

The Importance of Locus of Control, Health Belief and Empowerment in Determining Self Care Behavior in South Asian Patients with Type II Diabetes: A Qualitative Study

Hashim Mohamed¹, Badriya Al Lenjawi², Paul Amuna³, Francis Zotor⁴

¹Weill Cornell Medical College-Qatar, Senior consultant family medicine, Doha, Qatar

²Hamad Medical Corporation, Doha, Qatar

³Primary care corporation, Doha, Qatar

⁴Greenwich university, United kingdom

Available Online: 25th September, 2017

ABSTRACT

Objective: The aim of this qualitative study was to elucidate culturally relevant psychological, social and disease specific variables affecting life style decision making process of South Asian patients with type 2 diabetes. **Research Design and Methods:** We conducted a series of 20 focus group interviews with 200 adult South Asian patients with type 2 diabetes. Focus group interviews were audio taped and transcripts were coded using qualitative data analysis software. **Results:** The prevalent and most frequent themes that emerged from these interviews were 1) the impact of diabetes manifested in psychological terms "frustrated", fear of complications "wonder if I am next"; 2) concept of religion (God) as an important factor in the course of the disease, complications and fatality; 3) diabetes related stress "being watched" and feeling guilty; 4) patient-doctor interaction manifested in lack of empathy, lack of continuity of care and using medical jargon; 5) improper health education seen in terms of lack of privacy and didactic education; 6) locus of control was external among most respondents "doctors are not helping us"; 7) diet was explained in terms of "bondage" and "nourishing power"; 8) medications intake was a problem in terms of "skipping pills", and the use of insulin as "a punishment"; 9) empowerment was lacking among most respondents "fear of looking at the machine", "we need to sit together in a group"; 10) health belief as an important factor in diabetes management, being in control and belief in efficacy. **Conclusion:** Our findings suggest that factors influencing diabetes management among South Asian patients with type 2 diabetes are best understood by considering religious factors, psychosocial influences and health system related factors.

Keywords: Diabetes, Health care

INTRODUCTION

Diabetes is a serious, complex and debilitating disease which has reached epidemic proportions in South Asian populations including those living in the USA^{1,2}. Classically, educational interventions aim at changing a patient diet and promoting physical activity without taking into consideration psychological aspects. In a meta-analysis of 30 studies of patients suffering from chronic diseases, the authors found that enhancing patient knowledge alone is rarely sufficient to improve adherence to treatment regimens³. Similarly an educational intervention to encourage dietary modification in South Asian patients residing in the UK was also found ineffective⁴. Patient's decision to embrace a desired behavior in a chronic illness such as diabetes is influenced by many factors including locus of control, health belief, being empowered or not, and patient-provider interaction⁵. Other factors like patient's psychological status, peer support, family involvement, significant life events, and attitude, involvement in decision making, health system

setup, and the type and quantity of drugs prescribed also play an important role. Qualitative data related to ethnic minority populations suggests the importance of ethnicity, culture, coping skills, and perceived barriers to self-care playing a significant role in explaining certain behaviors and outcomes⁶⁻⁹.

The State of Qatar is a newly developed country going through rapid socioeconomic transition with a vast influx of different minorities including South Asians over the past 30 years. This has a profound effect on culture, behaviors, beliefs and habits of the people in the country. Consumption of calorie rich food accompanied by sedentary lifestyle became common over the years leading to rising incidence of obesity and diabetes.

To design a culturally sensitive theory based educational program (C-STEP) for South Asian patients with type 2 diabetes patient living in Qatar, we utilized a qualitative study approach to obtain a more detailed conceptualization of how certain psychological and social factors affect self-care behaviors. The study therefore aims to explore the

role of locus of control, health belief and empowerment in determining self-care behaviors.

Research designs and methods

Participants

A total of 430 South Asian participants with type 2 diabetes of more than 1 year were randomly selected from across the country including all primary care health centers and all diabetes clinics in the main general hospital. Invitation/consent letters were sent to all subjects to participate in scheduled focus group discussions at Qatar Diabetes Association main auditorium. The study conformed to the Declaration of Helsinki. The research and ethics committee at Hamad Medical Corporation approved the protocol for recruitment and conducting focus group discussions (Research protocol # 412/2006). Approval was also obtained from the University of Greenwich research ethics committee (UGREC). Out of 430 patients that were contacted, only 215 accepted the invitation to participate in the study.

