Socio-psychological Perceptions & Experiences of Etiology amongst Type II Diabetics; A Qualitative Study of Primary Health Care in Rural Sargodha

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The presented study explored the patients' perspectives and experiences regarding the cause of illness (etiology) and mode of onset. The study aimed to understand the socio-psychological factors that lead to certain decisions in terms of reaching the health facility for diagnosis and treatment. The study used the theoretical framework of patients' explanatory model of Arthur Kleinman (1978). The study was conducted in Chak 104 North Bound Sargodha by using District Health Information System. The above mentioned locale was found to have most number of diabetics without any outreach. An in-depth interview guide was designed based on preliminary field work and informal interviews with the registered patients in the catchment area of Rural Health Center (RHC) Chak 104 NB. The in-depth interviews were conducted with (N=71) adherent and non-adherent male and female diabetic individuals. The study found that most of the respondents related their illness with trauma, tragic episode(s) and experiencing grief and sadness. Respondents related the cause of diabetes with the death of a family member, downfall in business and experience of certain domestic and financial issues. The findings of the current study are consistent with various studies references, and it has implications for the stakeholders and primary health care providers the perceptions and experiences of the diabetics for capacity building and contextualizing the diabetes care in the rural areas of Punjab, Pakistan.

Keywords. Diabetes care, socio-psychological factors, etiology, type 2 diabetes, primary health care

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Diabetes Mellitus (DM) has become an emerging concern in public health. DM is one of the most chronic, common and increasing non-communicable diseases in the world, which has serious medical and economic consequences (Shaw, Sicree, & Zimmet, 2010). The prevalence of diabetes is at a rise and so are the related multiple complications.

People from South Asian and the Black-African descent have a two to four times increased likelihood of having Type 2 diabetes mellitus (Diabetes UK, 2017). However it is not all due to the genetic predisposition it can also be the influence of personal circumstances, which helps to explain the comparatively latest rise in the prevalence of diabetes in these groups. The socio-psychological and economic factors also seem to influence the prevalence of diabetes in various areas. Out of every three patients of diabetes, two are living in urban areas. Also there is a disproportionately increased effect in the lower socio-economic classes. Although the reasons behind these are still not clearly understood, however an important mediating factor could be there i.e. unhealthy lifestyle. Recent economic growth and urbanization in the lower-middle-income countries around the globe, have led to their larger contribution to prevalence of diabetes possibly due to recent changes in lifestyle and longevity (Nijpels, 2016). Physical inactivity is also known to be a risk factor for type 2 diabetes mellitus (Joslin Diabetes Center, 2017).

Approximately 7 million people in Pakistan were estimated to be living with diabetes in 2014 (Hakeem & Fawwad, 2010). This figure was estimated to reach about 11.4 million by 2030 (Khuwaja, Khowaja, & Cosgrove, 2010). Pakistan is ranked 7th in the world for diabetes prevalence; one of the major causes for this ranking is the poor utilization of primary healthcare services (Hakeem & Fawwad, 2010).

Various psychosocial factors play a part in the causes that people state for type 2 diabetes, and for not seeking or adhering to its treatment. Although depression is one of the outcomes of type 2 diabetes, it has equally been stated to have been playing a role in

its risk factors (Knol, et al., 2006). A study states that certain psychosocial factors such as emotional distress, exposure to life stress, more specifically job strain and work stress, early life adversity, and certain personality traits such as hostility are liable to cause type 2 diabetes (Hackett & Steptoe, 2016). Perceived mental stress tends to affect men more as compared to women in terms of being susceptible to type 2 diabetes (Kato, Noda, Inoue, Kadowaki & Tsugane, 2009).

Although many patients are unsure about the causes of diabetes, their perceptions are often influenced by their cultural and religious values. In another study conducted in Ethiopia, emotions and congenital characteristics such as rage, anguish etc. appeared to be the most common causes among the patients of type 2 diabetes. Many patients associated the occurrence and the initial point of their illness with sudden fury, an emotional episodic event, or with long-term sorrow and misery (Habte, Kebede, Fenta, & Boon, 2016).

Directorate General Health Services (DGHS) Punjab, along with the support of other technical and developmental partners, undertook an intervention development and evaluation activity in order to deliver integrated diabetes care at primary as well as secondary level health facilities. The care package after being evaluated is being implemented in all districts of Punjab through public funding. This implementation will make the diabetes care available at all sub-district hospitals and rural health centres.

