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# Clinical Scholars Review

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## Trustworthiness

The principles of credibility, transferability, dependability, and confirmability were used to strengthen methodological rigor (Lincoln & Guba, 1985). These methods of trustworthiness consist of (a) member checking, whereby participants were asked to give feedback on the researcher's interpretations of the transcripts; (b) prolonged engagement at the research site by the researcher, which enabled a more in-depth knowledge of the study; (c) verbatim accounts of the interactions to demonstrate that findings are grounded in the data; and (d) peer review of the transcribed interviews by research colleagues within the University of Kansas School of Nursing as well as colleagues in the clinic where the data was collected.

## Findings

Three themes were identified that described the perceptions, attitudes, meanings, and experiences of the participants in relation to their lives with diabetes. These themes included (a) psychological and cognitive negotiation of the emotional impact of the diagnosis of diabetes, (b) verbal information as the preferred method of receiving health education and instructions related to diabetes, and (c) preference to share disease information with other persons with diabetes.

### Psychological and Cognitive Negotiation of the Emotional Impact of the Diagnosis of Diabetes

This theme had three categories that provide a description of participant experiences as they move through the cognitive negotiation and emotional impact of diabetes.

#### *Denial of and/or Resignation to Initial Diagnosis*

Most participants described their initial reaction to the diagnosis of diabetes as denial. Some respondents reported that they were able to eventually cope with the news. Others admitted that they were still in denial. A 55-year-old man with a diagnosis of diabetes for 7 years passed through every stage of the grief process: denial, anger, bargaining, depression, and acceptance. He began the interview by saying he was in "good health" when asked to give a description of his general health. He then said his reaction to the initial diagnosis was, "Like, oh hell I do!" He then stated, "Well I ain't been keeping my end of the bargain. I kinda go crazy sometimes; it gets real bad, real bad. I'm just tired of it. Don't you think there are some pills I could take that would get rid of this—like vitamins or something? Oh, I know

I have to do it, sometimes I just wish my wife would give me the shot before I wake up, but I know she can't. It's me; I just have to do it."

Some of the participants saw how denial was related to their believed lack of symptoms at the time of diagnosis, or their perception that diabetes was not a serious condition and could be treated with pills.

I did not take it seriously. I really didn't want to think about it. It didn't really daze me. I went to the doctor and came home with diabetes. I told them it wasn't me; it was my husband they were talking about. I don't want it so I don't pay any attention to it. Blah, blah, blah, I don't believe I have it.

There were also those who were: resigned to the inevitability of diabetes and therefore saw it as something they could not alter.

I really wasn't that concerned because I knew a lot about it from relatives. I kinda expected it. I was heavy and my mother had it; it runs in the family. In the back of my mind I thought I would get it. It didn't shock me; I'm overweight and drink a lot.

One respondent recalled that the denial of her diabetes was because of the invisibility of the disease, "If I could not see it, it didn't exist." Many of the respondents, looking back to the time of their diagnosis, could see clearly how they had not accepted the severity of the condition, sometimes at a cost to their own health. This personal cost was in the form of worsening eyesight, kidney failure, hypertension, and heart problems. They knew these worsening signs signaled the need for insulin, and this was as great a fear as the diagnosis of diabetes itself.

#### *Fear of Insulin*

The degenerative nature of diabetes means that insulin initiation is often inevitable, and accepting this fate was again a distress for these participants. Taking insulin injections was often seen as a personal failure or major setback in their lives. The cycle of denial, bad feelings, and avoidance of medical care often occurred as their diabetes worsened and progression of the disease warranted use of insulin. The participants expressed many fears about taking insulin. These concerns were expressed as fear of the injection, feelings of failure, societal attitudes about injections, and insulin as the final step in the long march toward disability or death. Most participants came to terms with taking pills but saw the injections of insulin as a much more frightening thought.

I had a friend. He took shots. They told me if I watch what I did and what I eat I wouldn't have to take shots. I've seen my aunt taking shots when I was younger, that's what I associate with it. My mother had it, and I saw her give herself shots, I don't want to do that. Well, I'm just not a . . . I never was a heroin addict because I never wanted to stick that needle in my arm, okay, besides the fact what's the residue effect of taking insulin for all those years I mean is it gonna cause something else or anything; will that outweigh the good of insulin? I just think like, oh hell I'm done, its pretty bad news and I'll probably lose my legs.

### *Vivid Memories of Diabetes in Childhood*

Asking the question, "What did you already know about diabetes?" revealed a reality that was learned and imbedded from the past but still informs today. They had vivid memories of a relative who had diabetes when they were growing up and watching the relative descend into disabilities. Based on this experiential knowledge and the stories of their youth, they construct who they are as people with a diagnosis of diabetes and what they can expect in the future.

