



Published in final edited form as:

Chronic Illn. 2013 March ; 9(1): 43–56. doi:10.1177/1742395312450895.

Living with diabetes on Buffalo, New York's culturally diverse West Side

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Abstract

Objectives—This study explores the perceptions, attitudes, and beliefs that inform how people live with diabetes in a high poverty, ethnically diverse neighborhood with a growing population of refugees. The specific research objective was to examine participants' explanations of how their diabetes began, understandings about the illness, description of symptoms, as well as physical and emotional reactions to the diagnosis.

Methods—Qualitative design using semi-structured interviews. The transcripts were analyzed using an immersion–crystallization approach.

Results—Thirty four individuals diagnosed with diabetes for at least 1 year participated. The sample included 14 refugees (from Somalia, Sudan, Burma, or Cuba), eight Puerto Ricans, six non-Hispanic Caucasians, six African-Americans, and two Native Americans. Three broad themes were identified across ethnic groups: (a) the diagnosis of diabetes was unexpected; (b) emotional responses to diabetes were similar to Kubler-Ross's stages of grief; (c) patients' understanding of diabetes focused on symptoms and diet.

Conclusions—Patients were frequently stunned by the diagnosis of diabetes, and expressed emotions associated with the stages of grief including denial, anger, bargaining, depression, and acceptance. Our findings suggest that clinicians might consider addressing the patients' emotions or grief reaction as an early priority to promote acceptance as a first step to self-management.

Keywords

Diabetes; health disparities; qualitative research; community-based research; practice-based research

Introduction

Diabetes is among the most psychologically and behaviorally demanding of the chronic medical illnesses.¹ As a result, patients must overcome many barriers to successful self-management. These barriers may be particularly high for low income, minority, and refugee

The Author(s) 2012

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populations. In the United States, African-Americans and Latinos are more likely to live in poor communities, experience unemployment, poor health, and crime, all of which have a significant impact on the ability to manage a chronic illness such as diabetes.² These problems are confounded further for refugee populations. Limited healthcare infrastructure in their home country, coupled with a struggle to meet basic survival needs which require individuals to operate in constant crisis mode, have been cited as reasons for refugees' limited experience with preventive care and chronic illness management.³ Consequently, refugees often arrive in the USA with undiagnosed, well-established chronic conditions such as diabetes, as well as infectious diseases and mental illnesses.^{3,4} Differing cultural views and perceptions of health and illness also play a major role in refugees' understanding of diabetes and self-management.⁴

Patients' experiences and responses to living with diabetes as well as other chronic conditions have been well-documented.⁵⁻⁸ Anthropologists, sociologists, and clinical researchers have explored patients' explanations and perceptions of the causal factors of diabetes, patients' understanding of diabetes self-management, as well as patients' emotional responses to diabetes,^{6,9-21} underlining the characterization of chronic illnesses such as diabetes as 'biographical disruptions' with important emotional impacts.²²

In particular, several recent exemplary studies have shed light on patients' emotional reactions to diabetes. Campbell et al.,⁶ attempted a synthesis of the literature on patients' experiences with diabetes and diabetes care. The authors identified several factors related to the patient experience and ability to self-manage diabetes that appeared across multiple qualitative studies, including: the importance of time and experience, trust in self, a less subservient approach to care providers, strategic noncompliance with medication, support from care providers, and an acknowledgment that diabetes is serious. Schoenberg et al.,²³ explored the role of stress in the etiology and course of diabetes, as evidenced in interviews with a multicultural sample of individuals in Ohio, Michigan, and Kentucky.²³ Regardless of ethnicity or residential background, informants overwhelmingly agreed that stress not only precipitates diabetes, but that it can exacerbate the symptoms, worsen the course of the disease, and impede self-care behaviors. Informants' descriptions of stress-inducing and harsh environments underscored the importance of examining the impacts of political, economic, and social forces on health and disease.

