

ORIGINAL RESEARCH

Lived experience of diabetes among older, rural people

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Abstract

Title. Lived experience of diabetes among older, rural people.

Aim. This paper is a report of a study conducted to elucidate experiences and perceptions of self-management of diabetes as narrated by older people diagnosed with insulin-dependent diabetes living in a rural area.

Background. Older people worldwide are disproportionately affected by diabetes and are more likely to have co-morbidities and disabilities. Guidelines for management, developed by the American Diabetes Association, are not targeted for this population. A plethora of quantitative research has investigated self-management issues, with little change to outcomes. This pleads for consideration of a new diabetes education model, which includes consideration of experiences within clients' worldviews.

Method. Unstructured interviews starting with an open question were conducted from a purposive sample in 2005. Interviews were transcribed and analysed according to the tenets of existential phenomenology, a process which began with bracketing the researcher's biases.

Findings. Living with poorly controlled diabetes led participants to introspection and existential questioning. Four connected themes were identified: 'Your Body Will Let You Know'; 'I Thought I Was Fine, But I Wasn't'; 'The Only Way Out is to Die'; and 'You Just Go On'.

Conclusion. Currently designed from a medical perspective, diabetes education should be based on a nursing model incorporating the client's insights and experiences. When managing diabetes is viewed from a client's perspective, the focus becomes solving problems that arise in self-regulation of one's own regimen rather than in complying with doctor's orders. Nurses need to reframe the problem by excluding the compliance/noncompliance model and developing a conceptual perspective on self-management that is grounded in world and body.

Keywords: diabetes, gerontology, nursing, older people, phenomenology, rural health, self-management

Introduction

Every 10 seconds, two people develop diabetes and someone dies from diabetes-related causes. It is the fourth leading cause of death globally (International Diabetes Federation, 2007). The world is in the midst of an epidemic of diabetes, which if unchecked will produce an unbearable burden on quality of life and the worldwide healthcare system over the next generation. The World Health Organization (WHO) estimates that more than 180 million people worldwide currently have diabetes and this number may double by 2030. India, China and the United States of America (USA) are the top three countries with the most people with diabetes (WHO 2008). In the USA, over 23 million people are currently diagnosed with diabetes (American Diabetes Association 2009a, 2009b), and it is the sixth leading cause of death in the USA, being responsible for 225,000 deaths annually (Gambert & Pinkstaff 2006). Over 90% of older adults with type 2 diabetes are diagnosed with either insulin resistance or insulin deficiency, which is a conundrum for optimal treatment options (DeFronzo 2004). In a meta-analysis conducted by researchers from Sweden, Zimbabwe and Uganda, underlying causes for the pandemic of diabetes were attributed to genetic and environmental factors, longevity, changes from active to sedentary lifestyles, and over-eating. The researchers stated that this illness is a growing public health problem (Hjelm *et al.* 2003). The prevalence of diabetes is somewhat higher in rural than in urban areas, but racial/ethnic, socioeconomic and lifestyle factors also appear to be strong risk factors. Rural people with diabetes tend to be diagnosed later and receive substandard health care compared to their urban counterparts (Dabney & Gosschalk 2009).

Background

Guidelines for diabetes management developed by the American Diabetes Association are not specific for the older diabetic population, only the general adult population. There are no diabetes treatment differences targeted for patients who are 65 years of age and older. The American Diabetes Association in its 2009 revisions addressed new standards. Explicit in the revisions were inclusion of children, teenagers and younger adults. Specific recommendations were also made for people over 40 years of age (ADA 2009a, 2009b), but unique physiological changes in people aged 65 years and older were not taken into account. For example, the number of insulin receptors on cell membranes decreases with age; accordingly, glucose intolerance increases. There is age-related change to tissue sensitivity to insulin, and alteration of insulin receptor sites by the ageing process is thought to