Data collection and analysis

A series of 20 focus group discussions were held over a one year period each lasting for 2 hours. Interviews were conducted in English and facilitated by a trained and experienced nurse educator of South Asian. Audio taping was carried out by a co-moderator who was present during the discussions. Demographic data was collected during the signing of the informed consent letter to ensure privacy. All interviews were transcribed with simultaneous translation into English by the person who conducted the interviews.

Transcripts were regularly reviewed and discussed to discover emerging constructs and streamline subsequent interviews. The research team assigned a four member team to review all transcripts in details in order to agree broad constructs for analysis. Furthermore, transcripts were also reviewed by five experts in qualitative research - to avoid bias - who also highlighted major constructs and trends among the responses. Consensus among the reviewers formed the basis for generating a list of recurring constructs. From the list, major constructs were selected and a system of code categories (Table 1) was generated for further analysis using the QSRNUD 1st (Non-numerical unstructured Data: Indexing, searching and theorizing; Sage, Thousand Oaks, CA) qualitative data analysis software¹⁰.

Suggested topics for discussion included locus of control, the five basic dimensions as a basis for behavior; perceived severity of illness, perceived susceptibility, and vulnerability to the disease process, perceived benefits (belief in efficacy), cost barriers, and cues to action^{11,12}. In addition, patients' health beliefs, empowerment, autonomy, dietary and exercise behavior, source of stress, patient's perception of their disease, coping mechanisms, family support and quality of life were also looked at.

RESULTS

Impact of diabetes

Having diabetes was viewed by some respondents as a curse who stated; *"this is a disaster"*. Others felt embarrassed about having diabetes especially those

injecting insulin stating that; *"people will look"* at you with raised eye brows when you inject needles. Also if you inject insulin this means that *"kidney wash"* (dialysis) will be inevitable. The majority of respondents expressed physical and psychological ramifications of having diabetes. They felt *"stressed and scared"* worrying about *"who is watching"* what I eat and *"will my sugar go too low"*, *"will I have a coma if I don't eat enough sweets?"*. Others mentioned physical symptoms like *"tired and having headaches"* *'on many occasions, especially when I go for walks"* or *"if I forget to take my insulin"*. The psychological impact of diabetes was stronger and emerged as feelings of being scared *"When I think of my friends and their feet problem, I get scared and wonder if I am next"*.

"Checking my sugar reminds me of the possibility of going blind"

Many participants stated being *"frustrated, fed up and wondered about skipping medications"*. This was due to frustration with the amount, taste and type of medications, the chronicity of the disease, non-curability of diabetes, and the number of injections required on a daily basis.

Concept of God's (Allah) will

The majority of the respondents felt helpless because they believed in the misconception of fate *"no matter what I do, God (Allah)'s wish will prevail, it is my destiny"*

"If it is written that I will live long I will, and if it is written that I will die soon I will".

This abstract of evidence is in stark contrast to the Muslim belief as Holy Quran clearly states; *"The fact is that Allah never changes the condition of a people until they intend to change it themselves"*¹⁴⁰ i.e. it is much like changing one's locus of control from an external one to an internal one.

Patient-doctor interaction

Many respondents described their consultation experience with their doctor as non-satisfactory highlighting barriers to an effective therapeutic alliance, including paper work, medical jargon, and lack of eye contact and continuity of care.

"Doctors are too busy on computers and don't even know if I am looking at them or not".

"Doctors never explain why I am feeling down"

"They talk to you with names of drugs that they know, I don't know what they do"

"Doctors don't know how it feels to be a diabetic".

Improper health education

Most of the respondents agreed with the importance of health education however they complained that it is repetitive, short and too generic. Use of technical language, lack of privacy and outdated leaflets were also not helpful and many patients were unaware of the role of health educators or dieticians. Most patients suggested group based education and more information about self-monitoring of blood glucose.

