

The Role of Spirituality in Diabetes Self-Management in an Urban, Underserved Population: A Qualitative Exploratory Study

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ABSTRACT

BACKGROUND: Although many studies examine motivators for diabetes self-management, few explore the role spirituality plays in this disease, especially in low-income urban populations.

METHODS: This qualitative, focus group study elicits thoughts of diabetic patients regarding spirituality in diabetes self-care, at an urban primary care practice in Rhode Island. Focus group discussions were audiotaped, transcribed verbatim, and analyzed using the immersion/crystallization technique.

RESULTS: Themes included: significant impact of diabetes on daily life; fear and family as prominent self-care motivators; relationships with self, others, nature and the divine as major sources of hope and strength. Patients varied considerably regarding the role spirituality played in their illness, ranging from minimal to profound impact. All appeared comfortable discussing spirituality within the context of strength and hope.

CONCLUSION: Patients in this urban, underserved population are willing to discuss spirituality related to their diabetes care. They vary in the role spirituality plays in their illness experience.

KEYWORDS: diabetes, spirituality, chronic disease self-management, chronic disease coping

INTRODUCTION

Diabetes, a prevalent, often preventable chronic disease can be life-altering for patients and families. Outcomes heavily depend on motivation for self-care, such as lifestyle modification, glucose monitoring and medication compliance.¹ Many studies have examined diabetes self-management motivators such as family, support groups, anxiety, and education.² However, other possible motivators, such as spirituality, although identified as relevant,³ have not been explored in detail.⁴

Most studies on spirituality in medical care examine the role of spirituality in end-of-life care.⁵ Very few look at how spirituality influences prevalent chronic diseases, like diabetes, that affect morbidity more than mortality.⁶ Present studies on diabetes and spirituality are small exploratory

studies,^{7,8,9,10} primarily address nurses rather than physicians,⁷ or have focused on African-American women,^{7,8} or Latino patients,¹¹ subsets of the population identified as more likely to adhere to structured religion.¹² No studies examine the perspectives of patients from an urban, underserved Northeast population. Additionally, low-income, urban populations have an increased burden of preventable chronic conditions¹³ and have worse outcomes with management.¹³ Consequently, identifying and supporting all possible motivators for self-management is essential for enhancing health outcomes in this vulnerable population.

The purpose of this study was to explore motivators for diabetes self-management in patients from a low-income, urban population in New England. In particular we aimed to clarify the role spirituality might play as a self-care motivator in a previously unstudied and vulnerable population.

METHODS

Design

We conducted a qualitative study of focus-group participants. The study was approved by the Institutional Review Board and informed consent obtained from all participants.

Setting

Patients were followed at the Family Care Center (FCC), Memorial Hospital of Rhode Island – the Brown Family Medicine Department's resident-faculty practice that serves the underserved communities of Pawtucket and Central Falls, Rhode Island.

Participants

Patients were recruited from existing diabetes group medical visits, regularly conducted at the FCC. Therefore all participants carried a diagnosis of diabetes. The only exclusion criterion was lack of fluency in English.

Instrument

A semi-structured interview guide (**Table 1**) was developed for use during the focus groups. An adaptation of the HOPE questions for spiritual assessment,¹⁴ a previously published interview tool, was embedded in the interview guide. Questions followed a natural progression from how diabetes affects participants' day-to-day life and factors that motivate them to do the self-care tasks required of them (eg,

check sugars, adhere to diet), to their sources of strength and hope in dealing with their chronic illness, to whether spirituality is a source of hope or strength for them, and how, if at all, spirituality or religion motivates them to manage their diabetes.

Analysis

Focus groups were audio recorded and transcribed verbatim. Transcripts were analyzed using the immersion/crystallization method for qualitative analysis.¹⁵ Two researchers analyzed transcripts individually and then together in group analysis meetings until consensus was achieved regarding themes emerging from the transcripts.

RESULTS

Eighteen patients, all with type 2 diabetes mellitus, participated in this study. Eleven participants were female (61%), seven (38.8%) were married, and the majority (83.3%) were born in the US. Fourteen identified themselves as Caucasian, one as Native American, one as Cape Verdean, one as Hispanic and one as African American. The average age was 58, and average time since diabetes diagnosis was 9.26 years. Fifty five percent identified themselves as Catholic, 11.1% as other Christian, 5.5% as Jewish, and 27.7% as having no religious affiliation. Finally, on average participants were on 9.94 different medications.