render insulin less effective. Secretion of insulin may be depressed and the target tissue may have an increased resistance to insulin. Non-ketotic hyperosmolar coma is a condition exclusive to older people with diabetes and is characterized by extreme hyperglycaemia and hyperosmolarity. People with these symptoms exhibit mental status changes, dehydration and hypotension. This is often viewed as a neurological event rather than a complication of diabetes. These changes reflect a disturbing picture of self-management burdens for older adults and the need for individualized goal setting as opposed to a prescribed protocol to fit everyone. According to the study by Selvin *et al.* (2006), the higher rate of poor glycemic control in the older population as compared to middle aged people with diabetes represents differing burdens of the disease and need for diverse treatments in each group.

Recently, the American Association of Diabetes Educators and American Geriatric Society formulated guidelines for self-management education in older people; however, the guidelines were based on expert consensus and await empirical evaluation (Suhl & Bonsignore 2006). The American Diabetes Association, American Association of Diabetes Educators and American Association of Clinical Endocrinologists acknowledge that no long-term studies have been conducted among older adults with diabetes (Hainer 2006). Older people with diabetes have not been included in many studies, which may explain why a specific protocol for management has not been developed. It is crucial for our global, older population to be integrated into studies of diabetes. This will permit development of specific guidelines for self-management to ameliorate conditions such as co-morbidities and disabilities that can be prevented by early intervention rather than episodic management. Advanced healthcare planning may delay onset of complications, decrease hospitalizations and improve outcomes.

Individuals with diabetes carry out about 95% of their own care (Anderson *et al.* 1995, Funnell *et al.* 2008), and diabetes education is used as a tool for the development of effective self-management practices. Diabetes self-management is defined by the American Diabetes Association as the ongoing process of facilitating the knowledge, skill and ability for diabetes self-care (Anderson & Funnell 2000, Funnell *et al.* 2008). People with diabetes make many choices every day that affect their disease. The focus of diabetic education has been to provide information that will improve patient choices, promote better health and reduce complications. Educating the patient is essential in diabetes self-management, and it is considered a crucial factor in achieving optimal blood glucose levels (Gorawara-Bhat *et al.* 2008).

Diabetes education is usually carried out using a pedagogical approach which includes lecture content, knowledge tested for accuracy and demonstration-return demonstration of the necessary skills for self-management (Brown 1992, Bradley 1995). This strategy does not necessarily lead to long-term adherence to diabetes regimens. It is presumed by healthcare providers that if people are given adequate education, they will self-manage their disease.

An older individual, however, has accrued years of established patterns and behaviours, making adherence to, or change in, a diabetic protocol very difficult and challenging. There are several unique problems in the management of 65-year and older persons with diabetes. Visual disturbances occur as a result of the normal ageing process, which in this group are further exacerbated by poor glucose control. A decrease in activities of daily living results in decreased food intake, which may in turn contribute to a hypoglycemic state. If older people are physically inactive, they are more disposed to obesity. Adding to this conundrum, it is expected that many will become cognitively impaired, which may further decrease adherence to diabetes self-management. Although effective medications, methods of delivery and methods for self-monitoring have improved diabetic clients' ability to control hyperglycaemia, normal metabolic control remains difficult to achieve.

Jack *et al.* (1999) determined that diabetic education has not taken account of the impact of patients' social circumstances and environmental contexts. The isolation inherent in rural environments of older people with diabetes may be particularly challenging. A few researchers have studied rural and homebound populations but were not exclusively concerned with older diabetic participants. Adults living in rural areas often find it difficult to obtain adequate health care due to such factors as inability to drive, financial constraints, mistrust, illiteracy, or communication problems (IOM 2004). Rural women are known to have a greater risk of death from diabetes (U.S. Rural Assistance Center 2005). African Americans living in rural areas with high rates of poverty may not even be able to afford to purchase the prescribed medications. Studies indicate that this information is rarely discussed with their physicians (Saver *et al.* 2004).

The study

Aim

The aim of the study was to elucidate experiences and perceptions of self-management of their diabetes as narrated by older people with insulin-dependent diabetes living in a rural area.

