Résumé

L’identification et la compréhension des symptômes du diabète de type 2

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Bien que l’éducation sur le diabète encourage les gens à surveiller les symptômes de déséquilibre glycémique, il existe peu de recherches portant sur la façon de reconnaître et de comprendre les symptômes de cette maladie chez les minorités ethniques. Afin d’explorer cette question, des entrevues semi-structurées ont été menées auprès de 23 Afro-américains âgés de plus de 60 ans et atteints du diabète. Une analyse thématique a révélé trois types d’expérience quant aux symptômes. Les personnes éprouvant des symptômes importants comprenaient que leur corps communiquait de l’information claire sur les manifestations du diabète et sur leurs efforts pour gérer la maladie. Les personnes qui n’éprouvaient pas de symptôme concluaient que la maladie était bien maîtrisée. Les personnes qui éprouvaient des symptômes peu clairs ne pouvaient pas interpréter les messages qu’ils recevaient de leur corps. Elles étaient donc découragées de ce fait et avaient souvent l’impression qu’elles ne pouvaient pas faire confiance à leur corps. Les résultats indiquent la nécessité de mettre au point des stratégies novatrices amenant les gens à être davantage à l’écoute de leur corps et à mieux reconnaître et comprendre les symptômes qu’ils éprouvent.

Mots clés : diabète, symptômes, ethnique
Recognizing and Understanding the Symptoms of Type 2 Diabetes

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Although diabetes education encourages people to monitor symptoms of glycemic imbalance, there has been little research on how people from ethnic minorities recognize and understand their symptoms. To explore this question, semi-structured interviews were conducted with 23 African Americans over age 60 living with diabetes. Thematic analysis revealed 3 patterns of symptom experience. Those with prominent symptoms understood their body to be providing meaningful feedback on the diabetes and their efforts to manage the disease. Those with absent symptoms perceived no physical response to their diabetes, which they took to mean that the disease was well controlled. Those with perplexing symptoms could not interpret the messages they received from their body and were discouraged by this, often feeling they could not trust their body. The findings suggest that innovative strategies are needed to help people become more attuned to their body so they might better recognize and understand their symptoms.

Keywords: elderly, diabetes, symptoms, ethnic, qualitative, African-American

The everyday practice of diabetes management is complex and taxing. People are asked to adhere to demanding dietary restrictions and medication regimens and, moreover, to be continuously vigilant, watching for symptoms that might indicate altered blood glucose levels. Such symptoms usually demand immediate response if glycemic control is to be maintained and future complications prevented.

However, using symptoms to guide self-care practices is effective only if these body signals are accurately perceived and understood. Yet research has shown that when people with type 1 diabetes rely on how they feel, they often have trouble identifying when their blood glucose is too high or too low. They may be completely unaware of the accompanying symptoms (Clarke et al., 1995; Weinger, Jacobson, Draelos, Finkelstein, & Simonson, 1995) or may misinterpret their meaning (Pohl, Frohnau, Kerner, & Fehm-Wolfsdorf, 1997).

It has been shown that body knowledge is a requisite for expert self-care in type 1 diabetes (Paterson & Thorne, 2000). However, very little is known about this phenomenon in type 2 illness. Research has shown that symptoms experienced by persons with type 2 diabetes may not be consistent with physiological markers or commonly used symptom checklists (O’Connell, Hamera, Schorfheide, & Guthrie, 1990) and that...
people are often unable to estimate their blood glucose levels with any degree of accuracy (Diamond, Massey, & Covey, 1989). However, this research is very limited. While it indicates that people’s judgement may be lacking, it reveals little about body knowledge — that is, how individuals actually recognize and understand their symptoms in the context of everyday life.

In fact, symptom recognition and understanding may be a particular challenge for those with type 2 diabetes. This disease is most often diagnosed in older adults, who are likely experiencing symptoms of other chronic illnesses as well as age-related changes. Also, type 2 diabetes symptoms are often insidious, passing unnoticed for many years. For many individuals, the ability to identify diabetes symptoms may not come naturally or easily, which suggests that interventions to teach these important skills could be beneficial. However, the evidence in this area of clinical practice is sparse. Virtually no research has been conducted to determine how people with type 2 diabetes recognize and understand symptoms in the context of their everyday lives.

