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Patient and provider experiences with relationship, information, and management continuity

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Cover Page Footnote

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Patient and provider experiences with relationship, information, and management continuity

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Abstract

From 2003 to 2014, the Health Quality Council of Alberta (HQCA) monitored patient experiences with healthcare services through a biennial Satisfaction and Experience with Healthcare Services (SEHCS) survey. The findings consistently showed a direct link between coordination of care, an aspect of continuity of care, and healthcare outcomes. Specifically, it showed that better coordination is linked to positive outcomes; the reverse is also true. Given the critical role continuity of care plays in the healthcare system, the HQCA conducted in-depth interviews, interactive feedback sessions and focus groups with patients and providers to explore factors that influence both seamless and fragmented patient journeys. Continuity of care refers to “the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient’s healthcare needs and personal context”. Reviews of international literature have identified three major subtypes of continuity across healthcare settings: relationship, information, and management continuity. This study showed that from the patient perspective, relationship continuity is most valued and is foundational for experiencing information and management continuity. A trusting, patient-centred, and respectful relationship with a primary healthcare provider is central to this. From the provider perspective, information continuity is most important. Primary care providers get frustrated if information is withheld or delayed, and if other providers change treatment plans or medications. Patients highly value timely access to their own information. They also value having enough time during an appointment with a family doctor who listens and communicates effectively. Both patients and providers value and benefit from management continuity, which was described by many as a partnership or shared responsibility for managing and coordinating healthcare services. Future conversations about health system design should focus on how all providers and services can work together, and engage patients, to co-design a system that is built around patient-centred relationships.

Keywords

Continuity of care, patient and provider experience, primary healthcare, teamwork, communication, quality improvement

Note

The Health Quality Council of Alberta (HQCA) wishes to recognize the participants in this study who shared their continuity of care experiences in Alberta. The insights provided informed us about the current state of our healthcare system, as well as helped us develop metrics to measure and monitor continuity of care. These thoughtful insights and metrics will prove invaluable in future improvement efforts aimed at providing seamless journeys for patients in Alberta. Special recognition is given to the HQCA’s Patient/Family Safety Advisory Panel for the members’ openness, guidance, and unrelenting support in quality improvement within Alberta’s healthcare system.

Introduction and Background

The Health Quality Council of Alberta (HQCA) captures and listens to Albertans’ voices through various sector-specific and general-population patient experience surveys (<http://hqca.ca/surveys/>) and through the studies and reviews (<http://hqca.ca/studies-and-reviews/>) it undertakes. Over the past few years, the HQCA has explored the relationship between continuity of care and outcomes (patient experience,¹ healthcare service

utilization,² and health outcomes³). The HQCA’s findings consistently demonstrated a direct link between continuity of care, as well as aspects of it, and healthcare outcomes: better continuity is linked to positive outcomes, and poor continuity is linked to negative outcomes. Given the critical role continuity of care plays in the healthcare system, the HQCA conducted an in-depth study to understand the conceptualization and measurement of continuity of care by determining the factors that influence both seamless and fragmented patient journeys.

Continuity of care refers to “the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient’s healthcare needs and personal context.”⁴ It emphasizes healthcare users’, caregivers’, and healthcare providers’ perspectives on smooth and integrated care over time,^{5,6} care that is of high quality, and is cost-effective.⁷ In other words, continuity of care captures quality of patient care over time⁶ and how different aspects of an individual’s healthcare is connected across healthcare events and between healthcare providers.⁵ Reviews of international literature have identified three major subtypes of continuity across healthcare settings: relationship, information, and management continuity.^{4,5,8,9}

Relationship continuity refers to a trusting relationship with one or more healthcare providers that helps to bridge healthcare episodes over time, and which links past to current and to future care.⁴ *Information continuity* concerns the timely availability of relevant information through shared medical records, but also includes accumulated knowledge about the patient’s preferences, values, and context.⁴ *Management continuity* involves the communication of patient-related information across healthcare teams, institutional and healthcare professional boundaries, as well as between healthcare professionals and patients.¹⁰ Continuity of care, as defined by its three sub-types, aligns with concepts of coordination, case management,¹¹ and patient-centredness¹²⁻¹⁵ as well as with the ideals of a medical home model.¹⁶

The value of continuity of care, and its three subtypes, is that it greatly improves many aspects of quality of care, and patients’ and providers’ experiences in the healthcare system. Current research has found that continuity of care:

