The Perception of Continuity of Care From the Perspective of Patients With Diabetes

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Background and Objectives: Traditional indices of continuity of care typically capture frequency of physician visits but lack information regarding how patients themselves perceive continuity of care. The present study’s objectives were (1) to examine the meaning of continuity of care from the perspective of patients with diabetes and (2) to understand the factors that enhance or detract from continuity of care. Methods: Seven focus groups with 46 adult patients were held at a health service organization in Northern Ontario. All focus group interviews were tape recorded, transcribed verbatim, and analyzed using a phenomenological approach. Triangulation occurred through participant feedback of transcript summaries and consensus of themes by the multidisciplinary research team. Results: Patients conceptualized continuity of care in a broad and multifaceted manner that was comprised of five components: (1) access to services, (2) interactions with physician, (3) interactions with other health care providers, (4) personal self responsibility, and (5) communication. Conclusions: Continuity of care was perceived by patients to include a wider range of components than what is traditionally associated with continuity of care. The emphasis on personal self responsibility by some patients provides a deeper understanding of what patients feel encompass continuity of care.

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Continuity of care is a concept that has been garnering increased attention in the last few years.1-3 The concept of continuity has been examined in many health care areas such as nursing, mental health, and primary care.1 There have been multiple methods proposed by researchers for measuring continuity of care, most of which are based on proportions or ratios of visits to the same health care provider or center.4 While a consistent method for measuring continuity of care is lacking, increased continuity of care has been related to better well-being,5 lower health care costs,6 better glucose control in patients with diabetes,4 and higher satisfaction.7 The increasing prevalence and chronic nature of diabetes and its sequelae suggests that continuity of care would be an important factor in the management of this disease.

The patients’ perspective on continuity of their health care has begun to receive more attention.8,9 However, most research that has elicited patient views has been conducted using researcher-based definitions of continuity of care.10,11 For example, a recent study asking patients about their attitudes toward continuity of care focused on provider continuity by asking how many primary care providers (PCPs) they had seen in the past 5 years and how important it was to see the same provider for their care over time.11 While these studies offer helpful insights regarding patients’ perception of traditional definitions of continuity of care, a researcher-focused definition of continuity of care may be missing other important aspects that patients define as continuity of care.

Current research has found that physicians and patients sometimes have differences in their perspectives regarding the experience of having diabetes. For example, one study found that patients experienced the effect of diabetes in a more psychosocial than physi-
Another study demonstrated that patients and diabetes educators had differences in what they considered to be educational priorities for patients with diabetes. Given these differences in perspective, there may or may not be concordance between how patients with diabetes and their clinicians conceptualize continuity of care. Better understanding the meaning of continuity of care from the perspective of patients with diabetes might enhance effective management of this disease. This study explored the meaning of continuity of care for patients with diabetes and the factors that enhance or detract from continuity of care from the patients’ perspective.

Methods

Approach

This study used a phenomenological approach, since we were interested in patients’ lived experience of continuity of care. In keeping with standard phenomenological approaches, few parameters were placed on participants’ discussion of continuity of care. The researchers were careful about “bracketing their assumptions” by consciously acknowledging their own views and biases at the onset of the study and monitoring these as the study progressed. Ethics approval for this study was obtained from the Group Health Centre (GHC) and the Sault Area Hospitals Research Ethics Board in Sault Ste Marie, Ontario.

Setting

This research was conducted at the GHC, a health service organization (HSO) in Sault Ste Marie, Ontario. The GHC is a not-for-profit, multidisciplinary HSO that serves approximately 44,000 patients. Its funding is based on capitation, and there is an electronic medical record (EMR) system in place. The GHC was comprised of 33 family physicians, 31 specialists, and 44,000 patients at the time of the study. Of these patients, approximately 3,100 had a diagnosis of diabetes mellitus (DM) in their EMR. There is an active research program at the GHC, and the participants from this study were from a sample of 404 patients who were enrolled in a larger study examining continuity of care. At the time of the study, the GHC provided diabetes education and support through the services of a dietitian, a podiatrist, ophthalmologists, diabetes educators, and diabetes specialists.

