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# Self-Management of Diabetes in Low-Income Appalachian Women.

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Self-Management of Diabetes in Low-Income Appalachian Women

Thesis submitted in partial fulfillment of Honors

By

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## **Abstract**

### Background

Diabetes mellitus is a major health concern and the number of Americans diagnosed with the disease is quickly increasing, affecting all aspects of an individual's life and requiring significant self-involvement. Little is known about how low-income Appalachian women with Type 2 Diabetes Mellitus (T2DM) manage their diabetes from day-to-day. This population struggles to effectively manage the illness as they desire for many reasons. The purpose of this study is to better understand the experiences of Appalachian women in self-managing diabetes so that health care providers can better meet the social and cultural needs of this unique population.

### Methods

This study used a qualitative descriptive design. Data were collected by means of in-depth, semi structured interviews. The sample consisted of 5 low-income Appalachian women with T2DM who seek care at the Johnson City Community Health Center. The data analysis was completed by generating a set of themes from the narrative data.

### Results

Three themes emerged from the interview data: Achieving Care with Limited Resources; Consistent and Involved Health Care Providers; and Family Support.

### Conclusion

Life situations unique to this population can influence the self-management of T2DM. Financial difficulties hinder the overall care that they need and desire, but through consistent and involved care givers and family support, successful self-management can occur in spite of significant barriers.

## Introduction

The purpose of this research was to explore self-management practices in a sample of low-income Appalachian women with Type 2 Diabetes Mellitus (T2DM). Diabetes Mellitus is a chronic disease that affects all aspects of an individual's life. According to the American Diabetes Association, 23.6 million Americans have diabetes, 90% of whom have T2DM. Diabetes is the sixth leading cause of death in the U.S. and, if current trends continue, one in three Americans will develop diabetes sometime in their lifetime (CDC, 2008). Diabetes Mellitus also results in other health complications such as heart disease, stroke, and neuropathy and is the leading cause of new cases of blindness, kidney failure, and nontraumatic lower-extremity amputations. The treatment for T2DM requires daily monitoring of blood glucose levels, diet, physical activity and moderating stress levels; successful self-management requires education about diabetes, and significant involvement of the individual in self-management activities.

Many lifestyle changes are necessary when individuals are diagnosed with T2DM, impacting the individuals with diabetes as well as their families. Women were selected as the focus for this study because of their pivotal role in the structure of the home. Denham (2004) states that mothers have a major influence on health matters and production of health in Appalachian families. She concludes that it is the province of women, including women in Appalachia, to maintain health among and provide health education to individual family members. Women participants in Denham's study frequently described health-related advice that other women in their lives had provided.

The objective of this study was to determine the added challenges that low-income T2DM females living in Appalachian Tennessee may face in making these lifestyle changes. An estimated 542,000 adult residents in Tennessee are currently living with diabetes, and an

estimated 240,600 of these residents live in Appalachia (CDC, 2008). Individuals living in this geographic area may face significant difficulties, such as cultural issues and access to care needed to manage their disease. Appalachians struggle with negative stereotypes; their values, beliefs, behaviors and healthcare needs should not be overlooked, but rather considered as vital contextual factors in their care.

Deaths from preventable chronic illness are much higher for Appalachian residents. According to Murray (2006), state rankings have consistently placed Tennessee's health risks, disease prevalence, healthcare utilization, and age-adjusted mortality among the worst in the nation. She also states that low-income whites in Appalachia have life expectancies equal to residents of Mexico and Panama, and the average life expectancy for white women has actually decreased over the past thirty years. Knowledge is needed about the day-to-day life context of this population with T2DM and its effect of context on the quality of women's personal lives. This study will provide a beginning understanding of how these individuals can be assisted and motivated to attain the highest level of health possible, within the context of a chronic illness.

### **Research Question**

The research question to be addressed in this study is: What are the experiences of Appalachian women who receive care in a nurse-managed clinic for low income individuals in self-managing T2DM?

### **Literature**

Few studies have specifically addressed the way low-income Appalachian adults with T2DM live with their chronic illness. Other populations in the United States are more commonly

studied. Hispanic adults reported that diabetes affected the way they felt, how others perceived them, and their role in society (Hatcher, 2007). Hispanic respondents believed that having diabetes had become their whole identity and separated them from others. This study also found that providing culturally competent care reduced healthcare disparities and improved outcomes in ethnically diverse adults with T2DM (Hatcher, 2007). Results from another study focusing on low-income Mexican Americans suggested that culturally tailored interventions were effective in improving the health and knowledge of those diagnosed with diabetes as well as their families (Vincent, 2009).

