Published in final edited form as:

Holist Nurs Pract. 2018 ; 32(4): 196–201. doi:10.1097/HNP.0000000000000273.

Living With Diabetes in Appalachia:

A Focus Group Study

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Abstract

This article presents an innovative holistic practice application based on evidence from a focus group study on managing diabetes. The purpose of this study addressed the research question: How do persons with type 2 diabetes describe ways of managing the challenge of living with diabetes? A second purpose was to link the findings on ways to manage diabetes to holistic nursing practice through story theory. Nine adults with type 2 diabetes living in rural West Virginia participated in 3 focus groups. Using content analysis, the study findings integrated themes with core qualities, and are as follows: living life as an evolving process is awakening to the present and doing it your way, being on guard is a vigilant ongoing responsibility, attending to bodily experience is awareness of body and facing life stress, and knowing the consequences is awareness of potential problems and taking charge. Merging the study findings with the concepts of story theory led to the development of an innovative practice application for managing diabetes. Managing diabetes in this practice application goes beyond problem-centeredness to a patient-centered approach, offering attention to individual preferences. Since managing diabetes is a major problem in Appalachia, there is a need for innovative approaches. This study adds to the body of knowledge on how persons from Appalachia manage diabetes. In addition, it offers a story practice approach for managing diabetes—replacing a problem focus to a more holistic approach to practice leading to more meaningful and fulfilling outcomes.

Keywords

Appalachia; diabetes; focus group; story theory

Diabetes mellitus is a major cause of morbidity and mortality, costing the United States \$176 billion in direct medical care costs and \$69 billion in indirect costs from disability, productivity loss, and premature death.¹ According to the American Diabetes Association, approximately 1.25 million American children and adults have type 1 diabetes,² leaving 27.9 million (8.9%) having type 2 diabetes. The burden of diabetes is especially heavy in Appalachia, with Appalachians being 1.4 times as likely to have diabetes as non-Appalachians.^{3,4} As an area recognized for health disparity, Appalachia is characterized by high poverty, an aging population, and low educational attainment.⁵

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The authors have disclosed that they have no significant relationships with, or financial interest in, any commercial companies pertaining to this article.

This article presents an innovative holistic practice application based on evidence from a focus group study with persons from Appalachia on managing diabetes. Integrating the findings with story theory⁶ led to the development of an innovative practice application for managing diabetes. Managing diabetes in this practice application goes beyond problem-centeredness to a patient-centered approach offering attention to individual preferences. Since managing diabetes is a major problem in Appalachia, there is a need for innovative approaches.

This study was conducted in West Virginia, a rural state lying entirely in the Appalachian region. More than 1 in 10 adults in West Virginia were diagnosed with diabetes in 2014, calculating to a prevalence rate of 13% (compared with 10.5% nationally); thus, West Virginia is ranked fourth nationally in prevalence of diabetes.⁷ Furthermore, 6% of West Virginia residents lack health insurance.⁸ Social determinants of health known to lead to the complexity of managing diabetes and prevalent in West Virginia include a poverty rate of 19.2%, an unemployment rate of 7.9%, a per capita income averaging \$33733, and 17.6% of the rural population not completing high school.⁹

Qualitative research describing how people in rural Appalachia manage living with the challenges of diabetes are few in number. A literature search on EBSCOhost using the search terms of “diabetes,” “rural,” and “Appalachia” produced only 10 sources. Three of the sources were quantitative descriptive work on predictors of self-management, and 5 were qualitative studies describing living with diabetes. Of the 5 sources, 2 were of low-income Hispanic adults, and 1 of Aboriginal rural adults living in Canada. Only 2 were of rural persons living with diabetes, and not specifically from Appalachia. Descriptions of living with type 2 diabetes from rural people included barriers and facilitators, such as knowledge and motivation, and barriers, such as attitude, food, and stress.¹⁰ Themes that emerged from descriptions from older rural people living with diabetes have included “your body will let you know,” “I thought I was fine,” “the only way out is to die,” and “you just go on.”¹¹ Carpenter¹² found that living with the stress of diabetes involves suffering with pain, being frightened of the unknown, worrying about threats to family, trying to manage restrictions, taking on activities of living the everyday, and moving forward with confidence. In spite of suffering, fear, and worrying, participants were involved in living and moving forward.

