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Primary Care Visit Preparation and Communication for Patients with Poorly Controlled Diabetes: A Qualitative Study of Patients and Physicians

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Abstract

Objective—The purpose of this study was to examine how patients with diabetes and their primary care physicians identify and discuss visit priorities prior to and during visits.

Methods—We conducted a qualitative study involving patients with diabetes (4 focus groups, n = 29) and primary care physicians (6 provider practice meeting discussions, n = 67).

Results—Four key themes related to prioritization were identified: 1) the value of identifying visit priorities before the visit; 2) challenges to negotiating priorities during the time-limited visit; 3) the importance of “non-medical” priorities; and 4) the need for strategies to help patients prepare for visits. Both patients and physicians felt that identifying a concise list of key priorities in advance of the visit could help establish collaborative visit agendas and treatment plans.

Conclusions—Identifying and communicating mutually agreed upon priorities for discussion is a key challenge for time-limited primary care visits.

Practice Implications—Communication between primary care physicians and their patients with diabetes could be improved by strategies that help patients identify their top visit priorities before the visit.

Keywords

primary care; diabetes; doctor-patient communication

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1. Introduction

Patients with type 2 diabetes seen in primary care are increasingly complex.^{1,2} With the aging of the population and escalating prevalence of concurrent co-morbidities, these patients frequently present for care with multiple concerns.³ In parallel, advances in evidence-based care and widespread measurement of clinical quality metrics have resulted in a lengthy list of tasks that primary care providers are expected to accomplish at each office visit.⁴ These two trends have led to an increase in the number of items to be addressed in the limited time available during typical primary care visits.^{5,6}

The overwhelming majority of patients with type 2 diabetes are managed in the primary care setting.⁷ Although many care systems have now implemented care teams in which patients interact with diabetes educators, nurse specialists, pharmacists, and occasionally endocrinologists, the primary care visit remains a key opportunity for managing patients with type 2 diabetes. These primary care visits are particularly useful for helping to coordinate care with other team members and for placing the patient's diabetes management within the context of his or her other medical and non-medical concerns.⁸

Patient complexity and the limited time during primary care visits each represent increasing challenges to effective patient-provider communication. Prior research has underscored the difficulty patients and physicians have in effectively communicating and collaborating with each other, particularly in the setting of complex decision making and prioritization of care needs.^{9,10} Indeed, delayed or inadequate communication about both patient and physician concerns may represent a significant barrier to developing and successfully implementing an effective diabetes care plan.¹¹

To gain further insight into how patients and physicians identify and act on—or fail to act on—priorities for primary care visits, we conducted a qualitative study involving patients with poorly controlled type 2 diabetes (HbA1c > 8.0%) and primary care physicians. We focused our discussions with patients and physicians on the barriers and facilitators to identifying and discussing care priorities.

2. Methods

2.1. Setting and Participants

We enrolled patients with type 2 diabetes and primary care physicians from 6 primary care practices within Kaiser Permanente Northern California (KPNC), an integrated care delivery system serving a diverse population of patients in Northern California. We convened patient focus groups of adults (ages 35 – 80) with last measured hemoglobin A1C \geq 8.0% and continuous KPNC membership for the prior year. We used purposive sampling to create four patient focus groups of older (\geq 60 years) and younger (< 60 years) men and women with sub-optimal diabetes control (defined as last measured HbA1c > 8.0% because this is a common threshold for initiating more intensive therapy). Because we were ultimately interested in developing an on-line tool to help patients prepare for visits, we limited our population to patients who had registered for our system's on-line patient portal. In 2014, 63% of patients in our system were registered with on-line portal, including nearly half of

patients with diabetes. We also met with primary care physicians during provider practice meetings to describe our study proposal and elicit feedback regarding the type and format of information they would find most useful to receive from their patients prior to a primary care visit.

