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Blood Glucose Symptom Recognition: Perspectives of Older Rural Adults

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Abstract

Purpose—Blood glucose symptom recognition and the interpretation of how one feels with regard to low or high glucose can impact how diabetes is self-managed. Understanding interpretation of symptoms related to diabetes and ultimate glucose regulation can be challenging. Healthcare providers can develop strategies to improve care by listening to individuals describe their symptoms in the context of everyday life.

Methods—The perspectives of older rural adults were assessed through individual in-depth interviews conducted among 75 African American, American Indian, and white individuals. The study design included a sample balanced with regard to sex, ethnicity, and educational attainment. The Self-Regulatory Model of Illness and the concept that people construct their own Common Sense Models of health were utilized in this study.

Results—There were four dominant themes of symptoms described that were related to blood glucose. These categories included sensations, lightheadedness, energy level, and eyesight changes. Participants described symptoms they experienced at perceived levels of both high and low blood glucose. Results suggest that older adults were unable to distinguish whether their symptoms occurred because of high or low blood glucose.

Conclusions—Education that incorporates methods to help older individuals differentiate blood glucose levels related to diabetes symptoms could help improve self-management.

Individuals experience diabetes in differing ways and their responses can vary depending on their understanding and interpretation of their symptoms. The “Self Regulatory Model of Illness” represents a tool for understanding self-management behavior and is based on the premise that individuals can problem-solve and monitor symptoms based on daily experiences of their health.[1] Common Sense Models of chronic disease states such as diabetes incorporate beliefs and knowledge across a spectrum of self-care activities.[2] Basic

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to this framework is the idea that patients have their own way of understanding their disease that may conflict with the biomedical model.

Interpretation of symptoms may differ between age groups with older individuals experiencing greater feelings of vulnerability, and symptoms can signal a person to implement specific self-care practices.[3, 4] The understanding of a symptom can vary depending on the person's experiences and may be affected by ethnicity, gender, learning, and beliefs.[5] Diabetes symptoms can be subtle and individuals may not recognize relationships between their symptoms and the disease.[6] A diabetes educator is in a pivotal position to guide symptom recognition and management.

Diabetes is a chronic disease that often occurs in older individuals leading to morbidity and mortality. In persons ≥ 65 years of age, the incidence of newly diagnosed diabetes increased from 33,164 in 1994 to 40,058 in 2003.[7] Among persons ≥ 60 years in 2007, 12.2 million (23.1%) in the United States had diagnosed diabetes.[8] Complication rates continue to rise among older adults with diabetes. Furthermore, minority populations are disproportionally affected by diabetes.[8]

There is limited information reported about how older individuals interpret symptoms related to diabetes.[9] It is important to understand the relationship between interpretation and resulting action as it relates to blood glucose because it guides individuals' overall success in disease self-management. Previous data indicate that many older adults with diabetes failed to recognize symptoms of diabetes.[5] The purpose of this study is to identify what symptoms older adults with diabetes associate with high or low blood sugar using qualitative methodology. Such methods allow patients to express their experiences and beliefs in their own words.

Research Design and Methods

Sample

A total of 75 individual in-depth interviews were conducted. The study design allowed recruitment of equal numbers of men and women who were ≥ 60 years of age and had diabetes for at least two years from each of three ethnic groups (African American, American Indian and white). Participants were recruited from three south-central counties in rural North Carolina. These counties were chosen because of their large minority populations with a high proportion below the federal poverty level, defined by the US Department of Health and Human Services (http://aspe.hhs.gov/poverty/09poverty.shtml). The goal of the sampling plan was to recruit equal numbers of participants for each ethnic/gender cell, with each cell having participants spread across educational attainment categories (less than high school, high school, more than high school). Interviews were stopped at a minimum of 11 per cell.[10, 11]

A site-based sampling method was used to recruit a representative sample of individuals who met recruitment criteria.[12] Sites included places where seniors were likely to visit for recreation, services, or patronage, such as government offices, community organizations, senior recreation centers, senior apartment complexes, subsidized senior buildings, local businesses, congregate meal sites, civic organizations, and churches. Local community leaders were contacted and enlisted to help with study recruitment.