PURPOSE

The purpose of this study was to address the research question: How do persons with type 2 diabetes describe ways of managing the challenge of living with diabetes? Adults with type 1 diabetes have lived a majority of their lives managing this disease. However, the situation is different for persons diagnosed with type 2 diabetes. As adults, their lives were interrupted with this diagnosis, confronting them with a change in what was an established lifestyle. Thus, it is important to find out from these people how they have been managing their diabetes. Persons who have been managing diabetes have something to offer about the challenges of living with diabetes and approaches to self-management.

It is the premise of this article that best practices for holistic care can come from uncovering the individual’s perspectives on managing diabetes through a focus group study. A second

purpose is to link the findings on ways to manage diabetes to holistic nursing practice through story theory.

METHODS

Recruitment

Participants were recruited from sites that served persons living in rural areas across the north central West Virginia region. Participants were recruited by 2 methods: a telephone list of persons with type 2 diabetes obtained from a prior research study on diabetes, where willingness to participate in future studies was indicated on the consent form; and, an advertisement placed in a primary care clinic site in north central West Virginia; and a University research Web site that advertised the study to the community. Information on the advertisements included purpose of the study, inclusion criteria, time commitment, participant incentive, and contact information. Interested participants called the primary investigator, questions were answered, and directions for traveling to the focus group site were given.

To be included in the study, participants were required to be older than 18 years, have had a diagnosis of type 2 diabetes for at least 1 year, and speak English. Fourteen persons expressed interest, and 11 volunteered to participate in a focus group. One person could not physically get to the focus group location, 1 could not find a time in his personal schedule to attend a focus group, and 2 did not show up for the scheduled focus group session. Three separate focus groups were conducted with 3 participants per group.

Protection of human subjects

The study was approved by the West Virginia University Institutional Review Board. All participants read and signed an informed consent. To maintain confidentiality, tape-recorded interviews took place in a private room. No identifiable information was recorded.

Data collection

This study used focus group interviews, as described by Krueger.¹³ He described the purposes of a focus group to (1) collect qualitative data from a focused discussion, and (2) gather insights into attitudes, perceptions and opinions of participants. A focus group guide was developed that included 6 open-ended questions to guide each focus group (see Table 1). These questions were developed through a systematic process by 2 researchers knowledgeable about focus groups and qualitative research. The process included the following steps: brainstorming to generate a list of all questions on managing diabetes; highlighting critical questions from the list; and arranging the order of the questions from general to specific. This process was validated by an additional expert on the focus group method from a neighboring university.

The focus groups were held in a private location conducive to group discussion that was easily accessible to participants. Specific directions on where to park and enter the location were provided prior to the scheduled focus group session. For each focus group session, an audio recording was made. Each focus group was led by one of the authors experienced in

focus group methodology. In addition, the other author observed each focus group and recorded notes on process to augment the transcription.

To keep participants centered on the nature of the focus group, a sign was placed in the center of the table that read “Managing your diabetes.” Participants were encouraged to identify themselves to the group by filling out a name card and placing it in front of them at the table. Participants were encouraged to engage in conversation with each other. To provide focus to the interview session, a focus group script was used to provide consistent and sufficient background information about the purpose of the study, and read as follows:

The purpose of this study is to better understand what would be helpful in managing living with diabetes. We want to hear from you about managing your diabetes. Your participation is important because you are living the managing of your diabetes. We believe what you tell us can be helpful to others. We want to have a conversation with you, and it is important that you chime in so that we hear from everyone. We will take a break after 50 minutes, have some light refreshments, and then continue.

Each focus group lasted approximately 90 minutes. Participants received a \$50 gift card at the end of the session. At the end of the third focus group, redundancy in data occurred, indicating data saturation. This was evident by repetition about ways to manage diabetes offered by participants.

Data analysis

Analysis of data followed inductive conventional content analysis.¹⁴ Six iterative steps in the process of analysis were as follows: (1) transcribe the focus group conversations; (2) read the scripts for sense of whole; (3) identify specific descriptors from participants’ exact words that describe managing diabetes (4) abstract core qualities from the specific descriptors; (5) sort core qualities into meaningful clusters; and (6) lift meaningful clusters in abstraction to form themes.

RESULTS

A total of 9 subjects participated in 3 focus groups, with ages ranging from 40 to 90 years. The groups were reasonably homogeneous, yet broad and included a range of adults with type 2 diabetes who were experiencing challenges with self-management. Two were African American and 7 were Caucasian. Seven were employed and 2 were retired. Five were married, 3 were widowed, and 1 was single.

