and on the contacts they had with the health care system over the three month period subsequent to discharge from hospital. Prior to enrolment of patients in the study, interview questions were piloted with two individuals aged 60 years or more. Three interviews were conducted with each participant (and any family members present) over the three-month period. All interviews were audio taped and transcribed. A follow-up interview (approximately 6 months following the completion of the initial set of interviews) was conducted with three of the four participants to “validate” that the analysis and interpretation of data adequately reflected their “patient journey”. The fourth patient was lost to follow-up. Detailed notes taken by the research assistant during interviews were referenced during data analysis and interpretation.

**Participant Logs**

Participant journals/logs provided additional information over the three-month period and were used to aid in the interview process. The journal was pilot tested with two individuals over the age of 60 to ensure functionality. Each participant kept track of his or her contacts with the health care system. The journals provided relevant information such as date, time, type of contact, (phone or visit), whom they contacted, the reason for the encounter, outcome of the encounter, and pertinent comments or description. Each participant received a package in which a basic template guided this aspect of data collection (Appendix C).

**Health Utilization Data**

Health care utilization data were extracted from corporate databases (Home Care, Emergency and Urgent Care and In-patient databases) for each of the patients in order to complement participant journals.
**Analysis**

Data collection and analysis was an iterative process, with one data collection activity informing future data collection and analysis throughout the study. Themes in the data were explored and recurring patterns were identified. Thematic analysis was conducted on both interview and journal data using N6™ software.

In addition to thematic analysis, process maps were constructed from the data. The purpose of the process map was to provide a visual description of the patient journey, to highlight the care trajectory and identify the number and type of encounters with the health care system over the three-month period. Process maps and interview data were helpful in identifying common quality of care issues that all participants had raised.

Health care utilization data was compared to data from the patient log and interviews to further develop the patient journey and to assess the accuracy of self-report information provided by patients.

**RESULTS**

**Participants’ Demographic information**

Demographic information was collected for all participants (n=4). Three female and one male participants were recruited, ranging in age from 57 to 81 years. Two of the participants lived alone, while the other two lived with one or more family members. Incomes ranged from less than $25,000 to $55,000 per year. In addition to COPD, participants had several co-morbidities including: osteoporosis, scleroderma, lung cancer, heart disease, asthma, kidney cancer, stroke, and glaucoma. Primary diagnoses at admission to hospital included COPD with acute exacerbation, COPD with respiratory infection, and congestive heart failure (CHF). Secondary diagnoses included the following: diabetes; pneumonia; cancer of the lung and bladder; primary and secondary pulmonary hypertension; acute and chronic renal failure; tobacco use; CHF; heart disease; other pulmonary and lung disorders; non-infectious gastro or colitis; anemia; ascites; and, auto immune disease. The length of stay ranged from 3.74 – 17.72 days, with an average of 10 days.

**Themes**

Three overarching, interrelated themes were identified from the data: social support; system navigation; and, access. Each theme comprised smaller related sub-themes. The themes and their inter-relatedness are illustrated in Figure 2.
Social Support

Social support was a strong theme in each participant’s healthcare journey of the system. More specifically, the importance of family and friends contributed to quality of life and to the quality of interactions with the health care system.

Friends and family supported participants by helping with activities of daily living and enabling participants to overcome physical limitations, such as getting in and out of the bathroom, or moving about the house. “My friend in the building came down and helped me get into bed, because I couldn’t lift my leg.” (P01 Int01, Text Unit 218 – 220).

Access to family support also enabled participants to get around in the community. “I’ve got two nieces and one is willing to go shopping with me whenever I need.” (P02 Int02, Text Unit 486 – 488). One participant noted that familial support was critical in managing crisis...
situations. “One day I did fall. But the phone was right there and I phoned my daughter and her husband came over and got me back up on my feet.” (P03 Int01, Text Units 257 – 259).

Participants also underlined the importance of emotional support. Having access to supportive relationships improved participants’ ability to cope with their chronic condition. “It makes you feel good when you know that somebody is caring how you’re doing.” (P03 Int01, Text Unit 170 – 171). Participants often mentioned the importance of having someone nearby if there were a problem or emergency. The presence of a friend or family member decreased the anxiety experienced by participants both when at home and when interacting with providers in various healthcare settings. “I’m more secure doing stuff when I know there is somebody else in the apartment, so that if anything happens, I’m not going to be laying here alone for a couple of days.” (P02 Int02, Text Unit 329). Emotional support was most often attributed to the presence of family and neighbors, although one participant identified the religious clergy as a source of emotional support.