Services provision, however, does not lead to service utilisation. It is a known fact that in order to improve medical care, a more in-depth understanding and knowledge of local cultures and perceptions is a must (Glover, 2009). Realizing the impact of the various other factors on health, it seems to be essential that to ensure the success of any health intervention it is a prerequisite to study in detail all the possible determinants that could affect the health intervention. It is therefore necessary to understand the socio-cultural and psychological factors that are likely to play a

vital role in determining the health of the patient and the treatment given to the patient. Diabetes being a lifelong disease needs management for life (Federation, 2013). Therefore any intervention designed for care of such long-term disease should be sensitive to the socio-cultural and psychological environment of the population. This study is therefore an attempt to understand the perceptions of individuals with Type II diabetes; it may lead to a better understanding for various stakeholders at primary health care level. Our study will help enhanced use of these services being made available, by better understanding the socio-psychological factors affecting individual decisions to access and use care.

The *National Action Plan* for prevention and control of non-communicable diseases and mental health promotion in Pakistan holds a significant action agenda with priority action areas for diabetes. Both prevention and control of diabetes is not just relevant but is also becoming a dire need for the Action Plan to fill the void between academic researchers and administrators and policy makers for the overall betterment and improvement in health outcomes. The findings of the current study will help in developing evidence based strategies.

The current study also holds a significant relevance as there is hardly any diabetes interventional trials conducted in the native settings of Punjab, Pakistan. The diabetes care does demand a strong research support to understand the perceptions and adherence (at large) towards the proposed treatment (in local settings).

Theoretical framework

According to the champions of explanatory models (Kleinman, Eisenberg & Good, 2006), biomedicine dominatingly considers biological perspective as more real and clinically significant as compared to the other part of the ill health (i.e., social, cultural and psychological data. Disease though generally considered a wider phenomenon is actually the other way. The illness whereas, is wider, diffused, complex and is patterned by

socio-cultural and psychological factors. Kleinman (1978) used explanatory models in medical care, especially to microscope diagnosis and treatment (both success and failure) by bisecting patients' and providers' perspective (on the same disease and its treatment). Several other authors have endorsed the practicality of the explanatory models towards understanding of adherence issues and comprehension to physician's instructions. The socio-cultural and psychological construct of ill health is important analysis as stated by Engel as the meaning of the patient's report in psychological, physiological and biological terms. Social and cultural origins are important discovery that effects the overall adherence to the treatment such as trauma or stress, domestic responsibilities and occupational functions etc. (Zola, 1966).

The current study focused on the patients' explanatory model to explore the lay perceptions and experiences of the patients before reaching the health facility. This study also contributed in contextualizing the general socio-psychological factors that shaped the decision making of the patients in terms of selecting the treatment, acceptance of the biomedical label of type 2 diabetes and adherence to the treatment offered at the health facility. The etiology was adopted from the abovementioned model and operationalized as towards the understanding of how this disease has happened to the respondents? Also traditional and indigenous reasons to understand the cause of diabetes? In this case it encompassed various factors including economic pressures, social incidences that influenced the decision making towards seeking the treatment.

Method

Research design

The current study was exploratory and the data was collected through qualitative tools including participant observation, key informants, in-depth interviews.

Participants

The current study was conducted in the village 104 North Bound (NB) commonly known as *Chak 104 Shumali*. *Chak 104 NB* was given the title of Model Village of Punjab in 1965 by General *Musa Khan*, the then Governor of West Pakistan. The researcher used the District Health Information System (DHIS) Sargodha initially to understand the ongoing scenario regarding the non-communicable diseases in particular and performance evaluation of the selected heath facilities (as a pilot intervention for diabetes care). The DHIS has given an 'A' grade to RHC 104 NB on the basis of its functioning and commitment of the staff. The health facility had 71 registered patients of diabetes (who were offered the diabetes care package) as per the intervention. The researcher used the RHC 104 NB to enter the catchment village known as *Chak*104 *Shumali*.

The researcher collected data from Non-Communicable Disease card(NCD) at RHC 104 NB to further identify the respondents from the registered patients. The researcher met (informally) all of the registered patients (male and female). The patients were divided into four categories for the ease and understanding of the selection of participants of the study. The categories are adherent females, adherent males, non-adherent females and non-adherent males. The researcher interviewed $N=40$ ($n=10$ each group) patients from each category using the purposive sampling technique to understand their respective experiences and perceptions regarding Type II diabetes before they got labeled (diagnosed and registered) at the abovementioned health facility. Adherence was operationalized as at least four follow-up visits (excluding the registration), out of the required eight visits were considered as adherent to the treatment. Moreover, the current study had two key informants (i.e., Lady Health Worker & RHC paramedics) who helped understand the catchment area of RHC 104 NB. The key informants greatly helped in interpreting the local terms, issues and other related challenges. The key informants also assisted in correctly identifying the diagnosed and registered type 2 diabetics (at RHC).

