Moving From Undiagnosed to Diagnosed Diabetes: The Patient’s Perspective

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Background and Objectives: One third of diabetes cases in the United States are undiagnosed. Knowledge of the patient’s experience from symptom recognition to diabetes diagnosis will help clinicians and policy makers optimize their approach to diabetes detection. Methods: We interviewed 15 patients diagnosed with type 2 diabetes within the past 6 months about how they came to be diagnosed and about any barriers that might have prevented their diagnosis. We used grounded theory qualitative methods to approach and analyze the semi-structured interviews. Results: Most diagnoses of diabetes in these patients were either serendipitous, symptom driven, or patient initiated. None resulted from physician-initiated screening. Patients had only a superficial knowledge of the symptoms of diabetes prior to diagnosis, despite strong family histories of diabetes. Patients often incorrectly attributed symptoms of diabetes to other causes and sometimes physicians also did this. Barriers of cost, insurance, and trust were not deemed to be important by these patients. Conclusions: Many individuals with undiagnosed diabetes are likely unaware of the relevance of their symptoms. Clinicians must be vigilant in identifying people at risk for diabetes. Improved education of individuals at risk for diabetes may be a useful strategy to increase diabetes detection.

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One third of diabetes cases in the United States are undiagnosed.1 The prevalence of diagnosed diabetes for the United States was 5.9% for the years 1999–2000 among individuals ages 20 and older. During that same time, the prevalence of undiagnosed diabetes in this population was an additional 2.4%, representing 4.9 million people in the United States with undiagnosed diabetes.1 Undiagnosed diabetes is not a benign state. There are data to suggest that individuals whose diabetes has not been detected already manifest diabetes complications like retinopathy.2,3

Although there is information about the scope of the problem of undetected diabetes, and risk factors suggesting a need for screening have been identified,1,4,5 we have little knowledge about what factors might influence patients and their physicians to translate the vague, early symptoms of diabetes into a clinical diagnosis of diabetes. This study’s purpose was to investigate, from the patient’s perspective, the context, barriers, and beliefs associated with and leading to a recent diagnosis of type 2 diabetes mellitus. Additionally, we assessed the past health experiences and interpretation of symptoms in these patients recently diagnosed with type 2 diabetes.

Methods

This study used qualitative methods, including in-depth interviews of a group of adult patients with newly diagnosed diabetes. The use of grounded theory qualitative methods6,7 allows us to “go beyond the numbers” to investigate the context of a recent diagnosis of type 2 diabetes with the aim of illuminating this complex process. Grounded theory methodology consists of a set of guidelines with which to collect and analyze data in the field to construct a theory about the observed phenomena that is “grounded” in the data and that explains the collected data.7 Data collection includes seeking “thick descriptions” that inform the researcher about the sociological phenomenon being observed. Grounded theory differs from quantitative methods in that emerging theories shape ongoing data collection, and sample sizes and rigid hypotheses to be tested are not specified a priori but rather are chosen in response to the collected data.8
Subjects

Individuals diagnosed with diabetes within the past 6 months were recruited to discuss the experience of that diagnosis. We limited time of diagnosis to 6 months prior to the interview to approach their clearest memory of how they came to change from having undiagnosed diabetes to having diagnosed diabetes.

Participants were recruited from the Family Medicine Clinic at the Medical University of South Carolina (MUSC), a faculty practice site, from July to October 2003. The racial mix of the clinic is 72% black and 27% white. The payer mix for the clinic is 21% Medicare, 37% Medicaid including Medicaid managed care, 5% self pay, 18% other managed care, and 18% private insurance.

Recruitment took the form of flyers posted in waiting areas and patient exam rooms, broadcast e-mails throughout the medical university, and provider, nurse, and PharmD briefing on the research study. The PharmDs and nurse practitioner who do intensive diabetes education for the clinic sequentially offered all eligible patients an opportunity to participate in the study. Thirteen of the 15 participants were patients of the Family Medicine Center, and two were members of the MUSC community who responded to a broadcast e-mail about the research. We did not include patients younger than age 18 or those who had received a diagnosis solely of type 1 or gestational diabetes.