2.2. Study Goals

Our goal for this study was to examine patient and physician perspectives on how priorities for what to discuss during primary care visits are established. We were especially interested in finding out how patient and physician perspectives were different and similar to each other, and how they would differ from our initial thoughts regarding the importance of pre-visit preparation. We created a focus group guide based on the following domains related to in-person visits: 1) pre-visit preparation; 2) communication during visits; and 3) information that patients or providers wished they knew prior to the visit. After discussing these themes, we presented patients and physicians with a conceptual overview of a potential pre-visit tool that would be designed to help patients with diabetes prioritize their concerns prior to a scheduled primary care visit, and we elicited feedback about optimal design of this tool.

2.3. Qualitative Analyses

Focus groups were moderated by an experienced qualitative researcher (AA) who was not a clinician. Immediately after each patient focus group or provider practice meeting, two or more investigators debriefed and created field notes to capture key themes, quotes, and impressions. All patient focus groups were recorded and professionally transcribed to allow more detailed analysis. Transcripts were reviewed and discussed by a minimum of three investigators. We combined a modified grounded theory approach as has been described by Miles and Huberman¹² with a more general inductive approach described by Thomas.¹³ We coded the transcribed data using the constant comparative method of qualitative data analysis to develop key themes identified through iterative transcript review and discussion among the investigators. After establishing consensus on definitions, the remaining coding was completed until thematic saturation was achieved for all major themes. Any coding discrepancies (fewer than 15%) were resolved by consensus.

Physician discussions were led by a physician investigator (RWG). Due to difficulty in obtaining signed informed consent for recording physician practice meetings, these discussions were not recorded. Instead, members of the research team took notes on the discussions and these notes were reviewed prior to creating and coding our field notes. Due to the lack of transcripts, the coding of physician responses was based on detailed field notes.

We used the following techniques to ensure that data analysis was systematic and verifiable, as commonly recommended by experts in qualitative research:¹² consistent use of the discussion guide, audio-recording and independent professional preparation of the transcripts (for patient focus groups), standardized coding and analysis of the data, and the creation of an analysis audit trail to document analytic decisions. We followed recommended reporting guidelines.¹⁴ The institutional review board of the Kaiser Foundation Research Institute approved the study protocol.

3. Results

3.1 Patients and Providers

Patient groups included 29 participants. Fourteen were women, 15 were African-American, one was Latino, the mean age was 59.0 ± 11.0 years and the mean HbA1c was 9.1% ($\pm 1.3\%$). The 6 provider practice meeting presentations included 67 primary care physicians (61% women). In the following sections we describe the four themes identified by patients and by providers related to our key research questions.

3.2. Theme 1: The value of identifying visit priorities before the visit

Patients with poorly controlled diabetes varied in whether and how they prepared for upcoming primary care visits. Patients who engaged in little or no pre-visit preparation generally did not provide a specific justification for this approach. A typical description of this approach was: “Sometimes the doctors tell you he wants you to come in. Then when you get there they say, ‘Well, why are you here?’ I say, ‘Cause they called me!’” Other patients made appointments for a single specific reason without giving thought to their overall treatment plan. As one patient noted: “I don’t go to the doctor with a list of stuff half the time, I’ll be honest with you.”

Patients who identified their visit priorities in advance of their visit employed a range of strategies. Some patients made hand-written lists, while others reviewed their self-collected data or looked for information from sources such as the internet. Several patients described a very proactive and collaborative approach to preparing for visits by e-mailing back and forth with their physician ahead of the visit about issues they want to address at the appointment: “My doctor will call or e-mail when he has an agenda. If I have an agenda, I send him an e-mail and make an appointment. I’ll say, ‘I want to deal with this, I’ve got this or that’... That doesn’t prevent him from talking about what he wants to talk about.” These more proactive patients reported that this strategy tended to lead to more productive and collaborative visit interactions. As one patient noted: “If I email the doctor my concerns first, some of them seem to filter into his checklist.”

