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Cover Page Footnote

We are indebted to the staff of the PCMH clinic that contributed to this project immensely by informing patients about our research and providing us with space to conduct the interviews. And, of course, we owe many thanks to the people who so graciously agreed to participate in the interviews and share their experiences with us.

Patient & Family Partnership

Considering shared power and responsibility: Diabetic patients' experience with the PCMH care model

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Abstract

The patient-centered medical home (PCMH), an innovative primary care model that fosters a stronger, more personal patient-doctor relationship than traditional health care models, should be particularly well suited for the treatment of chronic conditions such as diabetes that require ongoing management by both patients and providers. Despite growing research on the effectiveness of PCMHs in diabetes care, relatively little attention has been given to diabetic patients' experiences. This qualitative study examines diabetic patients' experiences at one PCMH setting, using in-depth interviews to understand patients' perspectives of the shared power and responsibility between patient and provider in their diabetes care. Our results suggest that even when patients feel comfortable and cared for by the physician, they may choose to take a more passive role in discussions about their diabetes in the clinical encounter because 1) they may see diabetes as a secondary concern, or 2) they may be consciously differentiating between their physician's responsibility over the physical domain of the illness and the patient's responsibility over the lifestyle domain of the illness. Thus, in order to build a relationship that is characterized by shared power and responsibility between patient and provider, physicians should not only strive to create an atmosphere in which the patient feels both cared for and listened to, they also need to be aware of patient's preconceptions about the clinical encounter. This awareness would allow physicians to encourage more active patient participation in the clinical encounter and support patients more effectively in their self-management journey.

Keywords

Patient-centered medical home; diabetes; patient centered care; patient-doctor relationship

Introduction

The Patient Centered Medical Home (PCMH) is an innovative approach to redesigning primary care in the United States and is defined as a "team-based model of care led by a personal physician who provides continuous and coordinated care throughout a patient's lifetime in order to maximize health outcomes." 1 The PCMH aims to equalize decision-making processes by engaging and empowering a patient and establishing an ongoing personal relationship between patient and provider². Additionally, the PCMH is designed to promote timely and organized care through continuous access to providers, which ostensibly will be reflected in more consistent and reliable care delivery to all patients³. This approach is very different from the currently uncoordinated, episodic, and clinician-driven primary care infrustructure that takes care of the majority of diabetic patients that are associated with suboptimal diabetic outcomes⁴⁻⁶.

The "patient-centered care" approach is a core concept of PCMH care. While there is not one unified definition or

conceptual framework of patient-centered care, Stewart et al and Mead & Bower point to four common dimensions of this approach: 1) attending to the disease and illness experience, 2) viewing the patient as a whole person, 3) fostering a strong patient-doctor relationship, or what (therapeutic alliance), and 4) creating common ground, or sharing power and responsibility. Research has documented the importance of a "therapeutic alliance" between the doctor and the patient ^{7,8} including the personal bond between doctor and patient and the perception of the doctor as being caring, sensitive and sympathetic 9. Evidence also suggests that greater patient involvement through information sharing and decisionmaking is associated with better health outcomes 10,11. If patients and physicians can find common ground regarding the nature of the problem and the best plan for treatment, better health outcomes can be expected ¹² As a result, researchers are advocating for a shift in doctorpatient relations from the "co-operation-guidance" model, characterized by an asymmetrical relationship between doctor and patient, to "mutual participation," where power and responsibility is shared with the patient 8.

Patient centered health care approaches such as those found in PCMHs explicitly promote improved chronic disease management by encouraging significantly greater patient involvement in care as compared to the traditional care models. Diabetes, as a common and costly chronic disease that requires ongoing management by both patients and providers, is a condition that could be particularly well managed in the PCMH care model. Evidence for the effectiveness of the PCMH model in diabetes care is encouraging, but not definitive. For instance, several demonstration projects ¹¹ have shown better diabetes health outcomes and improved patient satisfaction, whereas a systematic literature review of the effectiveness of the PCMH model 10 for diabetes care found that improvements in metabolic outcomes were "trivial" ¹³. Most studies of diabetes care in PCMH settings up to date have focused on health care-related outcomes rather than patient experience 14, though researchers are increasingly highlighting the importance of the latter ¹⁵⁻¹⁸. The existing literature points to the importance of the patient-doctor relationship to the patient experience 19, particularly in the treatment of chronic diseases like diabetes, but relatively little research has given focused attention to patients' perspectives of the physician's roles and responsibilities in their diabetes care in the PCHM setting 15.

