

Profiles of people with type 2 diabetes mellitus: the extremes of glycemic control

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Savoca, MR, Miller CK, Quandt SA. Profiles of people with type 2 diabetes mellitus: the extremes of glycemic control. *Soc Sci & Med* 2004;58(12): 2655-2666. doi:10.1016/j.socscimed.2003.09.031

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Abstract:

For people with diabetes, hemoglobin A1c (HbA1c) is a measure of blood glucose control and an indication of the risk of developing diabetes complications. However, a given HbA1c value does not provide information about the diabetes self-management practices or philosophies of individuals in poor (HbA1c >8.0%) or excellent (HbA1c <6.5%) control. To contrast the experiences and attitudes of people at the extremes of glycemic control, interviews were conducted among 44 individuals (40–65 years old) diagnosed with diabetes for over 1 year. The participants were identified based upon their HbA1c value from a larger sample of people with type 2 diabetes that included African Americans, women, and persons with low income. Narratives were analyzed using a case-based and conceptually clustered matrix approach. The life course concept (life histories and natural transitions in roles and responsibilities across the life span) and the explanatory model of illness (individuals' beliefs about the causes, consequences, and treatment of a disease) provided the framework for the interview guide and the analysis of the narratives. Two self-management philosophy groups emerged from participants with excellent control (Committed [n=15] and Tentative [n=7]) and three groups were identified among the poorly controlled group (Hopeful [n=8], Hassled [n=6], and Overwhelmed [n=8]). Perseverance, coping skills, and age at diagnosis were life course concepts that distinguished participants within these groups. From the explanatory model of illness, beliefs about the cause of the disease, physical changes, and accepting the consequence of the disease influenced differences in these self-management philosophies. The profiles of people at the extremes of glycemic control can help those treating people with diabetes or seeking to improve self-management interventions understand differences in self-management philosophies and concentrate on specific issues hindering self-care control.

Keywords: Type 2 diabetes mellitus; Diabetes; Self-management; Health education; African American; USA

Article:

Introduction

Research on diabetes has established that following a set of behaviors related to glucose management (diet, exercise, medication use) will keep blood glucose under control and reduce incidence of complications (American Diabetes Association, 2002). Yet a large proportion of patients are not able to achieve optimal glycemic control (Harris, 2001).

A body of social science literature suggests that health behaviors, such as those lifestyle factors involved in self-management of diabetes and other chronic diseases, are shaped by individuals' life histories and their attempts to make sense of their conditions in the context of their lives. Understanding these underlying experiences may be essential to designing successful behavior change interventions.

These social and behavioral approaches have been applied to a diverse group of conditions, including arthritis, asthma, and nutritional risk. They have been effective in demonstrating how lay perspectives differ from those of health care professionals. Some have focused on a single aspect of self-management (e.g., Adams, Pill, & Jones, 1997 work on asthma medication compliance). Others have taken a more comprehensive approach and

have discerned patterns from multiple behaviors. Gray (1985) study of arthritis case histories, for example, demonstrated that life course and sociodemographic factors results in one of four strategies of disease management. Meyer, Leventhal, and Gutmann (1985) found two distinct treatment behaviors as the consequences of individuals' common-sense models of hypertension. Such an approach combining a variety of domains of self-management and arriving at a typology of self-management styles has not been used in previous research on diabetes.

The difficulties individuals face as they modify their lives to accommodate diabetes self-management have been studied extensively. Investigations have identified barriers to diabetes self-care (Glasgow, Hampson, Strycker, & Ruggiero, 1997; Schlundt, Rea, Kline, & Pichert, 1994; Schoenberg & Drungle, 2001; Snoek, 2000). Research has focused on groups bearing the greatest diabetes burden, such as the needs of older women (Schoenberg & Drungle), African-American women (Egede & Bonadonna, 2003; Samuel-Hodge et al., 2000; Reid, 1992), and Mexican Americans (Hunt, Pugh, & Valenzuela, 1998). Originating from the work of Bandura (1986), self-efficacy (an individual's confidence to perform a specific behavior under particular circumstances) has consistently related to self-management adherence (Anderson et al., 1995; Glasgow et al., 1989; Rose, Fliege, Hildebrandt, Schirop, & Klapp, 2002; Senécal, Nouwen, & White, 2000). What is needed is research that examines self-management philosophies across diverse individuals and identifies the antecedents associated with diabetes self-care behaviors.

In this study, we build on these previous works by using two approaches, one sociological and one anthropological, to identify lay approaches to diabetes self-management that characterize individuals at the extremes of the glycemic control continuum. The first is the life course perspective, which recognizes that an individual's life history and the transitions that occur at various life stages influence a wide variety of health-related attitudes and behaviors (Elder, 1985). Findings from previous research suggest that an individual's position in the life span and personal history can influence eating practices and attitudes toward health practices (Quandt, Vitolins, & DeWalt, 1997; Roos, Quandt, & DeWalt, 1993; Devine, Connors, & Bisogni, 1998), but this approach has not been applied to diabetes research. The second is Kleinman's explanatory models approach (Kleinman, Eisenberg, and Good, 1978), which proposes that patients hold a model of the etiology, symptoms, consequences and appropriate treatment of an illness developed from their cumulative experience. Previous research has shown that personal beliefs about the cause and treatment of diabetes are related to self-care practices (Chesla, Skaff, Bartz, Mullan, & Fisher, 2000; Hampson, Glasgow, & Toobert, 1990; Hunt, Valenzuela, & Pugh (1998) L.M Hunt, M.A Valenzuela and J.A Pugh, *Porque me tocó a mi? Mexican American diabetes patients' causal stories and their relationship to treatment behaviors*, *Social Science & Medicine* 48 (1998), pp. 959–969. Hunt, Valenzuela, & Pugh, 1998; Schoenberg, Amey, & Coward, 1998). Therefore, the purpose of this research was to provide a view of how diverse individuals who represent the upper and lower ranges of glycemic control differ in their beliefs and attitudes toward treatment within the context of their life course experiences and explanatory models of diabetes.