Participants noted that family and friends helped them manage their interactions with the health care system. Direct involvement of others helped participants share the burden of managing their care with friends and family. Participants relied on family to assist them in managing medication, as well as scheduling appointments with healthcare professionals. This type of support was especially important for those participants who were required to make several visits to health providers and/or were prescribed numerous medications. One participant noted that the presence of a family member was crucial during appointments, to help overcome the participant’s memory losses. “My memory isn’t as good as it once was and [having] somebody else listening to what you’re being told is good for me.” (P03 Int01, Text Unit 666 – 675). Family and friends played a critical role in advocating on behalf of the participants, ensuring that their health needs were met.

One participant lacked any form of support from neighbors and family. This participant was dependent on portable oxygen, and given that visits with friends and family required traveling some distance, there was limited access to social support. This contributed to feelings of isolation and depression, which reduced this participant’s interest in getting out of the home. “I feel really isolated now. I’ve got friends who live across the city, but now that I’m on the oxygen, that’s a long way to go.” (P02 Int01, Text Unit 276 – 277). Lack of desire to leave home increased this individual’s isolation and aggravated the depression. “I’m getting the mindset, I suspect its depression, where I just sit here and watch TV for three days straight, without doing anything.” (P02 Int01, Text Unit 313 – 314). The lack of access to social support left this participant totally responsible for managing a complicated chronic condition alone, which caused substantial frustration. None of the healthcare providers involved in the care of this individual recognized the social isolation or associated depression. The participant’s experience of the system stands in sharp contrast to that of other participants whose trajectory through the system was made easier by support from family and friends.

System Navigation

Effective communication among healthcare providers and participants was identified as an important contributor to participants’ ability to successfully navigate the health system. Participants often noted how difficult it can be to obtain appropriate and sufficient information from their healthcare providers. “I’ve gotten to that point where if I want something, I have to ask him, because he doesn’t say anything.” (P02 Int03, Text Unit 152). When asked if care
Providers had listened to concerns and really addressed them a participant responded, “We’ve never actually discussed them.” (P02 Int01, Text Unit 503). This lack of open information exchange between the participant and the healthcare provider resulted in needs, such as the unrecognized isolation and depression noted above.

A common theme emerging in the stories of all participants was lack of knowledge about what they should ask health professionals in order to help better manage their condition. Participants noted that when they asked specific questions about managing their care, they generally were satisfied with the response they received, although they were sometimes left wondering whether they had in fact received as much information as might have been helpful. They wondered whether there was more that health care providers had missed telling them that would have improved their capacity for self-care.

Participants also noted a frequent lack of opportunity to ask questions. “She was in and out so fast; I didn’t have time to ask a question.” (P01 Int03, Text Unit 589). In contrast, participants valued and praised providers who took time to listen to their concerns.

In one situation, a participant was sent home with a leg cast, but not given any instruction about cast care or how to manage at home. “There was no explanation what-so ever about how to even get up off that table that I was on.” (P01 Int03, Text Unit 566). When complications occurred (swelling related to a tight cast), the patient became anxious and later that day, was readmitted to hospital with COPD related symptoms. Although it is difficult to affirm that readmission to hospital could have been prevented, it is possible that better information about cast care, as well as what to do and whom to call if early warning signs appeared could have decreased this participant’s anxiety and averted the exacerbation of COPD. Once the need for information about cast care was recognized, the participant was able to manage care needs in the home, with the assistance of a physiotherapist and additional in-home support.

Previous experience with the system also played an important role in helping people subsequently navigate the health care system, as it allowed participants to anticipate what services might be available. Most often, participants used the collective experiences of family and friends as well as their own past experience to understand and guide their journey through the healthcare system. “I knew what they (homecare) offered, because I had them when my husband was alive.” (P01 Int03, Text Unit 191). Previous experience influenced expectations and use of the system, improved understanding of what the service offered and increased satisfaction when expectations were met. Lack of prior knowledge of a particular service sometimes contributed to unmet expectations.

There was a bit of a communication breakdown. I said I needed help in my apartment, but what I needed was help with the vacuuming and cleaning. She [homecare worker] was there for personal care; help in the shower or for medications and stuff like that (P02 Int01, Text Units 17-19)

This lack of experience resulted in a gap between what the participant expected and what was provided. Eventually the participant cancelled the service, as it was not needed.