"Brother, they (nurses) repeat the same story every time I see them"

"Nobody talks about how to protect yourself (prevention), but they are good at pointing out that I will be blind, I will

have a heart attack, I will be on dialysis, it is scary, I don't want to talk to them".

"Every time I want to ask a private question I see another person standing beside me as if I am told to get up, your time is up".

"Doctors and nurses talk a language they understand but we do not & they give us old leaflets thinking we will read them. We usually throw them out the minute we leave"

Stress

A considerable amount of stress was evident among female participants related to the disease and its complications. Three main constructs of stress included, stress related to complications, being in social gatherings, and facing the doctor. Specific terms used included "worry" and "fear" of having an amputation or being on "dialysis" and "loss of vision".

Arab women usually socialize on a regular basis and high calorific food rich in carbohydrates and saturated fat is a common feature in all social gatherings. Respondents expressed their stress in terms of "shame" "letting friends and relatives down" and "embarrassment" by not indulging in food and sometime "fear of being criticized and verbally attacked".

Facing the doctors was another prominent construct described as "Being nervous and fear of being blamed and shouted at by the doctors."

"Sometimes I feel I am going to be next when I see a friend of mine with an amputated toe. It is very worrying you know"

"The ideas of a kidney wash (Dialysis) makes me stressed especially when the nurse keep reminding me it, it's very stressing to hear it time and time again".

"I feel ashamed to tell people I have diabetes, it's a shameful disease, people don't understand how I feel"

"When I think of the doctor's visit I avoid rice that week because I know he will look into my eye and shout"

"Many of my friends invite me to weddings and I have to excuse myself all the time and when I have to go I am always afraid of being attacked by my friends for refusing to eat".

Locus of control

The majority of men in the focus group were having "an external locus of control" i.e. they did not perceive they had great control over their health. They expressed their attitude in terms of

"Doctors are not doing enough, they have studied for many years and still they could not find us a cure for diabetes"., "It's frustrating there is no cure" and "Good medicines are not prescribed to improve diabetes control".

"When people go to Thailand they give them good medicine to cure diabetes".

Diet and nutrition

Diet and nutrition is an important part of Arab culture since most activities culminate with a feast, birthday party, wedding ceremony, new job, passing exams and bereavements. Men see food as an essential part of their life describing as having "a bondage" and a "nourishing power" that bring people together. The food we eat has "power" unlike fruits and vegetables which make you "weak".

"Our parents always told us since our childhood that nourishing food are those which have meat and fat"

"Doctors are always telling us to eat vegetables, do they think we are goats"

Medications (insulin)

Participants acknowledged their difficulty with medications related issues like compliance, amount of medicines to take and side effects. They voiced their concerns in terms of "my stomach feels like a drug store" from all the medicine I am taking every day. Side effects were also cause for concern,

"I feel like I have raw fish in my mouth, especially after taking a big round pill for diabetes".

Other respondents on insulin expressed their feelings as "reached the end of the road", and "being punished"

"I often worry if my blood sugar goes really low I may hit a car, so I usually skip one or two pills a day and sometimes I go one whole day without medicine it seems to be ok to do that".

"Injecting insulin is like a punishment, imagine injecting yourself with needles three to four times a day for the rest of your life, its depressing".

Empowerment through knowledge

Women in the focus group supported the idea of empowerment, and suggested empowerment through knowledge, experimentation and group based education. Empowerment through knowledge could be attained through "Education delivered by nurses & friends". Empowerment through experimentation could be attained through "Fear of reaching high sugar level", "Lack of glucometer" and "Pain associated with checking blood sugar". Empowerment through group based education through " We want to belong to a group to share our feelings "and "Our painful experiences".

"Nurses make me stronger and can help me deal with my diabetes".

"My friends, you know, who have diabetes are experts; they show me how to check my sugar, tell me about ways of dealing with high or low sugar".