Data Collection

Data collection was completed from May to November 2007 using in-depth interviews that ranged in length from one to three hours. The interviews were scheduled at a time and location of the participant's choice. While most interviews were conducted in the homes of

the respondents, there were a few instances in which participants preferred to meet in alternate locations. Interviewers outlined the project objectives and obtained informed consent and permission to record the interviews from each participant. A small financial incentive was offered for completing the interview. All procedures were approved by the Wake Forest University School of Medicine Institutional Review Board.

The interviews were semi-structured and based on an interview guide. The interview captured information about diabetes beliefs, diabetes knowledge, consequences of diabetes, and self-management. Participants were queried about symptoms of high and low blood sugar in two ways. First, they were asked if they could identify when their sugar was high or low based on a particular symptom. This type of questioning was used to elicit individual identification of diabetes symptoms based on personal experiences. Later during the interview, a list of symptoms both related and unrelated to diabetes was presented, and participants indicated if they had experienced any of the symptoms.

Data Analysis

Data analysis was based on a systematic, computer-assisted approach. A preliminary codebook was developed based on the interview guide. Each interview was transcribed verbatim, coded by two team members and subsequently analyzed using ATLAS 5.0.[13] A summary of each transcript was assembled. Bimonthly meetings were conducted to identify a set of additional codes and broad themes to characterize participants. Qualitative analysis consisted of extraction of quotations around the topic of blood glucose symptoms. We identified segments of text where participants mentioned symptoms of high and low blood glucose. We reviewed text segments related to symptoms and the investigator summaries of each interview. Word searches were also completed to capture relevant information related to high and low blood glucose.

Results

A total of 36 men and 39 women participated. The average age at survey was comparable between genders (men, 72 years; women, 70 years). There were 15 men and 12 women who never received diabetes education. The average duration of diabetes was longer for American Indians and African Americans (≥30 years) compared to whites (20 years). Approximately one-third of the sample had more than a high school education with the remainder having lower educational attainment.

The way study participants described symptoms of high or low blood sugar can be grouped into four major categories: nerve perceptions (tingling, numbness, nervousness), lightheadedness (dizziness), energy level (tiredness, weakness), and eyesight changes (blurred or altered vision). Individuals with a longer duration of diabetes were able to describe symptoms in more depth and were likely to attribute symptoms specifically to either high or low blood sugar. Participants who reported a lack of symptoms relating to diabetes often concluded that no treatment was necessary for their diabetes.

Nerve Perceptions

Participants attributed a wide variety of sensations or feelings to blood sugar levels. Many made comments about remembering tingling, often associated with numbness. Some individuals described the feeling of their feet going to sleep. In general, African American men and women described experiencing sensations in their extremities more frequently than the other ethnic groups. One African American man related his blood glucose level to feelings in his feet.

Sometimes they [my feet] get a tingle and get numb…[Interviewer: What causes that?] I don't know. I put it on a lot of things, it depends. Most of the time I think when my feet get like that it's like the sugar level is too low. [So what do you do when that happens?] I mostly check my sugar test to see if my sugar is low. If the test comes out normal then I don't know what's going on. [ELDER048]

Nerve perceptions or feelings in other body areas were also described as "prickling". When asked about symptoms of low blood sugar, the following response was reported from an 84 year old White man who had diabetes for 19 years and experienced perspiring along with a variety of other feelings.

> [How do you know when you have low sugar, do you feel different?] Oh yeah, you have a sweat and you feel like, well, mine started like I've got pins and needles, you know a nerve thing. That sensation of pricking. It must be in all your nerves because it goes all over you then you feel like you're going to explode on the inside…you get that pins and needles feelings and that my way of knowing. [ELDER059]

Other participants experienced nerve perceptions but did not attribute them to blood glucose levels. Numbness was reported in conjunction with nerve sensations experienced. One white participant related numbness around her toes to her nerves rather than to her diabetes of seven years duration.