- Increases trust between the healthcare provider and the patient (this research looked at the effects of relationship continuity specifically).¹⁷
- Reduces errors and adverse events.^{3,23}
- Increases patient satisfaction with care.^{5,10,22,24}
- Reduces patients’ psychological distress and/or improves mental health.^{5,22}
- Improves patients’ health and quality of life.⁵
- Reduces long-term mortality among older adults.²⁵
- Decreases mental and physical healthcare needs.⁵
- Decreases utilization of healthcare services.^{2,26}
- Lowers healthcare costs.^{26,27}

In summary, continuity of care is the result of patients and healthcare providers working together to provide coherent, connected, and consistent care. The present study is focused on understanding continuity of care from the perspective of several stakeholder groups including

patients, families, healthcare providers, and other healthcare “team” staff.

Methodology

This study employed a dynamic mixed-methods approach and each stage informed the next.

Literature Review

The study began with an extensive review of the literature on continuity of care, identifying four reviews of international literature.^{4,5,8,9} These literature reviews informed the development of the interview guide (see Appendix I) for key informant interviews, interactive feedback sessions, and focus groups.

Key Informant Interviews

Respondents were recruited through the 2013 provincial survey about health and the health system in Alberta. 40 Albertans were identified who had used a variety of different healthcare services and had indicated a willingness to participate in further interviews; they were contacted and invited to participate.

Key informant interviews and focus groups were audio recorded and transcribed. Two researchers conducted these interviews and focus groups, with one researcher leading the discussion and the other overseeing the recording and taking detailed notes. The qualitative data was analyzed using a method adapted from grounded theory (Glaser & Strauss, 1967; Corbin & Strauss, 2008).^{28,29} A high-level analytic coding template was developed, based off of the literature and the three types of continuity of care. In addition, open coding was used to enable any new themes to emerge including any recommendations for improving continuity of care. This was particularly important, as patients’ experiences with, and perspectives on, continuity of care was a gap in the current body of literature on continuity of care. A sample of the transcripts was coded by two analysts, one of whom had been involved in the interviews and focus groups. Any discrepancies in coding were discussed and final decisions arrived at via consensus. Moreover, any medical terms were checked for accuracy and understanding.

Interactive Feedback Sessions and Focus Groups

The HQCA used two strategies to recruit healthcare professionals working in primary healthcare. The first was to attend three training sessions for primary healthcare providers to seek informal feedback from primary care physicians and from allied health professionals working in primary care clinics, public health, and other community settings (e.g., home care, mental health clinic). The second was to conduct four formal focus groups recruited from four primary care networks: three focus groups were solely with allied health professionals including registered nurses, a nurse practitioner, pharmacists, and a proactive office

encounter technician;^a and one focus group involved only primary care physicians.

Moreover, a series of feedback sessions were conducted throughout the study with the HQCA's Patient/Family Safety Advisory Panel,^b as well as with 10 individuals in leadership roles in Alberta's healthcare system recruited through the HQCA's professional contacts.

Findings from key informant interviews and feedback sessions/focus groups with primary care providers, as well as feedback from the HQCA's Patient/Family Safety Advisory Panel, informed the question content of newly developed continuity of care survey measures.

Qualitative Results

The following section highlights findings from in-depth interviews with patients and interactive feedback sessions as well as focus groups with primary healthcare providers. These findings are grouped under the three interrelated sub-types of continuity of care.

Relationship continuity

Patients described good relationships with healthcare providers as being patient-centred, including characteristics such as trust, mutual respect, good two-way communication, and caring. They spoke very highly of healthcare providers who treated them "as people" and not "as numbers".

"There are some doctors I would trust with my life and some [I would run from]...The doctors that care about you are on the ball." [Senior living with diabetes]

Patients recognized that trusting relationships take time to develop, so they talked about the importance of having enough time in appointments to talk through their health issues and of seeing the same healthcare provider over time. Patients also described appreciating healthcare providers who are knowledgeable but who also recognize they don't know everything (i.e., healthcare providers who welcome the knowledge that patients and their caregivers possess about what is normal for them, and what treatment options would work best for them in the context of their lives). In addition, some patients reported not having a trusting, ongoing relationship with a family physician or other healthcare provider, which contributed to experiences of being misdiagnosed and inappropriately treated, which then in turn contributed to poor physical and/or mental health.