In 2009, Berry examined the experience of diabetes through sixteen Native Americans; they shared what they felt would improve current management of diabetes and prevent the disease. They said their local healthcare setting lacked experienced and convenient health care providers who understood their unique family history and risk of developing T2DM.

When compared to the population as a whole, T2DM is more prevalent among African Americans. In a study of African American women and their daily struggles with diabetes, Burns (2005) found an overall concern that health care providers did not have the time to sit and talk to the clients about diabetes management; therefore they were concerned with major health factors associated with diabetes such as limb amputation. In 2004, Melkus found that women's self-confidence and social support in living with diabetes were the most consistent factors in managing daily needs. Rayman (2000) concluded in her study of women with T2DM that the patient perspective is a basic and essential component of quality care and practice, not merely a peripheral or optional area.

In one of the few studies that directly addressed diabetes among Appalachians, Lohri-Posey (2006) used the Colaizzi's method of data analysis for this phenomenological research study to analyze the interviews of 13 T2DM patients living in West Virginia, a state located entirely in Appalachia. Four themes emerged from her data.

- 1.) Family and living conditions were important in managing the disease
- 2.) Social and vocational issues were a concern
- 3.) Food, relationships with healthcare providers, and psychological issues were major concerns
- 4.) Participants were well aware of complications affecting quality of life

Findings that were closely aligned with Appalachian cultural beliefs were that healthcare providers were only seen as a resource for education, medication, and monitoring, but ultimately it was a matter of self-management that determined control over the disease. In a survey of northern Appalachians, 64% stated that good health is due to self-care, 39% identified family relationships, 36% identified heredity, 26% noted luck, 22% God's will, and 6% physicians. Lohri-Posey (2006) reported that more than 70% of patients in another study of rural Appalachians had engaged in self-treatment and two-thirds had initially sought advice from family or friends before seeking professional help. Healthcare providers should take into consideration this cultural characteristics so that they can support patients' health-seeking behaviors and lifestyles in the context of their cultural beliefs and values.

### **Rationale**

The prevalence of T2DM is growing in the U.S. Numerous studies have explored T2DM self-management in diverse populations. However, research using qualitative methods to understand the context and meaning of the disease to explore self-management in a sample of low-income women in Appalachian Tennessee is rare. As the rate of diabetes increases, so does the need for knowledge and understanding about particular populations at risk for diabetes including these in Appalachia.

### **Methods and Materials**

The sample for this study was drawn from patients at the Johnson City Community Health Center (JCCHC). The JCCHC serves low income, homeless, uninsured, and migrant clients. It is partially funded by a grant from the Department of Health and Human Services, Health Services Resources Administration to provide care to underserved populations. Five English speaking women, between the ages of 18 and 64, who had an appointment for T2DM care, were contacted via flyers posted at the clinic and asked to participate. In addition, the researcher attended the clinic on two different days and approached patients who were there for T2DM appointments. A shampoo, conditioner, and lotion (a ten dollar value) were offered to the women who participated in this study as a small token of thanks in exchange for their time. After willing participants' written informed consent was secured, the women completed a demographic information survey. The individual interview took place at a time convenient for them in a clinic space that guaranteed privacy. Approval of the ETSU Institutional Review Board and the administrative staff of the health clinic were obtained prior to conducting this study.

The interactions were guided by a semi-structured interview guide. The interviews included the following open-ended questions:

- 1.) Can you tell me about your experience of being diagnosed with diabetes?
- 2.) What are some factors that have helped you to manage diabetes?
- 3.) What barriers have made self-management difficult?
- 4.) How has living in Appalachia affected your experience?
- 5.) Is there anything else you would like me to know that we have not talked about in relation to self-management of T2DM?

Each interview lasted approximately 15-20 minutes. The interviews were tape recorded and transcribed by the researcher. The interviews were then read and reread to gain an overall understanding of the data. Each participant's description was read line by line and significant statements were extracted from each transcript. Formulated meanings were derived from the significant statements and themes were then developed from the women's stated experiences. A content expert in T2DM checked the overall findings to establish credibility of the study findings. The interview required a tape recorder and transcription equipment, which were available in the Center for Nursing Research, ETSU College of Nursing.