The major themes found in this study are summarized in **Table 2**. A significant theme was the tremendous effect diabetes had on participants' daily lives. The majority felt that diabetes was life altering and 'rules lives': *"I am practically ruled by my diabetes. It affects my food...it affects my sleep..."* It leads to a regimented life, *"I think you constantly stop what you are doing and check everything,"* and a constant focus on food, *"It affects what I cook..."*; *"Scheduling lunch and snacks and all that in between is a lot too..."* This leads to significant stress on patients and their loved ones. *"I don't want my eyes to go blind, my feet to fall off and [I don't want to] drop dead."*

Participants identified several motivators for diabetes self-management. Fear and a desire for self preservation were frequently discussed. *"Because you don't want it to go so far you lose your eyes or your feet or have heart problems or kidney problems or whatever. So I think fear motivates me to get back on track."* Family responsibility was also a common theme. One participant said: *"Just knowing I have to be there for my kids. Ya know. I mean, other than that I don't know what else would make me do what I have to do."* Another explained: *"...family...when I'm with my children or now with my grandchildren I feel that I need to be there. The more I can the better. I want to enjoy life with them."* Another stated: *"My daughter wants to know all the time what my sugars are."*

Other motivators included group medical visits, being able to continue working, and adequate education. In explaining

Table 1. Focus Group Semi-Structured Interview Guide

<p>We are holding this focus group to figure out what kinds of things motivate you to take better care of yourself and your diabetes.</p> <ol style="list-style-type: none"> 1. It must be really hard to take care of your diabetes everyday. How does your diabetes affect your day-to-day life? 2. What kinds of things motivate you to do all the self-care things we talk about and ask you to do (checking sugars, checking feet, doctors' appointments, eye check-ups)? 3. When things are rough for you, what keeps you going and working on your diabetes? <i>Suggested Probe:</i> What are your sources of strength and hope? 4. For some people their spiritual or religious beliefs act as a source of strength or hope. Is that true for you? <i>Suggested Probes (modify as appropriate):</i> How, if at all, does your spirituality or religion motivate you to manage your diabetes? Or help you cope with your DM? What, if any, is the role of organized religion in your life? (and DM self-care/coping) What, if any, are some of your personal spiritual practices? (related to DM self-care/coping) 5. Discuss other sources of hope mentioned early in the discussion. How does "X" motivate you to manage your diabetes?
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Table 2. Main Themes from DM Focus Groups

Themes	Sub-themes
Effects of diabetes on life	<ul style="list-style-type: none"> • Life altering • Rules life; Constantly something to think about • FOOD
Motivators for diabetes self-management	<ul style="list-style-type: none"> • Fear / Desire for Self-Preservation • Family responsibilities and family support • The DM group • Quality of life • Being Able to Work • Education
Sources of Strength and Hope	<ul style="list-style-type: none"> • Relationships with self • Relationship with others • Relationship with nature • Relationship with transcendent
Role of Spirituality in Illness and Self-Care	<ul style="list-style-type: none"> • Variable importance to individuals • Several with strong role, some with weak • More associated with strength/hope than with motivators

the value of group medical visits for education, one participant explains: “We learn a lot here. We learn about diabetes and other things. And that helps us.” Another says: “Yah, it is a shocker when it first happens. It was for me, anyways. This mini group helped a lot...you get all this information. You wouldn’t get all this just by coming in to see the doctor every three months.”

Given the significant stress that diabetes places on participants’ lives, they were receptive to questions regarding sources of strength and hope. The major themes that emerged here were their relationships. These included participants’ relationship with themselves: “I get most of my strength from myself;” with others, “You help each other out with the little hurdles that we’ve had to go through;” with nature, “Nature...things like that keep you grounded and away from the craziness,” and with the transcendent (God), “My beliefs...my religious beliefs make me strong, ya know.” **Table 3** summarizes these subthemes with representative quotations.

All focus group participants willingly contributed to the discussion regarding the role of spirituality in their chronic illness (**Table 4**). The majority (15) cited spiritual views as a source of strength and hope. These participants varied on whether spirituality played a major or minor role in their ability to cope with their illness. When asked, are spiritual beliefs a source of strength and hope; one individual replied, “That is a part of me, yes.” Another individual replied, “I am Catholic, but get most of my strength from myself and my daughters.”