Data and methods

Sample

A purposive sampling plan was used to recruit a sample (n=89) containing 60% women and 40% men with equal numbers of African Americans and Caucasians and people above and below 200% of the poverty level (US Census Bureau, 2002) from two urban communities in the southeastern United States. Recruitment was opportunistic (newspaper advertisements, health fairs, endocrinology practices, and diabetes education classes) and site based in order to identify a sufficient number of participants who met the recruitment criteria and individuals who would ordinarily not respond to general recruitment efforts (Arcury & Quandt, 1999). Sites included agencies offering health programs for women, organizations providing emergency resources, health fairs, and county health departments. A telephone screening interview established eligibility and obtained a brief medical history from qualified participants. Eligible participants were between 40 and 65 years of age and had a diagnosis of type 2 diabetes for >1 year. The criteria of Welborn, Garcia-Webb, Bonser, McCann and Constable (1983) T.A Welborn, P Garcia-Webb, A Bonser, V McCann and I Constable, *Clinical criteria that reflect C-peptide status in idiopathic diabetes*, *Diabetes Care* 6 (1983), pp. 315–316. (30)Welborn, Garcia-

Webb, Bonser, McCann, and Constable (1983) were used to distinguish those with type 1 and type 2 diabetes. The selection criteria did not include participants' current level of glycemic control and diabetes treatment regimen. The Institutional Review Board at the sponsoring university approved the study. Participants provided informed consent before participating and received a small honorarium upon study completion.

Data collection

Eligible individuals participated in a one-on-one semi-structured interview lasting 60–90 min. These were conducted by a single interviewer with extensive experience conducting interviews and focus groups, audio-recorded, and transcribed verbatim by a medical transcriptionist. Interviews were conducted in a private room with only the participant and interviewer present. The investigators developed an interview guide to elicit information about participants' illness history, diabetes education, past and present eating practices and exercise patterns, environmental influences on self-management practices (eating, exercise, and blood glucose monitoring), and the challenges of maintaining healthful habits. Questions about illness history adapted from the work of Kleinman et al. (1978) explored participants' beliefs about the causes and treatments of the disease and their recollections about the diabetes treatment and health outcomes of family members. The guide was pilot tested with seven individuals who were not included in the data set. These individuals recommended that "blood sugar" be substituted for "blood glucose" and questions with medical terms be rephrased to simplify the terminology. The introduction to the interview described its process and explained that its purpose was to understand how people adapt their lives to diabetes and not test interviewees' knowledge of self-care or compliance with self-management guidelines. Participants were told that while a common group of questions would be asked of all participants, individuals were encouraged to share any experiences or views they thought were relevant to the overall goal of the project. A measure of each person's hemoglobin A_{1c} (HbA_{1c}) was obtained from the same outpatient laboratory before the interview.

Data analysis

The interview transcripts of the 25% of participants with the highest HbA_{1c} values and 25% with the lowest values were analyzed. All discrete statements mentioned by participants were coded using a coding dictionary based upon the topics included in the interview guide and any additional areas mentioned by participants during their interviews (Strauss & Corbin, 1990). Ethnograph (version 5.07, 2001, Sage Publications, Thousand Oaks, CA) was used to label text segments of the interview transcripts.

The coded transcripts were analyzed using a case-based approach (Miles & Huberman, 1994). Transcripts were reviewed and individual case summaries were prepared including the participant's demographic characteristics, major life events, and diabetes treatment history. Participants' comments regarding their experiences and beliefs about diabetes or other health-related matters were included. A review of these case summaries identified themes relating to diabetes self-management and beliefs about the disease and its treatment. For example, initial reaction to their diagnosis was a theme that included several types of participant responses, such as fear, anger, or relief. Each case was summarized according to these themes. Then, cases within each of the extremes of glycemic control that shared similar views of diabetes and diabetes self-management were grouped into new categories called self-management categories. Finally, a conceptually clustered matrix condensed the analyses into rows (individual cases) and columns (demographic information, major life events, and treatment history for each case). This permitted further review to ensure consistency within and across the groupings and the identification of relationships within and between self-management categories (Miles & Huberman, 1994). The matrix helped to summarize the key patterns and themes distinguishing these categories.

Two investigators (MRS and CKM) independently coded 13 randomly selected transcripts (15%). The inter-rater agreement was 92.4%. A third investigator (SAQ) reviewed the themes and assignment of individuals to categories.

Each self-management category was characterized using treatment and demographic information. Descriptive profiles of these categories were prepared along with case summaries from select individuals representing the distinct self-management characteristics identified among each category's participants.

Results

Of the total sample ($n=89$) from which cases for this study were chosen, 62% were women, 48% were African American, and 43% were <200% of the poverty level. Sixteen percent of participants were treated with diet and exercise only, 57% with oral hypoglycemic agents only, and 27% with insulin. The HbA_{1c} (mean \pm SD) for the sample was $7.74\% \pm 1.76$ and ranged from 4.9% to 12.7%.

The HbA_{1c} of the 25% of participants with the highest values (poor control, $n=22$) ranged from 8.7% to 12.7%. The HbA_{1c} of the 25% of participants with the lowest values (excellent control, $n=22$) ranged from 4.9% to 6.3%. Those in poor control were younger, diagnosed at a younger age, had a higher body mass index, and were more likely to be using insulin. Both groups had similar diabetes educational experiences, past eating behaviors (eating large portions of food, particularly high fat foods, desserts or candy), and histories of being overweight. Nearly all the women and most men did not exercise regularly prior to their diagnosis.

Participants were organized into distinct categories based upon their beliefs of the cause of diabetes, self-care history, and views about the importance of self-management activities. Five categories emerged—two for those in excellent control (*Committed* ($n=15$) and *Tentative* ($n=7$)) and three for those in poor control (*Hopeful* ($n=8$), *Hassled* ($n=6$), and *Overwhelmed* ($n=8$)). Summaries of each group's distinguishing features and participant profiles illustrate the attitudes and experiences of these self-management categories. The profiles are labeled with a pseudonym and the participant's actual age, ethnicity, treatment regimen, and HbA_{1c} value.