Symptom recognition will become an increasingly important clinical issue as the population ages, especially in light of the rising prevalence of diabetes. Approximately 150 million people are affected worldwide, a figure that has increased five-fold in the last 15 years and is expected to double again by 2025 (International Diabetes Federation, 2000). Also of concern is the fact that minority populations are disproportionately affected. While between 13 and 20% of North Americans over the age of 60 have diabetes (Center for Chronic Disease Prevention and Control, 2002; Harris et al., 1995), the figure is significantly higher in certain ethnic groups. For example, the prevalence of diabetes among African and Asian Americans is twice as high as among Caucasians (Harris et al., 1995). In Canada, prevalence rates are three to five times as high among First Nations people as in the general population (Center for Chronic Disease Prevention and Control).

Specific complications are also much more common in certain ethnic groups than in the general population (Konen, Summerson, Bell, & Curtis, 1999). For example, Mexican Americans have significantly increased rates of diabetic retinopathy, and African Americans and Native Canadians are three times as likely as members of the general population to suffer end-stage renal disease (Center for Chronic Disease Prevention and Control, 2002; Harris et al., 1995; Harris, Klein, Cowie, Rowland, & Byrd-Holt, 1998). Clearly, there is a critical need to improve disease-management strategies for minority populations, and to not assume that what works for one group will work for all (Agency for Health Research and Quality, 2001). It is important therefore that nurses learn to better understand how elderly people from different ethnic backgrounds expe-
rience their diabetes symptoms, so that educational resources might be designed to meet the needs of diverse populations.

**Methods**

To address this gap in our knowledge, a qualitative study was conducted to address the following research question: *How do elderly African Americans with type 2 diabetes perceive and interpret the meaning of their symptoms?*

Institutional Review Board approval was obtained to conduct semi-structured interviews with a convenience sample of 23 African Americans over the age of 60. The participants lived in a variety of urban and suburban communities in a western US state and were recruited through hospital and community clinics, diabetes education programs, and home-care associations. They came from varying socio-economic backgrounds and had a broad range of experiences living with type 2 diabetes.

The interviews lasted approximately 45–60 minutes and were usually conducted in participants’ homes. Participants were asked open-ended questions about how they viewed and managed their diabetes and its influence on their lives. The interviews were audiotaped and transcribed verbatim.

A thematic analysis was conducted in three stages (Benner, 1994; van Manen, 1990). First, notes were written in the margins of each transcript describing and interpreting all statements that related to the individual’s experience of diabetes symptoms. Each case was then discussed with the research team, each team member having previously read through the transcript several times. The purpose of this discussion was to encourage team members to challenge the initial interpretations, thus opening the analysis to new insights and guarding against interpretive bias. Next, the 23 cases were compared to identify similarities and differences across individuals. Based on these comparisons, a richly detailed text was written to describe as completely as possible people’s perception and interpretation of their symptoms. Members of the research team reviewed this text for coherence and plausibility (Packer & Addison, 1989). The final stage of the analysis involved an in-depth reading back and forth between the text and the raw data in order to identify themes that best captured the full range of variation in the data by articulating the distinct ways in which symptoms were recognized and understood by the study participants.

**Results**

The sample comprised 12 men and 11 women with an average age of 69.9 years. Eleven of the participants were married and all but four were
retired. The duration of the illness ranged from a few months to more than 25 years. All participants reported having some form of health insurance, and all were receiving medical care for their illness. Fourteen participants were taking insulin and seven were taking oral hypoglycemic medications. The average hemoglobin A1c level across the sample was 8.5% (sd = 1.8). Most of the participants (n = 18) reported having received some diabetic education and more than half (n = 13) said they followed a special diet for their diabetes. The sample had significant comorbidity, with participants reporting an average of two additional chronic health conditions, most commonly hypertension (n = 11) and cardiovascular disease (n = 8).