Data were collected through semi-structured face-to-face interviews of approximately 30 minutes in length with consenting patients. Interviews took place in the MUSC Family Medicine Center.

Sample interview questions are shown in Table 1. Interviews were audiotaped and transcribed without identifiers. Following transcription of the data, the tapes were erased. Interview transcripts were analyzed for themes by each of the investigators independently, using a continuous iterative process. The three investigators met formally four times to discuss and reach consensus on emerging themes and to shape further sampling and questions. The MUSC Institutional Review Board approved this research.

The investigators include a social psychologist, a family physician, and a medical student with training in qualitative methods. We initially believed that our interviews with patients would identify sociodemographic barriers to the diagnoses of diabetes, reflecting racial disparities in undiagnosed diabetes. We also expected to find lack of trust as a barrier to diabetes diagnosis, similar to findings in patients diagnosed with cancer. We judged the interview process to be complete when new interviews did not yield additional information.

Results

We interviewed 15 patients who had been diagnosed with type 2 diabetes within 6 months of the interview. Our study group included three participants diagnosed with diabetes on the day of their interview and three more diagnosed within 1 month of their interview. Their average age was 50, with a range of 24 to 70. By self-description, 13 were black, one was white, and one was South Asian. Educational attainment ranged from 10th grade to PhD. Types of insurance included self pay, Medicare, Medicaid, private, and managed care. We identified the following themes in a majority of patients:

All diagnoses were either serendipitous, symptom driven, or patient initiated.

There were a variety of ways in which people, from their perspective, came to be diagnosed with diabetes, but they were all either accidental, in response to specific symptoms, or patient initiated. None appeared to involve asymptomatic screening specifically for diabetes by their physician. Three participants were diagnosed after they asked to be tested because they had symptoms they recognized could represent diabetes. Patient 1:

I just came in to check because, you know, listening to the commercials on TV and on the radio, and it said that it was one of the symptoms, so I said I wanted to be checked out.

Five participants were diagnosed when elevated blood glucose was found on lab work that was done to monitor other medical problems. Patient 15:

Dr __ [rheumatologist] filed lab work he was doing for me for the lupus and found that my blood sugar was high and he sent me to Dr __, my primary doctor.

Two participants had received preliminary diagnoses after screening at a community health fair, which were confirmed by their doctors. One participant was diagnosed in the hospital after presenting to the emergency department in hyperglycemic coma. Finally, four participants were diagnosed because of symptoms they reported during an office acute care visit. Patient 11:

Okay, it was last Monday. I was having a problem with burning and stuff like that. I thought I had a yeast infection. When I came in, Dr __ ran some tests, and he came back and told me that I was diagnosed with diabetes.

Patient 14:

I was feeling weak and tired. I had sores in my mouth, and I postponed it for a while. I got to the point I had to...
do something about it. I had to go see somebody. So that’s why I started coming here. I’ve been feeling this way for about a week, week and a half . . . Weak, very weak. Being in the line of work that I do, you got to sit in someone’s house and talk to them. I noticed that I asked customers and clients, ‘Do you mind if I use your restroom?’ Constant urination . . . I thought that it may be some problem with my bladder or something like that, overactive bladder.

Misattribution of symptoms of diabetes to other causes.

Patients with symptoms of diabetes misattributed them to other causes. Of the 15 participants, 13 recalled a history of polydipsia, polyuria, polyphagia, weight loss, fatigue, or visual changes, but seven of these 13 attributed these symptoms to something else such as summertime, aging, hard work, or the heater. Patient 5:

Even after having my lunch I used to feel hungry . . . and especially I used to feel thirsty at night time, but I used to think it was probably . . . because I had a very bad heating system . . . and probably it was not only the heating, but the diabetes which was making me thirsty.