Methodology

The study methodology was influenced by the phenomenology of French philosopher Maurice Merleau-Ponty which 'tries to give direct description of our experience as it is, without taking account of its psychological origin and the causal explanations which the scientist, this historian, or the sociologist may be able to provide' (Merleau-Ponty 1945/1962, p. vii). According to Thomas and Pollio (2002, p. 13), 'The aim of Merleau-Ponty's phenomenology is to describe the human experience on its own terms'. Based on these assumptions, phenomenology was the method of choice for capturing the experience of older people with diabetes.

Merleau-Ponty, heavily influenced by the work of Husserl and Heidegger, focused his work on perceptions of lived experience. In order to describe a lived experience, it must first be disclosed. Bracketing and phenomenological reduction are essential components of the methodology (Merleau-Ponty 1945/1962). Bracketing presumes that researchers are capable of separating their knowledge from personal experience, at least temporarily, while collecting and analysing data. The procedure, as defined by Thomas and Pollio (2002), requires a bracketing interview of the principal investigator. This is designed to heighten awareness of any preconceptions or biases arising from personal experiences and minimizes the potential for distortion of during data collection and analysis. The principal investigator (SG) reflected upon, and thematized the transcript of her bracketing interview prior to commencing participant interviews.

Participants

A purposive sample was drawn from local agencies on ageing between January and May 2005, and consisted of English-speaking people aged 65–85 years who were able and willing to talk at length about their diabetes, and to allow a researcher to visit them in their homes. Among the group were eight African American and two White women, all confined to their homes and living in a rural area. Everyone received Social Security as their only source of income. Length of time with diabetes ranged from 7 to 39 years. Five participants had been diagnosed over 25 years previously, and five were diagnosed less than 12 years previously. All had visible evidence of diabetes-related complications, and all had more than one chronic condition in addition to diabetes. All but one was a widow.

Data collection

All interviews were conducted face-to-face in the participants' homes, at a date and time of their choosing. No

specific directions were supplied to participants. They were free to discuss any life experience they perceived as representing their diabetes, and their experiences with diabetes self-management issues. Each participant was told that they could take as long as they needed to talk about their diabetes. Interviews lasted from 1 to 2 hours and began with the prompt: 'Please tell me what it is like for you living with diabetes'. From this point, participants could discuss the topic in any way they chose, and all started with an account of how terrible diabetes is to them. Comments and questions were followed-up with prompts such as 'Tell me more about that' and 'Tell me what that is like'. Following the interviews, a short survey was used to assess issues of self-management, such as frequency of testing blood glucose levels.

Ethical considerations

This study was approved by the appropriate research ethics committee. Initial contact with the participants was accomplished through a visit from the agency's home health nurse. The nurse gave potential participants the following information: purpose of the study, nature of the data to be collected, approximate time required, benefits and risks related to participation in the study. Informed consent was obtained from each participant at the time of the interview.

Data analysis

All interviews were audiotaped and transcribed verbatim. All transcripts were read and re-read while listening to the audiotape. This was done to ensure accuracy of the transcription. The transcripts were then read and re-read again to gain insight and a sense of the lived experience as described by the participants. To determine emerging themes, the data from selected transcripts was reviewed and read aloud by members of an interpretive, interdisciplinary, phenomenology research group. Group members have extensive experience using the Thomas and Pollio (2002) method of analysing phenomenological research data, and many have participated in the group for more than a decade. The group comprises phenomenological research students from a doctoral programme and doctorally prepared university staff member. Thomas and Pollio's (2002) interpretation procedures were used for data analysis. Existential-phenomenological interpretation is a process of relating parts (known as meaning units) to the whole narrative. Analysis is a constant process of seeking to grasp the meaning of the whole while also scrutinizing words and phrases line by line. Meaning units and themes (patterns observed across interviews) were identified and

related to one another until a final thematic structure was delineated and presented to the research group.