When we asked physicians how well their patients prepared for visits, there was a general consensus that primary care is more effective when patients came prepared to discuss diabetes care issues, whereas lack of preparation by the patient tended to create barriers to clinical care due to inefficient use of time. One physician noted: “I often get frustrated when new patients come in for an annual physical and I can’t get at what the patient wants.” Lack of preparation results in inefficient use of time because “a lot of times you are digging to find out why the patient is there.”

Despite this recognition by physicians of the benefits of patient pre-visit preparation, there was a somewhat mixed assessment of the benefits of patient list-making. Some physicians focused on how patients’ lists of concerns led to conflict over control of the visit agenda. Several physicians provided anecdotes of their patients who came in with “really long lists” that included both what the providers perceived as clinically important concerns and those they deemed clinically unimportant. “Wading through” these lists tended to detract from the goals that these physicians had for the visit. Other physicians worried that patients with long

lists have expectations for the visit that cannot be met in the limited time available. In contrast, many other physicians clearly supported this approach to patient visit preparation because it provided an opportunity for them to quickly scan the list as a first step towards setting a more limited agenda for the visit.

3.3. Theme 2: Challenges to negotiating priorities during the time-limited visit

Patients identified three key factors that were associated with more effective discussion of their visit priorities during clinic visits: 1) Their physician's willingness to be flexible in the flow of discussion topics; 2) The extent to which their physician listened to patient concerns; and 3) The patient's ability to be proactive in shaping the visit agenda. Conversely, patients described two important barriers to collaborating on visit agendas: 1) The sense that physicians were too pre-occupied with their own agendas; and 2) The restrictions imposed by time constraints. Issues related to time constraints included physician's lack of familiarity with the patient's recent life events, the challenge of trying to limit the number of discussion topics, and the frustration related to scheduling additional appointments to cover non-discussed concerns. Please see the Table for representative patient quotes from study participants for each of these themes regarding facilitators of and barriers to more effective communication about visit priorities.

Physicians confirmed the negative impact of time constraints on the ideal goal of fully eliciting patient priorities: "When I am in a rush, I often have an agenda that overrides the patient's agenda." In reflecting on the increasing number of recommendations and guidelines that physicians are asked to address during visits, one physician compared the total time available during a visit for each item to slices of a pie: "There are more and more slices in the pie, but the pie is not getting any bigger." One consequence of time constraints described by both patients and physicians was the patient's tendency to express their priorities nearer to the end of the visit, a strategy that leaves little time to fully address the concern.

3.4. Theme 3: The importance of "non-medical" priorities

Patient participants emphasized the importance of their doctor being aware of "non-medical" issues that they are facing. Such awareness appeared to serve two main purposes. One potential benefit was that this information represents one way of developing a more personal relationship. As one woman noted: "I would like the doctor to know about the type of work I do and some of the things that happen at home, with my family...and so, I, at any given time, I could be stressed at work and stressed at home." A second potential benefit is that "non-medical" information may have important implications for medical treatment plans. "Sometimes those stressors affect how bad you are as a patient...and to go in and see the doctor and he's telling you 'You didn't do this and this test is bad...' And you really want to do right. But you got these other issues." One patient specifically explained the connection between home issues and diabetes control: "when I had an infusion of people...into my house last night, going crazy, and I wrote to him, 'This is why I'm not able to keep my numbers down.' I just let him know that my numbers are here, and it's probably because I've been having to make mashed potatoes and gravy."

3.5. Theme 4: The need for strategies to help patients prepare for visits

At the end of our focus group sessions and provider meetings, we elicited feedback from patients and providers regarding the value of a tool to help patients prepare for visits. Patients identified two main ways that such a tool might help them. One was to help them remember issues that they tended to forget: “Because when you're in there with the doctor for that ten-fifteen minutes, you leave things out, and it's like [snaps fingers] ‘I forgot to ask him this!’ And so, you have a chance to write down some of your concerns.” The other potential benefit might be to help empower patients to direct the visit agenda more effectively. As one patient explained: “It can't all just come one-sided, ‘It's time for you to take a test, it's time for you to change your meds and stuff.’ It's got to be some give and take, and we need to be able to feel that we're part of the team as well. So, anything that helps the patient feel as though they are participants in their own healthcare, I think is a good thing, really.” This challenge of establishing a collaborative agenda was echoed by another participant who noted: “I think he feels like he has to hit certain points to make the visit good for him and then — so I'm just trying to make sure my concerns are heard. But sometimes, I don't feel like they're heard.”

