Exploring illness perception regarding causes of diabetes and factors determining preferred health seeking practices

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Abstract

Diabetes is a non-communicable disease which is now a major concern in urban slum population also. People only have access to some knowledge when they are diagnosed with diabetes or somebody else in family is suffering from diabetes, which shows there is need to spread awareness for diabetes. This qualitative study aim is to reveal the illness perception of causes of diabetes and factors affecting the health seeking practices of urban slum dwellers in Dhaka, Bangladesh. Both IDIs (In Depth Interview) and FGD (Focus Group Discussion) were conducted. In total 12 IDIs and 1 FGD was organized. Data was collected both from the diabetic and an diabetic group of population. After transcription, coding and analysis of data, they were categorized and patterns that emerged were compiled to derive reportable findings. Validity were checked through minimizing sampling bias, methodological triangulation and measuring inter coder reliability. The perceived cause of diabetes among slum dwellers are sedentary lifestyle specially sitting for long, eating too much rice or sweetmeat, old age, obesity and mental tension. Preferred treatment options are private hospital (BIRDEM), public hospital, local pharmacies, spiritual healer and herbal method. The determining factors behind health seeking practices includes affordability, accessibility, acceptability, availability, social influence, belief, previous experience, need, fear of insulin injection and apathy. This study aims to find illness perception focusing on causes of diabetes and existing factors determining the health seeking practices of urban slum dwellers. This finding will hopefully help in future to design a pragmatic intervention for slum dwellers.

Keywords: Diabetes, Slum, Urban, Health Seeking, Perception

Introduction

Non-communicable disease specially diabetes has turned out to be a major public health concern in low socio-economic countries (Rahman et al., 2015). According to World Health Organization (WHO), 2014, nearly 347 million people worldwide have diabetes and is predicted to become the 7th leading cause of death in the world by the year 2030.WHO (2014) also says that about 80% of diabetic patients are from low and middle-income countries. In South East Asia (SEA) 75 million people had diabetes in 2014 and it will rise to 123 million by 2035 if appropriate initiatives are not taken (International Diabetes Federation, 2014a). Diabetes which once called a disease of rich people, now affects mostly the poor and the slum communities suffer the most (Bhojani et al., 2013). Bangladesh has the second largest number of diabetic patients accounting for 5.9 million adults (International Diabetes Federation, 2014 b).Due to continuous urbanization, the number of urban slum dwellers is on rise leading to unfair health distribution of this vulnerable group (Bhojani et al., 2013).However, there is lack of sufficient amount of studies which explore peoples’ experiences and perception regarding diabetes and thus becomes a challenge for policy makers (Lewis & Newell, 2014).

Patients’ levels of comprehensive understanding of diabetes varies upon availability and accessibility of information which often affected by inequitable health care (Lewis & Newell, 2014). Studies showed that patients often experiment self medication or herbal remedies unless their symptoms get worse when they force to seek biomedical care, but their ignorance along with ‘wait and see’ culture held them back to seek health care on time (Nguma, 2010). A broad study has been done on, ‘Illness perception of diabetes and health seeking practices in urban slums’ by a group of six members including myself among 18 respondents. However, this paper will specifically focus on illness perception regarding causes of diabetes and factors affecting the health care practices for the choosing of particular treatment option of urban slum dwellers. In order to improve the existing knowledge upon it, the understanding and experiences of urban slum dwellers related to diabetes will be studied through this qualitative methods with the hope to reveal their perception regarding causes of diabetes, as well as, the influences and barriers in undertaking preferred health care. To find out the illness perceptions regarding causes of diabetes and to identify the determinants in health seeking practices that make the preferred treatment options of the slum dwellers of Dhaka, Bangladesh.