Rigour

The analysis procedure provided an analysis of the data that was systematic, disciplined, and reflective, and afforded the opportunity for meaningful comparisons across all the data. In addition to presenting the formalized thematic structure to the research group, Thomas and Pollio (2002) recommend that it be presented to participants for their response to its validity. The principal investigator revisited two participants and asked them if the thematic structure was accurate. Both were able to recognize their own experiences in the findings. One participant added, 'This is really good'. The second participant expressed being amazed at the themes and stated, 'You really knew what I meant'.

Findings

Survey results

The short survey, administered following the interviews, revealed erratic diabetes self-management. When asked how often they self-tested for blood glucose, participants indicated haphazard testing. One did not check because the glucometer was broken. Another admitted that she did not check at all. Four participants reported checking from 3 to 5 times a week, and four reported checking from 1 to 2 times a day. When asked if they knew whether they had ever had an HgbA1C (glycosylated haemoglobin), everyone responded, 'Don't know'.

When questioned about eating habits, such as eating differently since their diagnosis of diabetes, nine responded that they had made changes; one said 'No'. All participants reported eating at least once per day, but no one ate according to their healthcare provider's recommendations or recommendations of the American Diabetes Association. When asked if they had received any special teaching about diabetes, responses varied. For example, one participant had learned from her doctor and from the television. Other responses included family and friends, self-teaching, and obtaining diabetes knowledge through experience and observation with other diabetic family members.

Interview findings

All participants described what their life was like with diabetes and how they managed in their own way. Each spoke in a quiet tone and discussed experiences with sombre

affect. There was little laughter during the interviews, and descriptions of specific events seemed to bring back to immediate consciousness the reality that they had a serious and intrusive disease, for which there is no known cure. Each person seemed pleased to have the opportunity to talk about diabetes without any restrictions on scope or time. Voices would often trail off at the end of describing an experience, as though this had left them with lingering thoughts or questions about their long experience with diabetes. Past experiences were recounted as though still fresh in the memory. Expressions would change as painful experiences such as first using a needle were described. Pain was reflected in facial grimaces, and from time to time a melancholy appearance and sadness permeated the discussion.

Figural themes

In existential phenomenology, predominant aspects of participant perceptions (termed 'figural') must be understood within their environmental context (termed 'ground'). Using participants' own words, specific themes emerging from this research will be discussed. Four figural themes were identified across the interviews and were contextualized by the existential grounds of World and Body. The world of an older, homebound diabetic in a rural south-eastern environment is greatly restricted. Few people populate this small world. Most participants had few visitors and left their homes infrequently, perhaps to go church or a family gathering when someone provided transport.

Theme 1: 'Your body will let you know: If you miss it you'll wind up in a coma'

This poignant comment described how diabetes was experienced as a bodily phenomenon, most notably when the body signalled that they must take action. Participants' narratives were dominated by frightening episodes of hypoglycaemia. 'Awful' changes in their body mandated action, lest adverse consequences ensued. Participants vividly described feelings in their bodies as an antecedent to hypoglycaemia. The bodily cues included 'started floating', 'swimmy headed', 'knees like jelly' and 'slipping away'. One person said, 'You feel like you're gonna die'. This was participants' biggest fear.

Frantic attempts to find something to eat occurred. One participant said that it was important to be physically close to the refrigerator so that she did not have far to go when she became hypoglycemic. Her descriptions of experiences with hypoglycaemia indicated how she coped. Gesturing, she declared, 'There is my bed and there is the refrigerator. I

know when it [blood sugar] has got low, I have to make it to the freezer, and back in the bed before I black out'.

Experiences of hypoglycaemia generated fear of sleep. Not responding to bodily cues about hypoglycaemia could cause a coma. One participant stated, 'I'm afraid I would have just slept, slept, slept, if they hadn't found me'. What stood out most for people was dread of falling asleep and not being found. They worried they would not be able to wake up; being alone intensified this apprehension: 'I'm afraid I won't wake up'. Driven by fear of falling asleep at night, creative ways were adopted to stay awake as much as possible during the night. One participant said she consumed 'coffee all day and evening to stay awake'.