Ockleford et al.²¹ examined 36 patients' responses and experiences with diabetes education in the UK. The authors identified four personality types based on patients' emotional responses to the diagnosis and ability to implement diabetes self-management. Hinder and Greenhalgh²⁰ undertook a detailed ethnographic study of a socio-economically diverse, predominantly white British sample of 30 individuals in the UK with diabetes. They found that patients' diabetes self-management was significantly influenced by not only practical and cognitive tasks, but also socio-emotional ones, including coping emotionally with the illness, negotiating with family and community circumstances, and navigating the socioeconomic and political structures, which includes the healthcare system. Rayman and Ellison²⁴ document the ways in which women's ability to engage with diabetes self-management is intricately interwoven with their emotional responses to their illness. The authors conclude that 'it was not the intensity of the management routine per se that caused them difficulty but, rather, the strong emotional responses engendered by the diabetes management regimen' (p. 910), which both doctors and patients failed to recognize as a management issue that could be addressed in a clinical setting.

With a few notable exceptions, the majority of studies on patients' responses to diabetes have focused on specific ethnic groups, such as Mexican-Americans, Native American

groups, British Bangladeshi immigrants, ethnically white British, and African-Americans.^{18,19,21,25,26}

Rather than focusing on a particular ethnic group, this study sought to maximize variation along many possible patient characteristics to uncover shared experiences and/or shared explanatory models of illness that might facilitate or impede management of diabetes across ethnic and cultural groups (including Caucasians, Native Americans, African-Americans, Hispanics, and foreign-born refugees from multiple countries); levels of health insurance (in the current US context where healthcare is in crisis and no universal coverage is available); English language abilities; and educational levels. This broad sample allows us to provide understanding of factors affecting a diverse population that reflects more closely the clinical environment urban practitioners may face on a daily basis in the United States.

A major goal of this study, therefore, was to elucidate experiences of diabetes common to individuals in a low-income setting, which may transcend those traditionally associated with ethnic belonging. The specific research objective was to examine multiethnic participants' explanations of how their diabetes began, understandings about the illness, description of symptoms, as well as physical and emotional reactions to the diagnosis, and to analyze the extent to which themes persisted across ethnic, cultural, and racial boundaries.

Methods

We chose a qualitative design using semi-structured interviews to explore the subjects' experiences living with diabetes and their understanding of the illness. The semi-structured, open-ended interview questions allowed participants to describe their experiences and perceptions in their own words.

The setting

The West Side of Buffalo, New York, has a population of 40,737²⁷ in an area of approximately seven square kilometers (2.7 square miles) that extends north from the city's downtown core along an old semi-industrial corridor bounding the Niagara River. It is among the poorest areas of the city; with 38.0% of its residents living below the federal poverty level (the poverty rate in the neighborhood's 10 Census tracts ranges from 23.9% to 69.6%). According to 2000 Census data, the neighborhood is 16.5% Black or African-American and 27.7% Hispanic or Latino, with Puerto Ricans comprising the majority within this group.^{28,29} The West Side of Buffalo is home to a growing number of refugees speaking over 30 languages.³⁰ Some of the most common countries of origin include Somalia, Sudan, Burundi, Congo, Ivory Coast, Iraq, Burma, and Cuba.³⁰

Participants

Study participants were recruited through a primary care practice on the West Side of Buffalo that provides care regardless of ability to pay (approximately 70% of patients have Medicaid or are uninsured).³¹ The practice has a patient base of approximately 11,000 active patients which includes Hispanics (28%) and African-Americans (20%), as well as a large number of resettled refugees from over 70 countries.³² The practice is the largest provider of healthcare services for the region's international refugee population.

Patients of 18 years or older with a diagnosis of diabetes (ICD-9 code 250.xx) that were members of the practice for at least 1 year were invited to participate in the study. Patients with severe mental illness or cognitive impairments were excluded. This was a convenience sample of patients with diabetes who were recruited upon arrival in the practice waiting room. Participants chose the times and locations for their interviews.

The research team

The research team consisted of four medical anthropologists (LK, KG, RK, and BV), a medical student (RT), an undergraduate student (AD) completing a double major in Biological Sciences and Anthropology, an epidemiologist (LTB), a community health researcher (RCS), and a primary care physician (CHF).