Thematic analysis illustrates that diabetes symptoms were experienced in one of three distinct ways: (1) prominent, (2) absent, or (3) perplexing. The following discussion will explore each of these patterns using examples from the interview data to illustrate the meaning of each in terms of how people lived with their illness.

**Prominent Symptoms: “Your body talks back to you”**

*Symptoms of diabetes* were very prominent in the interviews of 11 participants. This group had been living with diabetes for an average of 10 years (range 0.5–26 years). Eight were taking insulin and one was taking an oral hypoglycemic medication. The average hemoglobin A1c in the group was 7.9%.

This group seemed to take their physical experiences as meaningful indicators of their diabetes. For example, Mr. J described his symptoms as follows:

*Your body talks back to you…. It reminds me. A lot of time I feel the diabetes is when it’s low. I get sweaty, hot, and hungry.*

Alternatively, when his sugar was high, he experienced considerable pain:

*When my sugar is high, this hurts [pointing to side]. I mean, it hurts! This will really expose my diabetes. It’ll tell me right on this side. All this side there’s a terrible pain!*

For Mr. J the diabetes was hidden away, brought out into the open only through his symptoms. His body “reminded” him of the diabetes when the symptoms “exposed” the underlying disease. For Mr. J, the symptoms were a direct consequence of his diabetes and, as the main source of his suffering, required immediate attention.

Like many of the participants, Mr. J considered symptoms to be more or less reliable indicators of dietary transgression; he trusted his symptoms and took them to mean that he had failed to follow his diet: “Generally, it’s because of what I eat.” Others also noted that when they did not
follow their medication regimen they “felt” the results. Mr. N. explained that he relied on

how I feel, because if I don’t do what is taught to me — I don’t do one thing or the other — [I’m] going to feel it later on in some kind of way. So I have to take my insulin.

Mr. N’s words suggest an underlying belief that symptoms are a kind of penalty for not following the rules. Almost all of the participants complained about the difficulty of adhering to their diet and managing their medications. Those who experienced prominent symptoms seemed to view their body as giving them feedback on how well they were adhering to a rigorous regimen.

For several participants, symptoms figured prominently in the historical recounting of their diagnosis. These were such powerful symptoms that they could not be ignored. Mr. A said:

Couldn’t get enough to eat. Whatever I ate [tasted] like nothing. Whatever I drank… Couldn’t get enough to drink. And I was going to the bathroom every half hour…. I never had these symptoms in my life before…. [Things began to appear hazy.] My teeth got loose.

This experience was paradigmatic to the extent that it shaped Mr. A’s subsequent efforts to manage his diabetes. Unmistakable symptoms such as these were uncomfortable and frightening, and he was intent on avoiding a recurrence: “I was just seeing that it would never happen again.” Mr. A explained again and again throughout his interview that it was important for him to take care of his body by constantly watching for symptoms of diabetes:

I knew how I was feeling. I know my symptoms, and [regarding] what else is in my life, well, it takes second and third place. [The diabetes] is number one.

Mr. A’s management strategies appeared to be driven by his desire never to relive this initial experience. Several other participants described a similar approach to the management of their illness. As long as the most severe symptoms did not recur, they tended to believe they were well.

Prominent symptoms were not always dramatic, however. In fact, a few participants described their diabetes symptoms as typically quite subtle. When asked how he knew his sugar was high, Mr. G responded:

I get a little drowsy. I have a nasty taste in my mouth. I don’t know, I can’t describe [it]. But it’s a lot of little ways — if you pay attention to yourself.
Although Mr. G’s symptoms were difficult to put into words and required a certain level of attention on his part, they were nevertheless clear messages, distinct and meaningful.

Often, symptoms stood out by virtue of how they impacted on everyday activities and family life. As one man explained, “My problem is just the physical stuff. It’s doing just normal things that other people do.” Several participants said that diabetes had its greatest impact on their daily schedules, as they had to carefully time their meals. One woman explained:

[Diabetes] has made quite a difference because… I have to get up at a certain hour to eat. And if I don’t eat, I get low sugar and it seems to give me blindness… like something always in front of my eyes.