My grandmother had it; she lost both her legs. I know some old guys that just got severely obese, no feet underneath them, no life. My grandmother had it, and then my mother got it. I saw her for the rest of her life and saw her getting those insulin shots. My grandmother died of it. They couldn't do anything about it back then you know. I saw her die, and it was terrible. My grandmother had it, and I lived with my grandparents when I was growing up. I knew what it took and everything else. My dad had it so I saw it with him; he broke his toe and it didn't heal. They amputated his leg; I wondered if that was going to happen to me.

### **Verbal Information as the Preferred Method of Receiving Health Education and Instructions Related to Diabetes**

Most participants stated they preferred to learn verbally; that is, having someone tell them about health information. None of the participants in this study had more than a high school diploma, and they tended to be older.

I'd rather hear it. Just tell me, no written, you can give me a pamphlet but I probably won't read it. Well you gotta hear it to do it. I read but mostly talk to my friends. I can't understand big words. I like to talk to them about it and that way you can stop them. Well verbal because when I read I get so tired. I like being

told better than sitting down and trying to read. Oh, I like just visiting with people. I like hearing it 'cause if I get something to read I usually lay it aside, and that's where it stays.

When asked, "Can you understand what is being said or written?" the response was usually a guarded expression such as usually, mostly, sometimes, and I think so. Only one person unequivocally said "Yes." When asked about the source of information they received, most participants stated they rely on the clinic for their diabetic knowledge.

Patients with reading difficulties cope with many situations by relying on visual clues and demonstrations by others. Many of the participants in this study gave reasons for preferring the verbal over written material by saying, "Reading gives me a headache," or "I can't understand big words, those college words." It is difficult to discern how much of the preference for verbal information is because of low literacy. Only one person stated he did not understand most of what was read. A person who is functionally literate in one situation may struggle to read what is presented in the health care setting.

### **Preference to Share Disease Information With Other People With Diabetes**

When participants were asked about community support in this small rural town, there was unanimous agreement that the community supported them. One man said, "Oh yes, sometimes I have to be careful what I ask for because they will take care of me too well." Likewise when asked, "What organizations or civic activity do you participate in?" Many said, "Oh, I really don't." But when pressed further and asked, "Well, do you help with the fair, or do you go to coffee with your friends or go to the senior citizen center?" They would say, "Oh, sure I do that. Everyone does that." Most had comments such as

Yes, very caring. They are wonderful compassionate people and how they reach out and help each other. Yes, I have friends that I go to coffee with everyday and sometimes twice a day. Oh yes, if I get in trouble, I get too many people sometimes.

The community was seen as supportive in general. When asked, "Whom do you talk to about your diabetes, and what is your family's reaction to your diabetes?" Most of the participants said they would only discuss their diabetes with someone who had diabetes. For instance, one

participant had a daughter whom she could discuss her problems with because “she understands how hard it is.” One man said, “I call my sister in Texas everyday and we can talk about it because she has it, too.” It was not acceptable to share ones diabetes story with the community even though the community was seen as supportive. There was a belief that their diabetes might be seen as a defect, especially if one was on insulin. This attitude was best expressed by one participant who said, “No one wants to hear about my failures.”

## Discussion

The diagnosis of diabetes and its ongoing requirements result in the patient experiencing many difficult feelings. The feeling of resignation can be mixed with shame or self-blaming. Denial or mental disengagement and resignation are normal coping reactions many people feel after being given the news that they have diabetes (Rapaport et al., 2000). Most participants were able to move beyond their initial denial and cope with the diagnosis and manage their diabetes. Some however did not move on and were found to be coping minimally with the daily requirements of caring for themselves and their diabetes. In this study, it took the form of either a total reliance on the health care team to manage their care (i.e., locus of control being externalized [Hull, 2008]), or the converse of never coming to the clinic and not reaching out to the medical team for help that was offered.

Among these participants, the concern about taking insulin was similar to the results of other studies (Polonsky, Fisher, Guzman, Willa-Caballero, & Edelman, 2005; Polonsky & Jackson, 2004). Participants also revealed the same negative attitudes about insulin injections found in other studies, such as fear of needles, feelings of failure, perceived loss of control over one’s life, fear of weight gain, and most significantly, the suggestion of worse or more severe disease (Hunt, Valenzuela, & Pugh, 1997; Peyrot, 2004).