Data collection

A semi-structured interview protocol was developed that drew upon several qualitative studies of patients living with diabetes.^{33–36} The protocol of semi-structured, open-ended questions was designed to elicit participant discussion about their experiences with and reactions to diabetes (Table 1). Volunteer translators from the medical practice were used for interviews with non-English-speaking refugees.

The same questions were asked at each interview. Occasionally, however, the questions were slightly modified to accommodate participants' language, culture, and comprehension. For example, one of the Burmese interpreters had difficulty translating 'diabetes self-management' into the Burmese language. Together with the interpreter, we modified the phrasing to 'taking care of your diabetes.' The interviews were recorded, uploaded, and transcribed.

A short demographic questionnaire was administered at the end of the interview. Chart reviews were also undertaken focusing on measures relevant to diabetes (HbA1c, body mass index (BMI), etc.). The University at Buffalo Health Sciences Institutional Review Board granted human subjects approval for this study.

Data analysis

The interview transcripts were analyzed by the research team using a content-driven immersion–crystallization approach to identify major themes. Immersion–crystallization requires researchers to immerse themselves in the data to identify patterns and themes.^{37,38} The process is repeated until the probability of new themes emerging is exhausted.^{37,38} This approach is content-driven, allowing the data to stand alone, without being driven by a theoretical model.³⁸

Qualitative analysis was undertaken in three phases. During the summer of 2010, preliminary qualitative analysis was undertaken with the principal investigator and the two students. Preliminary results were presented at a medical school forum and in a poster at an international conference (National Primary Care Research Group, 2010). A second, comprehensive qualitative analysis was undertaken with the larger team consisting of three medical anthropologists (LK, KG, and RK), the community health researcher (RCS), and the epidemiologist (LTB) during winter 2011, to assess the reliability and validity of the preliminary findings, identify additional themes, and search for contradictory evidence. Themes were identified around topics of discussion that arose consistently across several participants. Once these themes were identified from several readings of the transcripts, a codebook was developed which grouped and ordered the identified themes.

The team met regularly to discuss the transcripts and findings, until no new themes emerged and saturation was reached. A fourth anthropologist (BV) independently re-reviewed the transcripts to verify the consistency of the coding and identified themes. The primary care physician (CHF) was consulted throughout the project and contributed to the writing of the manuscript.

Demographic data and de-identified medical chart data were entered into Microsoft Access and analyzed using SPSS Statistics 17.0.

Results

Demographic characteristics of the 34 patients who participated in this study are detailed in Table 2. The sample is diverse, with 14 of the 34 subjects having refugee status – from Somalia, Sudan, Burma, or Cuba. The majority of patients interviewed, 26 of 34, were women. Over one quarter of the sample (8/34) worked in full or part-time jobs, which included a certified nurse's aide, various cleaning positions, cook, bus driver, and in transportation. Over half (23/34) of the patients in the study were either on disability or retired. Only 13 of the 34 participants had completed secondary school: significantly less than the 80% high school completion rate for Buffalo city residents as reported in the US Census.³⁹

Three broad themes were identified pertaining to patients' diabetes experiences and insights (Table 3). These include: (a) the diagnosis of diabetes was unexpected; (b) emotional responses to diabetes were similar to the stages of grief;⁴⁰ and (c) patients' understanding of diabetes focused on the symptoms and the effects of food or beverages.