Of the six patients who did not misattribute their symptoms, three correctly attributed their symptoms to diabetes, and the other three only recognized that they were having any symptoms in retrospect, after learning of their diagnosis of diabetes and its common presenting symptoms. In a few patients, the physician misattributed the symptoms as well. Patient 7:

Yeah, I guess I was tired. In fact, I had a second job, and I had to stop it because I was so tired. I did that for 5 years, and I was still tired even after that . . . I asked the doctor about that, and he said I was working too much, I needed to quit one of the jobs.

Patients had a superficial knowledge of diabetes before diagnosis.

Many patients we interviewed had a superficial knowledge of diabetes symptoms prior to diagnosis, even those caring for family members with diabetes. Fourteen of 15 patients had a family history of diabetes; nearly all of these family members were close relatives. Many also reported friends and spouses with diabetes as well as its complications. Yet most of these people also had little knowledge of the symptoms of diabetes. Despite the presence of such symptoms as polydipsia, polyuria, fatigue, weight change, and blurred vision, as well as a personal knowledge of family and friends with diabetes, many patients admitted that they did not know the symptoms of diabetes before their diagnosis and diabetes education. However many patients did relate stories of family members who had “lost” eyes, limbs, or were on dialysis due to diabetes.

Interviewer: “You mentioned that you started having symptoms similar to the ones that your brother was having, what symptoms were those?”
Patient 3: “I think it was like feeling dizzy, using the bathroom a lot, tired.”

Interviewer: “Did you know what the symptoms of diabetes were even before you were diagnosed?”

Patient 3: “No.”

Interviewer: “Even with your brother and father being diabetic, how much did you know about diabetes?”

Patient 3: “Hardly anything really.”

Interviewer: “Is there anyone else in your family who has diabetes?”

Patient 7: “My brother has it, my other brother’s son has it. My brother is taking insulin. So I have two people that I know of in my family. That’s the only two I know of.”

Interviewer: “You said that your brother is taking insulin and a pill. How do they manage their diabetes? Do they do well with it? Is it bad for them?”

Patient 7: “It’s kind of bad right now. He’s kind of sick right now because he ain’t doing the right thing. He hardly takes his medicine. He’s hurting, but he works so much that he just . . .”

Interviewer: “How much did you know about type 2 diabetes before you were diagnosed?”

Patient 7: “Nothing.”

Interviewer: “Did you know about the symptoms?”

Patient 7: “My wife knew about it. I didn’t know anything about it. She knew. She’s the one that told me.”

Issues of trust, comfort with doctor and clinic, cost, and fear of diagnosis were not reported as barriers to being diagnosed with diabetes.

We questioned each participant in detail about possible barriers to their diagnosis. Participants universally denied any issues of trust or communication barriers. Most patients were concerned about the cost of care but said that they would not let it be a barrier to their seeking care for a perceived problem. The only exception to this was that some patients said that lack of insurance might have delayed their getting a “check-up.” Patient 3:

Because it’s my health. I’m going to come and get checked, you know, even if I didn’t have the money. They would help me somehow, rather than just sit there and be sick and let it start taking over, and I start losing my sight and stuff. I’ll never just sit there and be sick.

A few patients noted that time and scheduling around their jobs was a potential barrier to receiving care. Fear of diagnosis was acknowledged to be present and in many cases strong. Patient 3:

 Basically I was very terrified.

However, fear was universally denied as a barrier to seeking care by the participants. Patient 8:

I still think I would come because . . . my faith is so strong that I feel God has given doctors medical science and the ability to help you. And I feel that God will help me through that so I would come, I mean reluctantly probably, but I would come.

Discussion

The results of this qualitative examination into the context of diagnosis of those newly diagnosed with type 2 diabetes revealed that it is likely that many individuals with type 2 diabetes are undiagnosed because they simply are unaware of the relevance of their symptoms. Serendipitous detection among individuals with several major risk factors for diabetes was a common story. According to these patients, active initiation of screening for diabetes because of their at-risk status was not a common occurrence.