The purpose of this qualitative study is to examine patients' experiences with the PCMH care model through in-depth interviews with patients diagnosed with diabetes and receiving care at one PCMH care clinic located in a Southwestern state. Specifically, our research focuses on patients' perceptions of the roles and responsibilities of the physician in their diabetes care, shedding light on the complexity of two of the core tenets of patient-centered care: 1) creating a therapeutic alliance between patient and physician and 2) sharing power and responsibility. Our results would be of interest to physicians, organizational decision makers, and policymakers who are concerned with improving diabetic patients' experiences in their primary care type settings.

Methods

A qualitative interview design was used to investigate diabetic patient experiences with the care they receive in a PCMH setting. This research design is particularly useful in examining the topics that have received little prior attention in the literature. This study serves as an initial exploration that took place in a single outpatient setting; thus the findings are not intended to be generalizable. Instead, they are meant to generate new knowledge that could inform future research inquires.

Sample Selection

Interview participants were selected using a purposeful sampling procedure ²⁰ to obtain a set of respondents that

would represent the diabetic patient population in this PCMH setting. Participants were recruited at the PCMH clinic after a diabetes education session or their regular office visit during December 2013-August 2014. Three members of the research team (OM, SB, and CP) recruited the study participants and conducted the interviews. Participants were at least 21 years of age and had been diagnosed with diabetes mellitus type. ² Twenty-five patients agreed to participate in the interview session. Each participant was given information about the voluntary nature of participation and signed the consent form. At the end of the interview each participant was given a \$25 gift card.

Data Collection

The interview protocol was developed by the three authors using an iterative process of question development that continued until there was consensus among the authors about the items for inclusion. The questions were crafted in order to elicit both detailed descriptions and evaluations of the patients' experiences in the clinic. The protocol used a semi-structured interview approach, which allowed the participants to deviate from the questions and add additional information when deemed appropriate.

Every interview began with a general discussion about the patient's history with diabetes (family history; information about diagnosis). Next, the participants were asked about their experiences with diabetes (prior knowledge about the disease; daily disease management strategies and struggles). Following this, the participants were asked about their general experiences with the PCMH clinic and, if applicable, how they differed from other healthcare settings where they have received treatment. Finally, the participants were asked specifically about their interactions with their physician and other aspects of PCMH model of care. Each interview was approximately 45 minutes in length; dialog continued until data saturation was reached ²¹. The interviews were digitally recorded and professionally transcribed.

Data Analysis

The data were analyzed using a grounded approach that involved a series of immersion/crystallization cycles ²². Three investigators (OM, SB, and MB) immersed themselves in the data by reading the transcripts several times, individually identifying some initial themes that emerged from these readings, and sharing these initial themes with one another during research meetings. The investigators then collaboratively developed a preliminary set of codes that mirrored the emerging themes. Next, the transcript analysis was repeated, with each excerpt fragment being independently coded by two investigators (OM, SB, and MB).

Results

Our final sample consisted of 11 Whites, 5 African-Americans, 4 Hispanics, 1 Asian, and 4 patients with unidentified race/ethnicity. Eleven were female and 14 were male. The age distribution of our sample was from 25 to 89 years. There were no significant differences found in the data between people from different age groups, genders, and racial/ethnic backgrounds.

We have used the following questions to organize our thematic results relating the patients' perceptions of the roles and responsibilities of their PCMH physician in their diabetes care: 1) How do patients characterize the type of relationship they would like to have with their physician? 2) What do patients identify as falling within the scope of the physician's responsibility in their diabetes care? 3) What do patients identify as falling outside the scope of the physician's responsibility in their diabetes care?

How do patients characterize the type of relationship they would like to have with their physician?