An unexpected and late diagnosis

The diagnosis of diabetes came unexpectedly and sometimes as a shock to participants in the study. Nearly, one quarter of the participants in the study (8/34) learned that they had diabetes during a medical crisis or hospitalization. An African-American woman [P no. 4] recalled feeling faint and going to the emergency room where she was told she had diabetes. Another African-American female participant received a phone call from the doctor's office instructing her to go immediately to the hospital:

[Physician's office] called me, she said, [Participant's Name] how do you feel? I said, I feel fine. Well, you were at the doctor's office today, you know, getting tested for diabetes. I said, yeah. She says, well, don't be alarmed, but you need to get to the hospital right now. When I got to the hospital, my blood sugar was 999. I was in the hospital for four days. [P no. 26]

A Puerto Rican female participant [P no. 5] went to the emergency room because she was 'losing a lot of weight – like [I was down to] 89 pounds.' At the hospital, she was told that her blood sugar was around 600 mg/dL. A refugee from Somalia [P no. 7] had a heart attack caused by the blockage of three arteries and underwent an angiogram. During his emergency hospitalization he found out that he had diabetes.

More than one quarter of patients (9/34) sought medical care for symptoms, including frequent urination, thirst, extreme fatigue, and general malaise. At the doctor's office, they underwent laboratory tests and learned that they had diabetes. A Puerto Rican woman described her symptoms:

Oh, I went to the doctor and told him I was tired most of the time, thirsty most of the time, I just wanted to be in bed. Tested my blood sugar and [it] was 500. [P no. 21: Puerto Rican female]

Ten participants found out they had diabetes during an office visit for another complaint and had no signs or symptoms of the disease. A Caucasian female participant [P no. 27] went to the doctor's office because she thought she had a urinary tract infection and 'They found out I was pushing sugar. I didn't have an infection.'

Explanations for the unexpected and late diagnosis—Participants diagnosed with diabetes during a medical emergency or after experiencing troublesome symptoms provided a variety of explanations as to why they had not been diagnosed sooner. Patients described lifestyles in which they worked long hours, sometimes multiple jobs:

I worked 95–100 hours a week, I did in-home care. I went from job to job. I was raising my family, and had to do my part, I worked up until I got sick and they told me I couldn't work no more. When my sugars were at 1600 that's what slowed me down, because my job wouldn't even take me back, because I fell down on my job. [P no. 3: African-American female]

Another individual developed serious diabetes complications that began slowly and impaired his eyesight, while he delayed medical care due to his work schedule:

And it came on kind of gradually... I worked a swing shift at my job ... I was driving different times of the day, different times of the night ... working a swing shift like that, your whole body is out of whack ... I did that for years. [P no. 28: Native American male]

One woman described working long hours in a nursing home while experiencing insatiable thirst and frequent urination:

I was working. I was always thirsty, always, and I could never get enough to drink, and everything that went in came back out, so I'm either drinking the water or going to the bathroom ... [P no. 26: African-American female]

The need to continue working coupled with rigid schedules compelled individuals to endure and/or ignore troublesome symptoms, only to find out that they had developed diabetes.

Refugees—Among refugees, diagnosis often occurred after immigration to the US. Refugees often noted that in their home country, people sought healthcare only when they were ill. The concept of preventive screening was introduced upon their arrival in the United States. A Sudanese woman [P no. 14] explained that medical checkups and medical screening did not exist in her home country: '... over there, they will go when they are sick. They don't have this medical checkup ...' Burmese refugees made similar remarks:

When she lived in Burma, there was no hospital in her village. She would go to the hospital in the city when she became sick, get drugs, and then get better. [P no. 15 (via translator)]

A Somali woman mentioned that she had never been screened for any condition until coming to the USA and enrolling in an English as a Second Language (ESL) class for refugees:

I never test my body all my life. When I come to school they said they test everyone... and when I was tested my blood sugar was 450, and they said you have to see your doctor right now. [P no. 9]

Another Somali woman [P no. 1] noted that she had never heard of diabetes until she was diagnosed after coming to the USA.

In cases when diabetes was diagnosed in the home country, refugees often described the medical care as inferior to that in the USA. A Sudanese woman recalled an Egyptian refugee camp provider advising her: 'if you don't feel like your body hurt and you tired, you don't have diabetes.' [P no. 33] A Cuban woman [P no. 23] described her experiences with prolonged symptoms of dizziness and fatigue, falling and breaking bones, until she was finally diagnosed with diabetes. The doctor sent her home with powdered milk to

supplement her diet of beans and rice. Although she was put on diabetic medication, there were no glucometers and she could not measure her blood sugar.