Patients specifically voiced hope that such a tool could contribute to ensuring their physician included non-medical concerns in the visit discussion. One patient suggested that such a tool “should be a steering mechanism where they should know, you know, when they walk in, this patient is diabetic, so I, the doctor, want to address lab results, medication, diet, and exercise. But wait, this is their priority. Okay. Let's stop because obviously [this other issue] is not a diabetic condition. You know, it has nothing to do with diabetes. Let me stop my priorities and deal with the patient's priorities.” The ability to specify a concise list of top concerns could serve as an effective means to help patients have other, non-diabetes issues addressed during a visit.

Physicians were in general consensus that any tool to help patients formulate their top priorities for a visit would be helpful. Physicians liked the idea of pre-visit preparation by patients because patients would be more prepared to efficiently communicate their concerns: “Patients need to put their story together and sometimes they are not good storytellers. Even the process of having to do this pre-visit prioritization will be helpful.” Having the patient's information in written form was also perceived as a potential benefit: “easier to absorb quickly, sometimes patients take a while to say what they have to say.” By encouraging the patient to focus on fewer issues, physicians felt that they could make more effective use of the visit time: “It sort of frees you up from having to address that 5th or 6th [issue]” – because the patient will be more satisfied that 2 concerns were definitely addressed.” Another perceived potential benefit is that this tool could make it easier for patients to indicate potentially embarrassing or sensitive issues like financial barriers or depressive symptoms that can sometimes interfere with effective diabetes care.

While the majority of physicians were highly supportive of a prioritization tool, several raised concerns that they would not want the tool to add new problems to the list. One physician expressed a concern that this tool could “use up” time talking about non-medical issues. In contrast, other providers agreed with the premise that knowing what issues were

topmost on the patient's mind would be helpful for managing the visit. One physician put it: "What's important to the patient is important to the doc – even if it's not important."

4. Discussion and Conclusion

4.1. Discussion

Patients with poor glycemic control and the primary care physicians who manage most of their diabetes care describe multiple challenges to establishing a collaborative and concise agenda during time-limited primary care visits. Patients and providers each identified important barriers to establishing shared visit agendas. These barriers centered around the need for more collaborative communication and the restrictions imposed by short visit lengths. Patients and physicians shared the opinion that identifying a concise list of shared priorities could help organize visits and enable more productive interactions.

Our findings suggest that for many patients with poorly controlled diabetes, lack of structured visit preparation represents a care barrier that is potentially amenable to patient education interventions. Such an approach could be helpful for patients who typically don't prepare, for patients who tend to forget during visits, for patients who currently prepare an overwhelmingly long list, and for patients who delay voicing their concerns until the end of the visit. Prior research has shown that patient coaching, delivered by clinicians, educators, or peers, can have a positive impact on diabetes care.¹⁵⁻¹⁸ One potential strategy to support more patient-centric and collaborative care is to adapt current diabetes educational strategies to include helping patients identify top visit priorities (both diabetes-related and diabetes-unrelated) for an upcoming visit.

The results of our study are consistent with the conceptual model that patients and providers enter into the clinical priorities with different types of priorities for the visit.¹¹ As has been validated in the "Four Habits Model" for provider communication, recognizing and aligning priorities at the beginning of the visit encounter is a key first step towards more productive and collaborative use of the available visit time.¹⁹

Our findings must be considered within the context of the study design. Because we used qualitative methods, our results should be considered as hypothesis-generating. Indeed, we believe that the insights we gained from both patients and providers can guide further work in developing tools to help patients prepare for visits. Our modified grounded theory approach focused on identifying key themes related to patient and provider prioritization. Other methods, such as ethnographic or phenomenological approaches may have yielded different insights related to the patients' experiences with visits. One important study limitation was that we were not permitted to record our discussions during the physician practice meetings. Because transcripts were not available for the provider meetings, our coding method for the physician analysis was less iterative. To compensate for this limitation, we undertook detailed field notes both during and immediately after these meetings. Finally, despite or purposive sampling by age and gender, our analyses were combined because our four main themes were consistent across the patient groups.

