

## **Identifying needs and barriers to Diabetes Education in Patients with Diabetes**

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### **Abstract**

**Objective:** To assess the needs, awareness and barriers to diabetes education for self management and to facilitate the initiation of an education programme promoting self care among diabetics and their families.

**Methods:** A qualitative study was conducted among adult diabetics attending outpatient clinics in a tertiary care teaching hospital in Karachi, Pakistan. Semi-structured interviews were conducted on 27 subjects (11 men; 16 women) to identify dominant themes and priority issues.

**Results:** Participants displayed great deal of variation with respect to level of knowledge and motivation for education. Most believed that diabetes was caused by stress. Family was perceived to be a source of positive support. Relative ease of adherence to pharmacological regimens as compared to diet and exercise was reported. Participants expressed frustration at chronicity of disease and fear of developing certain specific complications and inheritance by their children. Barriers to enhancing knowledge included 'No need for further information', distance from training institutions and other priorities.

**Conclusion:** Knowledge, beliefs and fears about diabetes, family influence and accessibility of healthcare, affects management behaviours and learning. Understanding needs and expectations of people with diabetes is essential in initiating and improving the outcomes of education programme for diabetes self care (JPMA 56:347;2006).

### **Introduction**

Demographic projections by the World Health Organization (WHO) and the Center for Disease Control and Prevention (using 1995 prevalence data from Pakistan's National Diabetes Survey<sup>1</sup>) estimates an increase in adults with diabetes in Pakistan from 4.3 million in 1995 to 14.5 million in 2025 making Pakistan the fourth highest country.<sup>2</sup>

It is therefore, imperative for Pakistan to implement optimum diabetes management strategies. At a global level, diabetes self-management education has long been considered a cornerstone of diabetes therapy coupled with pharmacological treatment. However, for the vast majority of Pakistani patients, knowledge of their condition remains low. Jabbar et al. from outpatient clinics in Karachi, found significant knowledge gaps in key areas, including insulin administration.<sup>3</sup> Similar results were reported in a study from an outpatient clinic in Quetta where 77.11% of diabetic patients had no knowledge of diabetes and its complications.<sup>4</sup>

In developed nations, patient education has been part of diabetes therapy since 1930s.<sup>5</sup> Norris et al. systematically reviewed 72 randomized controlled trials investigating diabetic education and found positive effects of self-management training in type-2 diabetes, particularly in short term follow-up.<sup>5</sup> However, knowledge alone is insufficient to bring about behaviour change<sup>6</sup> and patient's health

attitudes and personal barriers to diabetes care are influenced by social, cultural, socioeconomic and healthcare system factors.<sup>7,8</sup> The identification of underlying reasons for variations in attitudes and behaviours is increasingly being recognized as an essential element for designing and evaluating diabetes education programmes.

Traditional quantitative methods are inappropriate to address questions related to a situation or behaviour, which require a qualitative approach. As Greenhalgh<sup>9</sup> puts it, qualitative research studies address questions that tend to begin with "What," "How," "Why," or "In what way does."

Qualitative research studies provide important insight into health related phenomenon and are particularly useful in understanding diabetes-related attitudes and behaviours. Such studies facilitate in defining the best approach to patients from different ethnic or social groups. Qualitative studies have explored diabetes self-management practices and beliefs of Pacific Islanders,<sup>10</sup> Native Americans,<sup>11</sup> African Americans,<sup>12</sup> urban Caribbean Latinos<sup>13</sup> and Vietnamese diabetic patients.<sup>14</sup> Greenhalgh et al. used a variety of qualitative techniques to identify beliefs and behaviours in British Bangladeshis with diabetes.<sup>15,16</sup>

The purpose of this exploratory qualitative study was to identify care and education issues among persons with diabetes visiting outpatient clinics at a leading tertiary care teaching hospital in Karachi. It not only assessed the

individual's knowledge about their illness and their educational needs, but also their willingness to learn.

## Methods

An exploratory, descriptive research design utilizing a semi-structured interview technique was used. An interview question guide, pertaining to various aspects of living with diabetes, was constructed. Wherever appropriate, wordings of questions available in published literature were employed.<sup>10,12,13</sup> The guide was then translated into Urdu, the national language, for the interviews.