Health belief

Perception about the disease and its complication was different between educated and non-educated women. Educated women were more conscious of the seriousness and perceived vulnerability of their disease and coined the term God "Allah" gave me the disease and it is he who is going to take care of it". However perceived benefits "belief in efficacy" was falsely higher among illiterate female respondents "We are in control" "I am living happily and eating what I like, I think I am OK". Similarly cost /barriers to good diabetes care also varied, educated patients responded by saying it was "Lack of time" whereas those who were illiterate said it was the "Cost of good food" that was the barrier.

"Diabetes is non-curable you just have to live with it and do the best you can ,it will not go away by feeling sorry for yourself you know".

"It is easy to control my sugar with pills, you will see I live happily and eat what I want, and I am OK. Don't you think so?"

"Look, I will do anything, exercise, come every day but please no insulin, I hate the idea, my friend went blind after taking insulin".

DISCUSSION

Many significant findings emerged in this study including the impact of diabetes and its complications on life style decisions and psychological wellbeing. Although depression is common in those with diabetes¹⁴, it's usually undisclosed by the patient, frequently not searched for by the health professional who may underestimate its impact on management especially among ethnic minorities. Studies have shown that generic care by primary care physicians failed to recognize 30-50% of depressed patients¹⁵. This view is also supported by the U.S. Preventive Services Task Force (USPSTF) which advocates primary care physicians to routinely screen for depression¹⁶.

The effect of religion is of paramount importance in the lives of European-Arab patients as well as other ethnic minorities¹⁷⁻¹⁹. However unfortunately due to "abstract of evidence", century old beliefs and varying degrees of interpretation of religious teachings the true message is sometime lost placing a huge burden on physicians to provide care and appropriate counseling to rectify such thinking.

Patient-Doctor interactions has a been assessed in many studies including a recent study in Oman that looked at factors influencing Patient-Doctor relationship²⁰. In our study lack of eye contact, body language, medical jargon and empathy were highlighted time and time again. Logistic factors including privacy, phone interruption, time constraints and access to health care were also mentioned. Similar factors were also found in other studies²¹⁻²³ including improper health education in proper management of diabetes²⁴.

Stress was frequently mentioned by respondents in our study due to factors like lack of empathy by physician, being in a social event, family support and diabetes complications. Stress can lead to passivity which can ultimately leads to poor health outcome^{25,26}. However if stress is perceived as source of encouragement, than it can lead to control, satisfaction ,improved physical and mental health^{27,28}.

Patient decision's to take a particular course of action is also influenced by locus of control. Many studies in the literature have addressed the importance of locus of control among ethnic minorities²⁹. A study examining the relationship between perceived control and HbA1C level indicated that perceived control was negatively related to HbA1C level³⁰⁻³¹.

Dietary challenges in controlling diabetes are common among patients including Arabs. Our findings suggests the need for culturally sensitive dietary changes with less emphasis on starch and saturated fats and more emphasis on green leafy vegetables, fiber and proteins. The inclusion of practical ways of cooking and eating such as the "Idaho Plate" seems to be a valid and practical way of eating especially among diabetic patients. A calculated

compromise between dietary compliance and social duties also needs to be addressed in order to control diabetes³². Diabetes is a self-managed chronic disease that requires a patient-centered approach³³⁻³⁶. Empowerment as a philosophy of management places an emphasis on the partnership approach to enhancing self-directed behavior changes of patients³⁷. In order for patients to be empowered they need to acquire certain skills including healthy coping mechanisms, stress management, self-directed goal setting, obtaining social support and maintaining motivation³⁸.

Although empowerment is an essential, other researchers have suggested a move towards a psychological based approach addressing dysfunctional beliefs and modifying emotional responses to diabetes³⁹.

Strengths

Our findings have implications for those in the Arab regions who are interested in designing culturally based educational programs. Qualitative research methodologies employed in our study have enriched our comprehension of social, cultural and religious contexts in which diabetes self-management exists and its influences on self-care behavior.