Several participants spoke of symptoms as humiliating or embarrassing. One woman described incontinence as her most significant diabetes symptom, mainly because it limited her ability to go shopping:

You’re always spilling urine, and that is too embarrassing. And you’re never clean. That’s why you can’t go shopping…. You know how you try on clothes? You can’t do that [any] more.

Mrs. O was reluctant to acknowledge her symptoms because she did not want to be a burden to her family:

I let my sugar get too low last night. … I was just sweating and very weak. I get my husband up so much. I didn’t want to get him up and pass me a banana to eat. So I just suffered on through.

The symptom was a glaring indicator of Mrs. O’s growing dependence on others. Its significance for her health was secondary.

While most participants emphasized the immediate distress of symptoms, some also spoke of symptoms as threatening or as a warning of possible complications. These individuals worried about eventually going blind or losing a limb. One woman said, “I’m always afraid that I’ll go into a diabetic coma or something.” This was particularly evident for people who had experienced complications such as retinopathy or skin breakdown or had witnessed complications in family members with diabetes. These people tended to be particularly attuned to their symptoms, and some made a special effort to monitor themselves and take immediate action when they noticed a change. This was a common pattern amongst those with neuropathy, who watched their feet for signs of skin breakdown. Mrs. R had discovered a sore on her ankle when she was travelling:
It scared me half to death because it was bleeding. I immediately washed it off and put Listerine on it because I didn’t have anything with me at the hotel. And as soon as I got home I put some antibiotic cream and a band-aid on it. I kept watching it and it healed within a week, and that made me feel good.

Absent Symptoms: “I didn’t have any response to it”

In marked contrast to those who experienced prominent symptoms were seven individuals who did not perceive symptoms at all. This group had been living with diabetes for an average of 9.5 years (range 0.25–25 years). Three were taking insulin and four were taking oral hypoglycemic medication. The average hemoglobin A1c in this group was 9.1%.

In describing her absence of symptoms, one person said:

*“I don’t feel bad. I don’t tingle. I don’t have dry mouth. My feet aren’t hurting, and, so far, when I hurt my leg it healed.”*

Another said that when she was diagnosed with diabetes she hadn’t known that anything was wrong, because “I didn’t have any response to it.” For some individuals, the absence of symptoms meant that the diabetes was far in the background: “I don’t ever think about it”; “The diabetes [doesn’t] bother me.”

People who claimed that they had no response to the diabetes may have been attributing their symptoms to a different source. For example, several of the participants downplayed the significance of their symptoms as a sign of disease, arguing that these experiences were normal for them. One man said, “I’m tired most of the time, but I’ve been tired most of my life.” These participants may have been so accustomed to feeling tired or having poor vision that they no longer noticed it as unusual.

Other co-existing chronic illnesses were common in this sample, and some believed their symptoms were the result of a disease other than diabetes. One man insisted that his symptoms were due to his longstanding heart problems:

*“Every time I go [to the hospital] they say it’s my diabetes, and I say it’s got to be something else. …they…never tell me it [is] my heart.”*

For this man, the diabetes was not problematic, despite the efforts of his clinicians to convince him otherwise.

Symptoms may have seemed non-existent because people had other, more pressing, concerns. Many of the participants described busy, hectic lives. Some had demanding jobs, while others were responsible for the care of a partner, children, or grandchildren, and in one case even several foster children. Moreover, many were in difficult socio-economic circumstances. Given the multiple demands on them, these people may
have lacked the time or energy to be attuned to their body. Alternatively, failure to identify symptoms may have resulted from a value orientation in which one puts others before oneself. Mrs. C had been widowed for 23 years but maintained close contact with her children and lived in what she described as a “family building” where everyone knew and looked after one another. Mrs. C admitted that she often diagnosed herself incorrectly when she relied on how she was feeling:

“That’s why I’m not too good at [it]. I can always dose the medicine in everybody else but not in myself…. I was taking care of them but I guess I didn’t take care of myself.”

This woman felt that her deepest commitment was to others. “Even at my worst, I’m still of service to someone else. That makes me feel good.” Mrs. C’s obligation to family and friends came before her obligation to her own health. This may have led her to ignore her symptoms.