Patients also talked about how the structure of the healthcare system impedes relationship continuity. For instance, healthcare providers were perceived as being disconnected from patient care, especially when the patient is admitted to hospital, and the family doctor or other

healthcare providers seen in the community have little or no contact with the physician specialists and hospital staff.

"There's a huge disconnect between specialists and the family doctors." [Young woman with extensive healthcare experience as a patient]

Even within the hospital itself, particularly large urban hospitals, patients often stated they saw many different doctors (specialists and hospitalists), many different nurses, and numerous other healthcare providers, which they said made it difficult to establish a relationship. This was exacerbated when the patients were moved to different units.

Patients also spoke of having a trusting relationship permanently severed because either their healthcare provider moved away or retired, or the patient moved to a different town or city or into a long-term-care setting. Finding a new healthcare provider and getting medical records transferred, they said, was often difficult.

In contrast, feedback from primary healthcare providers emphasized their working relationships with other healthcare providers in the healthcare system.

"At least ... I know somebody who knows somebody. Hey, can you do me a favour? And I've done that lots. I mean I do have some connections in the hospital and so I'll say I'm sending this patient and I know this is what your process is. And that goes to a trusting, working relationship with other people. This is really important. So what is it I need to do in order get that done faster?" [PCN nurse]

Primary healthcare providers described these strong relationships with other providers as key to facilitating quicker access and thereby quicker care for patients.

Interviews with both patients and primary healthcare providers identified relationship continuity as an important factor contributing to quality of care. Negative patient experiences – and in the worst case those resulting in adverse events – were often described as involving many healthcare providers caring for the individual, and with no one clearly responsible for coordinating care or for communicating relevant health information.

"They don't have a history with you, so their perception of you only begins at the very moment they see you... Their lack of prior knowledge of your experience makes it so that most of the time any decision they try to make for your good is under-informed. So having them make any kind of decisions that could affect my health has turned out normally to be for the worse." [Young man living with complex medical problems]

Information continuity

When asked about information sharing patients talked about how online access to test results would be helpful for them in ensuring good information flow (i.e., information continuity). Specifically, patients talked about how online access helped doctors find and view test results the same or following day, regardless of where the test had been done in the province. Patients also talked about the value of the healthcare provider having enough time to discuss the patient's feelings and health, and to share information in a way that could be understood (e.g., possible diagnoses, test results, what to expect with a surgical procedure and post-op, etc.) as vitally important for good information continuity.

Patients and their caregivers were often described as the only source of information continuity across healthcare providers and healthcare services. For example, every time they see a new provider, they have to repeat their information. Consequently, valuable knowledge was said to be lost when healthcare providers did not listen to the patient or caregiver and value their knowledge. This knowledge could include areas such as their own health and body, what treatments had already been tried, and what had or had not worked previously.

"I find that when I see a new specialist what they do is they rely largely on me to get a sense of what my condition is. And then they only use my chart if they want to look something up or look at a previous test result... The chart is more of a record of the tests I've had done... It doesn't capture me or my problem really or my situation."

[Young man living with complex medical problems]

Primary healthcare providers talked about gaps in information continuity, especially between primary healthcare and acute care. For instance, staff or healthcare providers working in Primary Care Networks^c (PCNs) often described not knowing when their patients received emergency department care or were admitted to a hospital.

"Well, that's the biggest thing. We don't know they've been in hospital... There is nothing from the hospital. No information and you don't know what medications were discontinued and you don't know what was done. And you don't know what they're taking."

[PCN pharmacist]

Patients reported that they did not realize primary healthcare providers do not always have their hospital information. They are usually asked the name of their family doctor when admitted to hospital, and so they make the assumption that the hospital will send information to the family doctor about the care they received. Primary healthcare providers also talked about delays in receiving discharge summaries from the hospital or the emergency

department, and the lack of information contained in these summaries was said to make follow-up care difficult. Primary healthcare providers talked about 'chasing down' the information, having to call the hospital or emergency department themselves to get information about a patient's care. Additionally, the exchange of information between federally funded nurses working on reserves and provincially funded primary healthcare providers was also described to be problematic. Nurses who work on reserves do not have access to Alberta Netcare^d because it is a provincial (regional) resource; consequently, this lack of access hinders good information continuity among care providers.