> I have numbness around the toes, but I think it's because I have a kind of bad nerve in that leg, and I think it's the nerve. I don't think I have any problems with my being a diabetic in my feet yet… I don't think that would be related to it in a sense. [ELDER009]

This participant not only expressed the sensations she has experienced that she related to nerve problems, but also makes a critical link between what the symptoms are and what they mean. While she does not relate her current symptoms to diabetes "yet", she tacitly acknowledges that, in time, it will be diabetes related when it has progressed to being a complication. Participants held a variety of explanations for the causes of their feelings and sensations. Many attributed what they were experiencing to blood flow problems. Some of those interviewed described sensations associated with temperature as coming from beneath the skin or inside of their body.

> My feet at night time… just like somebody have some fire to it [my feet]. It was real, real hot you know. I guess like it might have been the tingling thing…like it [my feet] was on fire… [Interviewer: What do you think causes that?] ….some people say poor circulation…whether it's true or not, I don't know. [ELDER034]

One man used biomedical terms to explain the feeling in his extremities that he associated with his diabetes and high blood glucose level. Other descriptions related to nerve involvement but with non-biomedical explanations.

> Its [diabetes] affected my feet and my fingers. There's neuropathy there. [ELDER064]

> [Interviewer: And why do you think it makes your feet numb or tingly?] I don't really know. It's bad on the nerves in your body. That sugar eating nerves. [ELDER047]

Nervousness was also cited as a symptom related to diabetes and some individuals associated these symptoms more closely with their blood sugar level. For example, a White man talks about what happens when his blood sugar drops below 70 mg/dl.

> "Well I can tell when my sugar is real low because, like I say, I'm nervous. I feel like I've got to eat." [ELDER014]

Lightheadedness/Dizziness

Feelings of lightheadedness and dizziness were also identified. In general, American Indian and African American respondents reported more symptoms of lightheadedness or dizziness than Whites. The effects of feeling dizzy and symptoms experienced over time were also voiced in relationship to blood sugar.

> You know after you have it for a while you can tell if it's high or if it's low. If it's high you feel a little, not real dizzy but lightheaded… [ELDER030]

> Well, you can get mighty dizzy. I found that out. And it just is a weird feeling. I've had it. What is it hypoglycemia? [ELDER 063]

> High blood sugar makes you feel dizzy some ways. [ELDER037]

Several of those interviewed could identify a feeling in their head that made it difficult to think. However, they were unsure how the feeling related to blood glucose. The experience of feeling symptoms move through one's body was described and associated with blood sugar.

> I don't really know how to describe it, but I would get lightheaded, and it was as though I can actually feel it moving over my body. [ELDER062]

Energy Level

A majority of participants could identify how they felt with regard to overall energy level. Feeling tired and weak was cited as a common symptom related to diabetes. There were some interviewees who felt poorly but had a difficult time fully describing their energy level. Both low and high blood sugars were cited as the cause.

> The worst one is when it [blood sugar] gets too low. You know when it gets high. … I just get tired. I know it's high. But when it gets real low…. I get nervous and sweaty and I can't hardly, you know my heart rate is out of whack you know and I just be real…and it scares me. You know I get upset and then I get worse until I get it [blood sugar] down. [ELDER013]

> [Interviewer: So you still feel sluggish and kind of weak?] You don't have any energy, you just feel bad….Sluggish…no energy, you know, no appetite, no energy…[ELDER 060]

> I just get the blahs. You don't care whether you do anything or not and that's my way of knowing I've got high sugar. [ELDER059]

Descriptions of weakness and its relationship to low blood sugar were frequent. In general, women talked about weakness as a symptom more than men. Several interviews depicted specific feelings related to blood sugar. A number of individuals discussed low blood sugar being more difficult to handle than high blood sugar.