It is also possible that diabetes symptoms are so subtle or vague that they go unnoticed. The physical symptoms may be outside one’s conscious awareness. One woman spoke of realizing she was hungry only when she found herself standing in front of the refrigerator, eating. The way she described it, it was as if her body had its own tacit awareness, acting in response to its low blood sugar without her consciously perceiving, interpreting, and responding to an explicit symptom. Yet another possibility is that the body’s response to alterations in blood sugar becomes muted over time. One man commented that he was less aware of his symptoms since starting insulin:

“When [the blood sugar] was up, I used to tell just by the way I [felt]… That was before I started to take the insulin.”

The absence of symptoms was almost always seen as positive. Even though people knew their sugar might be out of balance, as long as they had no symptoms they were more or less indifferent. Mr. T, who emphasized that he knew his body, said:

“I’m not too concerned about low blood sugar. I think the other morning I was down around 68 and I had no glycemic reaction.”

People were even relieved by the absence of symptoms. Mr. J, who often suffered with pain, said:

“When I first wake up, regardless of whether my sugar is up or down [my body] is at peace — no pain or aches. And I just [lie] there and enjoy it.”

Several participants believed that the absence of symptoms meant that they were following the rules of diabetic management and were taking
good care of themselves. When asked what made him feel that he was managing his situation, Mr. L replied:

*What helps me is my feelings. You can feel if your blood sugar gets too low... If I feel okay, things [will] be managed. If I make a mistake, my blood sugar gets low. But if I eat at the proper times, take the insulin at the proper time, everything [is just] great.*

Most people in this group believed they were well as long as they felt fine and had no obvious symptoms:

*I look at my daily feelings. You know, if I don’t have... anxiety attacks or anything, I don’t get the sweats, then, to me, I’m feeling good. If I can go through my normal routine, that’s what I look at. That’s my measure.*

In other words, the absence of symptoms meant that everyday life was unaffected. The people in this group felt comfortable and were able to engage in their usual activities. “Everything’s just like before I had it,” said one man. “I do everything I want to do.” Even when they admitted that their glucometer readings were consistently high, these participants felt that as long as they had no symptoms they had a good quality of life free from the intrusion of diabetes.

**Perplexing Symptoms: “These were the symptoms, but I didn’t know what they were for”**

Five participants received messages from their body but had difficulty understanding their meaning. This group had been living with diabetes for an average of 13.4 years (range 1.6–25 years). Three were taking insulin and two were taking an oral hypoglycemic medication. The average hemoglobin A1c in this group was 9.0%.

In describing how he was perplexed by his symptoms, one man said, “These were the symptoms, but I didn’t know what they were for.” In part, this was a result of insufficient knowledge. As people gained more experience with the illness, they came to better understand their body’s responses. However, several participants commented that they would have benefited from further education. Even though they understood the theoretical facts, they were not always able to make use of this knowledge in the context of their own experience. One woman who had recently taken a course at a university hospital clinic said:

*I know the diabetes affects your eyes. Now, on occasion, my eyes are a little blurry, but I don’t know if that’s from my sugar being elevated.*

Symptoms were often experienced as ambiguous. Blurred vision might have been related to diabetes, but, as more than one person pointed out, it could also be caused by a cataract. Fatigue was common
in this sample, and some people simply did not know what to make of it. The confusion was particularly evident in those who had multiple health problems. Mrs. R, not only had experienced diabetic complications, but was living with rheumatoid arthritis and had been receiving chemotherapy and radiation therapy for breast cancer. All of this made it especially difficult for her to distinguish and make sense of her diabetes symptoms. She had been “tired a lot” when first diagnosed with diabetes but was not sure if this was related to the diabetes: “That’s just the way of my life. I’m tired.” This woman did not immediately assume that her fatigue was due to one of her other health conditions but, rather, was uncertain as to its meaning and significance.