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Materials and methods

The study was conducted in Korail slum, the biggest slum of Dhaka city just opposite to the Gulshan lake, Bangladesh. Both diabetic and non-diabetic people living in Korail slum was included. Both IDIs (In Depth Interview) and FGD (Focus Group Discussion) were conducted. In total 12 IDIs and 1 FGD was organized. Out of 6 IDIs (Diabetic) 4 were done in their house and 2 were done in their working place (shop). Out of 6 IDIs (non-diabetic) 4 is done in their working place and 2 in their house. Purposive sampling was done to include both diabetic & non-diabetic respondents irrespective of gender in Korail slum. Convenience sampling was done by selecting diabetic respondents as per our convenience (time & availability). Inclusion criteria includes- People living in Korail slum for at least a year, diabetic patient of any age and age more than 30 years for non-diabetic respondent. Exclusion criteria includes- diabetic and non -diabetic respondents were not from the same household. Developed group literature review, study tools and priori code list, study tools were pre-tested and revised before data collection. Each IDI was recorded on tape recorder and notes were taken during fieldwork. All the interviews were transcribed the very day they were done, by listening meticulously to the tapes and reconfirming again by going through the notes. All the transcripts were read by all the team members and thus familiarized. A priori codes were formed based on the research questions together with few of the sub codes, other sub codes and inductive codes emerged from data and it helped us to reduce the volume of raw data. Intra-coder & inter-coder reliability was checked. Then the group came up with different data display tables based on different codes that helped the group members to look at, find the data easily and summarize the data. Obtained data was compared with the different methods used and finally, data was analyzed using thematic analysis. Based on themes appropriate quotations were documented and used to make the findings reportable. Printed informed consent forms were provided, purpose of the study was explained and the respondents’ risks and benefits were confirmed. Permission was taken for tape recording & note taking. Privacy and confidentiality of the respondents was maintained carefully. Participation in the interview was entirely voluntary and had the right to leave anytime.

Results

Perception regarding causes of diabetes

All the study group have a common perception that sweetmeat and having too much rice can cause diabetes. They know that there is a food restriction for diabetic people but misinterpret it as a cause of diabetes. IDIs of both diabetic and non-diabetic groups had an idea that sedentary lifestyle is a cause for developing diabetes and its relationship with occupation was also mentioned. As one diabetic respondent mentioned: "Look I was a CNG driver. My job was running from here to there. For 2 years I have left this job. I am a shopkeeper now. It is a job of sitting down for a long time. That’s why I am affected by diabetes." (IDI#8, L56-58). However, only one respondent mentioned mental tension as a cause of diabetes and his perception was found to be influenced by his healthcare provider. He said: “It’s only the tension and it’s the only cause of diabetes. And no one in my family has diabetes”. (IDI#4, L117-18)

There was a non-diabetic respondent who couldn’t mention any cause but argued with his own experience regarding the causes of diabetes. He said: “Some people say that people get diabetes if they are too fat but I have no diabetes though I am fatty”. (IDI#5, L23-24) “There is a Rahul Amin Dulari who has crores of taka, you understand? He is such a slim person but then why he has diabetes?” (IDI#5, L52-53) . There was less response regarding the causes in non-diabetic group of population. After probing, some of them mentioned few. All of them were confused and respond according to their own views and believes or informed by other people around.

Preferred treatment option

Most of the respondents (5 out of 6 in IDIs) preferred private hospital (BIRDEM) over public hospital, few preferred local pharmacies. Few respondents from IDI preferred herbal options and spiritual healer, but none in FGD preferred so. Interestingly, no respondents mentioned about homeopathy. Ill treatment from the hospital staff in public hospital have a negative impact on health seeking practices, preventing patient from attending public hospital (Goudge et al., 2009) and that may be the cause of preferring private sector over public hospitals.

Motivators and Barriers behind their preference

Acceptability: Good behavior of doctors along with better treatment made treatment choice of the respondents acceptable to them. Behavior of health provider can affect positively as well as negatively. Good behavior of doctor attracts but bad behavior of doctors repels patients. One respondent mentioned: " Birdem provides better treatment, the doctors give much time and behaves well". (IDI#1,L63-64)

Social influence: Advice from relatives, neighbor, other influential surrounding and even from the doctors played considerable role behind their health seeking practices. In their own voices: “He is famous and till now many people go to that Hujur for treating their babies or any other problem and the Hujur gives the religious treatment. That’s why I took his advice”. (IDI#4, L33-35) "I always go to BIRDEM. My next door neighbor used to go there. So I knew that they provide better treatment"(FGD,L121-122). The quotes reflect their preference of private hospital (BIRDEM) over public hospitals as a result of social influence which can be linked with an article by Goudge et al,2009 mentioning preference of private sector over public as a result of ill treatment by health care provider.
Belief/self-experience: Sometimes some beliefs on controlling diabetes or self gained experience also influence respondents’ health seeking behavior. In their own voices: “I take sour food as it helps to lower the diabetes”. (IDI#2, L 135-136) “Now I can understand when to visit, I can realize that what happens when it increases and what happens when it decreases. Now it’s in decreased state. When it lowers down, it causes palpitation and tingling sensation in head”. (IDI#4, L 137-140).