4.2. Conclusion

Participants in our study confirm research from multiple different settings that time limits significantly restrict the number and depth of topics that can be discussed during a single primary care visit.^{4,20,21} Given that there is little chance that primary care will be substantially restructured to allow longer visits, the challenge for effective diabetes primary care is to help patients and physicians use the existing time more efficiently. Our results confirm the complexity of primary care visits and provide insights into how patient education in the domain of visit preparation may represent a novel and effective strategy for improving the care of patients with diabetes. Based on these results, we hypothesize that better use of time during visits would increase the identification and management of potential care barriers, improve patient-provider trust, and over time would facilitate physicians prescribing and patients adopting the lifestyle and medication changes necessary to achieve effective glycemic control.

4.3 Practice Implications

The results from our study highlight an important area for patient education and counseling: teaching patients the skills required to prepare for primary care visits by identifying their top concerns for the visit (both diabetes related and unrelated). Based on the insights of our patient and physician study participants, clearly identifying a limited list of key patient priorities holds the potential to support more productive primary care visits and ultimately lead to more effective diabetes management.

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Highlights

- Many patients with diabetes do not prepare for their primary care visits
- Patients that do prepare find that doctors are more likely to discuss their concerns
- Doctors report that they can be more productive when their patients are prepared
- Tools are needed to help patients identify priorities for time-limited visits

Table

Representative quotes from patient participants regarding facilitators of and barriers to more effective communication about visit priorities

<i>Facilitators of more effective communication during visits</i>
1) Provider flexibility:
"I know that she has a checklist ...so I'm sort of expecting that. And she does do that, but I feel that if any point of time I want to stop her and get more details about a specific issue that's she's exploring that a point of time, she usually stops whatever she's doing and listens to me and, you know, takes care of it."
2) Provider willingness to listen:
"What I do like about him is he allows me to talk. And he hears me! He doesn't just give me a deaf ear, you know. He actually talks to me about what I [bring up], he does talk to me about so I'm happy about this."
3) Patient willingness to be pro-active:
"The doctors don't know what's going with you if you don't tell them. You know, if you go there, he asks you how you been feeling you say, 'Fine!' well, that's almost the end of the visit. So you know what I mean? If there's anything been going on you need to let him know, even like you say if there's some stress in your life, 'Well, I've been kind of stressin', whatever but a closed mouth can't get fed, so you have to speak up."
4) Patient and provider ability to share personal life experiences
"I think that extra piece of having the extra information about your personal life, where you were, you know, when they come in—then, they can touch on that and say, "So, how's work going?" You know. "How's, you know, raising your family going?"
<i>Barriers to more effective communication during visits</i>
1) Lack of concordance on priorities
"the doctor's just kind of saying his spiel, trying to get it over as quickly as possible and so what I've had to do is be a little more pushy so that my concerns get heard and that kind of happens because I think he feels like he has to hit certain points to make the visit good for him and then – so I'm just trying to make sure my concerns are heard."
2) Consequences of time constraints:
Provider lack of familiarity: "The doctor should know more about their patients, their goals, their needs, but I don't think that's possible in this day and age when the doctor has a thousand patients to deal with."
The need to limit topics: "I always felt, I had to choose one or two things, otherwise, like—per appointment—otherwise, I kind of expected I wouldn't discuss that many things in one appointment."
Scheduling additional appointments: "You go to your appointment and you know there's a limited time, and it's—I either feel like, oh, I forgot to mention something that may have been related to my diabetes or it was, you know, 'We can't talk about that right now, let's make another appointment,' which is not my favorite thing to do."