Sampling

Forty-six patients with diabetes volunteered to participate in seven patient focus groups. Purposeful sampling was used to reflect the range of patients with diabetes at the GHC, and the final group composition included (1) patients with caregivers, (2) working patients, (3) patients of Italian descent, (4) patients of First Nations descent, (5) patients at high risk for organ damage, (6) patients who had previously been patients of fee-for-service physicians, and (7) an undifferentiated group.

As noted, patients invited to participate in focus groups were sampled from a larger study examining continuity of care for patients with diabetes (n=404). The inclusion criteria for this larger study included being over the age of 18 and having a diagnosis of diabetes in their EMR. Patients were excluded from participation if they had gestational diabetes; could not provide informed consent; could not communicate in English, French, or Italian; or had a life expectancy or residency expectancy of less than 3 years.

Data Collection and Analysis

A semi-structured interview guide consisting of 13 questions and subquestions was used to facilitate the focus groups. The focus groups began with a general discussion regarding what constitutes good health care. Participants were then asked to talk about what they felt was related to continuity of care. This initial discussion of continuity of care was prefaced by the provision of a general definition of traditional continuity of care as consistent and continued care. Participants were then asked to elaborate on aspects of their health care that they felt facilitated and detracted from continuity of care. Modifications were made to the focus group guide as groups progressed to capture emerging themes.

There were two research team members at each group. One individual facilitated each group, and an assistant took notes. A post-group debriefing was completed with both research team members after each group. All focus groups were audiotaped and transcribed verbatim.

All transcripts were read by three research team members to determine initial codes. A standard process for phenomenological data analysis was followed. Transcripts, focus group notes, and debriefing notes were all examined. A qualitative software program, NUD*IST, was used to help organize the data (QSR NUD*IST (4.0), 1997, Qualitative Solutions and Research Pty. Ltd, Australia). Lists of significant statements were developed, and statements were then grouped into main themes or meaning units. At each stage of the analysis, the data were checked for disconfirming evidence by rereading the transcripts and theme summaries. Theoretical saturation was used as a guide to determine whether enough data had been generated from the focus groups.

Data triangulation occurred through member checking, whereby all participants who attended the groups were sent a summary of their group for comment to ensure that the researchers had correctly interpreted the participants’ experiences. As well, consensus of the main themes generated by the multidisciplinary research
team ensured that different perspectives examined the data.

Results
Fifty-four percent of the 46 participants were female. The average age of participants was 59 years (standard deviation [SD]=12). Sixty-one percent were retired, and 9% were on disability status. Approximately 20% of patients had an income of less than $20,000 (Canadian) per year.

Overall, the findings indicated that patients’ conceptualization of continuity of care was broader and more comprehensive than traditional definitions of continuity of care. Patients indicated that continuity of care consisted of five separate, but related, components: (1) access to services, (2) interactions with physician, (3) interactions with other health care professionals, (4) personal self responsibility, and (5) communication. Within each component, there were two main facilitators and two main barriers to continuity of care. These have been summarized in Table 1. Descriptive quotations to illustrate each of the five components are included in Tables 2 to 6.

Access to Services
Access to clinical services in a timely and efficient manner was important to patients (Table 2). Patients appreciated that many of their health care providers were in one location and felt that this increased accessibility to services. There was a prevalent feeling, however, that long waiting times, cancelled appointments, and a lack of available providers detracted from continuity of care. Access to both primary care physicians and specialists was identified as problematic. Despite a centralized appointment system, many patients felt that they sometimes needed to problem-solve alternative methods for ensuring timely appointments. For some patients this included bypassing the central booking system and directly calling the physician’s office.

Interactions With Physician
There was an overriding sentiment expressed by patients that their primary care physician should be the central catalyst in ensuring continuity of care (Table 3). Physicians who were knowledgeable and attentive to patient needs were seen by patients as achieving continuity of care. As well, physicians who stayed current with developments in diabetes care were seen as demonstrating attributes that fostered continuity of care.