During one of the focus groups, a pharmacist spoke of the negative consequences of poor information continuity within a care team and across care teams. The pharmacist told a story about a patient who was underweight and on multiple medications. The patient was hospitalized, but appropriate treatments weren't provided, as they were not aware of the preexisting conditions. Due to the lack of information flow, the patient was readmitted to hospital with further medical issues.

The flow of information was described as being particularly challenging when the patients made the appointments themselves. Primary healthcare providers talked about not receiving information if an appointment was made by a patient, and only receiving information if and when they, or someone in the office, made the referral.

"Communication with and feedback to the family doc is important, but who of these many physicians is going to take the responsibility to do this; and then how do they communicate with each other?" [PCN nurse]

Management continuity

When asked who has responsibility for managing and coordinating healthcare services, the overwhelming majority of patients described this as a shared responsibility among patients and healthcare providers. However, some patients described themselves as being entirely responsible for managing and coordinating their own healthcare, while others (specifically the elderly) said a healthcare provider was entirely responsible.

"I would say I'm more the driving force of getting things done and following it through and making sure that I'm getting looked after. My family doctor was most helpful, definitely but I would have to go in and talk with him and ask him – if he could write out the letter to this doctor and say this." [Middle-aged woman living with serious mental health issues]

In the interviews and focus groups it was generally younger patients and those knowledgeable about their

health condition and how the healthcare system works who expected and wanted to play a greater role in managing and coordinating their own healthcare.

Some patients reported barriers involved with a shared-responsibility model. Patients spoke of feeling dismissed and ignored, and said their knowledge of their own health, as well as their previous healthcare experiences, was not considered valuable knowledge. They also talked about a lack of communication and listening skills in healthcare providers, being given insufficient time to discuss healthcare management issues with a healthcare provider, and consequently developing a non-trusting relationship with the provider. Others talked about how patients or caregivers are often required, but ill prepared, to assume the responsibility for managing and coordinating healthcare.

Primary healthcare providers talked about a lack of coordinator/navigator roles within the healthcare system, particularly to manage transitions in and out of hospitals and emergency departments. They described this need as critically important for complex patients and for those who have little support from family or friends.

In addition, a lack of social workers throughout the healthcare system meant there was little to no support for patients and families in understanding and accessing the complex network of social and financial supports available, thus impeding management continuity. As well, primary healthcare providers talked about the difficulty of facilitating access to mental health, pain management, publicly funded physiotherapy, and certain medical specialists. They also talked about the additional burden faced by patients needing to travel from rural settings to urban centres for care. Travel was said to be especially problematic and difficult for seniors and people with limited incomes, again compromising the experience of management continuity

Opportunities for improving continuity of care

Interviews with both patients and primary healthcare providers concluded by asking participants to identify the one thing they would change about our current healthcare system to improve continuity of care for patients and families. Their suggestions are described in relation to the three subtypes of continuity.

Relationship continuity

Patients talked about a need for more family doctors and better access to them. They wanted to work with a trusted doctor and other healthcare providers, someone with whom they have a mutually respectful relationship, who cares about them and listens to them, who helps manage their health and their healthcare, and whom they can see consistently. A number of patients wished that their

trusted healthcare provider could also be involved in their hospital care (this was usually a family doctor but sometimes a specialist). Patients in communities with a shortage of family doctors were also concerned about what would happen if their key healthcare provider retired.

“You need a doctor that you can go to on a regular basis that knows who you are and gets to know your family, gets to know what the hell is going on in it. Not just always going to walk-in clinics, where they see you for five minutes... We need more physicians that are available to us on a regular basis and we need the support systems that back that up.” [Woman living with chronic health conditions]

Primary healthcare providers reported that many patients, particularly those with chronic health conditions, developed close relationships with them and the healthcare provider team. Primary healthcare providers talked about ensuring that specialists pass ongoing patient care back to them when appropriate to help them build and maintain relationships with their patients. This appropriate hand-off was said to have the added benefit of decreasing patients’ need to travel for specialty services, which was described as creating significant hardships for many people (i.e., those living in more rural and/or remote areas).

Another area for improvement discussed was the need to change the way patients and healthcare providers work together in order to maximize the continuity of care experience. Patients and primary healthcare providers both talked about the ways that patients and their families work with healthcare providers, and how best to develop relationships whereby patients and their families are supported and trusted to make decisions. For example, a young parent of two, who suffered from chronic kidney stones, related that going to the emergency department had always been a nightmare for them. This person described being stigmatized for drug-seeking behavior, and having their symptoms dismissed and diagnoses delayed. These delays resulted in this person experiencing extreme pain, illness, and psychological distress; using more healthcare resources (i.e., emergency department visits and emergency surgeries); and, negatively affecting them and their family’s quality of life. This person talked about working collaboratively with a nurse practitioner, family doctor, and psychologist to develop a care plan that was placed on their hospital file.