Responses to life with diabetes: A grief reaction

When patients were asked about their experiences living with diabetes and how diabetes has affected their lives, they expressed a range of emotions that in many ways mirrored various stages of grief: denial, anger, bargaining, depression, and acceptance.⁴⁰

Denial and fear—Even individuals with family histories of diabetes expressed disbelief or denial when they learned of their diagnosis:

Absolutely terrible, it was horrible. I couldn't believe it happened to me. I was one of the people that always thought it would never happen to me. But then I realized it was passed on to me through my dad and my mother. They also had it. So it was only ... a matter of time before I got it myself by not taking care of myself. [P no. 8: African-American male]

A Caucasian male [P no. 31] admitted: 'Well, you don't want to hear it ... you know, hey that's the other guy, you know, not me, you know... In the beginning, it was a little denial, no, I don't have diabetes.' An overweight African-American woman with a family history of diabetes who had worked as a home health aide admitted: 'I worked with people who had diabetes, and I never thought it would be me.' [P no. 3]

Feeling frightened was a common response when people learned that they had diabetes. A Puerto Rican woman remarked, 'What did I think? I was crying. I was crying for long time.' [P no. 18] Another Puerto Rican woman worried about hyperglycemic emergencies and her responsibility for her children:

[It] is scary because my sugar goes high, I don't want to go to the hospital, I have two kids to take care of. And they help me too, thank God for them. [P no. 22]

Contributing to fear was the association of diabetes with amputations, blindness, and other complications:

I've seen it where I work. I've seen toes gone, fingers gone. I've seen amputees from the knees down. You know, yeah, I've seen it. [P no. 26: African-American woman]

Anger—Several patients expressed anger and frustration. This was occasionally seen in connection with the diagnosis itself:

I'm not happy with it. I figured I worked physically all of my blinking life and uh, here I come to this end. I can't work a frigging job because of other health problems and now I've got to put up with this bull ... [later she continued] Now I've got to do something about the health that I do have, and I guess I resent it. [P no. 16, Caucasian female]

However, more frequently patients directed their anger at the healthcare system. Some felt that their providers did not care about them or lacked adequate time:

[Dr.'s Name] don't care... You know what I'm saying, I mean she care up to the point where she, it's like I want you to do, but if you don't then ok. [P no. 8: African-American male]

They can care less if I, they said 'you could either do this or you don't, I don't care.' And then that puts a person in... if my own doctor doesn't care about me,

but they want me to care, you know what I mean?’ [P no. 28: Native American male]

The only problem is, it’s like putting a shoehorn in a shoe because it’s tough to get in and tough to talk to anybody... I mean normally they’ll say, we’ll have the nurse call you back, and if you’re lucky she’ll call you back. [P no. 31: Caucasian male]

One of these patients, P no. 8, also admitted throughout the interview that he had problems adhering to self-care. It is possible that his ‘noncompliance’ was a source of frustration to his healthcare team who responded to him with resignation.

Bargaining—The bargaining aspect of grief can be described in part as a patient’s desire to turn back the clock or wish that the disease had been addressed sooner.^{41,42} In our study, some informants expressed these emotions, wishing that they had taken the disease more seriously, or could go back in time to a period before the onset of the disease. One woman lamented that she resents her midlife status; that she must monitor her diabetes and can no longer take youth and good health for granted:

I wish there was a switch that you could hit that we would take this [diabetes] much more seriously than I do. Not so much so that it dominates the life, but enough that it will at least prolong it. [P no. 16: Caucasian woman]

Another individual described his initial reaction to diabetes as knowing he had a ‘vague’ condition with the potential of causing serious health effects down the road but not feeling a sense of urgency: ‘And so, I kind of like blew it off. I didn’t take it seriously.’ [P no. 28: Native American male]

Depressive symptoms—Other patients spoke at length about feeling depressed. Although the interview protocol did not ask specifically about depression and a depression screen was not included, participants described low mood and depressive symptoms. According to the chart review data, nine of the 34 participants in the study were diagnosed with depression and six were receiving treatment (Table 2).