In contrast, physicians who were not able to understand the patient’s experience of living with diabetes and did not provide individualized care seemed to create barriers to effective achievement of continuity of care. Patients also felt that sharing of information was an important responsibility of both the clinician and the patient. The reciprocal nature of clinical relationships necessitated that there was active participation by both parties. Finally, reinforcement by physicians

Table 1
Factors that Enhance or Detract From Continuity of Care

<table>
<thead>
<tr>
<th>Component</th>
<th>Factors That Enhance Continuity of Care</th>
<th>Factors That Detract From Continuity of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to services</td>
<td>1. The physician is able to provide health care services that are regular, timely, and efficient.</td>
<td>1. The patient experiences long wait times and cancelled appointments.</td>
</tr>
<tr>
<td></td>
<td>2. The patient is able to access specialists and have medical tests done when needed.</td>
<td>2. The patient experiences a lack of available providers, and appointments are not predictable.</td>
</tr>
<tr>
<td>Interactions with physician</td>
<td>1. The physician is able to provide clear and relevant information about diabetes and its treatment.</td>
<td>1. The physician is not knowledgeable about diabetes and current treatment practices.</td>
</tr>
<tr>
<td></td>
<td>2. The patient feels respected and listened to and that his/her treatment needs are understood.</td>
<td>2. The patient feels judged and that he/she is not supported in his/her self-management strategies.</td>
</tr>
<tr>
<td>Interactions with other</td>
<td>1. The patient is provided with individualized, realistic information regarding managing diabetes.</td>
<td>1. The patient feels judged by specialists and other health care providers.</td>
</tr>
<tr>
<td>health care providers</td>
<td>2. Most health care providers and services are at the same location.</td>
<td>2. Shortage of health care providers means that patients are not able to consistently see other health care providers.</td>
</tr>
<tr>
<td>Personal self</td>
<td>1. The patient is able to advocate for self and his/her needs within the health care system.</td>
<td>1. The patient feels that he/she is doing all he/she can to manage his/her diabetes but does not see any results.</td>
</tr>
<tr>
<td>responsibility</td>
<td>2. The patient is able to take responsibility for managing his/her diabetes.</td>
<td>2. The patient is in denial about having diabetes and is therefore not attentive toward its care.</td>
</tr>
<tr>
<td>Communication</td>
<td>1. The physician and other health care providers communicate with each other about the patient and</td>
<td>1. The patient feels that he/she must constantly repeat his/her story since his/her health care providers do not communicate with each other.</td>
</tr>
<tr>
<td></td>
<td>his/her treatment.</td>
<td>2. The physician does not offer information about treatment options or tests.</td>
</tr>
<tr>
<td></td>
<td>2. The patient receives feedback about tests that are done.</td>
<td></td>
</tr>
</tbody>
</table>
for self-management activities served to foster continuation of activities that would encourage patients to better manage their diabetes. For some patients, this allowed them to stay engaged with their care and contributed to their own maintenance of continuity of care.

Interactions With Other Health Care Professionals

Despite patients’ focus on their primary health care provider as the coordinator of care, patients also saw relationships with other health care professionals (pharmacist, nurse, ophthalmologist, podiatrist, diabetes specialist, and dietician) as important and necessary contributors to their continuity of care (Table 4). Patients felt that having most of their diabetes care providers and services at one location enhanced the continuity of their care. However, shortages of providers created frustration and lack of motivation to be diligent regarding self-management.

In a number of groups, patients voiced feeling that they had been judged by their diabetes specialists regarding their weight. Patients voiced wanting realistic and individualized diabetes care management strategies. They often felt that the only clinical advice they received was “lose weight,” without specific guidance regarding how to do so. The judgment felt by patients about their weight was a barrier toward patients maintaining appointments, thereby jeopardizing continuity of care.

Personal Self Responsibility

Patients felt that there were tasks and activities that they should do to maintain effective continuity of care (Table 5). In some cases, this meant being assertive about the need for appointments or information. Patients who could advocate for their needs felt that this contributed to their continuity of care.

As well, some patients talked about how emotional or psychological aspects of having diabetes influenced continuity of care. For example, there were a few pa-
patients who acknowledged a sense of denial surrounding their diabetes, which sometimes contributed to their lessened engagement with the health care system. For these patients, their lack of acceptance with having diabetes was exemplified through missed appointments, resistance to disclosure about diabetes to some health care professionals, and inability to initiate diabetes self-management activities.

Communication

Ongoing and consistent exchange of information with health care providers was mentioned by patients in all groups (Table 6). Patients were also vehement that communication between health care providers could facilitate continuity of care, since patients would be spared from unnecessarily repeating information. The additional burdens created by clinicians when not having up-to-date patient information and the ensuing role of patient as information broker were not seen as an ideal scenario.