All participants in each group were fully engaged, attentive, and thoughtful with each other. Focus group conversations were comfortable, respectful, and supportive—all in the context of managing diabetes. Participants’ were open and expressive in sharing with each other profound life experiences about managing diabetes. These conversations with each other led to different and meaningful ideas about managing diabetes.

This inductive process provided the grounding for 4 themes. Analysis will be presented by beginning with themes, core qualities, and specific descriptors that make the case for the

core qualities and theme. Each theme along with core qualities and specific descriptors follows.

Theme 1: Living life as an evolving process

Core qualities associated with this theme are awakening to the present and doing it your way. Awakening to the present for persons with type 2 diabetes is becoming present to a different way of living, and noticing the inevitability of change. Specific descriptors related to awakening to the present are:

- Thinking differently about managing your life
- Going in waves of managing and not managing
- Attending to the ups and downs of your week
- Being attentive to the ebb and flow of life
- Being open to changes in your life

Doing it your way for persons with type 2 diabetes is choosing actions that fit an individual life. Specific descriptors related to doing it your way are:

- Meeting me where I am by listening and solving things together with someone
- Becoming conscious when doing things right; becoming lax when everything settles in
- Continuing on, even when failing
- Following a rhythm of gaining, then losing, then gaining
- Finding what works because one size does not fit all
- Resisting advice that goes against personal will

Theme 2: Being on guard

Core qualities associated with this theme are vigilance and responsibility. Vigilance for persons with type 2 diabetes is about being watchful for threats to diabetes. Specific descriptors related to vigilance are:

- Keeping the numbers where they should be
- Thinking ahead so the day runs smooth and controlled
- Attending to physiological responses of increased blood sugar, and mental alertness
- Managing the impulses to purchase and eat snacks
- Attending to family history

Responsibility for persons with type 2 diabetes is about knowing how to manage and being accountable for following through. Specific descriptors related to responsibility are:

- Taking on what you worry about

- Knowing that I need to do it, even though I do not like it
- Using the resources to manage
- Owning life problems
- Accepting the benefits of diet and exercise

Theme 3: Attending to bodily experience

Core qualities associated with this theme are knowing body and facing stress. Knowing body for persons with type 2 diabetes means reflecting on subjective feelings. Specific descriptors related to knowing body are:

- Knowing when I feel better, and when I do not feel better
- Being present and aware of bodily experiences
- Knowing what my body is saying
- Attending to body symptoms

Facing stress for persons with type 2 diabetes is actively mobilizing resources. Specific descriptors related to stress are:

- Talking yourself out of it
- Finding people you can talk with
- Taking time for self
- Getting enough sleep
- Dealing with the frustration of unsupportive family members
- Taking on what you worry about

Theme 4: Knowing the consequences

Core qualities associated with this theme are potential problems and taking charge. Specific descriptors related to potential problems are:

- Preventing serious consequences
- Acknowledging that consequences are difficult and frightening
- Focusing on the positive when the situation is dire
- Continuing to do things even though not wanting to
- Knowing that ground rules change; what used to work does not work anymore

Specific descriptors related to taking charge are:

- Avoiding temptations by not bringing food into house and avoiding social events involving food
- Practicing strategies of portion control
- Keeping blood levels under 130, watching A1c, and keeping records

- Managing a disease of inconvenience
- Struggling with enabling behaviors from family
- Changing grocery store habits by limiting what is bought

Results of the study integrating the themes with core qualities are as follows: (1) living life as an evolving process is awakening to the present and doing it your way, (2) being on guard is a vigilant ongoing responsibility, (3) attending to bodily experience is awareness of body and facing life stress, and (4) knowing the consequences is awareness of potential problems and taking charge.

DISCUSSION

Appalachian culture

The findings of this study suggest congruence with Appalachian cultural values and life ways. Qualitative evidence describes people with diabetes from Appalachian culture as possessing qualities of self-determination, self-reliance, and responsibility,^{5,15} and being engaged in health-promotion, and holding values of self-care and self-determination.¹⁶ Furthermore, quantitative support indicated beliefs that were consistent with self-determination and self-reliance in decision-making for managing diabetes.¹⁷ Results of this study are in keeping with these contemporary views on the health beliefs and practices of people from Appalachia. These cultural views cohere most specifically with the core qualities. This is understandable since the core qualities were extracted from participant-specific descriptors. Self-reliance is related to doing it your way and taking charge. Being responsible is related to awakening to the present with vigilance. Engaging in health promotion and self-care is related to awareness of the body and facing life stress. Self-determination is related to awareness of problems and taking charge.