Previous experience also provided one participant with a greater sense of trust in a specific health care provider. “I had a lot of confidence in him, because he’s pulled my husband through in a lot of rough places.” (P04 Int02, Text Unit 65). Several participants identified specific individuals who advocated for them as they journeyed through the system. Advocates
were most often family members who supported the participant, both in the home and when interacting with the system. Advocates often filled gaps in healthcare services by stepping in and personally addressing healthcare needs. “My daughter came in [to the hospital] and got me off the table and put me in the wheelchair.” (P01 Int03, Text Unit 607). One participant, who had a high degree of familial support, had multiple advocates including a family member who was a nurse. As a result, the participant felt prepared when interacting with healthcare professionals as the family member provided information and facilitated information exchange between healthcare providers and the participant.

My daughter makes a point of going with me to that appointment. And they can carry on and talk words that I don’t even know. I’ve never heard them before, but they can carry on a conversation. She knows what questions to ask (P03 Int03, Text Units 312-315).

Advocacy obviously facilitated smooth navigation of the system, as there was a greater understanding of what services could be used to address certain care needs. Unfortunately, not all participants enjoyed this level of advocacy, either from family or care providers.

The quality of relationships with healthcare providers was associated with enhanced perceptions of quality in navigating the healthcare system. Participants clearly associated their relationships with providers with their ability to move smoothly (or not) through the system. Participants identified several characteristics that facilitated high quality provider-participant relationships. One family member stated, “I expect them to not treat her as just a number.” (P03 Int02, Text Unit 609). Providers who treated participants as an individual rather than “just a number” and who did not have their “hand on the door” during the visit were perceived as more caring.

Participants also underlined the importance of good interpersonal skills among providers as key to high-quality interactions with the healthcare system. Terms such as “very satisfied” or “it was very good” were used in describing interactions with providers who were felt to have excellent interpersonal skills. “I was satisfied because of the positive attitude of the girl that was coming in to see me. She was just really upbeat, a really nice person.” (P01 Int03, Text Units 81 – 83).

Access

Access to healthcare services was another theme emerging from the data. Several participants were physically restricted in accessing needed health care, in some cases due to the need for continuous oxygen. Having to rely on portable oxygen made it difficult to keep appointments, particularly when the waiting time to see a health professional was longer than anticipated. Several participants could only carry a limited supply of oxygen with them, and running out of oxygen created anxiety for them.

I got there [clinic office] and my oxygen bottle is almost empty. I was using up a bottle and it was less than half full, but I figured that will get me there and I’ll put a fresh bottle on when I get there. Well, I got there; I didn’t have a fresh bottle (P02 Int03, Text Units 358 – 365)

This limit in physical mobility not only affected the participants’ access to healthcare services, but also their ability to get out of the home to perform daily tasks such as grocery shopping.
Family members often alleviated this difficulty. “We have to get one of our grandkids to take us. We don’t drive, and so they have to take us over to the hospital.” (P04 Int02, Text Unit 162 – 164). In one case, several health care professionals (primary care physician, lab techs, homecare nurse) provided service in a facility located in the participant’s home community, making it easier for that individual with mobility restrictions to receive needed care.

Participants’ access to a regular primary care physician (PCP) varied. In two cases, PCPs managed the care and were responsible for initiating referrals to specialists. In these cases, there was good follow-up contact between the PCP and the participant and both participants expressed a high degree of satisfaction with their PCP. One participant received follow up contact from the PCP outside of the clinical setting (e.g., in a public mall). The PCP “took the time that night to phone me, to see what my problem was.” (P01 Int02, Text Unit 438). Follow-up contact by the PCP was highly valued by the participant.

One participant did not have a regular PCP and used a walk-in clinic for primary care. While their COPD concerns were well looked after through an ambulatory care specialty clinic, primary care issues were not addressed, other than the current episode for which the patient presented to the walk-in clinic. This individual, in contrast to the others who had a regular PCP, identified a number of unmet care needs. The participant described feelings of depression and social isolation which were not discussed with the walk-in clinic physician. Upon questioning from the interviewer as to whether this individual would feel comfortable talking to a health care provider regarding feelings of depression, the response was “I don’t have a problem with it.” (P02 Int01, Text Unit 522). Nonetheless, over the course of this study, this client’s social isolation and consequent feelings of depression remained unrecognized, and hence were not addressed by any of the healthcare providers involved in the care of this individual.

Access to specialist physicians was facilitated through the PCPs for the majority of participants. However one individual was encouraged by family members to see the specialists on a regular basis, to avoid the need to make repeated, and perhaps unnecessary visits to the family physician for the sole purpose of being referred back to a specialist.