In addition, many of the participants in this study witnessed as children their relatives having to take insulin and having poor outcomes such as loss of limbs, blindness, and subsequent disability and death. These mental images were imbedded from childhood and are the stigma that represents the disease process. It appears that the expectation of failure from these childhood experiences may be the reason why many of the participants give up too easily, think it’s too late for help, or feel they have no control over what happens. In order to understand the patient with diabetes, a health care provider should have a framework

for understanding that many factors influence healing and well-being. This study revealed that past life experiences are equally important to present circumstances when assisting a patient with diabetes.

It was also found that patients’ literacy skills were an important factor in negotiating the meaning of their disease. According to the National Adult Literacy Survey (NALS; Carroll, 2007), one cannot tell which patients are likely to have low literacy skills by looking at them. Similarly, education levels do not correlate with health literacy. According to the NALS study, 34% of persons who have completed high school with either a traditional or equivalency diploma are functionally illiterate (Carroll, 2007). There is evidence that individuals with limited health-related print literacy are likely also to have limited health-related oral literacy. Spoken information depends highly on cognitive abilities such as understanding relationships between multiple pieces of information (Baker, 2006).

It is well established that people do not change behavior from information or knowledge alone (Hibbard, Peters, Dixon, & Tusler, 2007; Nutbeam, 2006; Rapaport et al., 2000). This was born out in this study, indicated by patients’ reliance on the health care provider to tell them what they need to do, the ambivalence in accepting the diagnosis, and the difficulty of maintaining the lifelong regimen of managing diabetes. These responses show how emotions affect treatment compliance and disease self-control.

This study supports much of what has been learned about the older, high school graduate patient (Carroll, 2007). The participants preferred spoken messages, were reluctant to acknowledge their reading difficulty, and relied on the health provider to tell them what to do. Few admitted that they would stop a health provider and tell them if they did not understand what was being said or take material to the health provider for clarification of the information.

Because attention needs to be given not only to acquisition of knowledge but also to an individual’s social support, this study asked questions about social support from friends, family, and the community in general. Diabetes is believed to be influenced by the context in which the person lives (Gleeson-Kreig, 2008). Studies have indicated that influences from close social relationships and health care providers as well as from the community in general relate to higher levels of type 2 diabetes management (Glasgow, Toobert, Barrera, & Strycker, 2005; Strycker & Glasgow, 2002). This study emphasizes the importance of social support both from family and

the broader community. The participants believed the community was supportive of them as well as others in the community. Similar to previous research, participants in this study reported receiving high levels of support from the health care providers. However, they did not seek support in the community or in the immediate family for their diabetes management. For that, as mentioned previously, participants relied on someone who had diabetes. This is consistent with other studies that measured social and environmental support (Gleeson-Kreig, 2008). Clinicians should not assume that participants talk of their diabetes with family and others simply because they report family and community support for them in the social context.

### Limitations

In a qualitative descriptive study, multiple perspectives are sought, and therefore subject diversity is imperative. A limitation of this study is that it was conducted in a rural area of low population density and little cultural diversity, which created a more homogeneous group of participants than may be desirable in most qualitative studies. Further research on the impact of a diabetes diagnosis in individuals in other rural and urban settings with diverse cultural and socioeconomic participants would add perspective to the findings of this study.

### Conclusion

This study focused on the experience of diabetes as it is lived within the context of a rural community. The results of this study indicate that adjusting to a chronic disease like diabetes involves many changes to one's life, and the effect on the participant's everyday life is difficult to manage. The feelings and reactions that are associated with diabetes may possibly interfere with treatment adherence. Clearly the participants had a gamut of complex emotions, going beyond the cognitive aspect that is addressed by the health care team with usual diabetic education. The psychosocial discomfort resulting from the initial diagnosis and its ongoing daily treatment regime makes it difficult for patients to comply with some basic recommendations, such as glycemic control and medication adherence. What is revealed in this study is the complexity of feelings and emotional reactions to a diagnosis of diabetes. Reactions such as denial, resignation, and shame were informed and intensified by past childhood experiences of witnessing the chronicity and progression of diabetes among family and friends.

### Implication for Practice

In conducting this research, I gained an increased appreciation and deeper understanding of existing research done by Rapaport et al. (2000) in two particular areas: the importance of informed clinical listening and the importance of humility when dealing a patient with diabetes. Furthermore, this research reminds us that diabetes is a progressively debilitating disease, and patients, even with all good efforts, are powerless to contain that progression. When asking a patient to intensify management of diabetes, health practitioners must take into account the personal and social context of their patient's life and emphasize that this change in treatment does not signify a character defect. Treatment changes are predictable and indicate a different way to tackle the declining B-cell function. The health practitioner should explore the resistance to change by being patient with lapses in self-management. The focus of our efforts should be less on what patients should do and more on what they can and will do. The long-term relationship of patients with their diabetes requires compromise over a lifetime.

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