Weaknesses

Although this qualitative research has highlighted the importance of cultural beliefs, religious and social inputs among South Asian patients with type II diabetes, Qatar has a cosmopolitan population and future studies need to look at other ethnic minorities living in Qatar

Implications for practice

Experience of South Asian patients with type 2 diabetes with their health-care providers were described as unsatisfactory in the State of Qatar. Our data points highlighted a number of patients' concerns and preferences regarding diabetes management. We believe that patients' perceptions, locus of control, communication skills, patient-centred approach and cognitive counselling are must to manage diabetes appropriately. It is important to explore patients' health beliefs, social network, psychological status and religious beliefs to provide optimal care. This is the first study of its kind utilizing qualitative research in addressing cultural and religious factors among South Asian patients with type 2 diabetes in Qatar.

Ethical approval

Ethical approval in accordance with the principles of the 1996 Helsinki Declaration was obtained from Hamad Medical Research Committee, Doha, Qatar. All participants provided informed consent.

FUNDING

This qualitative study was supported by a national fund from Hamad Medical Corporation research department.

DECLARATION OF INTERESTS

The authors have declared no conflict of interests. The authors alone are responsible for the content and writing of the paper.

REFERENCES

1. Kulwicki A: Cardiovascular and Diabetes Survey.1990, Dearborn, MI, ACCESS.
2. Hammad A, Kysia R: Arab-American Primary Care and Health Needs Assessment Survey.1996, Dearborn, MI, ACCESS.
3. Mazzuca SA. Does patient education in chronic disease have therapeutic value? *J Chronic Dis* 1982; 35:521-29.
4. Samanta A, Campbell JE, Spalding DL et al. (1987). Dietary habits of Asian diabetics in a general practice clinic. *Human Nutrition, Applied Nutrition*; 41A:160–163.
5. Samuel-Hodge CD ,et al, Influences on day-to-day self management of type 2 diabetes among African-American Women .*Spirituality ,the multi-care giver role ,and other social context factors .Diabetes Care,2000.23;7,928-933.*
6. Fitzgerald et al. Differences in the impact of dietary restrictions of African American and Caucasians with NIDDM. *Diabetes Educ,1997, 23; 41-47.*
7. Chipkin St, de Groot M: Contextual variables influencing outcome measures in minority population with diabetes mellitus .*Diabetes Spectrum 1998,11:149-160.*
8. Bell RA, Summerson JH, Konen JC. Racial differences in psychological variables among adults with non-insulin dependent diabetes mellitus. *Behav Med, 1998, 21; 69-73.*
9. Gilliland SS et al: Recommendations for development and adaptation of culturally competent community health interventions in minority populations with type 2 diabetes mellitus. *Diabetes Spectrum 1998, 11:166-174.*
10. Sage publications software: QSR NUD*IST .Thousand Oaks.CA, Sage, 1997.
11. Becker M. H. (1974) The health belief model and personal health behavior. *Health Education Monographs,2:324-508.*
12. Becker M H ,Maiman LA. Socio behavioral determinants of compliance with health and medical care recommendations. *Med Care 1975; 13:10-23.*
13. Garvard J, Lustman P, Clouse R .Prevalence of depression in adults with diabetes: an epidemiological evaluation. *Diabetes Care1993; 16:1167-1178.*
14. Simon GE, Vankorff M. Recognition, management and outcomes of depression in primary care .*Arch Fam Med 1995;4:99-105.*
15. Sharp LK, Lipsky MS .Screening for depression across the lifespan: a review of measures for use in primary care settings .*Am Fam Physician 2002 sep15;66 (6):1001-8.*
16. Wilson-Ford V: Health-protective behavior of rural black elderly women .*Health and Social Work 1992, 17:28-36.*
17. Degazon CE: Coping, Diabetes, and the older African-American .*Nurs Outlook 1995,43:254-259.*