If you haven’t seen them (a specialist) in a year, you have to go and get another referral. So quite often, you make an appointment because you know that your year is going to be up and then, you won’t be able to get in to see him without another referral (P03 Int02, Text Unit 50 – 55)

In this case, access to specialists was not a concern as the individual took direct control over the frequency of visits to the specialist. However, this unmonitored access to specialists may have resulted in over utilization of healthcare services.

Utilization Data

Utilization data was collected for the three month period after discharge for each of the four patients followed for the study. Data were collected from various databases – e.g. acute care, emergency and urgent care, ambulatory clinics and home care. Data were then compared with data self-recorded by patients in their logs. Although corporate data provided accurate information on the actual number of contacts with secondary and tertiary components of the health care system, it was impossible to capture other contacts such as primary care physician visits, pharmacy, diagnostics, etc. Home care corporate data is also limited in that personal care is always batch entered, therefore the number of visits is impossible to determine. Patient logs on
the other hand varied from patient to patient in what was entered and the diligence of the patient in completing the log. Gaps in information were noted in some of the logs, while others included all contacts with various individuals, providing a rich data source from which to understand the health care journey as described by the patient. Health care utilization data collected from patient logs and regional corporate databases is described in Table 2.

Table 2. Number of contacts recorded by patients and regional corporate data

<table>
<thead>
<tr>
<th>Patient</th>
<th>Primary Care Physician</th>
<th>Specialist/ Specialty Services</th>
<th>Specialty Clinic+</th>
<th>Home Care++</th>
<th>Pharmacist</th>
<th>Lab/ X-ray</th>
<th>In-home Oxygen Services</th>
<th>ADL Supplies</th>
<th>Friends/family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient 1</td>
<td>0</td>
<td>4 (2 visits included a group stop smoking program)</td>
<td>4*</td>
<td>2 visits plus personal care</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>Not recorded</td>
</tr>
<tr>
<td>Patient 2</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>6 visits by RN; 1 by OT</td>
<td>5</td>
<td>0</td>
<td>6 (in-home &amp; office)</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Patient 3</td>
<td>2</td>
<td>6 (4 different specialists)</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>Not recorded</td>
</tr>
<tr>
<td>Patient 4</td>
<td>4</td>
<td>6</td>
<td>10*</td>
<td>2 visits</td>
<td>0</td>
<td>7</td>
<td>1</td>
<td>0</td>
<td>Not recorded</td>
</tr>
</tbody>
</table>

Note:
- + Data taken from Regional corporate data
- ++ Data taken from Regional Home Care database
- * All visits for respiratory services, pulmonary function testing, and respiratory clinic
- None of the 4 patients had visits to Emergency or readmission to hospital during the 3 months of the study follow-up

DISCUSSION

Results of this study suggest that social support, navigation of the healthcare system, and access to healthcare services are important overarching elements of quality, from the patients’ perspective. These themes have some similarities to the domains of patient experience identified in the literature.

In this study, social support, including emotional support and involvement of family and friends emerged as a domain comparable to that found in Scalise’s (2003) model. Support from family, friends and health care professionals positively influenced patients’ experience with the health care system. Those individuals with a higher degree of social support were better able to cope physically and emotionally with their chronic illness. Those with a high degree of social support often had a key person or personal advocate that assisted in the management of care needs. For health care professionals, this speaks to the importance of assessing for the presence
or absence of support systems and for including family members or significant others when planning care (e.g., discharge planning). In particular, it was clear that social isolation is a risk factor for depression in patients with chronic disease and health professionals must be sensitive to this when conducting patient needs assessments.

The concept of system navigation incorporates several of Scalise’s (2003) domains, including the importance of information and education, respect for patient preferences, continuity and transition, as well as coordination of care. The patients in our study were sometimes unsure of what they should be asking of health care professionals and were unaware of information that would facilitate self-care. Patients appreciate health care providers who can anticipate their needs and provide them with needed information without being specifically asked. A proactive approach to giving information is not only beneficial to the patient, but is desired by patients.