Story theory

Story theory can be used to bring the results of the study to a holistic practice focus. The theory is composed of 3 concepts: connecting with self in relation, intentional dialogue, and ease. It is defined as a “narrative happening of connecting with self in relation through intentional dialogue to create ease.”^{6(p229)} Furthermore, life as an evolving process (theme) is a narrative happening of moving into, through, and beyond one’s situation all in the present moment of the ever-changing process of managing diabetes. Connecting with self in relation with others and one’s world is a process of awakening to the present (theme). In telling their story, persons become aware of how being on guard, attending to bodily experience, and knowing the consequences (core qualities) expands personal meaning and can create ease about managing the complicating health challenge of diabetes. In a story approach to nursing practice, the nurse engages with the person through intentional dialogue by living a caring presence to invite telling the story. In this relationship, the story begins as the person identifies what matters most to them about a complicating health challenge related to the evolving process of living with diabetes.

Implications

Integrating the themes and core qualities with story theory, along with leading questions to guide a holistic practice process on managing diabetes, is proposed (see Table 2). These questions do not represent a list for which the person provides an answer. The questions guide intentional dialogue and are probes to enlarge the conversation about what matters most to the person. As the nurse moves through the story and listens attentively to what the person is saying, further issues about the complicating health challenge may come forth. Staying with the challenge identified by the person and querying the emergence of the story through the guide questions can lead to a full elaboration about what is going on in managing the challenge of living with diabetes.

The holistic practice process begins by inviting the person to awaken to the present specifically about what matters most in his/her daily life, about living the challenge of managing diabetes. As the story unfolds, with a focus on specific issues related to the themes and core qualities all in the context of what matters most to the person, thoughts and feelings are both revealed and concealed to the person in the practice session. While moving through the story with the nurse, the person is also telling the story to self, including personal reflection that will go beyond the practice session. Cocreating a story in the caring presence of the nurse reconstructs the past and future in the context of the present experience of managing diabetes. This articulated story in the presence of the nurse can reveal a different sense of self in relation to others and to a changed meaning about managing diabetes. In this way, the holistic practice session can be liberating, as the person may come to a changed view that managing the complicating challenge is doable.

The holistic practice process for managing diabetes was derived from the results of the study that were integrated with story theory. It is important because it is person-centered by engaging the person in managing his/her diabetes. Leading individuals through the holistic practice process, with the guiding questions, may help them see how they are managing their diabetes and what changes they can make in the context of their life. It takes managing from a problem-focused (diabetes) to a holistic approach that is person-centered. In the caring presence with a nurse, the person becomes active in care. When one speaks the story of managing diabetes, to a nurse who is intentionally present, it can make the situation real and bring about a heightened awareness for taking responsibility and taking charge of managing diabetes.

An unresolved question is, how does guiding the person through this holistic practice process centered on story lead to outcomes for managing diabetes? For example, after engaging a person in the process, on return visits, what changes have taken place in how the person is taking responsibility, listening to bodily experience, and attending to stress?

CONCLUSION

The finding of this focus group study adds to the body of knowledge on how persons from Appalachia manage diabetes. In addition, it offers a story practice approach for holistic management of diabetes. Replacing a problem focus to a more holistic approach to practice

is expected to lead to more meaningful and fulfilling outcomes. Insights gleaned by the person may contribute to more satisfaction in managing diabetes.

Acknowledgments

Research reported in this publication was supported by the National Institute of General Medical Sciences of the National Institutes of Health under Award Number 2U54GM104942-02. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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TABLE 1.**Focus Group Questions**

1. When you hear the words “manage my diabetes,” what comes to mind?
 2. How are you managing your diabetes at this time?
 3. Think back over the past years and describe changes you have made in managing your diabetes.
 4. What have you tried in managing your diabetes that was helpful and not helpful?
 5. How are others involved in managing your diabetes?
 6. Going forward, what do you think will help you in managing your diabetes?
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TABLE 2.

Leading Questions to Guide the Holistic Practice Process

Leading Question	Core Quality
1. What matters most to you about managing your diabetes now?	Awakening to the present
2. What have you done about this situation?	Doing it your way
3. How are you attending to this challenge?	Taking responsibility
4. What is your body telling you about this challenge of managing your diabetes?	Bodily experience
5. How does stress affect your health challenge?	Stress
6. What concerns do you have at this time about the challenge?	Potential problems
7. How do you think this challenge will resolve?	Taking charge