The characteristics of the study population (registered patients) are tabulated below, and presented in terms of gender segregation, number of adherents and non-adherents (both male and female – as per the intervention protocols), education, age and follow-up visits (as scheduled and reminded by the public health facility).

Table 1

Frequency Distribution of gender and adherence of the participants (N=71)

	Gender				Total	
	Female		Male			
	f	%	*f*	%	*f*	%
Adherents	21	52.5	20	64.5	41	57.8
Non adherents	19	47.5	11	35.5	30	42.2

The table above pictures the number of male and female patients registered at the RHC 104 NB. The registered female patients are greater in number as compared to the male patients mostly due to the sedentary lifestyle, limited social circle, domestic responsibilities (mostly inbound), patriarchy and stress. The male patients were found to be active in wider social circle; hadability to decide for health due to financial liberty; enjoyed more power in the domestic hierarchy; and engaged more in mobility and activity.

The table also reflects the number of adherent and non-adherent patients as segregated in terms of gender. It is found that the male patients were more adherent as compared to the female patients. The ability (of male patients) to remain adherent were found to be a socio-cultural construct including the support from the patriarchal structure, finances required for the said decision making, status in the family, access to transport and wider social circle. The female patients were found to be generally low towards adherence due to certain dependencies and barriers including need of an escort (mostly a male family member) to visit the public health facility, house chores, finances to commute and domestic hierarchy.

Table 2

Frequency Distribution of age of *the participants (N=71)*

| | Age groups of patients | | | | | |
| | Age= <45 | | Age= 45-60 | | Age= >60 | |
	f	%	*f*	%	*f*	%
Female	19	47.5	19	47.5	2	5.0
Male	14	45.2	16	51.6	1	3.2

The table above illustrates the age of the registered patients (segregated with gender). The age of the registered patients has been distributed in three major age groups. It is important to mention that the patients registered are newly diagnosed and most of them fall in the first two groups. Only two females and a male patient are above the age category of 60 years. The age is an important dimension as it affects the overall agility towards roles and responsibilities (both at domestic and community levels).

Measures

Following measures were used during the data collection:

In-Depth Interview Guide. An in-depth interview guide was designed based on preliminary field work and interaction with different stakeholders and community members. The tool was designed keeping in view the general model adopted from the explanatory model of patients. The interview guide was focused to explore the understanding of how this disease has happened to the respondents? Also traditional and indigenous reasons to understand the cause of diabetes? In this case it encompassed various influencers including economic pressures, social incidences etc.

Procedure

The data collection was done through finding key informants in the said locale. The informal interviews helped researcher design an in-depth interview guide for in-depth interviews with the abovementioned categories of the patients. An interview guide was designed before the collection of the data. The

interview guide was primarily divided into major themes including different lay man perceptions towards the etiology of type 2 diabetes. The theoretical framework of patients' explanatory model was used to better understand the socio-psychological factors before reaching the health facility for clinical diagnosis and biomedical treatment.

The researcher used the informal technique to interact with the patients so that they may discuss the issues more openly and less formally. The researcher had informal interviews with nearly half of the patients so that an acquaintance may be developed for the upcoming in-depth interviews. The researcher kept in mind the busy schedule and routine of both the male and female respondents.

An in-depth interview guide was designed based on the preliminary fieldwork and informal interviews with the patients. The researcher did ask for the permission of interview from each respondent. The in-depth interviews lasted from one hour (at least an hour to around two and a half hours). The variation in the duration of the in-depth interviews was due to the explicit nature of few respondents.

Most of the respondents shared the information during the in-depth interviews at their respective house or work place. The respondents were not restricted, and were allowed to respond to any question for as long as they want to. The researcher also took verbal consent before recording the interview(s). The researcher did the same before taking each and every picture in the locale (especially with the respondents).

All recorded and handwritten materials of conversations, interviews were transcribed and field notes were completed for all observations and conversations. Documentary evidence was also summarized from the data recorded at the health facility (through non-communicable disease card). Time was spent listening and transcribing recorded interviews and reading the field notes. Field notes taken in the course of observations were completed. The

transcripts and documentary evidence were typed accordingly. The transcripts captured features of conversations such as emphasis, speed, tone of voice, timing, and pauses. These elements made up the crucial aspect of the interpretation of data, given the multiple events that produced them. Reading and completing the transcripts and making notes from them lead to identify ideas, make observations, and get insights and inferences. Researcher organized the data, and sorted out all the materials needed to enable getting on with the initial analysis. Once each transcript was read and classified, it was dissected, pulled apart, and scrutinized transcript by transcript to enable the full understanding of the nature of the data collected.