An African-American woman lamented:

sometimes I feel depressed because I say, ‘why me?’ because I never take drugs, I never do something bad...I believe that people who take drugs and do things like that are the ones that get sick. I don’t understand that. But now I understand. [P no. 4]

A Puerto Rican woman described having to take Valium to deal with depression:

My mood? I guess sometimes, like today I feel tired today...many times I feel depressed. Many times I take Valium, sometime, 3 Valium a week. [P no. 21]

A Burmese refugee woman described her sadness in terms of her whole body feeling heavy: ‘Right now she’s say like it’s not happy, and like she’s very, very sad that, you know, like the whole body feel like very heavy.’ [P no. 2, via translator]

Other participants described feeling overwhelmed by the disease and discouraged by their unsuccessful attempts to self-manage. A Caucasian woman commented that diabetes is a full-time job that can ‘take over your whole life if you let it.’ [P no. 27] An African-American woman agreed with this perspective: ‘just maintaining it, it’s a job. Diabetes I didn’t know it was as hard as it is.’ [P no. 3]

Acceptance—Several participants emphasized maintaining a positive attitude. One woman described being diagnosed with diabetes many years ago as a single mother with

seven young children. [P no. 19] She recounted feeling initially depressed but had to ‘snap out of it’ and be very strong to take care of her family. This acceptance was something that took time for many:

Like I'm ready to accept the fact that I can still do everything but I have to do them slower, and maybe different. And that's hard for me because I'm used to being in control. [P no. 20, Caucasian female]

Another woman living alone recounted being in denial upon diagnosis but then making radical alterations in her lifestyle that included walking or biking rather than using a car. [P no. 27: Caucasian female] This woman has become a positive influence for healthy living in the neighborhood as well, and told the interviewers that she ‘hollers’ at her neighbors who have diabetes to watch their weight and blood sugar. A former chef and restaurant owner, she described altering recipes to create healthy muffins and other baked goods for her neighbors and friends.

Patients' understanding of diabetes: Focus on symptoms and diet

Few participants endorsed a biomedical explanation of diabetes and how it might affect the body. One informant told the interviewer that diabetes originated in the lungs: ‘I know it break[s] us down in time if you don't take care of yourself. Start at our lungs and work its way through our body.’ [P no. 8: African-American male]

Focus on symptoms—When asked, ‘What is your understanding of diabetes?’ informants often provided descriptions of symptoms rather than biomedical explanations. Elevations in blood sugar and feeling tired or stressed were among the symptoms mentioned. Indeed, some informants mentioned that they could tell when their blood sugar was elevated based on symptoms such as fatigue or stress. A Sudanese woman [P no. 33], speaking through a translator, associated fatigue upon awakening with elevated blood sugar: ‘She said like sometimes when she feel her, the blood is up and then like when she wake up, she can't open her eyes, she feel like she want to sleep again. Then she feel always very tired.’ An elderly Cuban woman [P no. 23] explained, ‘when you are very worried, sugar goes up.’

Diabetes complications, especially loss of vision and kidney disease were a frequent response to the question, ‘What is your understanding of diabetes?’ One African-American woman remarked ‘That it tears you up and you have to take care of it right. You have all kinds of medical complications and stuff.’ [P no. 4] A Sudanese woman mentioned that a long time ago in her home country she heard from people that ‘diabetes could paralyze you.’ [P no. 13] Still another informant, a Cuban woman [P no. 12], mentioned, ‘it can affect my vision, kidneys.’ When asked, ‘what is the most important thing to know about living with diabetes?’ another Cuban woman [P no. 24] emphasized the importance of being careful ‘because you don't want to lose a finger or a leg.’

