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ORIGINAL RESEARCH

Perceived Barriers to the Effective Management of Diabetes Mellitus among the Wakhi People: A Qualitative Study

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ABSTRACT

Self-management is one of the effective strategies used to maintain glucose levels and prevent complications associated with diabetes. It is the diabetic's responsibility to manage their chronic condition. The management includes monitoring blood glucose levels, taking diabetic medication as prescribed, adhering to a diabetic diet plan, and focusing on physical activity to maintain a healthy blood glucose level. These practices are necessary for the self-management of the disease; however, patients cannot self-manage their disease due to various obstacles.

This qualitative exploratory study investigated the perceived barriers to diabetes management among the diabetic Wakhi population in District Hunza.

Sixteen participants were interviewed in-depth to gain insight into their perceptions of obstacles that impede diabetes mellitus self-management. Four major themes emerged from the analysis, including sociodemographic and cultural barriers, personal barriers, healthcare system-related barriers, and diet-related barriers. Each central theme had subsidiary themes. Diet-related obstacles, healthcare system issues, and social engagement in rural areas constituted the most significant barrier to the management of diabetes.

This study's findings may assist healthcare providers in educating their patients about self-management practices, designing and developing interventions to educate patients, and conducting awareness sessions involving dietitians to educate patients about culturally and socially appropriate diet plans. In addition, the study's identified barriers may guide relevant authorities toward patient-specific self-care interventions.

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INTRODUCTION

Diabetes Mellitus has become a major global challenge and is expected to continue gaining prevalence [1]. According to the International Diabetes Federation, one in eleven people suffers from diabetes [2]. Globalization has increased the availability of unhealthy goods. Consequently, people in middle/or low-income countries are becoming more susceptible to obesogenic environments that promote a sedentary lifestyle, unhealthy behaviors, and an unhealthy diet [3]. According to the National Diabetes Survey, Pakistan 2016-17, the prevalence of diabetes is 26.3%, equating to 27.4 million people living with the condition [4], whereas between 1994 and 1998, only 7 million individuals were affected [5]. This increase in diabetes is attributed to psychological, ecological, and social changes [4].

Lack of effective prevention strategies and access to healthcare has contributed to an increase in the incidence of diabetes and, in turn, the number of deaths resulting from diabetes and its complications [6]. Inconsistent diabetes treatment can result in nephropathy, diabetic foot, retinopathy, and other complications. Self-management training and education can reduce these complications [7]. Low health literacy and a dismissive attitude toward diabetes have also been linked to poor management and treatment adherence [8]. The health belief model can determine self-management and various factors affecting it. According to this model, preventive strategies and their development and consistency in health behavior are determined by perceived barriers, perceived sensitivity, experiences of patients, perceived benefits, and perceived seriousness [9], previously shown as applicable to diabetic populations [10, 11].

While medical intervention to improve glycemic control in patients is prevalent, reports of adherence by patients in a rural setting are very scarce. Therefore, this study aimed to determine the perceived barriers to adherence to diabetes management among the Wakhi diabetic patients living in the rural setting of district Hunza, Pakistan.

The Wakhi Context on Management of Diabetes Mellitus

This study focuses on the Wakhi ethnic group of Gojal, Hunza. The Wakhis are an Iranian ethnic group living in rural regions of Pakistan, China, Tajikistan, and Afghanistan. Predominantly, the Wakhis are centered in the Wakhan corridor in the northmost part of Pakistan, China's Xinjiang region, and the Gorno-Badakhshan region of Tajikistan. In Pakistan, most Wakhi people live in the upper region of the Hunza district, popularly called Gojal, in the extreme north of Pakistan. The Wakhis call themselves Khick, and they are Muslims by religion. Like every ethnic group in the country, the Wakhis have their unique conventional customs, culture, and lifestyle. The Wakhis generally maintain a simple lifestyle.