Others expressed a deep faith and reliance on their spiritual beliefs and practices to get them through the challenges they face with their diabetes. One stated: “There is a force up there that keeps me going and affects how I feel.” Others spoke about spiritual practices that helped them: “I’m always praying,” and others expressed a belief in God’s intervention in their lives to help them, “...You weren’t there by accident. There’s a reason...Yeah, it was like divine intervention.” Three participants stated that spirituality was not important to them; however, two followed up with referring to a belief in some force in the universe. “I think there is a force

Table 3. Sources of Strength and Hope: Relationships

Subtheme	Representative Quotations
Relationship with Self	<ul style="list-style-type: none"> • “I get most of my strength from myself.” • “Sometimes you need to just escape and find your own space.” • “Bubble bath, books ... take time to spend time with yourself.” • “That’s one of the kind of things that gets you through the humps, ME time.” • “It’s all about making a deal with yourself.”
Relationship with Others (Family, friends, community, healthcare providers)	<ul style="list-style-type: none"> • “My family, my kids and even the caseworkers have been wonderful to me.” • “Family is very important.” • “Friends and family” • “So we can come here and tell our problems which you may not be able to do at home because you’re busy being the mom ... But we can come here because we know that we all face diabetes and we can tell our problems and sometimes talking might help someone else, too.” • “We’re in it together.” • “You are not alone.” • “You help each other out with the little hurdles that we’ve had to go through. And we’re reminders of hey, this is not just you, alone. There’s everybody else here to help you if you need them. That helps a lot.” • “You have to believe in the doctors and what they are telling you to do.”
Relationship with Nature	<ul style="list-style-type: none"> • “Nature...things like that keep you grounded and away from the craziness.”
Relationship with God (Transcendent) <ul style="list-style-type: none"> • Prayer • Meditation • Having faith 	<ul style="list-style-type: none"> • “My beliefs...my religious beliefs make me strong, ya know.” • “I say the Rosary. I have been saying the Rosary since I was a little kid and when things don’t go right, I say the Rosary.” • “If I have depression or frustration, then I do some kind of relaxation, like deep breaths.” • “I’m Catholic, so I pray every day.”

in the universe too. Why do you think Star Wars is so popular?” In general, participants thought of spirituality more as a source of strength than as a specific motivator for diabetes self-management. Participants, including those who did not endorse personal importance of spirituality, appeared comfortable with discussing this topic within the context of hope and strength related to coping with chronic illness.

Table 4. Variable Role of Spirituality in Patients' DM Illness Experience

Theme	Range of Responses	Representative Quotations
Personal Spiritual Beliefs and Role in Illness Coping	Not important	<ul style="list-style-type: none"> • "Um ... it really doesn't actually." • "No ... I'm Catholic. But I get my strength from myself and my daughters." • "Not so much for me. I do believe, but I don't practice." • "I don't think I'm spiritual at all."
	Plays some role	<ul style="list-style-type: none"> • "That is a part of me, yes." • "To give you strength." • "See, I believe something powerful is there. We don't know how it's working but it sits somewhere. You understand?"
	Plays an important role	<ul style="list-style-type: none"> • "I'm always praying." • "I read spiritual books all that time. That helps a lot... (in terms of DM). There is a force up there that keeps me going and affects how I feel." • "And there's always intervention, like you were there for L in the supermarket. You weren't there by accident. There's a reason ... Yeah, it was like divine intervention."

that patients are willing to engage in conversations regarding spiritual coping strategies, when the conversation is initiated using a patient-centered approach within the context of sources of strength and hope. Further studies, with larger sample sizes, non-English speaking populations and different settings, need to be undertaken to further clarify the role of spirituality in diabetes chronic disease management.

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CONCLUSIONS

In this exploratory study, participants confirmed the profound impact of diabetes on their daily life¹⁶ and the need for support to help them cope with chronic illness. Although they varied in the role spirituality played in their own lives, all participants appeared comfortable discussing spirituality within the context of sources of hope and strength¹⁷ as they faced the challenges of diabetes, with many describing spirituality as playing a central role in their life. However, in this population, fear of illness complications and family needs seemed to be stronger motivators for diabetes self-management than spiritual/religious belief.

Most studies regarding spirituality and diabetes focus on populations identified as placing a high value on religious practice, such as African American^{18,19} and Latino patients,¹¹ or who present culturally diverse perspectives on health.¹⁰ Findings of our study in an urban, underserved, New England setting suggest that patients with a broad spectrum of personal beliefs (highly religious to secular) are willing to explore spiritual coping strategies, when the discussion is initiated within the context of sources of hope and strength in dealing with their illness, and that for many this is an important and valuable conversation. Study limitations included small sample size, and restriction to English speaking subjects who attended the same clinic.