Patients in all groups also mentioned the need for medical test information to be conveyed back to the patient. Not having this information created a missing link for patients whereby they did not feel sufficiently informed to communicate with their care providers.

Discussion

The findings of this study indicate that patients conceptualized continuity of care in a broad and multifaceted manner that included five main components: access to services, interactions with physician, interactions with other health care providers, personal self responsibility, and communication. This set of linked components goes beyond traditional definitions of continuity of care that focus on quantifying visit frequency.

Regular visits to health care providers were seen as an essential ingredient in maintaining continuity of care. This reinforces the importance of visit frequency but also highlights that frequency and regularity of visits must also coincide with patients’ life circumstances (ie, seeing their physician when they feel they need to). Interactions with the primary physician were seen as a key factor that enhanced or detracted from continuity.
of care, which is congruent with the existing literature regarding patient-physician relationships.\textsuperscript{12,18-21}

Patients’ inclusion of personal self responsibility as an element that fosters or hinders continuity of care is an important finding. This has obvious implications for both the delivery of care and the measurement of continuity of care. For example, patients who score poorly on continuity of care indices may do so in part because of their own behavior (eg, not attending a scheduled appointment). This suggests that new measures of continuity of care should include an assessment of personal self responsibility.

The present findings are in keeping with Haggerty et al’s recent literature review that described two core concepts that distinguished continuity of care from other concepts: (1) care of an individual and (2) care delivered over time, and three major types of continuity of care: (1) relational, (2) informational, and (3) management continuity.\textsuperscript{1} This review emphasized the experience of care as connected and coherent as a requirement for continuity of care.\textsuperscript{1} Another recent review of continuity of care conceptualized continuity of care in terms of three dimensions: (1) informational, (2) longitudinal, and (3) interpersonal continuity of care.\textsuperscript{9} Both these comprehensive reviews highlighted the need to consider interactions between patients and their health care providers when examining continuity of care. But most relevant is the fact that taken together, these two reviews included four of the five components found in this study, and it was only through discussions directly with patients that the aspect of personal self responsibility was evidenced.

There were generally consistent findings across all groups, with the exception of the First Nations Group, where references to culture were more predominant. Some patients felt that their health care professionals were not aware of the cultural context of diabetes in their lives, which is consistent with research conducted with diabetes patients from particular ethnicities.\textsuperscript{22-25} This group was also unique, since some patients also sought services on their reserves where culturally relevant services were in place. Further research examining the similarities and differences of continuity of care perception across cultures would be of value.

Survey data have indicated that patients do value continuity of care\textsuperscript{11} and that an adequate level of continuity of care is seeing the same physician “a lot of the time.”\textsuperscript{10} Patients may not, however, have realistic expectations for this dimension of their care\textsuperscript{16} or other components that they feel encompass continuity of care. Certainly, the present findings offer goals that the present health care system may not be able to accommodate. However, by starting to understand the many components of continuity of care that patients value, health care providers and policy makers can begin to formulate standards that are amenable to all parties in the health care system.

This study used a number of techniques to strengthen the rigor of its findings. The researchers examined and monitored their own assumptions and biases. Three researchers completed the initial transcript coding, allowing for multiple perspectives to inform the data analysis.\textsuperscript{26} Member checking ensured that participants’ experiences were being accurately captured.

Still, a number of limitations exist for this study. The participants volunteered for these groups and so may not reflect the average patient with diabetes. As well, patients in this sample were aware of (albeit frustrated by) the current health care provider shortage in Northern Ontario. Therefore, their definitions of regular care may well have been different than those of patients in other regions where physician services are more available. Finally, this study was only conducted with patients who had diabetes and, as such, further research will be necessary to determine whether the definition of continuity of care generated in this study applies to patients with other chronic conditions.

In conclusion, this study offers a new way of defining continuity of care that is based on what patients with diabetes consider important. The inclusion of personal self responsibility in this definition provides a more comprehensive view of the true complexity of continuity of care. The findings from this study have been used to construct a quantitative measure of continuity of care that will provide further verification regarding this definition of continuity of care.

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\textbf{REFERENCES}