Focus on effects of food—The effects of different types of foods and beverages on diabetes frequently arose in discussions. Participants spoke about replacing sugary beverages with water. The perceived need to increase fluid intake, especially water, was a common theme. A Puerto Rican female participant [P no. 5] mentioned that she has to ‘drink a lot of cold water and things like that [to take care of her diabetes].’ A Burmese woman, speaking through a translator, touted the benefits of increasing her fluid intake, particularly lemon tea: ‘She drink a lot she become better. When she drink lemon tea then diabetes is better then. Diabetes go away like that. Her friends say that.’ [P no. 11, via translator] Another Burmese woman noted that if she eats ‘a lot of meat’ she becomes dizzy and has difficulty sleeping, so she changed foods and now eats more vegetables and fish paste. [P

no. 6, via translator] An elderly Puerto Rican man [P no. 29] attributed the prevalence of diabetes to the American diet, noting that in his family there was no history of diabetes. He commented that when he lived in Puerto Rico people ate a lot of sugarcane. Now the sugarcane is gone and people eat a lot of foods with sugar.

Some responses to questions regarding understandings of diabetes suggested that informants did not fully understand the mechanisms of their illness or relationship between food intake and blood sugar:

... in the morning it is 120. If I drink or have any bread it goes up to '2-something' real fast. I ask, I ask why does it go up so high? I don't understand that. [P no. 5: African-American female]

In general, the refugee patients from Burma and Somalia seemed to have the most limited grasp on the causes of diabetes and how to manage it. This might be a reflection of the predominantly female sample, and the limited formal education received by the women in the study from Burma and Somalia. When asked to describe her understanding of diabetes, one Burmese woman, via translator, commented that 'doctors say she has to take a shot and take medicine and take her blood out.' [P no. 11]

Discussion

Our study sheds light on the patient perspective of living with diabetes, or explanatory models which are often distinct from the biomedical models of health providers. Arthur Kleinman differentiates between patients' subjective experience of their illness, involving social, cultural, and personal aspects, and clinician's biomedical orientation.^{7,43} Striking in this study are the ways in which the patients' experiences of diabetes are similar across the wide variety of ethnic and cultural groups who participated. Regardless of their ethnic belonging, participants' described similar emotional responses, limited understandings of the biomedical processes underlying diabetes, and delayed diagnosis and treatment. This may result from their shared low socio-economic status, which in the US context may generate factors that influence their disease experiences in ways that transcend ethnic/racial/linguistic compartmentalization.

The patients' explanatory models of illness may include emotional and psychological processes embedded in the illness experience, which may include trauma and suffering. In our study, people reacted to the diagnosis of diabetes as they would to a loss. Our findings support those of an earlier study by Brown⁴⁴ who observed that patients newly diagnosed with diabetes may experience a reaction similar to that of the grief in bereavement. Patients in our study were frequently stunned by the diagnosis of diabetes, and expressed emotions associated with the various stages of grief including denial, anger, bargaining, depression, and acceptance.⁴⁰ Elizabeth Kubler-Ross noted that the stages of grief are not limited to the terminally ill, but may be applied to other conditions or even everyday living.⁴⁰ Our findings reinforce the recognition that among some patients, a chronic illness such as diabetes can provoke a grief reaction.

Our results also highlight the importance of health literacy, particularly diabetes self-management education, delivered in a manner that is accessible and relevant to the patient. The majority (19/34) of participants in our study did not complete high school. When asked to describe their understanding of diabetes, native and refugee participants alike often fixated on the symptoms or profound complications such as amputations or blindness. Our interviews suggest that information considered clinically important to physicians, including family history and the pathophysiological aspects of the disease may be of less relevance to the patient. Additionally, we might consider that the problem is not entirely patients' lack of

understanding or limited insight, but the limited overlap between patients' and medical practitioners' understanding of diabetes.

Limitations

There were several limitations to our study. The sample size was small and predominantly female. This was a pilot study confined to patients at one primary care medical practice on the West Side of Buffalo, New York. Each person was interviewed only once. To address language barriers, volunteer translators were deployed. Although the translators were vetted by the practice, we did not have the resources to engage professional translators for each language group and train them on the interview protocol. The sample was ethnically diverse. The small number of individuals with each ethnic group precluded analyzing each separately. Thus, we were not able to focus on any one group – although all participants shared a common chronic illness, diabetes, and were receiving medical care at the same practice. In addition, the themes identified in our study were common across all groups.