Results

The data was collected with the help of a thematic interview guide carefully designed during the preliminary field work (that included informal interviews with health care providers, patients and other community members). The themes were adopted from the patient's explanatory model. The participant's observation also supported in analyzing the factors other than the perceptions of the respondents. The observations were used to logically associate the responses of the respondents under identified and emerged themes. The responses were initially transcribed under each theme. The similar responses under the focused theme were used to create sub-themes. The overall approach was to understand, draft and analyze the episode of etiology. The important statements of the respondents were included as verbatim in each theme.

The results are presented qualitatively under different themes. Most of the responses are quoted as verbatim (both in local language and translated in English). The themes were adopted from the patient's explanatory model. The already adopted themes helped sorting the responses of respondents under each theme. However, the sub themes emerged from the focused theme of *etiology* as common reactions.

The observations were used to logically associate the responses of the respondents under identified and emerged themes. The responses were initially transcribed under each theme. The results are presented under three major themes i.e. Layman's perceptions towards etiology, experience and perceptions of physical illness and experience of reaching the health facility.

Layman's perceptions towards etiology

The respondents did share their respective perceptions towards etiology (cause of the illness) especially by recalling when they did not know the label of diabetes. They shared their experiences by relating it with certain incidents, traumatic and tragic episodes. The perceptions towards the illness were found to be greatly influenced by the local wisdom regarding tiredness, loss of stamina, frequent urination, obesity and body aches. The details of the results are given below:

Table 3

Layman's Perceptions towards Etiology of Type-2 Diabetes (N=71)

Group	Theme
Adherent Male	Trauma Tragedy Staying away from home
Adherent Female	Black Magic Evil Eye Death of blood relative(s)
Adherent Male & Female	Feeling of loss i.e., physical, financial psychological
Non-Adherent Male	Trauma Tragedy Staying away from home
Non-Adherent Female	Black Magic Evil Eye Death of blood relative(s)
Non-Adherent Male & Female	Feeling of loss i.e., physical, financial psychological

The abovementioned table shows that most of the respondents were unsure about the specific etiology of their diabetes condition(s), but did relate it with an episode of stress and trauma. Most of the respondents did relate the cause of their illness with the death of a family member. A few of the male respondents also related it with stress regarding the downfall of business and also the issues of inheritance of property (especially cultivable land) that emerged (as a critical issue) after the death of the father or head of the house.

A few of the female respondents linked the cause of their illness with the concept of *nazar lagna*[1] and *kala jadoo*[2] (mostly claimed as spelled by another female family member). The female respondents also generally related their illness with the death of a family member.

It was also found that most of the female respondents did relate their illness with the death of their family members (mostly their blood relations). On the other hand, the male respondents were found to relate it with the stress and trauma caused by the death of family members (both closed and extended family members). A few of the male respondents also linked the cause of the illness with their respective position of becoming the *wada*[3], that is, the head of the house (and taking care of the finances, budgets and distribution of property after the death of the father), and also due to the complications arising out of the distribution of the property (in cases if they were not eldest among siblings).

A male respondent shared that he used to work for naval force and was deputed near the coastal areas. He believed that he became diabetic due to the damp environment where he lived for

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1 Nazar lagna: Evil eye
2 Kala jadoo: Black Magic
3 Wada: Head of the house; used in a specific context when one takes position/status in the family after the death of a father (previously head of the house).

many years. He further expressed that he also used to be *kalla*[4] and detached from his family back in the village. He expressed it as:

Meri jithay posting si oo than bari nami wali si tay menoo lagda aiy kay shayd sugar taan kar kay hoi aiy. Kam kaaj bota okha nhi si par ghar di tay bachyan di bari yaad aandi si khaas toor tay duty karan tu baad.

Translation:

I think that it was the damp environment where I was deputed for years that caused me diabetes. The workload was not very tiring, but I felt very emotional and missed my family especially after the duty hours (adherent male).

An elderly female respondent shared that she has been in trauma since she lost her elder sister. She emotionally expressed her situation as:

Lagda aiy kay mera poora jisam odhi yaad vich gal he gyaaiy kyun kay oo meri sahelivi si. Umar vich meray toun ziada wadi nhi sit ay meno har velay yaad aandi aiy. Odhi dhian tay ik putar di bari pareshani aiy.