Participants asserted that conventional diabetes management techniques did not work for them. They perceived healthcare providers as being unwilling to listen, and as directing them to adopt a regimen they could not follow. This created frustration and mistrust. Descriptors of provider responses included 'Didn't believe me', 'Wouldn't listen', 'Tried to tell them'. Their self-prescribing diabetes management ultimately led to accelerating progression of the disease, leaving them to wonder what went wrong: 'I did everything I was supposed to'.

Theme 2: 'I thought I was fine, but I wasn't'

The disconnection between participants and providers is captured in Theme 2. Participants had unwittingly chosen high-risk behaviours that had worked for many years. However, as the disease progressed they developed irreversible, disabling, diabetic complications. They thought that they would be fine with diabetes if they took their insulin and ate 'right'. They believed 'doing the right thing' would keep their diabetes under control. For most, their sense of 'fine' was demonstrated by self-management behaviours and strategies that gave them the greatest degree of freedom without causing adverse consequences. One person explained, 'Sometimes I cut my shot in half'. She made this decision because taking the entire amount of insulin would require eating more food, which she mistakenly believed would have an undesirable outcome: 'Too much eating, I'd gain weight'. Participants struggled between what the doctor advised and their personal knowledge and experience. Most felt compelled to devise their own diabetes regimen without the advice of a healthcare provider.

Theme 3: 'Only way out is to die'

Participants knew that diabetes is a lifelong process and a disease for which there is no known cure. They perceived that diabetes had taken over and dictated how they were to live each day for the remainder of their lives. Neither traditional

medicine nor their own experience gave them any hope for significant improvement in their condition; in fact, quite the contrary, most were faced with escalating degradation in the quality of their lives and the condition of their diabetes. They believed that 'The only way out is to die out'. They are aware and realistic about the prognosis and were sombre in their acceptance of their condition. Illustrative quotes included 'They say they don't have no cure for it', and 'You never will get well'.

Theme 4: 'You just go on'

'You just go on' reflected the stoic endurance exhibited by these older diabetic participants, resigned to management of a disease which they perceived would ultimately claim their lives. One person, a diabetic for 35 years and facing another amputation, stated, 'You just go and do what you got to do'. Participants had spent a lifetime managing diabetes to the best of their ability. In essence, they believed that they were doing everything they knew to keep their lives going with diabetes. They did not expect to get better and reconciled themselves to the limitations produced by the disease. This was reflected in expressions such as 'I've been a diabetic for so long, you gets used to it. In other words, you have to do it so long, and you just do, I says, doing what come naturally'.

Part of 'Just going on' was sometimes to defy what people told them because, after all, they already knew that the 'only way out is to die'. For example, one participant stated, 'I love chocolate and they don't know where chocolate goes in my sugar. It doesn't run my sugar up. I can eat all I want'. Another confessed, 'I love sweets; I'd make a cake every weekend and eat it up all through the week. My sugar'd be over 600'.

Thematic structure

The thematic structure is illustrated in Figure 1. The structure represents the interrelationship between all four themes as never ending. It shows 'You just go on' at the top of the structure because that is where participants can begin or end their diabetes experiences. Going on represents the resignation described as a result of living with frightening hypoglycaemia episodes, expressed in 'Your body will let you know, if you miss it, you'll wind up in a coma'. Across from this theme are participants' perceptions of 'I thought I was fine, but I wasn't'. From the sequence of life events, they arrived at the conclusion, the 'Only way out is to die', which is illustrated as linked to the first two. If their only way out is to die, then 'You just go on', which is inextricably connected to the other three themes.