Eleven men and sixteen women were randomly selected from a larger study looking at knowledge, behaviour and practices amongst persons with diabetes. The purpose of this study was explained to participants, with an assurance that responses would not influence treatment at the hospital. Selection criteria included - previously diagnosed with type 1 or type 2 diabetes; age 18 years or older; Pakistani national; attending outpatient clinics at either the Community Health Centre or the Endocrinology Consulting Clinics at the selected hospital; and provided voluntary informed consent. Fourteen participants were recruited from the Community Health Centre and 13 from the Endocrinology Consulting Clinics.

Interviews were conducted by one investigator, in the language decided by the participant (two interviews in English, and twenty-five in Urdu). To reduce participant intimidation, responses were transcribed during the interview using shorthand and details filled in immediately after the interview.

The interview guide and specifically placed probes were used only to facilitate the interview and participants course of the dialogue was not forcefully redirected.

## Organization and Analysis of data

Interviews, including those in Urdu, were transcribed in English. A Codebook was constructed using descriptive headings to consolidate every independent thought unit (word, phrase, sentence or paragraph). Each code thus became a frequency table, which was analyzed for the five predetermined themes: (i) Knowledge of diabetes; (ii) Management issues; (iii) Social Aspects of Living with Diabetes; (iv) Fears and Emotions; and (v) Diabetes Education. Data analysis and presentation methods used by key published qualitative studies, particularly those of Wang et al.<sup>10</sup> and Anderson et al.<sup>13</sup> were emulated.

## Results

The mean age of the 27 respondents was 44.4 years (age range of 18 to 70 years - Table 1). The first diagnosis

**Table 1. Characteristics of the interviewed subjects.**

	Men (n=11)	Women (n=16)
Age (years):		
18-30	1	2
31-50	8	7
51-70	2	7
Education:		
Illiterate	1	4
Primary	0	4
Secondary	3	2
Intermediate	0	4
Graduate	7	2
Type of Diabetes:		
Type 1	1	2
Type 2	10	14
Duration of Diabetes:		
< 1 year	1	3
1-5 years	5	3
6-10 years	3	5
>10 years	2	5
Type of treatment:		
Oral medication	9	8
Insulin	1	6
Oral + insulin	1	2

of diabetes was either, on visiting their physicians with symptoms (7 men, 11 women), during hospital admission (2 men, 3 women), or during pregnancy (2 women). Two men, however, reported being diagnosed at a public health screening camp.

The following paragraphs summarize the different thought units, with patient frequency presented in round brackets ( ).

## Knowledge of diabetes

Knowledge varied significantly, from lack of understanding of the term "diabetes" to participants requesting information on stem-cell transplants.

Only three men and two women correctly stated having type-2 diabetes; others described it as "the type in the blood" and "the type that you get from your parents". Men displayed better knowledge than women. Two men displayed exceptional knowledge acquired through extensive reading, seven had acceptable and two had little information about their condition and its complications. Comparatively, only two women had good knowledge, eleven had some information and the remaining three had very poor knowledge. While knowledge corresponded with longevity of disease, educational status appeared to be the

single most important factor associated with the level of knowledge.

The most dominant theme was the association of stress or worry with diabetes, either as a cause or a precipitant of acute symptoms (13). Other causes included heredity or genetics (9), poor dietary habits, sweets or obesity (7). Only four participants were aware that diabetes is a disorder of the pancreas.

Almost all participants (26) were aware that diabetes caused multiple complications. Those with complications were more knowledgeable of their condition and its management. Commonly mentioned complications were kidney disease (14), eye disease (10), heart disease (6) and stroke (6). An uncommon yet important theme was the sentiment that awareness was based on actual occurrence (4). As one participant pointed out "I was never told about the consequences of diabetes. No one had ever mentioned to me, that this could happen (erectile dysfunction). I only discovered it after it happened".