Translation:

I feel as if my entire body is melting in her longing as she was my best friend. She was not very old, only two years older than mean I miss her all the time. I am really worried about her daughters and a son. (Non-adherent female)

A male respondent shared that her daughter was diagnosed with thalassemia.He used to donate his blood to her as part of the treatment, but she could not survive longer and passed away in a span of two years. He further shared that his entire life revolved around the disease of his daughter. He stated that he had used

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4 Kalla: alone, to feel all alone

every available treatment and therapy in his access, but she died. He believed that it is the death of her beloved daughter that made him ill (as expressed by him he received the illness).

It was also found that almost none of the respondents related the cause of their illness with being overweight, poor diet habits or lack of physical activity. Only couple of respondents shared that one of their parents had diabetes, and it was hereditary in their opinion (as a cause for their illness). None of the respondents related the illness with episode of any other sickness as a cause of diabetes.

A few of the female respondents did share the cause of their illness as a by-product of man-made etiology i.e., causing harm through black magic and evil eye. The complaint of black magic was found mostly in case of female respondents having an active presence of mother-in-law and sister-in-law (even if she is married in another village or in the same village).A female respondent expressed:

Viyah day foran baad toun meray tay dabaoo aiy tay naal menoo kamzoori rehndi aiy tay thakawat vi hondiaiy. Meri saas tay nand meray naal nafrat kardian nay. Menoo shak penda si kay meray saurian vichon kisi nay amal tay kala jadoo karayaaiy.

Translation:

I have been under a lot of pressure since my marriage. I am becoming physically weak and tired with time. It is due to the hatred for by my in-laws (mother in law and sister in law). I think that some of the extended (in-laws) family members were also involved in designing and casting of black magic. (Non-adherent female)

I have been under a lot of pressure since my marriage. I am constantly tired and weak. My mother-in-law and my sister-in-law hate me. I think that someone from my in-lawsis involved in casting black magic on me. (Non-adherent female)

The initial perceptions were mostly related with a tragic episode both in terms of losing a family member and going through stress due to inheritance or business related issues. The initial experience was found to be closely associated with heart sinking, going to bed early, being lethargic and losing focus. The female respondents, in particular, also added the phenomenon of being in the impact and influence of black magic or evil eye.

A few of the male respondents shared information about the experiences regarding the wave of depression and loneliness felt during the early days of the illness. Also couple of elderly female respondents related the same experience with age and associated it with general weakness that emerges with growing old. Most of the female respondents also reported of loss of temper during early days of illness. A female respondent shared:

Mein kisi tay ghusa nhi kardi, par ajeeb thakavat si jidi wajah toun meri monhmari meri saas day naal, banday day naal tay bachyan day naal vi hui.

Translation:

I was never angry at people around me and was a calm personality, but due to fatigue I remember of having quarrels with my mother in law, husband and even daughters.

Most of the respondents said that they did not share the issues of fatigue, weakness, and frequent urination etc. with anybody and did individual efforts to overcome it. A female respondent shared that she started having hot milk before going to sleep. On the other hand, a few of the male respondents shared that they increased the sugar intake to overcome the heart sinking feeling and weakness.

The time and mode of onset was mentioned specifically in terms of (what year or how many months ago it happened). Most of the respondents shared different circumstances and year of onset. As expressed by a male respondent:

Meray walid sahib pichlay saal janvary vich foot hoaiy nay. Ami gee walid sahib toun teen saal pehlan foot ho gaiy san. Ami gee toun baad walid sahib di wafat nay achanak dhachka dita. Meno or aatnu baar baar peshab aandasi, pehlay tay mein sochya kay shayd mein raati pani bota peen lag gyan. Baar baarh ajat di waja naal wazu nhi rehnda si tay takleef hondi si kaas kar namaz wastay.

Translation:

My father passed away in January last year. My mother had died before my father around three years back. After the shock of my mother's death suddenly came this shock. I started having frequent urination afterwards. I thought that probablyI was drinking a lot of water before going to sleep. The urination problem also compromised my religious life especially in terms of ablution (for daily prayers). (Adherent male)

A few of the respondents also recalled the occurrence of disease attached with some unusual routine, that was attributed with the possible cause of illness. A male respondent recalled how the holy month of Ramadan (last year) was hard for him in terms of fasting. He shared that most probably due to the *habas*[5] and long fasting hours (due to summer cycle) he became diabetic. He also expressed that he started feeling weak and having body aches. He further stated that:

Mein apnay ghar di chath tay soota si namaz toun farigh ho kay tay achanak tabiat bari kalli pai (kamzoori mehsoos hoi). Pehlay tay menoo lagya kay rozay namaz di waja toun tabiat kharab hoi aiy par agli raat fair tabiat kali pai. Taay naal saray jisam vichv idar dhonda si khaas kar sweray tay raat noo soun toun pehlan.