The information offered by symptoms was sometimes found to be indeterminate and not very helpful. Mrs. D described her particular dilemma as follows:

_In the morning my energy runs out because my sugar is too low; in the evening it runs out because it’s too high._

Even though the symptom was apparent, it was not particularly meaningful. Mrs. D could not use the information to help her decide how to respond.

Perhaps because symptoms could be so inscrutable, a full third of the participants used their glucometer to help them judge how their disease was being managed. “It will tell me the truth!,” said one man. People often noticed that the readings bore little relation to how they felt, which further supported their belief that they could not rely on their own bodily perceptions. One woman explained that the previous night she had woken “feeling” that her sugar was low but when she measured the levels in the morning she found it was 97.

_That was better than I thought. I thought my sugar had dropped down to about 40, but it was up... So it was just a bad dream, a nightmare or something I was having._

This woman did not assume that the machine had given her an inaccurate reading or that her blood sugar simply increased since the middle of the night, but instead concluded that she could not trust her own body and wondered if she had just dreamt the entire thing.

Often, people continued to experience significant symptoms despite their best efforts to control their diet. This may have been partly because they had inaccurate information in this area. It was a common belief, for example, that simply avoiding extra salt and sugar could keep blood glucose under control. When observance of these rules failed to change their symptoms, some participants became discouraged, feeling their body could not be trusted: “I’d just like to know why [the blood sugar]...
is up with me trying to control what I eat.” These individuals concluded not that they had made a mistake with their diet but rather that their body was erratic and unreliable. Diabetes was a force of uncertainty in people’s lives. “I don’t trust the diabetes,” said one man. “I just don’t know what it’s going to do next.”

**Discussion**

One focus of diabetes education is helping people to monitor their blood glucose levels and develop effective strategies for maintaining glycemic control. Often, little attention is paid to how people recognize and understand their diabetic symptoms. The findings of this study demonstrate the variability of symptom experiences and the impact of these experiences on self-care practices and management strategies.

Prominent symptoms forced people to take note of their diabetes. The participants who experienced prominent symptoms believed their bodies were sending them messages that the diabetes was not being adequately controlled. These symptoms could not be ignored. They caused discomfort, interfered with daily activities, and served as a warning of future complications.

Given these negative meanings, it is not surprising that people tended to feel relieved when the symptoms subsided. But physiologic alterations caused by diabetes can be subtle and produce no easily discernible symptoms, and, as with hypertension, the pathophysiologic consequences are often hidden until organ damage becomes significant. Many participants in this study did not seem to grasp this, generally believing that if specific symptoms were mild, the disease was under control. As long as they felt well and could do their normal activities, they were unconcerned.

This phenomenon was particularly evident amongst people who spoke of being reassured when they did not “feel” their diabetes, when symptoms were notable only by their absence. It is possible that diabetic symptoms truly do not exist if one’s body has become unresponsive to changes in blood glucose. Hypoglycemic unawareness is well documented in type 1 diabetes (Clarke et al., 1995; Weinger et al., 1995) and may also apply to some individuals with type 2 who require insulin (Samuel-Hodge et al., 2000). However, the findings of this study point to the possibility that many people with type 2 experience symptoms but do not associate these with their diabetes. Several participants said that a particular symptom had been with them most of their lives or was the natural result of growing older. Others identified their symptoms as belonging to a co-existing disease that they considered far more serious. In short, diabetes symptoms may not always manifest if people have concerns that direct their attention elsewhere. In the face of multiple
demands, it may be difficult for people to attend to their bodies. They do what they can with regard to diet and medications, but symptoms simply do not stand out in the context of busy, stressful lives.

The participants with prominent or absent symptoms trusted their bodies to tell them the truth; the meaning of their symptoms was unambiguous. However, many of the participants were confused by their symptoms. The addition of other chronic health conditions seemed to make it difficult for them to distinguish and interpret symptoms. Moreover, even though most participants had received diabetes education, their beliefs and health-care practices were often at odds with the recommendations of their health-care providers. Thus when symptoms of glycemic imbalance appeared despite their best efforts to manage the disease, they became discouraged. They did not consider the possibility that their management strategies were ineffective or misguided, believing instead that their body had failed to provide accurate feedback.