Committed

Once diagnosed, the Committed group spent little time grieving and made self-management a priority. They believed that overeating, weight gain, and lack of exercise contributed to the onset of the disease. Women and lower income respondents were almost equally represented and a third of the group was African American. All educational levels and people working outside the home or retired were represented. On average, they were 57 years old, were diagnosed at age 50 and had been diagnosed from 2 to 30 years. The group did not have diabetes-related comorbidities such as neuropathy, retinopathy, or proteinuria. All treatment regimens (insulin, oral hypoglycemic agents only, and exercise and diet only) were uniformly represented.

These participants described a disciplined approach to eating and most were committed to an exercise program. More than half of participants reported weight losses from 10 to 60 lb since diagnosis. Maintaining this weight loss was viewed as a great accomplishment. The majority measured their blood glucose at least several times per week. Their physicians were viewed as partners in their treatment and often their best information source. Several participants described how poorly managed diabetes caused the deaths of family members and attributed their commitment to self-care to these experiences. Diabetes was not the most difficult challenge they faced. Participants raised families on their own due to death or divorce, had chronic debilitating diseases and severe accident injuries, and life-threatening diseases. Depression, binge eating or other psychological conditions were not reported. All described supportive family relationships.

These individuals believed they had a responsibility to themselves and their families to address the requirements of diabetes and faced this challenge as they had faced others. Essentially, they felt that while there were no guarantees to long-lasting health, they would do everything possible to live long and productive lives.

P094: Elizabeth, 65, African American, diagnosed at 57, oral hypoglycemic agent, HbA_{1c}=6.1%

Elizabeth raised six children alone while working as a teacher's aide. Now living alone, her children, 17 grandchildren, and 11 great grandchildren continued to be the center of her life. Aware of an extensive family history of diabetes, she expected to develop the disease. About 8 years ago, she began to experience symptoms and sought a diabetes test. Once diagnosed, she believed that family history and weight gain were the cause and immediately changed her diet habits and added exercise to her activities.

Elizabeth devised her own diabetes self-management plan. “First of all I did it myself. I just thought that maybe I could eat a lot of vegetables, a lot of fruit, not eat a lot of sweets and starches. I got that right, that's kind of related to sugar.” Elizabeth never had exercised before her diagnosis. She added walking to her schedule and 3 days a week went to a fitness center offering memberships to low income people. Elizabeth learned from many sources—newspapers, television, and diabetes seminars offered by the public health department.

Elizabeth attributed her dedication to self-management to watching family members endure painful deaths from diabetes. Her sister's legs were amputated and she had heart attacks and strokes. Her sister's sons died from heart attacks while in their 30s. She said: “They just didn't seem to care, and they were all overweight. And they would anger me because there was nothing I could tell them. I was learning from their mistakes all the time.”

Elizabeth valued her family's support and encouraged her children to have healthy lifestyles. She had a straightforward belief about her own health. “When it came to me, nobody needs to tell me, because I love me. I am going to do what I think is right by me.”

Tentative

The Tentative group's reactions to their diagnosis included disregard, sadness, relief, and resentment. Almost all felt that their lifestyle contributed to the disease's onset. Several did not have a family history of diabetes. The group included one man and several African Americans. Participants had higher incomes, at least some college education, and worked outside the home. They were on average 53 years old, diagnosed at the age of 50, and knew they had diabetes for 1–6 years. Two participants reported a diagnosis of neuropathy. Most participants used oral hypoglycemic agents and no one used insulin.

Following diabetes nutritional recommendations was their primary self-management practice. They maintained healthful eating patterns and, for the most part, made a successful transition from past eating practices. Only two participants stressed the importance of exercise and tried to walk every day. Others felt that it would be helpful if they could maintain the commitment. The majority did not report any weight loss. Only one participant monitored blood glucose regularly. Most reported neutral or poor relationships with their physicians. The experiences of family members with diabetes did not motivate these individuals. A few participants reported suffering from major illnesses and most participants described serious bouts of depression. Several told of receiving treatment for depression or reported binge eating in response to emotional stress. The level of family support ranged from “none” to “strong” support from a spouse.

This group expressed a commitment to managing the disease; yet they had not adopted all aspects of diabetes care. The limited self-care practices of this group could be eroded by emotional stress or lack of social support.

P117: Joan, 60, African American, diagnosed at 58, oral hypoglycemic agent, HbA_{1c}=6.0%

Joan was diagnosed with diabetes shortly after retiring. Unaware of the symptoms and without a family history, she was surprised and continued to wonder how she developed the disease. She felt she would have to radically change her eating practices and lose weight. Joan had been treated for colon cancer and was diagnosed with hypertension 20 years ago. Hypertension worried her more than diabetes because she felt that her diabetes was easier to control than her blood pressure.

After diabetes counseling, Joan began to follow the dietary guidelines and monitor her blood glucose three times/day. “I was real good right way. I lost thirteen pounds, and I gained them back and more.” After 6 months, she began working part time and reduced monitoring to once a day or less. “I think I thought I had it under control. I had thought I had changed my eating habits enough that I was fine and then I didn't need to take it.” Living alone made cooking difficult, especially evening meals.

Exercise was a recent priority. Encouraged by family, she recently joined a fitness center with a friend. She said, “I knew that I should be exercising because of the hypertension and the diabetes. And so it's great if you don't have enough self-motivation then it's great to have a partner because we motivate each other.” Joan attributed her self-management success to dietary changes: “So I'm doing something right and I guess it's the food; I've made enough changes to keep it at a normal level.” She said: “I think even if you didn't do the exercise, if you've got your food plan right, you would live a little longer. The exercise is like the icing on the cake.”

Hopeful

The Hopeful group reacted to the disease with delayed acceptance. Most were fearful but were not initially compelled to aggressively reduce the risk of complications. The group included only one man. All had family members with the disease; the majority acknowledged that lifestyle contributed to the onset of the disease. These individuals stressed the importance of self-care and were hopeful that if they adopted self-care recommendations, they could control the disease. Most did not work outside the home; the group included low- and high-income individuals. They were on average 49 years old, diagnosed at the age of 45 years. The time since diagnosis ranged from 1 to 7 years. Slower healing, proteinuria, and the appearance of retinopathy and neuropathy had developed along with heart disease, cancer, severe osteoarthritis, and asthma. The majority was treated with oral hypoglycemic agents only.