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5 Habas: Humidity

Translation:

I was sleeping on the rooftop after the night prayers and felt really unwell (weakening in the body). I initially linked it with the tight routine of fasting and prayers, but I felt the same the next night also. And I started having body aches especially in the mornings and before going to sleep. (Adherent male)

A few of the female respondents shared that they started gaining weight (after an episode of stress or trauma). The respondents shared that they initially thought of cutting down the food portions but it did not help. A female respondent explicitly shared that:

Jeri jooti menoo saal pehlan poori andi si oo katan lag gai. Menoo lagda si kay shayd mein kisi hoor di (wadi beti di) jooti paal aiaiy (wesay meri dhee vi meray jinni aiy).

Translation:

The same footwear I had been using since a year was hurting my feet. I still remember those nights whenI thought that I have mistakenly worn the footwear of my eldest daughter (though she is of my size). (Adherent female)

Most of the respondents did share the unusual occurrences that were further attributed as the cause for their illness. The respondents generally shared the incidences with the year (also in what season and month), part of the day (as in mid-day or night or middle of night), event (as in funeral, traumatic episode). Some of the respondents also even shared the month (Ramadan) as onset.

Most of the respondents also attributed their onset of illness with symptoms related to the abovementioned occurrences and time. It was generally found that the respondents experienced symptoms such as *khali*[6], *kamzoor*[7]*(khalipun, kamzoori)*,

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6 Khali: Empty, feeling empty

overweight, head spinning, blurry vision, frequent urination and body aches.

Experience and perceptions of physical illness

The respondents were found sharing different perceptions about complications of illness while answering the current theme. The most common answers were weakness, fatigue, and exhaustion of stamina. The details of the themes are given below:

Table 4
Experience and perceptions of physical illness (N=71)

Group	Themes
Adherent Male	Loss of stamina
	Anxiety
Adherent Female	Emptiness
	Weakness
Adherent Male & Female	Shallow and hollow feeling especially in the legs
Non-Adherent Male	Loss of stamina
	Anxiety
Non-Adherent Female	Emptiness
	Weakness
Non-Adherent Male & Female	Shallow and hollow feeling especially in the legs

The above-mentioned table shows the experiences and perceptions of physical illnesses. A few of the male respondents also used indigenous terms to express their respective perceptions of illness. A male (adherent) respondent expressed it as:

Mera tay dil kaala penda si dobda si, tay naal kamzoori wi si.

Translation:

My heart used to sink, and I felt weak Another male (non-adherent) respondent shared his perception as:

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7 Kamzoor: Weak, weakness

Maan gee di wafat toun baad na sirfd ukh tay dard si balkay meray saray jisam vich on taqat vi khatam ho gai si.

Translation:

Since the death of my mother, not that I feel low and down but there is this loss of energy in every inch of my body

A few of the female respondents also stated similar perceptions. An elderly female (non-adherent) respondent (while touching her both calves and legs) expressed:

Menoo aithay khali khali mehsoo Shonda si

Translation:

I used to feel so empty here Another female (adherent) respondent expressed her perception as:

Mein Chaudhry sahib di haveli vich kam karniaan. Menoo lagda si kay meri roz kam karan di taqat ghatdi jarahiaiy. Pehlan mein sara kam dopeher tak mukal enisaan par hun sham pay jandi aiy. Hun kam day doraan saanh vilena penda aiy tay raat tak bari thakawat hindi aiy

Translation:

I work for *Chaudhry sahib* (at his *haveli*). I feel as if I am losing my stamina every day. I used to complete most of my responsibilities by early afternoon but now the work goes beyond late afternoon. I take more breaks while completing the chores, and also feel tired at the end of the day.

A male (adherent) respondent also shared his experience of losing the stamina and feeling tired as mentioned below:

Pehlan mein baray kam naal naal kar lenda si tay challan phiran tay khaloon vich vi koi lachari nhi si. Hun menoo kam kaaj wastay motorcycle lena peya aiy. Hun tay ik ghanta vi khloon hi honda tay agay mein sara sara din faslan da raakha karl enda si.

Translation:

I used to do multiple tasks and was never tired of standing and walking for hours. I have recently bought a motorcycle for the purpose of my daily commute. I cannot stand for even an hour now, earlier I used to stand for hours to monitor my fields.