Information continuity

Patients discussed the importance of timely and up-to-date information that is easily accessible and potentially shareable online. They reported, for example, not getting enough information before procedures or being asked for their complete history at every hospital admission even though they assumed that there would be an updated record. Patients also emphasized their need for time to process information and to talk to their healthcare

providers about it. In particular, they wanted to be able to ask questions and have healthcare providers be open and encouraging of patient involvement. They also wanted healthcare providers to be routinely updated and to be aware of what was going on with their healthcare; they felt these updates should not have to come from the patient all of the time.

"Whenever you do a nursing history that is on the system or readily available for that hospital or the next hospital or the nursing unit wherever you went to ... it would be nice for your family doctor to be automatically flagged and made aware of if you were admitted. Like made aware of why you were admitted and what happened for your treatment. Even if it was a summary. So that at least he would know to talk to you about it the next time you saw him or maybe call you to request an appointment for you to come in." [Senior living with diabetes and chronic back pain]

As part of improving the information flow among healthcare providers, primary healthcare providers talked about the importance of having a single, universal electronic health record. They suggested that the system be available to all providers, with integrated links to physician and clinic electronic medical records. As part of this universal electronic health record, a patient portal was also said to be vital – a system that would allow patients and caregivers to see medical information. Primary healthcare providers suggested that an initial step could be to make improvements to Alberta Netcare by including more information, and by organizing the information in a more user-friendly way. Suggestions included having automatic alerts to providers when patients are admitted to hospital, when patients visit an emergency department, or when patients pass away.

Management continuity

Many patients said they would like to have access to someone to help them navigate the healthcare system.

"I actually have said many times over the last five years that the Alberta healthcare system needs some--oh, kind of like a guardian---advocate, a senior advocate to go with, because there's a lot of older people, or really ill people ... who don't have family. So there really ought to be positions doing what I did. And people paid to do those things." [Senior living with a number of chronic health issues]

Patients also discussed a need for better management continuity experiences with providers helping them to coordinate access to services/specialists and to avoid travelling long distances to get needed follow-up care. Some patients expressed concerns about services such as mental healthcare and physiotherapy, which are not directly managed by the healthcare system and often

require patients to manage on their own and to pay out of pocket. They also talked about the extremely variable and confusing referral processes for specialists, which were also acknowledged by primary healthcare providers. The providers suggested standardized referral processes for specialists as one important strategy for improving continuity of care in the healthcare system.

"I think the long-term goal of the government to have a centralized referral system alone would improve in some ways, at least communication with continuity of care. So that more of the family physicians have a clue of what's happening, where are my patients sitting in the system." [PCN family physician]

From the healthcare provider perspective, there were mixed perspectives on how much responsibility patients and families could take on with respect to the difficult job of managing their own health and healthcare, limited in part because of how confusing the system is to navigate. Some healthcare providers felt very strongly that patients had to take on more responsibility. Others felt that it would be challenging for patients and their families to be responsible for managing care because of the lack of access they currently have to their own healthcare information, the lack of standardized referral processes for specialists, as well to care coordinators/navigators within the healthcare system. Ultimately, primary healthcare providers reflected what patients said, in that patients and caregivers needed to be actively supported in co-managing health and the coordination of healthcare services (e.g., better education, access to relevant information) because it is a shared responsibility.

"Engaging patients more in their own care, which is that whole shared-responsibility piece ... how do we actually have a system that helps patients be more involved and also ensures that there are supports in the system to support people. Because the system is so darn confusing, you can't leave people out there trying to navigate it on their own." [PCN nurse]

In addition, primary healthcare providers said that for patients with complex health issues, and potentially limited family support, having community-based care coordinators/navigators was essential. Primary healthcare providers felt that if care was not coordinated between multiple services and left to patients to manage, including those who may not have the capacity to do so, then management continuity would suffer and the primary healthcare provider would not be fully connected.