Most maintained prior eating practices but had an increased awareness of the weaknesses in their meal planning. Many were unable to choose healthful foods when dining out. Blood glucose monitoring varied from never to daily. A few individuals enjoyed exercise and appreciated its importance but struggled with injuries and illness. They hoped that their health would improve so that they could exercise regularly. The others recognized its importance but had not organized their lives to include regular exercise. Most appreciated the support of their physicians.

Binge eating, alcoholism, and depression were reported in this group. While family and friends encouraged them to take care of themselves, these individuals were realizing that it was solely their responsibility to change their lifestyle and recognized that major changes were needed to successfully manage the disease.

P117: Carol, 57, Caucasian, diagnosed at 53, oral hypoglycemic agent, HbA_{1c}=9.1%

Carol was disabled for many years due to arthritis, hypertension, and other conditions. A brother's diabetes diagnosis prompted her to request a test for the disease. Carol believed that she had diabetes because of its prevalence in her immediate and extended family. She believed that she had diabetes at least 10 years earlier. At that time, she was drinking alcohol and believed she may have attributed diabetes-like symptoms to excessive alcohol consumption.

Her immediate reaction was fear of amputation, blindness, and, particularly, kidney failure. To calm her fears, she tried to look at her diagnosis logically: “If I hadn't gotten it diagnosed and didn't get help; then those would not just be possibilities but definite realities.” She attributed diabetes onset to heredity and lifestyle. “I felt like if I had taken better care of myself years earlier then maybe it wouldn't have happened,” she said. Afraid but hopeful—she believed the disease was treatable and, unlike in the past when insulin was the only treatment option, advances in oral medication had improved health outcomes. Her family's experiences with diabetes had been mixed. Her mother had done well but others had suffered from retinopathy and kidney disease.

Initially, Carol took advantage of support programs available through the public health department. These included diabetes education classes, weight loss and diabetes support groups, individual counseling, and exercise programs. She learned about diabetes from magazines and the Internet. Efforts to control portion sizes of food and plan meals led to a 20 lb weight loss that was regained. She began to exercise at least twice a week and acknowledged that the discomfort associated with diabetes and osteoarthritis was reduced when she was active. However, insufficient meal planning, failure to limit portions, and ice cream binges eroded her progress.

Carol understood the seriousness of diabetes and its requirements. She said, “I try to on a daily basis to believe that as long as I’m doing the best that I can, at least, I will put these things off and maybe they won’t happen to me.” Recently, she became distracted by her daily routine and worries about her health, such as recent kidney problems and deteriorating vision. This increased her depression leading to binge eating and fatigue. Carol was close to her family but they were not a source of support. She believed health support groups would help her most.

Carol tried to apply to diabetes what she learned from the alcoholics support group she participates in: “Each day I feel that I’m starting from scratch, so that helps me because that way I don’t have to let the past weigh me down if I’ve done poorly. I’ve always had that ability to say, ‘where there is life, there’s hope’.”

Hassled

Anger was the primary reaction of the *Hassled* group to their diagnosis. Some began to recognize its seriousness after being placed on insulin. All but one believed that family history alone contributed to the disease's onset and a single person attributed it to job stress. Although not surprised by the diagnosis, they had never tried to minimize the risk of developing the disease. These participants resented diabetes and felt that proper diabetes care would prevent them from leading a normal life. Their self-management behaviors were erratic: organized around other priorities and the need to live spontaneously. The majority were African Americans working outside the home with higher incomes. They were on average 53 years old and were diagnosed at the average age of 41 years. Their time since diagnosis ranged from 2 to 27 years. The majority had not experienced any diabetes-related health conditions, most used insulin and the remainder used oral hypoglycemic agents.

Self-care was minimal for all in this group. Many did make dietary concessions such as occasionally making healthful food choices when dining out. One person made an effort to walk each day and perform daily blood glucose monitoring. All spoke about the time, cost, and inconvenience of a regular exercise routine. Most said they could tell how high or low their blood glucose was by how they felt and then might monitor to confirm their actual level. The majority did not report problems with depression but a few mentioned binge eating and excessive alcohol use. They had changed doctors repeatedly seeking someone more supportive and understanding.

Nearly all participants in this group had close family members with the disease and many had family members who died due to complications. They were accustomed to parents, aunts, uncles, and older siblings with diabetes, but did not report any strong impressions about the disease based on family members’ experiences.

None experienced other major illnesses but all complained about the effects of diabetes. Their constant fatigue attributed to diabetes was considered a reason they were unable to effectively manage their care. Support from family members took the form of concern rather than active participation. Many felt they would eat healthier meals if their home lives were more structured and family members would adopt new eating behaviors.

The Hassled category saw diabetes self-care as an undeserved burden that caused them stress and intruded into their hectic lives. They were not compelled to change their lives to minimize the risk of complications and improve the way they felt.

P123: David, 51, African American, diagnosed at 33, insulin, HbA_{1c}=10.9%

David, diagnosed with diabetes in his 30s, was not surprised because his mother had the disease. His initial reaction was his lifestyle would change dramatically. He had been active in many sports and believed then and now that people with diabetes were unable to engage in these activities. David lived with his wife; his children lived on their own. His work required four 12-h days; a schedule he believed complicated his diabetes care.

David described these early years: “I knew about diabetes and read about diabetes but I was 33 and age and youth has a lot to do with it. I had diabetes and I was feeling good. If there was a piece of cake on the table, I ate the cake.” Now, more conscious of his eating, he tried to eliminate all sweets, a practice supported by his understanding of the fundamental cause of the disease: “Basically what diabetes is, is the pancreas’ inability to process artificial (added) sugars.” He eats what is available and tries not to “go overboard”. He saw his doctor every 90 days and consulted with a dietitian each time. Despite nutritional counseling, he said he was never told to limit portion sizes of food and did not believe that high fat foods were a factor in the management of the disease. Instructed to count carbohydrates, he described the practice as “Not practical. Not interesting.”