> I get weak. Now I've had those spells for years and years. Like all of a sudden, I think that it's that I used to have a low [blood sugar], I was borderline low diabetic, if that's even the word they use…. all of a sudden I'd get the shakes and real weak and… I was going to vomit if I didn't get just a bite of something…[ELDER036]

> Now, when it starts getting low, you start feeling very weak, and you start slowing down, and you feel like you can't hardly go; and I think a person has to really be a

> diabetic to really know these symptoms, but you can automatically tell if it's going up or down. [ELDER009]
>
> Diabetes changes the way you feel; you feel weak when sugar is up. However, symptoms are not bad. Well, they're not really bad. Sometimes I feel like maybe the sugar is up but then I check it and it's okay and all so, everybody's body is different anyway so with my body it's just hard to tell from the way it feels and everything. [ELDER015]

Eyesight Changes

Eyesight changes, including blurred or altered vision, were commonly reported. Many individuals reported more extreme eyesight changes such as an inability to see. Blood sugar was the most common cited etiology for eyesight symptoms. However, vision alterations were described in relation to both high and low blood sugar. Many individuals talked about how they knew their diabetes was not well controlled if they had blurry vision.

> You get blurred vision a lot of times; and, so, when you have all these symptoms usually if you are where you can take – do a finger test on your sugar, you can see that your blood sugar is really, really high. [ELDER 009]
>
> [Interviewer: What does it mean to have a high blood sugar?…]. You know like blurry vision, you'll be dizzy and you'll get confused… Well when your blood sugar is too low and you want to bring it back up to keep from having all these funny feelings, blurry vision, all this stuff, you get you a little sugar. [ELDERS 067]
>
> My vision gets blurry. That's how I know when my sugar is up. [ELDER001]

Some participants with long-standing diabetes reported symptoms related to eyesight. Eyesight changes were a worrisome symptom described by participants and a variety reported feeling like there were particles resembling sand in their eyes. An American Indian man who had diabetes for 20 years talked about the relationship of eyesight to low blood sugar.

> …I can tell if mine [blood sugar] gets a little bit low. I can tell in my eyes. I can't see… [ELDER 027]

Discussion

The goal of this study was to examine how older adults related their experience of symptoms to high and low blood glucose. Among a tri-ethnic population of 75 rural adults, in-depth interviews were conducted to capture individuals' experiences with symptom recognition. The importance of symptom perception and interpretation lies in the fact, pointed out by the Common Sense Model, that individuals' illness representations are directly related to their coping and personal action to protect or restore "health".[2] Symptoms experienced by older adults can impact how they react and use potential treatment plans. The interviews from this study indicate that elders experience and interpret diabetes symptoms in a variety of ways.

The most common reported symptoms were those grouped under the heading "Nerve Perceptions" which included tingling, numbness, or nervousness. Some participants loosely used a biomedical model to explain what was going on in their body, often citing disturbances in circulation as a cause for their numbness. However, others, while experiencing symptoms, did not align these with diabetes, which left the cause of the symptoms unexplained. These findings are similar to those in a study among a cohort of 87 Mexican Americans with type 2 diabetes; when asked about their perceptions of symptoms, over half described numbness or tingling and 44% did not perceive the symptoms as

serious.[14] In the current study, symptoms for the "Nerve Perceptions" category were often attributed to low blood glucose levels and to circulation problems.

The category of "Lightheaded/Dizziness" was also reported and often related to both high and low blood sugar. These symptoms were more frequently cited by the African American and American Indian respondents. Participants were often unable to distinguish the level of blood glucose for this symptom. Most individuals who described feelings of dizziness were also able to associate physical discomfort with this symptom.