Need: Sometimes respondents’ realization of the need of the treatment for improving life quality, leads them to seek health care. Like one said: “When I went PG, they saw my medicine and told me that what would be the benefit, if we keep giving the treatment and you keep eating whatever you want, Allah will take the responsibility whether you live or die…Then I said them that whatever you say, I need at least some solution to live my life.” (IDI#4, L78-83)

Accessibility: Distance from home also plays as a triggering factor behind health seeking practices. They often preferred nearer treatment options due to their convenience. One respondent said, “I go to korrail slums pharmacy. Don’t know he is an MBBS or not but he sits there. When I feel pain in my legs I go there. Because it is near to my home”(FGD,L148-150)

Previous experience: Perceived benefits of previous treatment can also influence health seeking practice in some way as one mentioned: “My wife also asked me that why I was going to PG without visiting other famous doctors. I told her that I would only go to PG as I was improved by their treatment. I would not go anywhere else beside PG. They treated me very well, treated me with fresh mind.” (FGD, L132-35)

Fear: Many respondents preferred to have less treatment or no treatment than having insulin injection because of the fear factor. In their own voice: “I flew away two times after seeing the needle…. Then I took injection for 1 month, thrice a day as my diabetes was 24 at that time. As I had no one to push the injection in my house and I didn’t want to take injection, I requested my doctor to prescribe some oral drug rather than injection (Insulin).” (IDI#11, L59-64)

Affordability: Financial issue or poverty often acts as a barrier and does not allow them to stick to a strict regime. One mentioned: “sometimes don’t take(insulin) actually. Again price of insulin is also high”(IDI#8, L80-82).

Apathy: Some respondents seemed to be frustrated because of the life time regimes of treatment or control of diabetes. As one mentioned: “I don’t follow any restrictions now. Nothing at all. (frowning). Because today or tomorrow everyone has to die. So what is the point of controlling the foods almighty has given to us? For last 6 months I stopped controlling my food intake...But I noticed there is no point of controlling as it really does not matter. Everything remains the same whether you control it or not. Moreover, if I control my food, I get weak and tired easily. So I don’t do anything at all to control diabetes”. (FGD, L156-162)

Unavailability: unavailability of specialized doctor also acted as barrier. As one said: “in this area there is nothing for diabetes. Nobody knows the treatment of diabetes” (IDI#8, L91-92). In addition to poverty, lack of facilities & expenses incurred for reaching treatment centre also determines patient’s health seeking behavior (Goudge et al., 2009). A study done at West Virginia by Tessaro, Smith & Rye (2005) concludes that people only have access to some knowledge when they are diagnosed with diabetes or somebody else in family is diagnosed with diabetes, which shows there is need to spread awareness for diabetes and we can totally link this with our study.

Conclusion

The study found that there is a variation regarding perception of causes of diabetes between diabetic and non-diabetic respondents. Diabetic respondents explained more regarding illness perception of diabetes than non-diabetic respondents indicating clear knowledge gap. High cost and fear of insulin injection is affecting health seeking practices more in comparison to perceived benefits of treatment. Thus, findings about barrier and motivators for health seeking practices will hopefully help in future to design an effective intervention with pragmatic approach for slum dwellers. Study was conducted only at single place and study time was limited. All of the researchers were new and for most of us it was our very first qualitative research. Data were initially collected in Bangla, translated to English and analyzed in English version. Language was the barrier for international students. Finding a good number of diabetic respondents in a short period of time was another big challenge. Free camps for checking blood glucose level can be organized frequently. Existing facilities can be collaborated with government program from where slum dwellers can avail free services. Information, education, & awareness strategy can be designed to address the knowledge gap of diabetes among the urban slum dwellers.

Competing interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

References

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