Long workdays made it difficult to get enough sleep, keep up with his church activities, and maintain a regular exercise program. David enjoyed exercise and knew he felt better when he walked 2 miles a day. Because of the hypoglycemic risk, he believed that vigorous exercise was off limits to him.

David often felt lethargic and unable to do anything. Because he frequently felt poorly, he appreciated his wife's concern for his condition. “The easiest part of managing my diabetes is an understanding mate.” He had few friends and limited support from co-workers.

David described the important elements of self-management as “Stay away from sugar, eat a balanced diet and every four or five hours, do your exercise, and don’t worry,” he said. “And for most people that's very difficult to do.” Despite his doctor's concern that his blood glucose was too high, when asked if there was anything he would like to improve about any aspect of his care, his reply was “No, not really.”

Overwhelmed

The *Overwhelmed* category reacted to their diagnosis with denial, fear, stress, or depression. These individuals either had no idea what caused the disease or attributed it to family history or lifestyle. They were concerned about diabetes consequences but had so many other problems that diabetes was a low priority. Most of the group was African Americans, had never attended college, were unemployed or disabled, and all were in the lower income category. Participants were on average 53 years old and diagnosed since the age of 41. They were diagnosed for 2–27 years. Most were treated with insulin. The majority had neuropathy; two people had undergone foot surgery due to infections that failed to heal. Retinopathy and heart disease were reported.

One person made an effort to follow dietary recommendations and exercise on a regular basis. Others ate what was available and affordable and did not exercise. Daily pain and discomfort prevented them from exercising. Many relied on their own feelings to judge their blood glucose level and three were never instructed to monitor. Many received treatment for depression. Alcoholism and binge eating were reported. Two reported recent positive relationships with physicians.

All had family members who had the disease but only a vague awareness of the progression of their disease. These participants lived with poverty, illness, and psychological problems. Diabetes was one of many problems, and they did not believe that self-care would greatly influence the outcome of the disease. A few indicated that family members and co-workers were concerned about their well-being. The Overwhelmed were resigned to having diabetes and feared its consequences, but felt little control over their health or their lives.

Cynthia, Caucasian, age 44, diagnosed at age 42, insulin, HbA_{1c}=9.1%

Cynthia lived with her young son and had full-time and part-time jobs. Three years ago, she experienced dizziness, fatigue, and depression. Without health insurance, she avoided going to the doctor until the dizziness became worse. She was not surprised by the diagnosis because her father died at 55 from diabetes complications. She said “It was kind of like ‘something else to have to deal with’, you know?” Along with her father, her uncle, grandfather and grandmother had diabetes and she anticipated getting the disease “sooner or later”.

Cynthia briefly took oral medication but was quickly placed on insulin, which she preferred because it was easier to control her blood glucose and less expensive than the oral medications. She ate what was affordable and available. She said, “If you put something in front of me, I’m going to sit and eat it all. And why, I don’t know. Then, adjust my insulin. That’s important.” Disappointed by the self-management class she attended because of its limited dietary guidance, she wanted to know how to put together the appropriate combinations of the foods she liked to eat. “I’m kind of a picky eater”, she said. “I’d like to know how to put the foods that I like into a breakfast, lunch, and dinner.” Exercise played a limited role in Cynthia’s care. She joined an exercise facility but was concerned because her blood glucose dropped too low as a result of the activity. Now she took a brief walk during her workday.

Cynthia thought people with diabetes were not well informed about the effects of the disease and its treatment. Uncontrollable hunger, severe headaches, debilitating fatigue, constant pain in legs and feet, the inability to control blood glucose, and, ultimately, death were considered to be inevitable consequences of the disease. “You know the doctors don’t tell you that you’re going to get dizzy headed or that your feet and legs are going to hurt so bad you want to sit there and cry,” she said. “My father died from it, I know eventually it’s going to get me. It might be ten, twenty years down the road, but that’s what’s going to do.”

Themes for life course concepts and the explanatory model of disease

The life course concept and the explanatory model of illness helped to identify characteristics that distinguished these categories. Table 1 summarizes across the categories the themes that reflected these conceptual frameworks. Three themes from the life course concept emerged—*perseverance*, *coping skills*, and *age at diagnosis*. The *perseverance* that individuals applied to diabetes may reflect how they faced challenges in the past. The Committed category described personal histories filled with many difficulties. These participants faced diabetes without grief or anger and maintained consistent lifestyle changes. The Tentative category began their care with determination but became complacent or distracted by other concerns. Those who were Hopeful had many difficulties in their lives but maintained a commitment to their care. For the Hassled group, work and other commitments created pressures that compromised efforts to eat regularly, exercise, monitor blood glucose and live spontaneously. The Overwhelmed category lived with poverty. Diabetes self-management could not compete with the pressure they felt to ensure their basic needs were met. *Coping skills* were a key component. Lifelong struggles with depression were a challenge for many participants. It sapped their energy and eroded their resolve. Depression was present to some degree in all categories except the Committed group. There were reports of binge eating and eating in response to emotional distress that eroded self-care commitment and increased anxiety. The *age at diagnosis* distinguished groups. The Hassled and Overwhelmed categories were diagnosed at a younger age than other groups. They began to cope with the disease in their 30s or 40s when family and work demands were the greatest. They initially had minimal physical effects from diabetes and made lifestyle adjustments that presented few conflicts with work or family activities. Further changes were resisted regardless of deterioration in glycemic control or the occurrence of diabetes related complications.