Experience of reaching the health facility

It was found that almost all of the registered patients (at the said health facility) did not directly reach or consult the health facility as their first option. Most of the respondents were found to discuss the emerging symptoms initially with the family and nearby family friends, which led them to visit local herbalist and holy man. It was also found that most of the respondents (both male and female) did visit the abovementioned optionsat least once. A few of the registered patients also visited the shrine located near the village for the purpose of spiritual healing. The details of the themes are given below in the table:

Table 5
Experience of reaching the health facility(N=71)

Groups	Themes
Adherent Male	Influenced by consulting the Paramedic in evening (after office hours) and peer group
Adherent Female	Influenced mostly the peer group especially meeting in the morning and mid-days after completing the house chores
Adherent Male & Female	Consulted the already diagnosed elderly patients in the vicinity and community
Non-adherent Male	Influenced by consulting the Paramedic in the evening (after office hours) and peer group
Non-adherent Female	Influenced mostly the peer group especially meeting in the morning and mid-days after completing the house chores
Non-adherent Males & Females	Consulted the already diagnosed elderly patients in the vicinity and community

All of the male respondents did visit the paramedic (informally) before consultation and diagnosis. It was found that the male respondents generally discussed the situation with the paramedic in the evenings, since evenings are comparatively freer and offer more space for social gatherings and meetings. The female respondents, however, discussed the issues mostly with their peer group in the mornings and mid-days, since it was easy for them to find time during and after house chores.

It was also shared by the respondents (both male and female) that they did consult the already diagnosed patients in the vicinity who had similar symptoms.

The role of paramedic was found to be of extreme importance as most of the respondents did discuss and rely on his opinion especially regarding visiting the rural health center as mentioned by an elderly woman who was also handicapped:

Meri rakh chak mera putar tay meri noo karday nay. Mein apni noo day naal ik waderi nu wekhan gaiy si jeri kool ai rehndi aiy tay sugar di mareeza aiy. Oos day akhian asi doctor sahib (paramedic) nu milan wastay gaiy warna asi dispenser sahib kooljan asi. Doctor sahib (paramedic) nay meray putar nu mat dassi kay jald tu jald hospital chakar laa loo ta'kay ilaaj hovay.

Translation:

I rely on my son to transport me. I am also dependent on my daughter in law. My son and my daughter-in-law take care of me. With the help of my daughter in law we went to see another elderly woman who lives in our neighborhood and is also a patient of diabetes. She forced us to meet the paramedic and not to consult the dispenser who sits at a local dispensary. Paramedic not only convinced me but also my son to take me to the rural health center as soon as possible for initial examination and tests. (Adherent female)

It was also found that none of the respondents got diagnosed on their first visit to the health facility. Most of the respondents had to come again and even for the third time especially regarding the test of fasting blood glucose. Most of the respondents confused the instruction(s) regarding the fasting blood glucose. Most of them considered a cup of tea or a fruit as fasting as expressed by a female respondent:

Meri sugar teesray chakar tay check hoi si kyun kay menoo pata nhi si kay khali pait da asal ki matlab aiy. Dosray chakar tay meins weray tar kay chaa pee lai si tay doctoran nay wapis ghal dita. Teesray chakar tay fair akheer meri sugar check hoi.

Translation:

I got my fasting blood glucose tested on the third visit as I was not aware of what it meant to be empty stomach. On my second visit I had a cup of tea early morning, therefore the doctor sent me back. Finally, on my third visit I managed to get the test done. (Non-adherent female)

It was found that most of the respondents did not accept the labeling of being a diabetic. Nearly all of the respondents went for second opinion. It was shared by most of the respondents that the doctor who runs clinic in the city, or sees patients in the district headquarter hospital has a better understanding; and his expert opinion is more reliable and authentic. To confirm the diagnosis most of the respondents also discussed their individual cases with the peer group and family members. A male respondent expressed:

Mein kam toun do din di chuthi laitay waday hospital (district headquarter) chakar laya tay unhaan nay vi dasya kay menoo sugar aiy. Doctor sahib nay vi menoo sugar check karan da pora nizam samjhaya. Hun mein apnay RHC toun he checkup karwana.

Translation:

I took two days off from my work and went to the district headquarter. They confirmed that I am a diabetic. The doctor at the

DHQ also briefed me regarding the standard procedure of diagnosis (testing blood sugar level regularly). That greatly helped me to rely on my rural health center for follow up checkups. (Adherent male)

A few of the respondents also visited the already diagnosed diabetics from the same community to discuss their experience of disease. The respondents used information given by them validate their own experiences. Based on the discussion, the respondents started devising a strategy to cope and manage with the label of diabetes.