Research conducted in the 1980s and 1990s found that “knowing the body” is a necessary skill for diabetes self-management (Paterson, Thorne, & Dewis, 1998). However, most of that research was based on interviews conducted with well-educated Caucasian married women with type 1 disease. The present findings show that the experience of elderly African Americans with type 2 diabetes may be quite different. Schoenberg, Amey, and Coward (1998) found that even though African-American women with diabetes used the same information sources as white women, they had less knowledge of their illness. The reason for this is not known, although sociocultural and environmental factors likely influence self-care practices (Samuel-Hodge et al., 2000; Whittemore, 2000) and almost certainly influence the reception and use of available health information (Brody, Jack, Murry, Landers-Potts, & Liburd, 2001). This issue should be a focus of future research.

The participants’ descriptions of their self-care practices indicate a growing dependence on technology for monitoring the disease. Indeed, most participants who monitored their blood glucose levels believed that the numbers reflected “the truth” even if this did not agree with what their bodies were telling them. However, the incongruence between symptom experience and monitoring results also caused tension and confusion, contributing to some participants’ lack of trust in their bodies.

This finding could have implications for diabetes self-management, especially in light of research showing that blood glucose monitoring may not result in tighter metabolic control (Koch, 1996). For example, a study with 98 African Americans with type 2 diabetes found that blood glucose levels were similar for the 61 individuals who regularly self-monitored and the 37 who did not (Oki, Flora, & Isley, 1997). It is possible that only through an embodied awareness of symptoms are people with
diabetes prompted to take action. For many, a number on a glucose monitor may simply not be a sufficiently salient cue. Of course, this awareness must be an informed one; people need to know how to respond to their symptoms appropriately. The results of the present study suggest that this is not always the case, given that blood glucose was poorly controlled even in the group experiencing prominent symptoms.

Misinterpretation and misunderstanding of symptoms were common in this sample of elderly African Americans with type 2 diabetes. This suggests that people with diabetes require more complete information. But offering individuals a comprehensive list of possible symptoms along with a thorough explanation of their significance may be insufficient to help them identify their own symptoms. Benner and Wrubel (1989) argue the theoretical point that, as experiences of the lived body, “symptoms can seldom if ever be separated into pure sensation and pure emotional responses” (p. 212). Symptoms embody a depth of personal and cultural meaning that can be fully understood only in the context of a person’s past and current life situations. Asking people to match their symptoms to those on a list may serve only to promote further distrust of one’s body when it does not behave according to abstract, decontextualized definitions.

Ultimately, if nurses are to help people better manage their diabetes, we will need to develop strategies to bring them more in tune with their body so they will see how it responds to the illness even when symptoms are subtle and difficult to discern. An area that needs further research is precisely this — how to refine people’s body awareness so they are able to more accurately interpret their own unique symptoms and respond appropriately (Hernandez, Bradish, Rodger, & Rybansky, 1999). It is especially critical that such research be conducted with socially and ethnically diverse populations.

Such research will inform nursing’s theoretical understanding of symptom management. Current theory in this area proposes a model with three components: symptom experience, management strategies, and outcomes (Dodd et al., 2001). The findings of the present study deepen our knowledge about the first component by underscoring the idea that recognizing and understanding symptoms is a matter of not just grasping facts about one’s illness but also coming to an embodied understanding of the illness over time (O’Flynn-McGee, 2002). By developing this kind of body expertise, those with type 2 diabetes might be able to achieve better glycemic control and have fewer long-term complications.

As a final note, the present findings are limited in that participants were asked to report retrospectively on experiences that may have been difficult for them to discern or recall. Indeed, participants often had trouble describing their symptoms, thus raising the possibility that symp-
toms were absent or perplexing less frequently than the interviews suggest. The symptom experiences may have been forgotten, or may have been taken for granted such that the participants found it difficult to reflect on them in an interview.

Future research in this area should include additional data-collection techniques such as direct observation or symptom diaries that would permit the collection of data as symptoms occur. Future research should also consider participants’ medical details, including specific diagnoses and medications, as these factors can greatly influence symptom experience.

References


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