18. Ford ME, Tilley BC, McDonald PE: Social support among African American adults with diabetes: part2: a review, *J Natl Med Assoc 1998; 90:425-432.*
19. Abdulhadi N, Al-Shafae M, Freudenthal S ,Osteson CG ,Wahlstrom R. et al . Patient provider interaction from the perspectives of type2 diabetes patients in Muscat, Oman: a qualitative study .*BMC Health Serv Res 2007; Oct9;7:162.*
20. Van Dam HA ,van der Horst F, van den Borne B ,et al .Provider-patient interaction in diabetes care :effects on patient self-care and outcomes .a systematic review[J].*Patient EducCouns,2003,51:17-28.*
21. Mead N, Bower P: Patient-centeredness: a conceptual framework and review of the empirical literature. *Soc Sci Med. 2000 Oct, 51(7):1087-1110.*
22. Street RL Jr, Gordon HS, Ward MM, Krupat E, Kravitz RL. Patient participation in medical consultations: why some patients are more involved than others. *Med Care. 2005; 43(10): 960-969.*
23. Simmons D, Weblemoe T, Voyle J et al .Personal barriers to diabetes care: Lessons from a multi-ethnic community in New Zealand .*Diabetes Med 1998; 15:958-964.*
24. Brown JB, S Harris SB, Webster-Bogaert S, Wetmore S, Faulds C, and Stewart M. The role of patient, physician and systemic factors in the management of type 2 diabetes mellitus. *Family Practice (2002) 19 (4): 344-349 doi:10.1093/famp/19.4.344.*
25. Lawson VL , Lyne P.A. ,Harvey J.N. et al, Understanding why people with type 1 diabetes do not attend for specialist advice: a qualitative analysis of the views of people with insulin-dependent diabetes who do not attend clinic .*J Health Psychol 2005;10:409-423.*
26. Heijmans M. The role of patients' illness representations in coping and functioning with Addison's Disease.*Br J Health Psychol 1999;4; 137-149.*
27. Rutter CL, Rutter DR. Illness representation, coping and outcome in irritable bowel syndrome(IBS).*Br J Health Psychol 2002 Nov;7:(Part 4):377-391.*
28. Helder DI, Kaptein AA, Van Kempen GM, Weinman J, Van Houwelingen HC, Roos RA. Living with Huntington's disease: illness perceptions, coping mechanisms, and patients' well-being. *Br J Health Psychol 2002;7:449–462.*
29. Morowatisharifabad MA ,Mahmoodabad S.S.M, Baghianimoghadam M.H. and Tonekaboni N.R. Relationship between locus of control and adherence to diabetes regimen in a sample of Iranians. *Int J Diab Dev Ctries. 2010.Jan-March ;30(1): 27-32.*
30. Maccrodimitris SD, Endler NS .Coping, control and adjustment in Type2 Diabetes .*Health Psychol 2001; 20:208-16.*
31. Surgenor LJ, Horn J ,Hudson SM ,Lunt H, Tennes J .Metabolic control and psychological sense of control in women with diabetes mellitus. Alternative considerations of the relationship .*J Psychosom Res 2000 Oct;49:267-73.*
32. Greenhalgh T, Helman C, Chowdury AM .Health beliefs and folk models of diabetes in British Bangladeshis. A qualitative study.*BMJ1998 March 28; 316 (7136):978-983.*
33. Anderson RM: Patient empowerment and the traditional medical model A case of irreconcilable differences? *Diabetes care1995, 18 (3); 412-415.*

34. Anderson RM, Funnell MM: Patient empowerment: Reflection on the challenge of fostering the adoption of a new paradigm. *Patient Educ Couns* 2005, 57:153-157.
35. Anderson RM, et al: Patient Empowerment: results of a randomized controlled trial. *Diabetes Care* 1995, 18:943-949.
36. Funnell MM, Tang TS, Anderson RM .From DSME to DSMS: Developing empowerment-based diabetes self management support .*Diabetes Spectrum* ,Oct 2007; 20;no.4, 221-226.
37. Arnold MS et al. Guidelines for facilitating a patient empowerment program . *Diabetes Educ* 1995, 21:308-312.
38. Harvey JN, Lawson VL. The importance of health belief models in determining self-care behavior in diabetes .*Diabetic Medicine*, 2009; 26 (1):5-13.
39. Mohamed H, “Culturally sensitive patient-centered educational program for self-management of type 2 diabetes: a randomized controlled trial”. *Prim Care Diabetes*. 2013 Oct;7(3):199-206. doi: 10.1016/j.pcd.2013.05.002. Epub 2013 Jul 3.
40. The Quran. Surah 13. Ar-Ra'd, Ayah 11.