In order to optimally support patients in their diabetes self-management,¹⁹ we need to identify all possible motivation and coping strategies. This exploratory study suggests

References

1. Norris SL, et al. Self-Management Education for Adults with Type 2 Diabetes: A meta-analysis of the effect on glycemic control. *Diabetes care.* 2002;25(7):1159-1171.
2. Spinale J, Cohen SD, Khetpal P, Peterson RA, Clougherty B, Puchalski CM, Patel SS, Kimmel PL. Spirituality, social support, and survival in hemodialysis patients. *Clinical J Am Soc Nephrology.* 2008 Nov;3(6):1620-7.
3. Leeman J, Skelly AH, Burns D, Carlson J, Soward A. Tailoring a diabetes self-care intervention for use with older, rural African American women. *Diabetes Educ.* 2008 Mar-Apr;34(2):310-7.
4. Deatcher J. Spiritual self-care and the use of prayer. *Diabetes Self Manag.* 2002 Nov-Dec;19(6):57-9.
5. Daaleman TP, Kuckelman CA, Frey BB. Spirituality and well-being: an exploratory study of the patient perspective. *SocSci Med.* 2001 Dec;53(11):1503-11.
6. O'Neill DP, Kenny EK. Spirituality and chronic illness. *Image J Nurs Sch.* 1998;30(3):275-80. Review.
7. Newlin K, Melkus GD, Tappen R, Chyun D, Koenig HG. Relationships of religion and spirituality to glycemic control in Black women with type 2 diabetes. *Nurse Res.* 2008 Sep-Oct;57(5):331-9.
8. Polzer RL. African Americans and diabetes: spiritual role of the health care provider in self-management. *Res Nurs Health.* 2007 Apr;30(2):164-74.
9. Newlin K, Melkus GD, Chyun D, Jefferson V. The relationship of spirituality and health outcomes in Black women with type 2 diabetes. *Ethn Dis.* 2003 Winter;13(1):61-8.
10. Cattich J, Knudson-Martin C. Spirituality and relationship: a holistic analysis of how couples cope with diabetes. *J Marital Fam Ther.* 2009 Jan;35(1):111-24.
11. Welch G, Schwartz CE, Santiago-Kelly P, Garb J, Shayne R, Bode R. Disease-related emotional distress of Hispanic and non-Hispanic type 2 diabetes patients. *Ethnic Dis.* 2007 Summer;17(3):541-7.

12. Quinn MT, Cook S, Nash K, Chin MH. Addressing religion and spirituality in African Americans with diabetes. *Diabetes Educ.* 2001 Sep-Oct;27(5):643-4, 647-8, 655.
13. Kramer H, Dugas L, Rosas SE. Race and the Insulin Resistance Syndrome. *Seminars in nephrology*. Vol. 33. No. 5. WB Saunders. 2013.
14. Anandarajah G, Hight E. Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. *AmFam Physician*. 2001;63:81-89.
15. Borkan J. Immersion/crystallization. *Doing qualitative research* 2. 1999;179-194.
16. Devlin H, Roberts M, Okaya A, Xiong YM. Our lives were healthier before: focus groups with African American, American Indian, Hispanic/Latino, and Hmong people with diabetes. *Health Promotion Practice*. 2006 Jan;7(1):47-55.
17. Underwood LG, Teresi JA. The Daily Spiritual Experience Scale: Development, Theoretical Description, Reliability, Exploratory Factor Analysis, and Preliminary Construct Validity Using Health-Related Data. *Annals of Behavioral Medicine*. 2002;24(1):22-33.
18. Walker EA, Basch CE, Howard CJ, Zybert PA, Kromholz WN, Shamon H. Incentives and barriers to retinopathy screening among African-Americans with diabetes. *J Diabetes Complications*. 1997 Sep-Oct;11(5):298-306.
19. Samuel-Hodge CD, Headen SW, Skelly AH, Ingram AF, Keyserling TC, Jackson EJ, Ammerman AS, Elasy TA. Influences on day-to-day self-management of type 2 diabetes among African-American women: spirituality, the multi-caregiver role, and other social context factors. *Diabetes Care*. 2000 Jul;23(7):928-33.

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