When talking about their relationships with their physicians in general, the study participants consistently pointed to a desire for their health care providers to treat them as a whole person, as opposed to a mere source of income or a body to be tested. While different patients offered different characterizations of the type of relationship they wanted their physician to have with them (e.g., guide into uncharted territory, friend/family member, strict authority figure), the participants' descriptions of ideal interactions with physicians revealed several recurring themes:

- Feeling comfortable/welcome
- Feeling cared for
- Being listened to
- The physician's willingness to take extra time to talk to patient
- Being able to talk about topics other than health issues
- Non-verbal communication (e.g., eye contact, body positioning, facial expressions)

The following illustrative quotes are reflective of these themes:

"... Up at X practice, everybody up there is, from the time you walk in, they greet you...you can talk to them. They treat you like a person, not a statistic or a chart number. They actually make you feel welcome. Not you're just there to get some medicine or a shot or something like that. They ask how you're feeling today, any problems. You feel welcome. You don't feel that you're just being shuffled through to see a doctor or whatever."

"They show a lot of compassion. They show a lot of interest in me as a person, and that's what I like about

this place. They're not too busy to talk to you, or if they are, they say to give them a minute and they'll be right back. In other words, they're people. To me, that's showing that I'm not a number to her."

Similarly, the majority of the study participants expressed a desire to play an active role in their health care, and they stressed the importance of a physician who allows them to ask questions and responds to their concerns:

"I'm not going to let you tell me without having the right to ask you a question and expecting a civil answer in English. You're not going to over talk me. You're not going to talk down to me. You're going to spend time or you're not going to be my doctor."

"That's the first thing I look for in a doctor, to be able to talk to them. If you don't want to talk to me and give me at least five minutes of your time and answer my questions, I'm going to look for someone else."

Overall, when describing their ideal interactions with their physicians, the study participants consistently described scenarios in which the physician creates opportunities for dialogue about both medical and non-medical topics. Notably, several of them described interactions in the past with physicians who did not fulfill these ideals. For example:

"I had told [my previous doctor] that I thought I needed a different medication, and she didn't say she was going to check up on it or anything. She just walked out. And I probably sat there maybe five minutes, and she didn't come back. Pretty soon her male nurse came in and said, "Well, you're still here? Why haven't you left?" I said, "What do you mean?" He said, "Well, you're done." I said, "She didn't give me any answers." And he said to me as far as she's concerned, she's done with you today. And I said, "Well, she's done with me for good." And I haven't been back since."

Such descriptions were used by the patients not only to illustrate what they expect during their clinical interactions, but also to highlight the level of comfort they felt when meeting with their physicians in the PCMH clinic.

What do patients identify as falling within the scope of the physician's responsibility in their diabetes care?

While study participants were selected because they had been diagnosed with diabetes, many seemed primarily concerned with health issues *other* than diabetes. When asked about their experiences with health care in general, many discussed in great detail their experiences seeking out care for different health issues, including chronic back pain, arthritis, pneumonia, and heart problems, while only bringing up their experience with diabetes during the interviews when asked about it specifically. Even when discussing acute health issues that likely were related to

diabetes, such as neuropathy or blurry vision, very few drew explicit connections to their diabetes. In other words, diabetes was presented as a distinct, and less important, concern. In the words of one:

"My higgest concerns are with my heart, not with my diabetes...I'm worried about my heart and [my physician's] worried about my diabetes. Between the two of us, we're taking good care of me."

Because diabetes was understood to be less of an immediate concern, many explained how they relied on their physicians to keep track of their diabetes and let them know of any problems. When asked to describe the role their physicians play in their diabetes care, study participants focused primarily on the physician as managing the measurable or tangible aspects of their care. Some common statements patients made explaining their perception of what the physician does or ought to do in relation to their diabetes include:

"Taking the blood test and making sure everything's good. She gives the pills for everything else."

"If I get a bad anything [regarding blood glucose levels], I'm sure the doctor will let me know."

Although it is reasonable to expect a physician to be responsible for these aspects of care, such as interpreting the results of blood tests, it is notable that in their interviews, the patients we interviewed consistently focused on aspects of their care that do not require them to play an active role. In addition, several of the study participants spoke positively of physicians who told them what to do, placing the patients as recipients of a one-way flow of knowledge within a relatively unequal hierarchy of power. For example:

"He tells me my sugars up too high, or I don't like your A1C. It's 7, and I want to see it at 6. You've got to cut down on not only your carbs, but you've got to cut down on your cholesterol. He's good."

"Put it like this — I've got a good doctor (...) if I don't do what she says, she's going to drop me...Like I said, I need someone to be firm with me that can get through to me, because I'm hard-headed sometimes."