### Management issues

Commonly reported symptoms were pain in the feet (9), weakness or fatigue (8), vision changes (5), chest discomfort (4), sweating (4), sleep disturbance (4), anxiety (3) and dizziness (3). However, two individuals reported to be completely asymptomatic.

Many participants felt their diabetes was not optimally controlled (9), while some felt they were in control most or all of the time (5).

All participants expressed relative ease of adherence to pharmacological regimens. Eight participants reported ease in adhering to dietary regimens, against twelve who expressed difficulty; others followed advice only when blood sugar control was poor. Six participants adhered to recommendations regarding exercise (mainly walking), while others were either irregular or did not exercise at all. Seven respondents felt that they got enough exercise through routine work and did not need additional physical activity; (key barriers to lifestyle modifications listed in Box 1). In both men and women lower educational level and poor knowledge about the disease was associated with poor compliance and poor control. Of the participants reporting good compliance and good diabetes control (4 men; 4 women), all men and three women had higher education while three men and three women had good knowledge.

Eight participants accentuated the importance of understanding their condition and adapting self-care in diabetes management. Participants were also aware that uncontrolled diabetes can lead to complications; one woman stated "It is very important to know about diabetes so that we can take care of it. After all diabetes is taken care

#### BOX 1

##### THEMES PERTINENT TO LIFESTYLE CHANGES

###### Difficulty in following dietary advice:

"If something [sweet] is offered to me then I cannot resist at all."

"Because I am single I eat outdoors, so you can imagine my diet management"

"In terms of diet, I've been told low diet, low cholesterol, but I have not been told specifically what I should or should not eat"

###### Barriers to exercising:

"Even if I walk a little, my body starts to hurt"

"The doctor has told me to walk, but where should I walk? I live on the 3rd floor, going up and down hurts the ankles. So basically my exercise is the work I do at home"

"I do not get time to exercise"

###### Effectiveness of lifestyle intervention:

"I think exercise and diet have made a big difference [to my diabetes control]"

"For 8 to 10 years, I never had to eat a single tablet for my diabetes. It [Exercise] would keep it in absolute control"

##### THEMES PERTINENT TO FEARS AND EMOTIONS

###### Feeling of dejection at the chronic nature of the condition:

"These things [diet and exercise] would be of benefit if the illness came to an end, or even decreased. But now I know that this illness is around for good "

###### Resentment and frustration at not being in control in spite of best efforts:

"My father also had diabetes. He used to be very adherent [to diet and medication]. But despite this he died of a stroke. Since then, I have become non-adherent. I think, what is the point?"

###### Fear of complications:

"There is psychological stress.....to know that so many people with diabetes have died of heart attacks....I am most afraid of heart attacks that come without pain...sudden death"

"I am afraid for my eyes. My cousin lost her eyesight recently"

"When we see whole fingers...or kidneys being destroyed it scares us, and that makes us more worried"

of only by the individual who has it".

Two participants were, however, sceptical of preventative advice in the absence of symptoms. One man stated "The doctors just told me about how to take care of my feet. But I don't really understand why. I already keep them clean".

Despite doubts about the effectiveness of alternative or traditional herbs and medicines, five participants reported visiting traditional health providers with the hope of cure. One participant reported visiting a 'peer' based on a newspaper advertisement. However, all of them stated that the therapy had not been useful. As one participant stated, "I tried 'desi' (traditional) medicines as well, in the beginning, but they didn't work. I also tried ayurvedic, purees, etc. but nothing works"

Another prominent theme was the trust and respect that participants had for their physicians; only one patient expressed an overtly negative experience. One man and one

## BOX 2

### THEMES PERTINENT TO EDUCATION

#### **Doubt about the usefulness of education programme:**

"I don't really feel the need to learn much because my son already knows and he takes good care of me"

"I know what I need to know. Whenever I lose control, it's not because of lack of knowledge but just lack of will"

"I have come to a sort of balance. I do what I do. I don't really have the energy to try anything new"

#### **Fear of being overwhelmed and not being able to comprehend what was being communicated:**

"I am not an educated person. I do not even understand. The doctor tries to tell us things, like its causes, but we don't understand"