Discussion

The perceptions of the respondents were found to be of great importance and relevance towards the proposed treatment. It has helped to construct a much larger picture that includes the perception of target population for better outcomes. Another study (Cohen, Tripp-Reimer, Smith, Sorofman, & Lively, 1994) also emphasized on documenting and understanding the patients' perspective with the lens of explanatory model that may help to contribute designing a better framework of improving adherence. Similarly (Tripp-Reimer, Choi, Kelley, & Enslein, 2001) discussed that larger cultural context is very effective in the understanding, designing and implementing diabetes care. It is also emphasized by the same study that socio-cultural and psychological factors are of great importance to understand experiences and perception about Type II diabetics as they affect all aspects of diabetes including the perception, process of diagnosis and treatment at large. Another study (Osman & Curzio, 2012) also stressed to explore the cultural determinants that may help design holistic care in case of chronic diseases and diabetes in particular.

As discussed above that the current study has explored and documented the complex nature of diabetes as seen and explored through the lens of respondents and may be found consistent with earlier studies that also label and explore diabetes as a multi-factorial disorder(Hales & Barker, 1992; 2001; Szathmary, 1994).

The study also found a different perspective as compared to the clinical nature and understanding of diabetes care. The current study had insights as a lived experience of diabetes that may be useful in further capacity building and content design (for health education tools) of primary public health care system. The local perspective was not only insightful but the subjective realities also produced certain common themes that may be considered as serious approach in understanding the adherence towards the treatment. The subjective perspectives are also backed by other similar studies which have used anthropological perspective towards explaining the diabetes as lived experience, which is the need of the hour and may reflect a sensible subjective lived experience of diabetics. (Mendenhall, Seligman, Fernandez, & Jacobs, 2010; Rock, 2003; Young, 1980)

Similar to this study, social sufferings and emotional distress are prevailing factors found in poor Mexican Americans, in Chicago. According to this study, the participants have experienced Type2 diabetes as the product of these social sufferings. Thus, they regard diabetes as the *idiom of distress*. Using the explanatory model, it has been found that many acute stressors are linked with *susto*, i.e., frightful experiences. For instance, a respondent linked the cause of his diabetes with the burning of his house which had frightened him. Another implied that his body turned diabetic immediately after he went through a traumatic injury. A respondent connected his cause of diabetes with chronic stress as being a product of social suffering, which in his case was high-crime neighborhood which had him under fright all the time. Many participants linked the prolonged stressors, majority of which are family-related conflicts, isolation, and violence, as the causes of diabetes. It also revealed that both the culprit and the victim associate these forms of distress with being diabetic. Therefore, by considering the ways in which the psychological and social distress interface with the onset of some chronic diseases, such as Type2 diabetes, it can be recorded how they become a part of the experience of the disease themselves (Mendenhall, Seligman, Fernandez, & Jacobs, 2010).

Another study among Mexican-American respondents revealed the patients' own concepts and causal stories of Non-Insulin Dependent Diabetes Mellitus (NIDDM), or Type-2 Diabetes. All the patients shared their respective personal history or biography, linking it to the time of the onset of diabetes in their respective lives. The respondents expressed their explanations to the disease, apart from the biological explanation. These concepts, the provoking factors, trigger diabetes according to the participants, which is there in every individual and is triggered by traumas, or operations. Majority of the respondents regarded their own behaviors to be the cause of diabetes, such as heavy drinking, smoking, high-sugar diet, or over-eating. A respondent said to have been diabetic due to her addiction of sweets; another implied improper sleep to be the cause of diabetes. Participants also cited that some sudden events made them diabetic. A 55-year-old woman believed a car accident she had survived had triggered diabetes, and a musician associated his onset of diabetes with a chemical reaction in his body due to some medications of heart disease. Some respondents, while adhering to the treatment, still associated specific events with the prevalence of the disease, such as a 54-year-old who was on her treatment, yet had low levels of glucose control. She admitted that she had been a heavy drinker, but it was due to her father's death which caused the treatment to not work. Another respondent considered his brother's suicide, which was emotionally stressing for him, to have caused him diabetes. Thus, in this study, respondents have been found connecting their life histories and experiences with the onset of Type-2 Diabetes, and hence, creating their own etiologies for their disease (Hunt, Valenzuela, & Pugh, 1998).

It is concluded that patient's perspective was found to be an important dimension in informing the relevant stakeholders at primary healthcare level. The local perceptions and experiences were found to be a process of various psycho-social and cultural factors that shapes the decision making in terms of seeking healthcare and especially adhering to the proposed treatment at the rural health center.

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