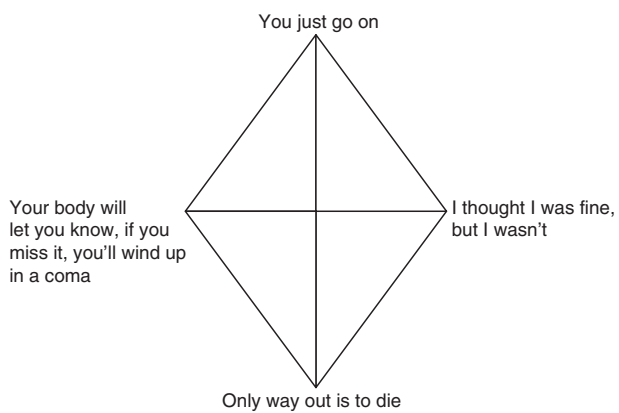


Figure 1 Themes of the experience of older rural adults living with diabetes.

Discussion

Study limitations

Although the small sample size may be viewed as a limitation, in a phenomenological study it is common for samples to be small: 'An appropriate sample size for phenomenological research can range from 6 to 12 persons' (Morse 1994, p. 220). The goal is depth of understanding of the phenomenon; saturation or redundancy is achieved when no new thematic material is heard in the interviews. Generalizability of the study is limited by the environmental location (rural, southern USA), absence of men and absence of other minority groups such as Hispanic Americans, Asian Americans and Native Americans, who have a high prevalence of diabetes. However, the descriptions provided by this predominantly African American rural sample are a valuable contribution to literature: their voices have not been heard. Moreover, transferability of phenomenological findings largely depends upon the reader of the research report; a clinician can apply findings of a phenomenological study when they are judged applicable to patients expressing similar concerns (e.g. isolation, chronic illness, fear of dying alone). Fear of dying alone, for example, is undoubtedly a universal theme among human beings.

Self-management by older people with diabetes

What is new in this study is the first-person perspective of self-management provided by the narratives of older persons with diabetes. This allows nurses to step into the world of rural older individuals with diabetes and understand the fright of hypoglycaemia, bewilderment when well-intentioned self-care did not have the intended results, frustration with healthcare providers who do not listen, and stoic endurance while waiting for death. Tragically, many of the

What is already known about this topic

- Older people diagnosed with diabetes have more co-morbidities and complications, but guidelines for self-management are not targeted for clients who are 65 years and older and have concomitant ageing impairments such as visual changes and decreased mobility.
- The majority of people with diabetes manage their own care based on what they were taught from a pedagogical approach, based on a presumption by healthcare providers that if people are provided adequate education, they will successfully self-manage their disease.
- An older individual has accrued years of established patterns and behaviours, making adherence to or change in a diabetic protocol very difficult and challenging.

What this paper adds

- Living with poorly controlled diabetes led participants to introspection and existential questioning.
- Four connected themes were identified: 'Your Body Will Let You Know'; 'I Thought I Was Fine, But I Wasn't'; 'The Only Way Out is to Die'; and 'You Just Go On'.

Implications for practice and/or policy

- Improved education is needed, based on the International Diabetes Federation model adapted to the older population and specifically individualized to clients' experiences and patterns.
- Nursing care should be provided with understanding and sensitivity toward cultural values.
- An approach to diabetes is needed that is grounded in understanding of clients' contextual world and experience of their own body.

participants had misunderstandings that had never been dispelled (e.g. eating chocolate will not affect blood sugar). They believed that they were doing their best to coexist with the debilitating disease that had caused their bodies to decline. Similarly, 'Doing My Best' was thematic in a recent study of another vulnerable group: patients having both schizophrenia and diabetes (El-Mallakh 2007). As in the present study, limited education, income, and other barriers constrained participants' ability to care for themselves. These barriers affect millions of people with diabetes.

The sombre effect of the women in our study matches that of diabetics in a study by Moskowitz *et al.* (2008). They

assessed affect as a risk predictor for diabetes mortality in 715 participants with diabetes and 2,673 participants without chronic illness. Those with diabetes reported lower Positive Affect subscale scores and higher Negative Affect. Those with diabetes had a statistically significant higher risk of mortality.