Data collected in this study were not intended to be generalized but may be transferable, or provide understanding that is helpful to other Appalachian women with T2DM and their health care providers. By understanding the themes of the study, nurses working with

Appalachian populations may gain beginning insight into their lived experiences. This may guide them in providing education and nursing care to best meet the needs of this population.

### **Findings**

The researcher identified that self-pay was the most common method used by participants to pay for their health care; next was through the assistance of TennCare. These participants reported that the time since T2DM diagnosis ranged from three years to fifteen years. The participants were closely related in age (47 to 61 years), however, one participant was much younger (29 years). The difference in the number of years since diagnosis and age did not appear to influence their current ability to self-manage.

Low-income women in the study described their experiences of managing T2DM while living in Appalachian Tennessee. Three themes emerged from the interview data: Achieving Self-management with Limited Resources; Consistent and Involved Health Care Providers; and Family Support.

#### **Achieving Self-Management with Limited Resources**

Participants reported their most serious hindrance to self-management was lack of finances. Although insurance for low-income families, such as TennCare, have some advantages, the many disadvantages still limit their access to care. Furthermore, lack of finances influences every aspect of successful self-management. For example, Participant A confided that because she has TennCare, she receives only a limited number of strips per month for self-checking blood glucose, a hallmark of self-management. She went on to say, “I am used to checking three or four times a day, and I can only check twice a day now.” Monitoring blood glucose levels is

crucial in adjusting medications, diet, and exercise as needed to maintain desired glucose levels. Clearly, the lack of tools needed to even assess their glucose is a major limitation for this population.

When asked to identify barriers to self-management, participant C explained that she does not currently have a job: “Reading about it and actually being able to do it is not an issue now, [but] having the money to do it is.” At some point, participants have even gone without taking medications or checking glucose levels. Participant C stated she could not get her prescription filled “one time, for a few days,” but her church stepped in to help her. Participant B went six months without taking her medications: “My sugar went up to 1200. I had to go to the hospital and get IVs and all that stuff.” She continued that although she was not seeing a health care provider regularly at the time because she did not have insurance; knowledge of the Johnson City Community Health Center (JCCHC) or other resources would have been helpful.

The majority of the participants expressed that they never considered the possibility of having diabetes until they were diagnosed with prediabetes or had another major health concern. These women were unable to seek regular health care before these diagnoses were made because of their financial status. When participant D was explaining why she was unaware of having diabetes until she had a heart attack and sought health care, she simply stated, “I wasn’t insured.”

Participant B was seeing a primary care provider for diabetes care until she lost her insurance. Like the other participants, she understands the importance of seeing a health care provider regularly, but lack of insurance makes it very difficult: “I lost my insurance and they didn’t want to see me.” She mentioned that the care at the JCCHC clinic is the only care she can afford.

Although the participants were worried about being able to pay for diabetes supplies, they also mentioned services that are beneficial to them. Participant A said, “The good thing about TennCare, they do provide a ride.”

Lack of necessary tools, nutritious food and exercise opportunities, to manage T2DM is a major concern for these individuals and finances hinder access to what is needed. All the participants knew the importance of diet and exercise in the self-management of T2DM. Likewise, each had a baseline knowledge of diet and exercise expectations to manage T2DM. Participant B confirmed this by stating, “You just gotta watch what you do, what you eat, and exercise.” However, each discussed barriers that prevent them from eating or exercising as expected.

Participant B reported the least exercise; however she showed great interest in Zumba and Pilates. She would like to attend activities like these but, she says, “It costs too much to go to them things. If they had a program where they wouldn’t charge you to go...and I like that water aerobics. I went there but then the prices went up so I couldn’t go.” Participant A stated, “Because we are on food stamps sometimes toward the end of the month or just before we get our next food stamps, we might be running low on what I should be eating.” Relating to her diet, Participant E stated, “I grew up in a very large family, and we had hardly any money, so you just ate whatever was there. So when I went to college I took that into effect...because I grew up thinking you don’t spend money on food. I mean we never had fresh fruit because it was too expensive.”