Table 1. Summary of self-management categories across elements of the life course concept and explanatory model of disease

Self-management category (HbA _{1c} ±SD)	Life course concepts			Explanatory model of disease			Self-care practices
	Perseverance	Coping skills	Age at diagnosis (yr ±SD)	Beliefs about the cause	Physical changes	Accepting diabetes consequences	
Committed (5.8±0.46)	Consistent	No history of depression or binge eating	50±9.1	Lifestyle	Maintained weight loss; few complications	Lessons learned from family experiences	Complete
Tentative (6.2±0.18)	Vacillate	Depression and binge eating	50±8.2	Lifestyle	Few complications	Not motivated by experiences of others	Dietary compliance only
Hopeful (10.2±1.04)	Inconsistent	Depression, binge eating, and alcoholism	45±8.4	Lifestyle	Some complications	General fear of the disease, not motivated by experiences of others	Sporadic efforts (diet, exercise, and blood glucose monitoring)
Hassled (10.0±1.04)	Continually compromised	Some binge eating and excessive drinking	41±5.1	Family history	Few complications; constant fatigue	No strong impressions of the experiences of others	Limited dietary focus
Overwhelmed (10.7±1.23)	Absent	Depression, binge eating, and alcoholism	41±8.4	Unclear	Diabetes complications	Focused on daily challenges and not on the risk of diabetes	No established practices

The Explanatory Model provides a framework for three elements that distinguished these groups. Differences in *beliefs about the cause of the disease* paralleled participants' commitment to diabetes care and may indicate an individual's acknowledgement of the role of lifestyle in diabetes treatment. The Committed category were dedicated to diabetes self-care and believed that lifestyle played some role in diabetes development. The Hassled category, frustrated by diabetes management, believed that family history alone caused diabetes. However, the Hassled participants were diagnosed for many years, received extensive diabetes education, and many were treated by more than one physician. It is unlikely that they were not informed about the role of lifestyle in the onset of diabetes. *Physical Changes* provided feedback on the consequences of the disease and reinforced concepts about the effectiveness of self-management practices. Those with poorly controlled diabetes experienced many physical changes that they considered a natural progression of the disease. Even among those without serious complications, fatigue was a daily problem and was often the reason given for not exercising. Those with excellent glycemic control either did not feel any differently or felt better than before their diagnosis. They associated controlling blood glucose levels with the ability to manage their responsibilities and enjoy activities with family and friends. *Accepting the consequences of diabetes* reflected individuals' acknowledgement of their personal risk of early death or disability from poorly managed diabetes. The participants were not naïve about the consequences of the disease. Many in the Committed category observed diabetes destroy the lives of loved ones and did not expect protection from these consequences if they failed to manage the disease. This was the foundation of their self-care.

Discussion

The differences in self-management philosophies between those at either end of the glycemic control continuum were highlighted by the design of this research. First, the retrospective approach considered how events throughout someone's life and their experiences with the disease shaped their current viewpoint. Second, the

diversity of participants' characteristics made it possible to observe distinctions in self-management philosophy among men and women with different ethnic backgrounds, income levels, and types of medical management. Clearly, there were challenges for those with limited resources and taking insulin but themes emerged that transcended these differences. Finally, the case-based approach illustrated how complex characteristics converge in an individual to help or hinder their diabetes self-management.

Of the three life course concepts (*Perseverance*, *Coping Skills*, and *Age at Diagnosis*), the dimensions associated with coping skills (depression and binge eating) have been reported frequently. In previous research, the presence of diabetes doubled the odds of depression with higher odds among women (Anderson, Freedland, Clouse, & Lustman, 2001; Egede, Zheng, & Simpson, 2002). In another study, severity of depression was associated with poorer adherence to dietary guidelines and medication regimens as well as functional impairments and higher healthcare costs (Ciechanowski, Katon, & Russo, 2000). Several studies reported greater prevalence of binge eating among people with diabetes (Marcus, Wing, Guare, Blair, & Jawad, 1992; Kenardy, Mensch, Bowen, & Pearson, 1994; Crow, Kendall, Praus, & Thuras, 2001). The behavior is more prevalent among women where estimates have ranged from 14% bingeing at least twice a week to 26% meeting clinical criteria for the disorder.

The age of diagnosis has not been directly studied. However, Chesla et al. studied a group of European Americans and Latinos who were approximately 50 years old and diagnosed with diabetes for 4 years. Both groups reported decreased spontaneity in their lives and changes in their social lives. Additional research studied the factors that influenced self-management among African-American women with type 2 diabetes (Samuel-Hodge et al.). The women who lived alone or were retired reported the least amount of stress in their lives. While, those working or caring for multiple family members reported the greatest stress. This is consistent with our findings that diagnosis during one's 40s, while the demands of family and work are greatest, may present a particular challenge for people with diabetes.

In contrast to the specificity of self-efficacy, we found a more global concept (perseverance) that seems to influence the self-care philosophy of people with the disease. The erosion of individuals' commitment to self-management practices was reflected in the research of Nothwehr and Stump (2000). This longitudinal study of 733 retired person ages 50–62 with diabetes found that compared to baseline after 4 years, 30% who followed a special diet and 55% who were exercising no longer maintained these practices. Additional research is needed to identify the specific characteristics of those who do and do not persevere with self-management practices. The Explanatory model of disease as described in these results included three elements, *Beliefs About the Cause of the Disease*, *Physical Changes*, and *Accepting the Consequences of the Disease*. Consistent with previous research using this model, we found that those who believed their behavior contributed to the development of diabetes were more likely to take a more active role in their own care. How the experiences of family members with the disease prior to participants' own diagnosis affected their understanding of the disease and their self-management philosophy has not been reported elsewhere. Finally, the interpretation individuals give to their own physical changes and the influence that has on their self-management practices should be further explored.

Many participants were committed to their own care, mastered the complexities of diabetes self-management, and sustained these efforts over long periods of time. However, many still needed to understand or accept the fundamental role of continuous and comprehensive diabetes self-care. Clinicians could apply these findings by exploring patients' awareness of the self-care practices and diabetes outcomes of family members who had the disease as a way to provide a direct and meaningful link between self-care activities and the risk of complications. For many, diabetes self-care was either a cyclical commitment or restricted to a limited number of behaviors. The status of self-management practices should be continually revisited to encourage consistent and complete care.