"Classes should be arranged for people like yourself [educated] but for us [illiterate] it will not hold any benefit"

#### **Family/Friends as a source of diabetes knowledge and information:**

"I have knowledge because my mother had diabetes. I was the one who used to go with her to the doctors. So in her care I learned about sugar. She would not take care of her sugar herself, so I was the one who would treat her"

"My daughter is a nurse. I learned a lot from my daughter. At first, she used to do all the monitoring and injecting and things, but now I can do them myself"

"I also have discussions with other diabetic patients. We sit around and compare notes about different doctors, and different medicines"

woman expressed difficulty in discussing certain issues with doctors of the opposite sex.

## Social aspects of living with Diabetes

A dominant theme was the positive support by family members (23), including, helping with adherence to recommended diet (6), providing moral and mental support (5), taking over household chores (4), visiting the clinic (5), sharing diabetes information from their own knowledge or experience (3), providing physical care e.g., massage (3), and being a positive role model of good self-care (1). As one person pointed out "Mentally, they (family members) kept me from feeling low".

In contrast, only four participants reported lack of family support as their children were too busy with their own lives.

As many as two-thirds of the patients (18) stated that diabetes had negative consequences in creating household concerns, coping at work due to fatigue, and reduced social meetings. One participant associated diabetic complications with his inability to maintain employment or get married.

## Fears and Emotions

Themes relating to fears and emotions associated with diabetes are listed in Box 1. Interestingly, the most frequently expressed fear or concern was that of inheritance by their children (7); all reported having had their children tested. Several participants reported fearing complications,

especially heart attacks (2), eye problems (2), death (2), and infertility (1). Six participants expressed no fears.

Another commonly expressed emotion was anger or frustration, particularly in association with the knowledge of diabetes as a chronic disease with no imminent cure (6), and the experience of failing to maintain control or avoid complications despite adherence or best efforts (5).

## Diabetes Education

Most participants recognised that significant improvement in their lives can occur by diabetes education and learning self care. As one person commented "Of course diabetes education is very important. Half of treating diabetes is education".

The most commonly mentioned source of diabetes knowledge and information was their physician (20); in some cases the exclusive source (4). Many participants (16) consulted written material, including newspapers, magazines, books, medical journals and booklets; one participant used the internet while another used audio/video cassettes for additional information. An important source of education was family members who either had diabetes themselves (6) or were health professionals (6). Other useful teachers included friends with diabetes (3), nurses (2), and experience gained through caring for parents with diabetes (2). Two participants had previously attended diabetes education classes.

Thirteen participants expressed interest in formal diabetes education, while 10 women and 4 men were not interested. The most common reasons for those not interested were 'living too far away from the hospital' (9), 'cannot come alone' (6) and 'having no free time as a result of taking care of children or job commitments' (5). Older women with little or no formal education and dependent on family members were least interested in furthering knowledge. Two educated women and two men, having long association with diabetes felt they had enough knowledge to deal with their condition.

The most common purpose for formal diabetes education was, 'wanting information on primary prevention that they could share with their children, friends and family members' (6). One participant stated he would bring his younger, non-adhering friends to the clinics, to help them prevent the complications he was now experiencing. Given the chronic nature of diabetes, participants wanted to learn about research efforts aimed at developing a cure (4). Other desired information was on 'how to avoid complications', 'causes of particular symptoms', 'effects of aging with diabetes', 'whether it will affect children', 'whether it will affect fertility', 'why sugar levels fluctuate', 'care in pregnancy', and 'causes of diabetes'.

Suggestions regarding structure, accessibility, timing and format of diabetes education methods included group sessions, between 1-2 hours, involving children and family members; some thought that inviting friends with diabetes would help to reduce transportation costs; individuals with more advanced complications recommended adapting multidisciplinary approach involving dieticians and psychiatrists along with the diabetes specialists. Few wanted sessions attached to their checkups whereas others opted for classes once a month.

## Discussion

In assessing the needs and barriers for delivery of quality diabetes education, the foremost consideration is the diversity of patient population from multiple perspectives, including education, levels of knowledge, management practices, disease control, and importance of diabetes education. Thus Educators and training materials need to be versatile to respond to this tremendously heterogeneous population.