Implications for clinical practice

In her 1972 article, Elizabeth Kubler-Ross suggests that by inviting patients to express their thoughts, emotions, and experiences, physicians can help patients accept their terminal illness and prepare for their imminent death.⁴⁰ The patients in our study were confronting diabetes – not death – yet they manifested many of the same emotional responses documented by Kubler-Ross. While others have long noted the important role emotions play in health experiences,⁵ the experience of the patients in this study suggests that clinical practice has not yet effectively developed a means of addressing patients' emotional needs. Our findings suggest that Kubler-Ross's recommendations for treating terminally ill patients serve as a way to close this gap for those with a chronic illness. For example, clinicians might consider prioritizing patients' grief reactions to the diagnosis. By providing empathetic listening and helping patients address denial, rage, or other emotions soon after diagnosis, physicians might be able to promote patient acceptance of the diagnosis as a first step to engage the patient in self-management. Brown⁴⁴ recommends that clinicians incorporate psychological assessment and treatment into the patient's care when providing diabetes self-management education. Rayman and Ellison²⁴ also note the need for providers to recognize and engage with women's emotional responses to illness diagnoses and the demands of a self-management regime. Our results suggest that this may be equally important for men with chronic illness as well, who may face different cultural barriers to verbalizing and acknowledging their emotions.

In addition, effective self-management support may require that the healthcare team adapt counseling and support programs to the patients' approach to understanding diabetes. Self-management support may entail finding ways to make clinical outcome measures (e.g. glucose testing) relevant to patients' lived experience of the disease, rather than expecting patients to internalize a clinical, allopathic concept of disease, and disease management. This might involve engaging patients as partners to develop practical, patient-centered approaches to improve diabetes management.

Acknowledgments

The authors express their gratitude to Ramon Santiago, B.A., who helped with Spanish translations, and Peter Wald, M.P.A. who helped with editing.

Funding

This project was supported by a Civic Engagement Research Fellowship awarded to Dr. Linda Kahn by the UB2020 Civic Engagement & Public Policy Initiative, and grants from the National Institute on Minority Health

and Health Disparities (NIH) award no. 1R24MD004936-01 (Dr. Tumiel, Berhalter, P.I.); the New York State Health Foundation (NYSHealth); and The Community Health Foundation of Western and Central New York.

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Table 1

Key semi-structured interview questions

How did you first find out you had diabetes?

How would you describe diabetes? What is your understanding of how diabetes affects the body?

Being diagnosed with diabetes can be a big change in someone's life. How has it affected you?

What else that has not been said can you tell me about living with diabetes? What are the most important things you want me to remember about living with diabetes?

Table 2Characteristics of the sample ($N = 34$)

Characteristics	<i>N</i> or mean (SD)
Female	26
Age	58 (11)
Married or with partner	22
Employment	
Full time	5
Part-time	3
Disabled	11
Retired	9
Unemployed	3
Other (student, homemaker)	3
Education ^a	
<8th grade	14
Some high school	5
High school graduate	10
Some college or technical school	2
College	1
Ethnicity	
African (Somali, Sudanese)	6
Asian (Burmese)	5
Latino (Puerto Rican/Cuban)	11
Non-Hispanic white	6
African-American	4
Native American	2
Disease duration (years)	10
BMI	31 (6)
HbA1c	8.4 (2)
Depression diagnosed	9
Depression treated	6

^aTwo respondents did not answer the question on education.

BMI: body mass index.

Table 3

Summary of findings

An unexpected or late diagnosis
Surprise
Symptoms
Hospitalization
Explanations for unexpected, late diagnosis
Refugees: lack of preventive care; screening
Responses to life with diabetes
Denial
Anger
Bargaining
Depressive symptoms
Acceptance
Diabetes knowledge and understanding
Focus on symptoms
Focus on effects of food