Some people with diabetes accept physical changes as an inevitable consequence of the disease. This parallels the findings of Egede and Bonadonna (2003) about the role of fatalism in the self-management practices of African Americans. Altering this perception by relating patients' physical changes to self-management practices

may encourage more effective self-care. Among people needing to modify their health habits, there are subgroups at greater risk for inadequate adherence to critical health behaviors (King et al., 1997). Interventions that tailored messages to individual needs (Campbell et al., 1994) and programs designed to target the concerns of particular groups, such as low income people with multiple chronic conditions (Rimmer, Silverman, Braunschweig, Quinn, & Liu, 2002), have demonstrated success. These results suggest that those who were younger at the time of diagnosis (<50 years old), are working full-time or caring for others, have a history of depression or binge eating, and differ in their beliefs about the causes of diabetes could provide a focus for future diabetes research.

Despite the insights gained from this research, there are some study limitations. First, the attitudes and experiences of those whose HbA_{1c} level were between these extremes were not considered. To confirm the utility of these results, the self-management philosophies of individuals across the spectrum of blood glucose control should be considered to identify these or other characteristics relevant to their philosophies. Second, adaptation to a chronic disease is a dynamic process. The views of these participants were captured at a single time point. It would be valuable to conduct interviews across time to see if and how the people in these groups change. Finally, diabetes is one of many diseases that require adoption of self-care behaviors. Because self-management practices are influenced by the symptoms and comorbidities of the disease, we limited our findings to the social and cultural context of diabetes and identified parallels to the diabetes literature only. Evaluating the experiences of those with diabetes began with a cross section of individuals sharing the disease and requirements for its treatment. Beyond that, their life experiences and views of diabetes gave each a unique set of circumstances that framed their approach to managing the disease and influenced their level of glycemic control. It is within these contexts that opportunities to improve self-management should be created.

Acknowledgements

The authors extend their appreciation to the participants who, by sharing their personal stories, made this research possible. Funding was provided by the North Carolina Institute of Nutrition.

References

- Adams, Pill and Jones (1997) S Adams, R Pill and A Jones, Medication, chronic illness, and identify: The perspective of people with asthma, *Social Science & Medicine* **45** (1997), pp. 189–201.
- American Diabetes Association (2002) American Diabetes Association. (2002). Evidence-based nutrition principles and recommendations for the treatment of diabetes and related complications. *Diabetes Care*, *25*, 202–212.
- Anderson, Freedland, Clouse, & Lustman (2001) R.J Anderson, K.E Freedland, R.E Clouse and P.J Lustman, The prevalence of comorbid depression in adults with diabetes, *Diabetes Care* **24** (2001), pp. 1069–1078.
- Anderson et al. (1995) R.M Anderson, M.M Funnell, P.M Butler, M.S Arnold, J.T Fitzgerald and C.C Feste, Patient empowerment: Results of a randomized controlled trial, *Diabetes Care* **18** (1995), pp. 943–949.
- Arcury & Quandt (1999) T.A Arcury and S.A Quandt, Participant recruitment for qualitative research: A site-based approach to community research in complex societies, *Human Organization* **58** (1999), pp. 128–133.

- Bandura (1986) A Bandura, *Social foundation for thought and action: A social cognitive theory*, Prentice-Hall, Englewood Cliffs, NJ (1986).
- Campbell et al. (1994) M.K Campbell, B.M DeVellis, V.J Strecher, A.S Ammerman, R.S Devellis and R.S Sandler, Improving dietary behavior: The effectiveness of tailored messages in primary care settings, *American Journal of Public Health* **84** (1994), pp. 783–787.
- Chesla, Skaff, Bartz, Mullan, & Fisher (2000) C.A Chesla, M.M Skaff, R.J Bartz, J.T Mullan and L Fisher, Differences in personal models among Latinos and European Americans, *Diabetes Care* **23** (2000), pp. 1780–1785.
- Ciechanowski, Katon, & Russo (2000) P.S Ciechanowski, W.J Katon and J.E Russo, Depression and diabetes: Impact of depressive symptoms on adherence, function, and costs, *Archives of Internal Medicine* **160** (2000), pp. 3278–3285.
- Crow, Kendall, Praus, & Thuras (2001) S Crow, D Kendall, B Praus and P Thuras, Binge eating and other psychopathology in patients with type 2 diabetes, *International Journal of Eating Disorders* **30** (2001), pp. 222–226.
- Devine, Connors, & Bisogni (1998) C.M Devine, M.M Connors and C.A Bisogni, Life-course influences on fruit and vegetable trajectories: Qualitative analysis of food choice, *Journal of Nutrition Education* **30** (1998), pp. 361–370.
- Egede & Bonadonna (2003) L.E Egede and R.J Bonadonna, Diabetes self-management in African Americans: An exploration of the role of fatalism, *Diabetes Educator* **29** (2003), pp. 105–115.
- Egede, Zheng, & Simpson (2002) L.E Egede, D Zheng and K Simpson, Comorbid depression is associated with increased health care use and expenditures in individuals with diabetes, *Diabetes Care* **25** (2002), pp. 464–470.
- Elder (1985) G.H Elder, Perspectives on the life course. In: G.H Elder, Editor, *Life course dynamics: Trajectories and transitions (1968–1990)*, Cornell University Press, Ithaca (1985), pp. 23–49.
- Glasgow, Hampson, Strycker, & Ruggiero (1997) R.E Glasgow, S.E Hampson, L.A Strycker and L Ruggiero, Personal-model beliefs and social–environmental barriers related to diabetes self-management, *Diabetes Care* **20** (1997), pp. 556–561.

Glasgow et al. (1989) R.E Glasgow, D.J Toobert, M Riddle, J Donnelly, D.L Mitchell and D Calder, Diabetes-specific social learning variables and self-care behaviors among persons with type II diabetes, *Health Psychology* **8** (1989), pp. 285–303.

Gray (1985) D Gray, The treatment strategies of arthritis sufferers, *Social Science & Medicine* **21** (1985), pp. 507–515.

Hampson, Glasgow, & Toobert (1990) S.E Hampson, R.E Glasgow and D.J Toobert, Personal models of diabetes and their relation to self-care activities, *Health Psychology* **9** (1990), pp. 632–646.