Previous experience with the health care system emerged as an important element in facilitating navigation of the health care system and promoting the capacity for self-care. The importance of supporting the involvement of patients in decision-making about care and enhancing their self-care capacity cannot be underestimated. Health care professionals can act as “coaches” for patients and families and not merely “providers of care” (Harrison & Verhoef, 2002). Patients should not have to “learn the ropes” each time they have an encounter with the health care system, but should be helped to build on prior experiences in enhancing their capacity to effectively manage their care. In this study, it was also reported that relationships that are characterized by compassionate and caring communication between health care professionals and patients was an important asset in enabling patients to more effectively navigate their way through the system. Unfortunately, it was clear from this study that communication structures and processes among providers (e.g., acute care, family physician, home care, community pharmacist) were often less than ideal, contributing to fragmentation in care delivery and duplication of “storytelling” for the patient.

Patients’ description of challenges in accessing healthcare services was consistent with the access domain of the Scalise model (Scalise, 2003). Given the complex care needs and consequent physical limitations of patients in this study, it is perhaps no surprise that ability to access health care services emerged as a major concern. The need to carry portable oxygen limited how long and how far patients could go to receive treatment. Having a regular primary care physician was an important element of access. The fact that many people in this city lack access to a regular family physician likely reinforces the negative perceptions that many Calgarians express regarding the perceived lack of quality in health service delivery in the Region. Regular primary care allows for the development of a relationship with the provider, which was seen to be particularly important to some of the patients who participated in this study.

Our intent in this study was to determine the utility and feasibility of various approaches to data collection as means of tracking patients’ journeys through the health care system. As previously noted, Regional corporate data provided an accurate record of patient encounters in secondary and tertiary care. The patient log, though less complete or accurate, nonetheless provides a rich source of information related to patients’ contacts with other health care services. As should be expected, patients with chronic diseases typically have many more contacts with health care services in the community, rather than in secondary or tertiary facilities. Patient logs also provided the basis from which to engage patients in discussion of their journey through the
health care system during interviews. In essence, all three sources of data were important to our understanding of the patient’s journey as described by the four individuals who participated in the study.

TRANSFERABILITY AND LIMITATIONS

Case study findings can “oversimplify or exaggerate a situation leading the reader to erroneous conclusions about the actual state of affairs” (Guba & Lincoln, 1981, p. 377). Nonetheless, when early findings from this research were shared informally with nurse educators and other ‘users’ of the health care system, there was acknowledgement that the findings “resonated” with their experience. The small sample size is obviously a limitation of this study, which we have tried to overcome by providing a rich, thick description of each patient’s journey, while triangulation of data sources increased the validity of the results (Yin, 2005).

CONCLUSION

An understanding of the patient’s journey through the health care system from the patient’s’ point of view is essential to improving quality of care. Current indices of quality often rely on provider developed patient satisfaction surveys. In this study, a variety of data collection methods and process mapping were utilized to create a picture of patient journeys through the health care system, as a means of understanding quality of care from the patient’s perspectives. The overarching themes emerging from this study were consistent with several of the domains of patient experience articulated in Scalise’s (2003). Prior experience of the healthcare system emerged as a factor in improving patients’ ability to manage their care, a theme not found in the literature review. In this study, process mapping proved useful in visually describing the many encounters patients have with the health care system, each of which can influence positively or negatively the patient’s perceptions of quality of care and self-care ability. Understanding the patient journey from the “user” perspective can inform health care professionals of the potential to enhance the quality of care and quality of life for patients and their informal caregivers. The patient journey study described in this report lays the groundwork for future research related to the development of indicators and tools to measure quality of care from the patients’ perspective. It is likely that effectiveness and efficiency in health care delivery can be enhanced by focusing more attention on patients’ experiences as they navigate our complex health care system.
REFERENCES


APPENDIX A: CONSENT

PARTICIPANT CONSENT FORM

TITLE: Using Patient Journeys to Develop Patient Perspective Health Care Indicator Domains: A Feasibility study

SPONSOR: Research Initiatives in Nursing and Health, Calgary Health Region

INVESTIGATORS: Jeanne Besner, Calgary Health Region
Nelly D. Oelke, Calgary Health Region
Karen Jackson, Calgary Health Region
Alexandra Harrison, Calgary Health Region
Dan Leffelaar, University of Calgary

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND
Our health care system is complex. Patients, particularly those suffering with chronic disease often see many providers and access services in many different health care settings. The goal of this study is to develop an understanding about factors that impact your experience with illness and health care services. Analyzing the journey of patients through the health care system provides opportunity to improve the experience and outcomes for patients. Various methods including interviews, a patient journal, health services utilization data, and chart reviews will be used to gather information about your health care experience.

WHAT IS THE PURPOSE OF THE STUDY?
The goal of this study is to begin to lay the groundwork for a broader program of research that will seek to understand patients’ experiences in our health care system. The ultimate goal of the research is to begin to identify indicators that can be used to measure quality of the patient experience.