"I think we should start there with the patients who don't have key family or caregivers; the ones that are kind of falling through the cracks. They need to have someone who is assigned to them." [PCN nurse]

Discussion

Continuity of care encompasses quality of patient care over time and how an individual's healthcare journey is connected across healthcare events and providers.⁶ In essence, continuity of care is the product of patients and healthcare providers working together to provide coherent, connected, and consistent care. Continuity can be directly experienced in the context of the patient and his or her immediate healthcare professional (i.e., 'continuous caring relationship') or indirectly in the context of the wider organization (i.e., 'seamless service' or 'integrated care').³⁰

Results from this qualitative study showed that:

1. Relationship continuity refers to a trusting relationship with one or multiple providers.⁴ From the patient perspective, relationship continuity is most valued and is foundational for experiencing information and management continuity. Most positive relationships are built with the family doctor. The quality of these relationships is described as being patient-centred, with an emphasis (among other quality characteristics) on being treated with respect and as a person, not as a 'case number'. Patients recognize that it takes time to build these relationships. From the provider perspective, working relationships with other providers are described as often being key to providing timely access for their patients and thus improve the experience of management continuity.
2. Information continuity concerns the timely availability of information, including patient's preferences, values, and context.⁴ From the provider perspective, information continuity is most important, and primary care providers get frustrated if information is withheld or delayed, particularly when other providers change patient treatment plans or medications. From the patient perspective, timely access to their own medical information both for themselves and for healthcare providers working with them, is highly valued. Patients feel that information continuity requires patient-centred relationships, in which the provider offers enough time during an appointment, listens to the patient to assess what has been tried previously and what has worked well or not, and provides clear communication with the patient, such as what to expect from a certain procedure.
3. Management continuity involves the communication of patient-related information across healthcare teams, organizational, and professional boundaries, as well as between healthcare professionals and patients.¹⁰ Both

patients and providers value and benefit from management continuity, which ideally includes a partnership or shared responsibility for managing and coordinating healthcare services. However, some patients, particularly young people with complex conditions, prefer a more active role in their care management; others prefer a more passive role, particularly elderly people. Patients and providers felt that shared responsibility is enabled through coordinated and timely access to healthcare services, easy access by both to the patient's medical information, enough help from providers to coordinate and manage their care, and planned follow-up care.

Overall, throughout the patient journey, primary care is usually the first point of contact. Primary care is provided in community settings such as doctors' offices, community health centres, ambulatory care, and urgent care and walk-in clinics. As has been shown by this study's findings, primary care providers can often play a crucial role in working collaboratively with their patients to manage their care, as they build trusting, ongoing relationships over time, refer patients to other healthcare services, coordinate care and information received from other providers, and provide follow-up and ongoing care for their patients. Moreover, the family physician is often viewed as the central continuity of care hub, responsible for coordinating access to healthcare services, including specialized care, rehabilitation, and mental health services.³¹ In order to achieve better clinical, functional, experiential, and cost outcomes, an integrated healthcare system is needed with a strong primary healthcare foundation – one that would allow for patient-centred, coordinated care over time.

A number of healthcare professionals described foundational, system-wide issues such as the funding model that negatively affects continuity. Interest was expressed by some in changing the funding for family physicians from a strictly fee-for-service model to a "blended/ capitation" funding model; and putting in mechanisms for ensuring system accountability for continuity of care. Moreover, countries differ in their payment systems; for example in Canada, the funding for family physicians is mainly fee-for-service, however "blended capitation" and other models are being pilot tested. All payment systems need to realize the importance to incentivize physicians for making time to support continuity of care.

Implications for Management

Lessons from the patient and provider experiences suggest structuring primary care practices and processes to function as a 'continuity of care hub'. Built around a single most responsible healthcare provider, and emphasizing team-based care, the hub is an integrated group of

resources designed to support continuity of care. For the majority of Albertans the most responsible provider is the family doctor, however, it can also be a nurse practitioner, particularly in rural areas or a team of providers such as a multidisciplinary transplant team. The concept of a medical or health home aligns with this concept of a 'continuity of care hub'. Such a hub can act as foundation for an integrated healthcare system; that is, a system where primary care, specialist care and acute care are well integrated.

Relationship continuity can be improved by improving patient access to family doctors and to team-based care, especially for those with serious ongoing health issues, and by improving coordination and teamwork between family doctors and specialists.