Harris (2001) M.I Harris, Racial and ethnic differences in health care access and health outcomes in adults with type 2 diabetes, *Diabetes Care* **24** (2001), pp. 454–459.

Hunt, Pugh, & Valenzuela (1998) L.M Hunt, J Pugh and M Valenzuela, How patients adapt diabetes self-care recommendations in everyday life, *Journal of Family Practice* **46** (1998), pp. 207–215.

Hunt, Valenzuela, & Pugh (1998) L.M Hunt, M.A Valenzuela and J.A Pugh, *Porque me tocó a mi?* Mexican American diabetes patients' causal stories and their relationship to treatment behaviors, *Social Science & Medicine* **48** (1998), pp. 959–969.

Kenardy, Mensch, Bowen, & Pearson (1994) J Kenardy, M Mensch, K Bowen and S.A Pearson, A comparison of eating behaviors in newly diagnosed NIDDM patients and case-matched control subjects, *Diabetes Care* **17** (1994), pp. 1197–1199.

King, Kiernan, Oman, Kraemer, Hull, & Ahn (1997) A.C King, M Kiernan, R.F Oman, H.C Kraemer, M Hull and D Ahn, Can we identify who will adhere to long-term physical activity?: Signal detection methodology as a potential aid to clinical decision making, *Health Psychology* **16** (1997), pp. 380–389.

Kleinman, Eisenberg and Good (1978) A Kleinman, L Eisenberg and B Good, Culture, illness, and care: Lessons from anthropologic and cross cultural research, *Annals of Medicine* **88** (1978), pp. 251–258.

Marcus, Wing, Guare, Blair, & Jawad (1992) M.D Marcus, R.R Wing, J Guare, E.H Blair and A Jawad, Lifetime prevalence of major depression and its effects on treatment outcome in obese type II diabetic patients, *Diabetes Care* **15** (1992), pp. 253–255.

Meyer, Leventhal and Gutmann (1985) D Meyer, H Leventhal and M Gutmann, Common-sense models of illness: The example of hypertension, *Health Psychology* **4** (1985), pp. 115–135.

Miles & Huberman (1994) Miles, M. B., & Huberman, A. M. (1994). Within-case displays: Exploring and describing. In: *Qualitative data analysis: An expanded sourcebook* (2nd ed.) (pp. 90–142). Newbury Park, CA: Sage Publications.

Nothwehr and Stump (2000) F Nothwehr and T Stump, Health-promoting behaviors among adults with type 2 diabetes: Findings from the health and retirement study, *Preventive Medicine* **30** (2000), pp. 407–414.

Quandt, Vitolins, & DeWalt (1997) S.A Quandt, M.Z Vitolins and K.M DeWalt, Meal patterns of older adults in rural communities: Life course analysis and implications for undernutrition, *Journal of Applied Gerontology* **16** (1997), pp. 152–171.

Reid (1992) B.V Reid, “It's like you're down on a bed of affliction”: Aging and diabetes among black Americans, *Social Science & Medicine* **34** (1992), pp. 1317–1323.

Rimmer, Silverman, Braunschweig, Quinn, & Liu (2002) J.H Rimmer, K Silverman, C Braunschweig, L Quinn and Y Liu, Feasibility of a health promotion intervention for a group of predominantly African American women with type 2 diabetes, *Diabetes Educator* **28** (2002), pp. 571–580.

Roos, Quandt, & DeWalt (1993) G.M Roos, S.A Quandt and K.M DeWalt, Meal patterns of the elderly in rural Kentucky, *Appetite* **21** (1993), pp. 295–298.

Rose, Fliege, Hildebrandt, Schirop, & Klapp (2002) M Rose, H Fliege, M Hildebrandt, T Schirop and B.F Klapp, The network of psychological variables in patients with diabetes and their importance for quality of life and metabolic control, *Diabetes Care* **25** (2002), pp. 35–42.

Samuel-Hodge, Headen, Skelly, Ingram, Keyserling, Jackson et al. (2000) C.D Samuel-Hodge, S.W Headen, A.H Skelly, A.F Ingram, T.C Keyserling, E.J Jackson, A.S Ammerman and T.A Elasy, Influences on day-to-day self-management of type 2 diabetes among African-American women, *Diabetes Care* **23** (2000), pp. 928–933.

Schlundt, Rea, Kline, & Pichert (1994) Schlundt, D. G., Rea, M. R., Kline, S. S., & Pichert, J. W. (1994). Situational obstacles to dietary adherence for adults with diabetes. *Journal of the American Dietetic Association*, 1994, 874–876, 879.

Schoenberg & Drungle (2001) N.E Schoenberg and S.C Drungle, Barriers to non-insulin dependent diabetes mellitus (NIDDM) self-care practices among older women, *Journal of Aging and Health* **13** (2001), pp. 443–466.

Schoenberg, Amey, & Coward (1998) N.E Schoenberg, C.H Amey and R.T Coward, Stories of meaning: Lay perspectives on the origin and management of noninsulin dependent diabetes mellitus among older women in the United States, *Social Science & Medicine* **47** (1998), pp. 2113–2125.

Senécal, Nouwen, & White (2000) C Senécal, A Nouwen and D White, Motivation and dietary self-care in adults with diabetes: Are self-efficacy and autonomous self-regulation complementary or competing constructs?, *Health Psychology* **19** (2000), pp. 452–457.

Snoek (2000) F.J Snoek, Barriers to good glycaemic control: The patient's perspective, *International Journal of Obesity* **24** (2000), pp. S12–S20.

Strauss & Corbin (1990) A Strauss and J Corbin, Basics of qualitative research, Sage Publications, Newbury Park, CA (1990).

US Census Bureau (2002) US Census Bureau. (2002). Poverty 2000—poverty thresholds. Available at: <http://www.census.gov/hhes/poverty/threshld/thresh00.html>.

Welborn, Garcia-Webb, Bonser, McCann and Constable (1983) T.A Welborn, P Garcia-Webb, A Bonser, V McCann and I Constable, Clinical criteria that reflect C-peptide status in idiopathic diabetes, *Diabetes Care* **6** (1983), pp. 315–316.