Research by Brody *et al.* (2008) has shown that self-management is compromised when individuals live alone in a rural setting with lack of family, friends, community, and neighbours who could provide emotional or physical support. In this structural equation modelling study of older African American adults with type 2 diabetes, better social support was positively related to improved self-management of the disease. The rural women in the present study did not have access to social support. They were seemingly doomed, based on location, fearing that they would die alone in the night.

The self-reliance and stoicism shown by these older women was typical of rural women interviewed about health information seeking by Wathen and Harris (2007). Regardless of age, the mantra of these women was 'I try to take care of it myself'. Self-reliance is perhaps the only available option for people with diabetes when the disease management regimens prescribed by healthcare providers fail to prevent the recurrence of terrifying hypoglycemic episodes. Only their own bodies seemed to be reliable indicators of needed self-care actions. Dissatisfying relationships with healthcare providers were also prominent in a grounded theory study with insulin-dependent diabetics conducted by Zoffman and Kirkevold (2007); many people in that study expressed frustration when providers did not listen to them, and they engaged in resistance to the 'orders' they received. Similar resistance, traditionally labelled 'noncompliance', was displayed by the older participants in our study.

Findings from this study suggest that healthcare professionals need to listen more carefully to the voices of clients. Misunderstandings of the disease and the desired treatment regimen abounded. Experiences related by participants in this study did not reflect 'noncompliance' in their own views. Each described how they managed diabetes, knowing that their self-management regimen was not considered appropriate according to the instructions of their healthcare providers. It was self-management within their own world-views.

Conclusion

The international community of nurses has been educating people about diabetes using guidelines designed from a medical perspective. Diabetes self-management education should be based on a nursing model incorporating cli-

ents' insights and experiences. Nurses should consider a client's pattern if any adaptations or modifications are required, rather than continuing to force diabetes care into an intellectual, financial and psychological system that will continue to frustrate clients and providers and may not improve blood glucose levels, complications, or escalating costs associated with diabetes. When managing diabetes is viewed from a participant perspective, the focus becomes solving the problems that arise in self-regulation of the person's own regimen rather than complying with (or not complying with) a doctor's orders. Noone had worked collaboratively with the participants in this study to reduce the frequency of the hypoglycaemia that was the figural problem in their day-to-day existence. Perhaps participants did not realize that hypoglycemic episodes could be reduced with better control of their disease.

Our findings challenge the traditional compliance paradigm in which current diabetes education is grounded. Healthcare providers need to develop a new approach to diabetes education for older adults that is grounded in understanding of clients' contextual World and experience of their own Body. Homebound clients need to be heard in order for healthcare providers to become creative with addressing their diabetes concerns. Reframing the problem of noncompliance may offer a new view for developing nursing interventions that could make a difference by improving the quality of life for this population. What is needed, based on this study, is an innovative approach to self-management with potential for global applications. The International Diabetes Federation, Section on Diabetes Education, has developed an International Curriculum for Diabetes Health Professionals (International Diabetes Federation 2009). The document was developed to assist healthcare providers in preparing a high quality diabetes education programme that can be used throughout the world. It includes planning timely nursing care, with evaluation of clients' environments and experiences; furthermore, it emphasizes that diabetes education should be individualized and negotiated in partnership between nurse and client. If client views and beliefs are not taken into account, only short-lived changes in self-management may result. Adoption of the International Diabetes Federation model, with consideration of unique client experiences with self-management such as those described in this study, will promote a collaborative relationship. The voices of our participants call us to act, so that they do not spend their older years merely waiting to die.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

SG was responsible for the study conception and design. SG performed the data collection. SG performed the data analysis. SG and ST were responsible for the drafting of the manuscript. SG and ST made critical revisions to the paper for important intellectual content. SG obtained funding. SG provided administrative, technical or material support. ST supervised the study.

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