WHAT WOULD I HAVE TO DO?
You will also be asked to provide your Personal Healthcare Number (PHN). The PHN will be used to gather information on services utilized within the Calgary Health Region. This information will be combined with the journal and interview data to provide a detailed overview of your experience.

You have been asked to participate in four face-to-face interviews that will take place over three months. The interviews will take approximately 30 minutes to one hour to complete. Interviews will be completed in a mutually agreed upon place. Interviews will be conducted by one of the research team members and permission will be requested to audio-tape the interviews to provide an accurate record of our conversations. You may request that the tape recorder be turned off at anytime during the interviews. Notes will also be taken.

In addition to the interviews you will asked to complete a journal of health encounters (contact will healthcare services) over the three month period. You, or a family member, are to record relevant information regarding interactions with healthcare services. Journal recording will require 5-10 minutes for each health encounter. A journal will be provided outlines information to be included. The journal will aid in the interview process and provide valuable information to the project.
WHAT ARE THE RISKS?
There are no known risks to participating in this study.

WILL I BENEFIT IF I TAKE PART?
There is no direct benefit to participating in this evaluation.

DO I HAVE TO PARTICIPATE?
Your participation in the study is voluntary. You may decline to answer any of the questions and end your part in the study at anytime. Should you wish to withdraw from the study, inform the interviewer or contact the individual listed below. You also have the right to ask questions and ask for more information whenever you like.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?
You will only be asked for as much time as needed to complete the interviews and journal.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?
You will not be paid to participate in this interview and there will be no cost to you for participating, except for your time.

WILL MY RECORDS BE KEPT PRIVATE?
The information that you provide will be kept confidential. Code numbers will be used on tapes and notes. Lists of participants along with the code number will be stored separately from the data. All other information from the study will be used only in an aggregate form; your name will not be identified. Only principal and co-investigators, interviewers, and research assistants will review tapes and notes. All data collected will be stored in a locked cupboard at Research Initiatives in Nursing and Health, Calgary Health Region for a period of five years.

Ideas and quotes from interviews and journals will be used for, interim and final reports, publications and presentations of research information, but at no time will you be known by your name or in any other way. Anonymity and privacy will be assured as much as possible. You may have a copy of interim and final reports.

SIGNATURES
Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact:

Nelly D. Oelke
Research and Evaluation Consultant, Research Initiatives in Nursing and Health,
Calgary Health Region
(403) 943-1177
If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

<table>
<thead>
<tr>
<th>Participant’s Name</th>
<th>Signature and Date</th>
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<td>Participant’s Phone Number</td>
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<td>Investigator/Delegate’s Name</td>
<td>Signature and Date</td>
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<td>Witness’ Name</td>
<td>Signature and Date</td>
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The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.
APPENDIX B: INTERVIEW GUIDE

The following questions are designed to gather information about the patient’s health care encounters.

1. Tell me about your experiences with health care encounters you’ve had in the last month. [Have patients describe their encounters in detail.] 
   Probe for:
   - transition
   - efficiency in coordination of care
   - continuity of care
   - accessibility to service
   - interaction
   - safety and physical comfort
   - acceptability and emotional support

2. What were the events around why you sought health care? 
   Probe for:
   - why they sought care

3. What were your needs and expectations of these health care encounters?
   [Have patients describe their expectations in detail.] 
   Probe for:
   - respect for patient preferences
   - appropriateness

4. Is there anything else that has happened since we last talked that has affected your health?
   Probe for:
   - events which may impact the patient’s health but which the patient may not associate with “health care”
APPENDIX C: PATIENT JOURNAL LOG

Patient journal template

<table>
<thead>
<tr>
<th>Date &amp; time of contact</th>
<th>Type of contact (e.g. phone, visit)</th>
<th>With whom did you talk or visit? (type of provider)</th>
<th>*Type of location.</th>
<th>What was the reason for contact?</th>
<th>What was the result of this contact?</th>
<th>Description or comments about the contact</th>
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Box 4: * Type of location options:
- Emergency Room (indicate which hospital e.g. Foothills hospital)
- Walk in Clinic
- Home visit
- Community health center (indicate name of center e.g. Bowness Community Care Center)
- Long term center?
- Urgent care center (indicate name of center e.g. South Calgary Health Center)
- Hospital clinic (for example, Foothills Pain Clinic)
- Personal physician
APPENDIX D: PROCESS MAP