In other words, despite the prevalent recurrence in our data of patients expressing a desire to take an active role in their health care, several of the study participants described and evaluated positively clinical encounters in which their diabetes care was driven primarily by the

physician's expertise, rather than by collaboration and dialogue.

What do patients identify as falling outside the scope of the physician's responsibility in their diabetes care?

The majority of the study participants described themselves as trying to take an active role in managing their diabetes in their daily lives, for example by testing blood glucose levels, taking medications regularly, being careful with their diet, and exercising. At the same time, many pointed to a range of factors outside of their control that stood as obstacles to controlling their diabetes, including erratic work schedules, stress, physical pain that prevented exercise, and budgetary concerns. Notably, though, many patients described these topics as not relevant to the clinical encounter (even when recognizing that they have adverse effects on their blood glucose levels and even after expressing that they felt comfortable bringing up issues with their physician at the PCMH clinic). Interestingly, although none of the patients reported bringing up diet, exercise, or stress in their clinical encounters, when asked directly about whether they talked about these issues with their doctor and, if so, who brought them up, patients consistently mentioned that if they did talk about them, their doctor brought them up. Thus, it seems that the patients are willing to talk about these lifestyle issues during the clinical encounter, but only when directed by the physician. They do not feel comfortable bringing it up themselves. Below are some illustrative examples of the study participants' explanations for not bringing up lifestyle concerns with their physicians:

<u>Interviewer</u>: Do your doctors here have conversations with you about stress and its potential impact on your diabetes?

Participant: I haven't told her that. Then I stress because I feel like I'm gaining weight, and why am I gaining weight if I don't eat that much? (...). Then my husband asks if I tell the doctor that I work two jobs, and you don't eat and don't rest. I don't. That's my problem.

<u>Interviewer:</u> Why don't you want to talk about food with your physician?

Participant: I don't know. When I go see the doctor, I go for my medical stuff, not for my food stuff. I feel like I'm wasting her time if I get into a foods discussion with my doctor. I'm sure she'd have no problem with it, but I'd feel I'm taking her down the wrong road and I don't want to do that.

<u>Interviewer:</u> Would you be interested in discussing [stress] with her, or not?

<u>Participant:</u> That's getting a little too personal. She's my doctor.

Interviewer: Do you talk about food with her?

<u>Participant:</u> Not too much. Not really, no. <u>Interviewer:</u> Why?

Participant: Because I go to [diabetes education] classes like the one I just did and I learn that way. I feel like a dummy. She's a doctor. (...) She's got all this training and stuff, so I figure she knows what she's talking about, and I'm going to trust her for all this stuff.

In these examples, we see a range of reasons patients identify for not bringing up certain topics in their clinical encounters, though these reasons are thematically unified by a clear distinction between the study participants' perceptions of the physician's responsibility of addressing the medical domain of the illness and their own responsibility of addressing the lifestyle domain of the illness.

Discussion

Our main findings indicate that, before physicians can know what it means to most effectively build productive relationships with their patients marked by shared power and responsibility in their diabetes care, they first need to understand the preconceptions their patients bring to the clinical encounter. Specifically, the results of our study indicate that it is important to foster an atmosphere in which the patient feels both cared for and listened to by the physician. These findings are in line with previous studies 18 that describe the importance of the perceived interest the provider has in the patient as a person, which contributes to the development of trust and the patients' willingness to follow the physician's recommendations. Importantly though, our data builds on these findings and shows that patients' perceptions that a provider is caring and willing to listen is not necessarily enough to open up lines of communication. For example, our study participants were reluctant to bring up "personal" issues such as stress and practical obstacles to eating well and exercising during the clinical encounter, even when they felt comfortable with the doctor and they felt that the doctor was willing to listen to them and their concerns. The reason for this reluctance is unclear, though it may result from pre-existing ideas about the role of the doctor or previous experiences with health care providers. Our study also found that diabetic patients viewed diabetes as a lower priority in relation to other health conditions, an issue noted earlier by Loewe and Freeman ¹⁹. Furthermore, the patients often times did not draw a connection between diabetes and other health issues that likely were related to diabetes. One possible explanation for this is that high blood glucose levels, while dangerous, are not experienced as acutely in the body as conditions such as chronic pain or pneumonia. Consequently, several patients relied heavily on their doctors to let them know when something was wrong regarding their diabetes and expressed a preference that discussions of their diabetes