Participant A used to ride her bike to help take care of her diabetes, but has now found it impossible with all the hills in the geographic area where she lived and her increasing age. She is

also unable to continue riding her bike because “I have a lot of problems with my feet,” a consequence of poorly managed diabetes. Participant E found it easy to exercise growing up and was involved in cheerleading; however, her physical activity decreased once she got out of college. Participant B walks to the park regularly and is on her feet at work. Participant D exercises regularly and through a nutritious diet and exercise routine she has not needed medication for about a year: “I still watch my diet and try to exercise as much as possible. I am trying to get into maybe water aerobics and stuff like that. I found out on my own the new senior citizens place up here.” The facility, she says, has a pool and exercise equipments.

As far as balancing her dietary intake of carbohydrates, which is essential for individuals with T2DM, Participant A states, “I think I am doing things right, but then I will go and take a reading and it will be way off than what it is supposed to be.” Participant E discussed the obstacles she encounters when trying to control diabetes at work:

“It really would be difficult because a lot of times I would be out on the floor or with a client or something and I wouldn’t get to run off and take my sugar and take my medicine or eat lunch right when I was supposed to. Therefore, for a long time, I battled my sugar up and down. I would get really shaky, and feel like I am going to pass out. Then it would get sky high after I ate. So it really took me a lot of discipline to say, you know what I need to sit down for a minute, I need to take a break, I am sorry that you are busy right now but I have to do this for me.”

Holiday sweets were a concern for Participants B and D. When asked if she finds it difficult to eat right and exercise Participant B stated it was “especially around Christmas time.” Participant

D stated, “It is a little bit high now because around the holidays. I love my sweets so, you know it has gotten a little bit higher, but it is under 150 because she [the nurse practitioner] is watching it for me.”

### **Consistent and involved health care providers**

Participants indicated that they feel more satisfied with their health care if they have consistent health care providers. When asked about factors that have helped manage their diabetes, Participant A stated, “A good primary care provider, and she is on top of everything just as much as I am. She is my biggest cheerleader. When my last A1C was at 6.8, she called me and she was more excited than I was.” When discussing the previous clinic that she attended she said, “they were good to me and everything, but going to different providers, they don’t know what you are going through... they don’t know your history and your complaints, or what you are doing right.” Participant E felt as if “all they do is talk.” She goes on to say, “They will tell you what you need to do but they are not really keeping an eye on what you are doing. The doctors know it is a serious thing and it has to be managed but they really just leave it up to you. She would like to see “interest in your situations because you know it is easy to hand somebody a book, and that is about as far as it goes.”

### **Family Support**

The initial feelings among all the participants in this study were compared, and were found to be similar to any individual recently diagnosed with T2DM. However, financial setbacks can lead to negative emotions regarding the disease. Support from family and the community can positively impact how individuals handle T2DM emotionally and physically.

Participant E experienced denial in the first few years after being diagnosed. At the time she was a college student, on her own, and had no support for self-management. She clarified this by stating how she felt at the time: “It is just diabetes, who cares? It is not a big deal... I just pretended it didn’t exist because it wasn’t that relevant in my daily life. All the symptoms that came along with it, I just thought were completely normal, and I didn’t want to waste my time. So, for about the first few years I didn’t do anything with it.” She expressed that once she became happy with her life, and met her fiancé, she decided to change her perspective on her self-management. With new support at home, she wanted to be a healthier person for her fiancé. Participant E also gained further support from other family. After explaining that her fiancé’s dad also has T2DM she states, “If his mom brings out a pie, he is always, Oh Participant E and me can’t eat it. We got to watch our sugar. So, it is kind of like a family thing. So we can kind of keep an eye on it all together.”

Participant A was also diagnosed with gestational diabetes, which helped her manage her emotions when diagnosed with T2DM. She educated herself about the disease and applied what she learned to her daily practices. Although she was confident that she could live a happy life with her diagnosis, it is the stress of daily with which she struggles. In the interview she explained that she is most stressed with constant worry about children’s health: “I am worried about both of my kids. My daughter is being treated for pre-diabetes; she is trying to lose weight.” She explained earlier in the interview that lack of money for proper food and lack of food stamps at the end of the month limit healthy eating. The support and encouragement that she showed her daughter helped her improve her own health and yet, she experiences many day-to-day stresses and worries.