Despite denial of fear as a barrier to seeking physician consultation, patients acknowledged that it was present. A diagnosis of diabetes carries significant weight for a person, resulting in changes in their self-concept of health and the specter of a decreased quality of life associated with the possibility of complications or the use of insulin. In the face of the ill-defined, vague symptoms of early diabetes and a superficial knowledge of these symptoms, patients might well be inclined to ignore or misattribute these symptoms rather than acknowledge a possible illness such as type 2 diabetes. As long as patients are not experiencing the consequences of diabetes and are not feeling ill, postponement of a doctor visit is likely to occur. When patients do develop symptoms of diabetes that interfere with their quality of life, or when their awareness of these symptoms is raised by family, friends, or the media, the patient is more likely to cross the threshold from believing “I am well” to believing “I am ill” and to seek medical consultation. These concepts are similar to those detailed in the health belief model, in which patients use information about perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy to make decisions about health-related behaviors.

One of the reasons that diabetes in its early stages may go undiagnosed is that symptoms may be ill defined. Communication of these ill-defined symptoms is likely difficult. Some groups of patients may have delays in diagnosis based on their interpretation of early, vague symptomology as well as deficits in their ability to formulate them, both for themselves and for their family and peers who they might seek for lay consultation. Patients experience “illness;” physicians and other health care providers diagnose “disease.” Physicians who diagnose disease are participating in a
health care transaction in which they are required to translate the experience of illness from the patient’s sociocultural explanatory model into the biomedical disease model. These sometimes disparate clinical realities have implications for the way we conceive, label, and react to disease. The majority of “illnesses” do not, in fact, reach a physician, which may further delay diagnosis.

The results of this study suggest that not only do patients need to be educated regarding the importance of some of these vague symptoms but that both patients and physicians may need to be reminded of the importance of screening for diabetes in patients at risk for the disease. Neither the American Diabetes Association (ADA) nor the US Preventive Services Task Force recommends general population screening for diabetes. The main reason for the recommendation against population screening is that we do not have enough evidence that early detection decreases morbidity and mortality, although we know that aggressive treatment of known disease does decrease complications. However, the ADA suggests that clinicians should be more diligent in disease detection and screening among individuals with major risk factors, such as being a member of a minority group (African American or Asian) or having a family history of diabetes, which were common among our participants. It may be useful to not only emphasize to patients with these risk factors that they are at increased risk and are candidates for screening but to promote the concept of screening for diabetes based on risk factors to primary care physicians.

Limitations
There are several limitations to this study. Although the goal of qualitative analysis is to investigate context from the experience of the participant in a focused way, the design is inherently not oriented to large-scale generalizability. Thus, stories told by patients in other states or clinics may not be the same as what we heard from our patients. However, as a hypothesis-generating strategy, we have gained useful information for a more generalizable investigation, and the design does allow for theoretical generalizability.

Second, the information we gained is from the perspective of the patient. Thus, the actual screening behavior of the physicians is unknown. From the patient’s perspective, diagnosis was determined through their own initiation, but this could be affected by retrospective sensemaking of the experience. Also, we did not confirm the participants’ diagnoses of diabetes, trusting in the physicians of this faculty practice to accurately diagnose type 2 diabetes.

Third, our sample was largely African American, which reflects the clinic population from which the sample was drawn. This study was not designed to look at cultural differences in beliefs about diabetes.

Lastly, our sample includes those recently diagnosed. Those patients who remain undiagnosed might identify barriers to diagnosis that our patients did not encounter or which they considered to be important. Unfortunately, those who remain undiagnosed may not be easy to identify.

Conclusions
Delays in detection and treatment of diabetes may lead to diabetes microvascular and macrovascular complications. Knowledge of the patient’s experience from symptom recognition to diabetes diagnosis will help clinicians and policy makers optimize our approach to diabetes care. It would appear that improved education of individuals at risk for diabetes might help patients with early symptoms seek earlier consultation with their physician and would be a potential future focus for improved diabetes detection.

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