care in their encounters be driven by the physician's expertise, rather than a collaborative effort. Our results echo previous ^{23,24} studies revealing that some patients prefer to have a more prescriptive, practitioner-led, as opposed to a patient-led, style of interaction in the medical encounter. This reliance on the physician's expertise, which is focused on the *physical* signs of the disease, might help explain why patients don't find "personal" issues such as stress and other obstacles to effective diabetes management in daily life to be relevant to the clinical encounter, even though they have a direct effect on their physical health.

Implications

Ultimately, our results indicate that building a personal bond is a key first step to opening up productive dialogue between diabetic patients and their physicians, but even when physicians do this (as in the case of this PCMH setting), it does not guarantee that patients will take an active role in discussions about their diabetes. Physicians need to be aware, then, that even when patients feel comfortable and perceive that the physician cares for them, they may choose to take a more passive role in discussions about their diabetes because 1) they may see diabetes as a secondary concern, or 2) they may be consciously differentiating between their physician's responsibility over the physical domain of the illness and the patient's responsibility over the lifestyle domain of the illness. Given the evidence 25 suggesting that enhancement of the patient's active participation in diabetes care is a key factor to improving the care outcomes, the creation of shared power and responsibility between patient and provider should be given particular attention.

Furthermore, due to the chronic nature of diabetes, a diabetic patient makes approximately ninety-five percent of the health decisions, (food choices, physical activity, or blood glucose monitoring) without health care professionals even knowing them ²⁶. Thus, it is important that physicians should be aware of all issues affecting the decisions that may be impacting patient's health, particularly in the care of diabetes, where physical and lifestyle domains of the disease are intimately connected. With this awareness, physicians might more effectively tailor their interactions with their diabetic patients, for example by prompting patients to share their "personal" issues on a more regular basis, thus building a "habit" of active participation in the clinical encounter and a two-way flow of dialogue that is crucial to a truly productive collaboration between physician and patient. This would be particularly beneficial to patients who prefer a more practitioner-led style of interaction.

Limitations and Directions for Future Research

One important limitation of this work is that it relies on data that was collected in one PCMH clinic, which limits the generalizability of the findings. However, the qualitative data in this study address an issue of growing importance for policy and practice, patient experience, and provides rich and novel information that could be useful for identifying hypotheses for further research. Second, our study only relies on the patients' perceptions about their diabetes care and how they share power and responsibility with their physicians. It would be worthwhile to obtain providers' perspectives on the same issues to reveal potential similarities and differences in perceptions. 16 Third, given our research design, we only had access to small "snapshots" into the lives and experiences of those we interviewed. Long-term qualitative studies involving additional in-depth interviews, ethnography, and patients' reflective journaling of their experiences both in their daily lives and in the PCMH setting would offer more insight into how patients' perspectives of the physician's roles and responsibilities in their diabetes care might change over time. Employing such methodologies would also reveal a more in-depth understanding of the broader social and psychological factors, such as experiences with stigma, and cultural factors, such as traditions and beliefs, ²⁷⁻³¹ that might be shaping how patients choose to interact with their physicians in the clinical encounter. Additionally, future studies could examine the relationship between levels of shared power and responsibility and patient's activation measures.

Conclusion

Truly effective diabetes care involves active participation of both patient and physician, and the PCMH care model is designed to facilitate productive therapeutic alliances in the management of this chronic illness. Even when the physician takes steps to ensure that the patient feels comfortable and listened to, though, our results show that diabetic patients' preexisting ideas about both the disease itself as well as the roles and responsibilities of the physician can significantly affect the types of dialogue and collaboration that take place in the clinical encounter. Importantly, diabetic patients tended to downplay the importance of diabetes in their life and don't share "personal' aspects" (stress, diet, exercise) of their selfmanagement with their personal physician. Our findings would be of interest to health care providers involved in diabetes care, helping them be more aware of patients' experiences and potential preconceptions and to adjust their communication appropriately. Furthermore, health care managers may use our results to design and implement more effective training programs for practitioners involved in diabetes care, particularly those working in PCMH settings.

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