A single universal electronic health record that includes a patient portal will enable better information continuity. This will in-turn facilitate shared responsibility and thus management continuity. Management continuity can also be improved through the use of coordinators/navigators for vulnerable patients such as those with complex health issues and/or limited family support, and through the implementation of a standardized referral system to improve coordinated and timely care.

Conclusion

From a patient and provider perspective, the gaps in continuity suggest that healthcare services do not function as a system; it may be asserted that healthcare services have never been designed from a systems perspective. Importantly, this study confirms the work of others, which found that continuity of care is most at risk at transition points and many of these occur across organizational boundaries, particularly transitions within and between primary, specialist, hospital, and continuing care; and within the hospital, transitions between physicians, nursing staff, and units. Future conversations about health system design should focus on how all providers and services can work together, and engage patients, to co-design a system that is built around patient-centred relationships. These relationships are the foundation for both information and management continuity.

Endnotes

a. A Proactive Office Encounter Technician (POET) is charged with managing patient data and getting patients prepared for their appointments with their family physician (taking blood pressure, etc.). The POET works closely with the referral coordinator to help patients navigate the health system (e.g., make sure referrals haven't been lost; provide patients with an estimated wait time).

- b. The Patient/Family Safety Advisory Panel identifies, studies, reviews, advocates and advises the HQCA on patient safety and quality issues from a citizen, patient, and family perspective. Through the HQCA, the Panel works to promote patient safety principles, concepts, and actions in all aspects of Alberta's publicly-funded healthcare system.
- c. A Primary Care Network is a network of doctors and other health providers such as nurses, dietitians and pharmacists working together to provide primary health care to patients. The network can be comprised of one clinic with many physicians and support staff, or several doctors in several clinics in a geographic area.
- d. The provincial electronic health record (EHR) is called Alberta Netcare, a system of inter-functional applications delivered and operated by multiple public and private organizations.

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Appendix I. Interview Guide

Introduction and Consent

- Thank you for agreeing to participate in this interview.
- The purpose of this interview is to talk with you about your experience with the healthcare system - using a variety of services and interacting with a variety of health professionals - over time.
- Through this project we hope to identify and describe those factors that influence how patients experience their journey through the healthcare system. That is, when it is seamless, when is it fragmented, and why?
- Go over consent form, and get taped consent to proceed with the interview.

Open Ended Questions

1. *Could you briefly tell us about the kinds of health services you've used over the past year or more (e.g., family doctor; specialist(s); other health professionals – nurses, counselors or psychologists, pharmacists, physiotherapists; hospital services – inpatient, ED; tests; etc.)?*
2. *Can you describe both your good and bad experiences with the care you received from different health services and health professionals?*
 - a) *The quality of your relationship to various healthcare professionals?*

Areas to probe:
Relationship Continuity: with whom and quality of relationship, trust, time made available, support/help/navigation received, communication; personal choice to not have a relationship and why (potential reasons might include access, preference, selective use of different providers, convenience, not wanting to engage beyond a certain level, social factors, inflexibility of job and family obligations, resource or transportation limitations, stigma, social deprivation, poverty, literacy, cultural factors,...)
 - b) *The sharing of your medical information / test results / care plans between your care providers and with you?*

Areas to probe:
Information Continuity: sharing of relevant medical information, understanding of condition/symptoms and treatment, recognition that different ways of receiving information exist, professional communication skills, time available for discussion, trust
 - c) *The coordination / management of your care?*

Areas to probe:
Management Continuity: access / appointments, referrals and transitions between healthcare services, smooth discharge planning, care coordination, involving caregivers and/or family members in care pathway, team work
 - d) *Can you think of any other things that influenced your experiences with your healthcare?*
3. *What would you wish for in the future in order to ensure high quality healthcare services that meet the needs of patients and families/Albertans? How would things work in such a health system?*
4. *What has changed in your life/personal situation because of your health and your interactions with the healthcare system?*

Areas to Probe:

 - a) Work: retired or unable to work or working shorter hours, impact on financial situation
 - b) Social Interaction / Recreation: taking part in fewer community or social activities, avoiding having visitors, pay less attention to family, don't joke with members of family as much as usually
 - c) Household Management: daily household chores including shopping, cleaning, washing clothes, gardening; taking care of household business affairs such as paying bills or doing household accounts
 - d) Can you think of anything else which has changed because of your health?
5. *Is there anything else you wanted to say (i.e., that we haven't had a chance to talk about yet)?*
6. *Do you have any questions for us?*