How a person feels related to their energy is another dominant category of symptoms that was labeled as "Energy Level." Most elders related tiredness to high blood sugar, and weakness was more commonly associated with low blood sugar than high. Several individuals reported that some days they did not have much energy and related this symptom to their diabetes. Chronic conditions, such as heart disease, were often mentioned in conjunction with energy level.

The other major category was "Eyesight Changes." Most individuals with vision changes ascribed the symptoms to their high or low blood sugar and recognized the seriousness of their situation when the vision changes progressed to blurry or altered vision. The ability of participants to attribute changes in eyesight to the correct level of blood glucose was difficult for a large majority of those interviewed.

Overall, most study participants had little trouble describing the sensation they felt in their extremities, in their eyes, and in their bodies in general. What is significant is that few clearly associated the symptoms with high or low blood sugar and with the complications that arise from these blood sugar levels.

A limitation of our study includes the lack of generalizability of our findings to other populations with diabetes. However, in addition to age, diabetes diagnosis, and ethnicity, participants were recruited with regard to educational attainment and socioeconomic status to ensure a representative sample. A potential caveat in this study is that additional domains of symptom recognition related to high and low blood glucose may not have been identified.

Diabetes self-care is multifaceted and requires patient understanding of symptoms. The American Association of Diabetes Educators (AADE) recognizes the importance of behavior in diabetes self-management and diabetes educators can inventory and frame their interactions on the basis of the AADE-7 Self-Care Behaviors which include problem-solving, healthful coping, and reducing risks.[15] Self-care management with the awareness of the complexities inherent in the support needs of diabetes as a chronic disease has been studied.[9] The symptom management of elders in this study indicates that there was a variety of awareness levels among the participants of how they were able to interpret common diabetes symptoms. Illness behavior has also been evaluated using health diaries of older people with the finding that those who experience few symptoms and assess their health positively are more likely to normalize new or unfamiliar symptoms.[16] Other research has shown that in an older cohort of patients, lower educational attainment and health literacy, as related to insurance status, were found to impact perceptions of self-management.[17] In a group of African American women with diabetes, a wide variety of symptoms were found with poor perceptions of the relationship to general health and physical function.[18]

Symptoms can be indicators of how the body reacts to a specific stimulus and the importance of patient recognition of high and low blood glucose can be an essential component to optimizing self management. Being diagnosed with a chronic disease such as diabetes may be an emotional experience and management can be challenging for individuals.[19] Patients' acceptance of their disease, making adjustments in lifestyle, and

developing self-care skills are all crucial to appropriate management.[20] The information from our qualitative analysis can be used to influence self-management by understanding that older individuals reported more feelings and symptoms in the categories related to nerve perceptions, lightheadedness/dizziness, energy level, and eyesight changes. Many individuals were unable to distinguish if the symptoms were occurring because of hyper- or hypoglycemia and the symptoms identified were associated in most instances to both high and low glucose levels.

Implications for Diabetes Educators

Several trends emerged from this qualitative analysis regarding symptoms of high or low blood glucose. The overarching theme of the study is that older individuals with a long duration of diabetes were more likely to describe their feelings in more depth. The implication for diabetes educators is that older individuals experience and interpret diabetes symptoms in a variety of ways. For example, fatigue can be related to a person's diabetes or just attributed to being older. Individual symptoms may not necessarily provide the cause and the patient's ability to learn how to interpret their symptoms individually within the context of their behaviors can be useful for disease monitoring. Symptoms of both high and low blood glucose can often be very similar (i.e., fatigue, weakness, lightheadedness). In this study, older rural adults with diabetes were able to describe a wide variety of symptoms, but their ability to differentiate high versus low blood glucose and the relationship to the symptom they were experiencing was variable. Diabetes educators can gain a better understanding of what patients are experiencing in relationship to their diabetes by helping patients identify symptoms and appreciate symptom recognition with regard to self-management. Methods and systematic approaches to teaching patients about diabetes symptoms and recognition are needed for diabetes educators to fulfill the goals outlined in the AADE-7 for problem solving, reducing risks and healthy coping.

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