Half the participants associated emotional stress with occurrence of diabetes; this was also observed in Vietnamese diabetic patients who identified 'worry' and 'sadness' brought on by stress as a cause for their disease.<sup>14</sup> Many participants blamed stress as the underlying reason for loss of glycaemic control and decreased adherence during these periods; stress seems to provide an easy "excuse" for justifying non adherence. Given the need for support at such times, it is necessary that assistance and counselling is incorporated into diabetes education programmes.

Non-compliance with defined management practices requiring lifestyle behaviour changes was reported by many participants, which is consistent with the findings of Glasgow and colleagues.<sup>17</sup> Similarly, Wang et al.<sup>10</sup> identified socio-cultural practices leading to dietary non-compliance and lack of motivation for exercise as important factors. Our study also highlighted the socio-cultural factors hampering change, especially for women, such as non-availability of socially appropriate facilities close to their homes where they can exercise. It is therefore necessary for educators to identify settings and facilitate support groups to promote behavioural change.

In their quest for cure, participants visited traditional healers and tested herbal therapies even though they doubted the effectiveness of alternative remedies. The use of eastern (herbal) medicine was also seen in Vietnamese patients<sup>14</sup> who believed that it lacked the harmful side effects of western medicine, while some believed that it could cure their disease. Similar to our study, Vietnamese patients also abandoned eastern medicine after their serum

glucose levels soared. Considering the misguided claims of providing cure made by quacks and possible harm from raised blood sugar levels for long periods, discussion on effects of alternative therapies should be part of diabetes education.

Most participants identified their families as a source of positive support in the management of their diabetes. This is in contrast to the study by Anderson et al.<sup>13</sup> on Latinos with diabetes, where lack of family support was one of the most dominant psychosocial issue.

An important consideration emanating from the study was that patients were community-centered or family-centered individuals. Participants' fear of their own potential complications was equally matched by the fear of diabetes in their children. Thus the desire for acquiring knowledge for protection of their children. This cultural strength prevalent in society must be incorporated in the curricula to enable those with diabetes to become advocates for primary prevention within their families and communities.

The most alarming factor is the association of awareness of complications with actual experience. The importance of making such information available to the patient early in the diagnosis and treatment cannot be overemphasized and highlights the inadequacies of available diabetes education.

Another central challenge for educators is the pre-contemplative nature of many patients with respect to motivation for education. It is critical to not only reach those that desire education but more importantly those who have reconciled with the disease or feel helpless against it. The curricular should create an effective balance between intellectual appeal and practical usefulness to cater to this diverse group.

In contrast, certain participants expressed high enthusiasm for knowledge seeking updates on research findings, although not directly associated with self-management practices. Colagiuri et al. found that while it may be important for patients to set their own priorities, education directed solely at patient priorities leaves knowledge deficits that would compromise diabetes care.<sup>18</sup>

As observed in a study of Bangladeshi immigrants,<sup>15</sup> most of our participants identified their doctors as the primary source of diabetes information. However, with high patient volume, it is unlikely that physicians are the most effective medium of patient education; Shera et al.<sup>19</sup> in their survey found that family physicians spend a mean of 8.5 minutes per case. The trust that patients have in physicians must be channelled towards allied health professionals that may be able to fulfil this role more effectively. The development of specialized diabetes educators and their

acceptance by patients will be crucial in the delivery of quality education.

Many participants were dependent on family members for followup visits. The issue of regularity of visits and continuity of care can be another challenge as it is dependent on access to healthcare, willingness of the individual and investment in health care which is generally the last priority for many. It is therefore a natural conclusion that unless a patient is adequately educated about the disease she or he would not necessarily exercise appropriate care.

### Conclusion

The study strongly endorses the need for a vibrant education programme to address the diverse patient population, identifying key strengths and weaknesses associated with socio-cultural factors that should inform the curricula formation and engaging allied health professionals with emphasis on specialized diabetes educators in imparting diabetes education, to supplement the effort of the physician.

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