Participant C explained her heart attack a few years forced her to consider improving her health. Prior to the heart attack she was a “borderline” diabetic: “so I didn’t worry about it. I didn’t pay much attention to it, but then I had to.” She was diagnosed with T2DM after her heart attack and explained she was scared: “I knowed what diabetes basically was. My sister was diabetic. One of my brothers was diabetic. I just figured I wouldn’t be able to do what I needed to because I was diabetic.” Her sister helped her manage diabetes successfully: “She has always given me advice and telling me this and that and like I said I knew a little bit about it before I was actually diagnosed because she has been diabetic for years.” With little income right now because she is not working, the support from her sister helps her successfully manage diabetes.

With family support, nutritious diet and exercise, and effective self-management, Participant D has not needed her medicine for about a year. This could be from her confidence in her management and desires to remain healthy: “When I had my heart attack that’s when they diagnosed me with it and in a way I was surprised and in a way I wasn’t. You know, because I was and I am over weight and everything.” When asked how she felt at the time of diagnosis she stated, “Well, sort of shocked and then I was relieved that it was just Type 2 and not the other type you know. I realized that it can really get under control by diet and exercise.”

### **Limitations**

The objective of the qualitative design of this study is not generalization of findings, but to explore the experiences of participants, and gain an understanding to guide future research. One limitation of the study is that the participants were from a specific geographic location; other rural clinics may provide different services for these patients unlike the JCHC.

Recruitment of those diabetic patients who were at the JCCHC on certain days of the week may differ from patients with appointments on other work days.

### **Discussion**

Diabetes self-management is a lifelong journey and is directed towards successful care. This study shows that self-management, as described by Appalachian women with diabetes, goes far beyond compliance. Self-management is undertaken within the context of unique lives in which individuals establish their personal self-management strategies. Not all participants attained or maintained the same level of self-management. However, they all shared aspects of the three themes that emerged from the interviews. The three themes were: Achieving Self-Management with Limited Resources; Consistent and Involved Health Care Providers; and Family Support.

Unlike previous study populations, participants did not believe that diabetes affected the way they felt, how others perceived them, and their role in society (Hatcher, 2007). The participants were comfortable with who they were, and they made no statements indicating that diabetes defined them. The findings confirmed the importance of cultural characteristics seen in the other studies. Results from a study focusing on low-income Mexican Americans suggested that culturally-tailored interventions were effective in improving the health and knowledge of those diagnosed with T2DM as well as their families (Vencent, 2009). Many of the participants in this study mentioned how a program specific to them should be developed so that they can receive more precise care unique to their health concerns and cultural needs.

Burns (2005) found an overall concern that health care providers did not have the time to sit and talk to the clients about their diabetes. This was expressed through several comments made by the participants in the study. The participants agreed with Lohri-Posey (2006) that healthcare providers were sought only as a resource for education, medication and monitoring, but ultimately self-management determined control over the disease. Understanding the process that underlies self-management enables nurses to provide diabetes health coaching, which helps clients beyond education, symptom management, compliance, and glucose control.

Lastly, the study results are consistent with Melkus (2004) finding that women's self-confidence and social support were the most consistent predictors of managing diabetes. Women with diabetes frequently mention that family members have assisted them with diabetes-specific self-management activities. In this study, women with diabetes experienced the participation of family as positive and helpful, which then improved self-management, and how they felt about their health and self-care.

### **Nursing Implications**

Nurses working with low-income women from Appalachian Tennessee should be aware that these individuals have multiple risk factors that keep them from effective management and healthy lifestyle. Nurses should focus on providing diabetic individuals with the necessary practical skills needed for independently exercising self-management tailored to their unique needs. Nurses can help these individuals find resources within the community that are beneficial to them while providing self-management strategies such as nutritious diet and exercise that are within the women's financial means. Health care providers should take the time to listen to how each individual manages diabetes and understand that a consistent and trusting relationship with

their health care providers is important to them. If family members are involved in managing the individual's diabetes, the nurse should encourage family members to come to appointments and be sure the patient and family feel free to discuss their concerns and experiences about managing the disease. Low-income women with T2DM struggle with self-management. If nurses consider the needs and unique factors that affect this population, these women will have hope for improvement in the self-management that they practice.

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