Their livelihoods depend on small-scale businesses, agriculture, and farming. The Wakhis cultivate crops in spring and take their cattle to various valleys in summer for pasture. The people of Hunza have a traditional way of following their lifestyle within a family. Almost all the families are extended, and almost all family members follow the same menu at home. The agro-pastoralist lifestyle of the people involving outdoor work, including farming, growing crops, pasturing, and social activities and events, makes it challenging for diabetic people to follow the specific routine they need to manage their disease. Winters in the region are harsh, and people get limited to their houses due to a lack of opportunities, technologies, and facilities. They suffer from poverty, inadequate health care, food insecurity, lack of access to opportunities and facilities, and lack of variety of food due to harsh weather. The rationale for selecting the Wakhis for the study is the issues they face due to their settlement in the extreme north

of Pakistan, where they lack access to healthcare facilities. No effective intervention and strategies are implemented to tackle the burden of any disease, and health education and counseling on managing diabetes are lacking. Self-management of diabetes may help reduce the burden of the disease in such circumstances.

No previous research has been conducted on the Wakhi people to investigate the obstacles people with diabetes face in managing their condition. Therefore, it is crucial to explore the barriers people face to managing and treating diabetes so that the targets of the intervention programs are prioritized.

AIMS OF THE STUDY

This study aimed to determine the perceived barriers to adherence to diabetes management among the Wakhi diabetic patients living in the rural setting of district Hunza, Pakistan.

METHODOLOGY

Recruitment: The inclusion criteria for this study were an age of at least 30 years, being a permanent resident of Gojal and Wakhi, and being diagnosed with type 2 diabetes mellitus for >2 years.

Participants provided informed consent prior to involvement in the study. Sixteen participants, nine males, seven females with an average age of 51.2 ± 7.1 years (37-65 years), were recruited for this study. (Further demographic data of all patients is available in supplementary table 1).

Study design: The study employed a qualitative research design with a phenomenological approach. A phenomenology is an approach to inquiry focused on understanding a particular phenomenon and the life world of individuals from their perspectives as experienced people who have perception and can derive meaning from a particular situation and phenomenon [12].

Phenomenology has been known as an appropriate approach for health-related research because it seeks to obtain in-depth and detailed knowledge about any particular experience [13]. A qualitative study focuses on understanding any social phenomenon and perceptions by listening to the opinion of the participants [14]. Keeping with the tenets of the phenomenological approach, the present study was approached with open minds, curiosity, and non-judgmental attitudes concerning the barriers the Wakhi people face regarding self-managing diabetes.

Data collection: Semi-structured, face-to-face interviews were conducted with the participant cohort between December 2019 and February 2020. The interviews focused on the areas of experience with diabetes, knowledge of self-management of diabetes, consequences of diabetes on daily life, and impediments to self-management. The selection of follow-up questions and the order of the questions were dependent on how and what the participants shared about their experiences.

This approach helped produce participant-led accounts with a particular focus on the barriers they face in self-managing diabetes. Each interview was conducted for 30-50 minutes and was recorded on an audio recorder and later transcribed verbatim. All the transcripts were uploaded to NVivo software to manage the gathered data.

Data analysis: Phenomenologically - informed thematic analysis was used to analyze the data [15]. This method guided the researchers to focus on the subjective perspectives of each participant regarding the barriers that impede their self-management of diabetes. Thematic analysis resulted in the emergence of basic patterns of meaning and perceptions across the samples.

The researchers reviewed the transcripts and identified sections that were the subject of interest. Emergent codes were used to guide a de-novo analysis for overarching sub-themes. The NVivo software was used to record sub-themes that emerged in each interview which ensured the accuracy of the presentation in the analysis. The central theme was developed after combining the sub-themes that expressed similar patterns.

Reliability and Validity: In this study, the validity and reliability of the coding categorization and themes were established in three steps. First, the transcribed data was grouped into themes independently by the researchers. An external researcher with expertise in qualitative methodology coded each interview. Inconsistency was not identified. All the themes were then compared until a consensus was reached.

Finally, the study's validity was further strengthened by an expert panel comprising the members of the local health board of Gojal, diabetic educators, and the researchers who reviewed the themes and interpretation of the findings.

RESULTS

Perceived barriers to the effective management of type 2 diabetes:

Four cultural and demographic themes emerged regarding the perceived barriers to managing diabetes at home and maintaining behavior to manage it. These were have been defined as; social barriers, personal barriers, health care system-related barriers, and diet associated barriers (Figure 1).

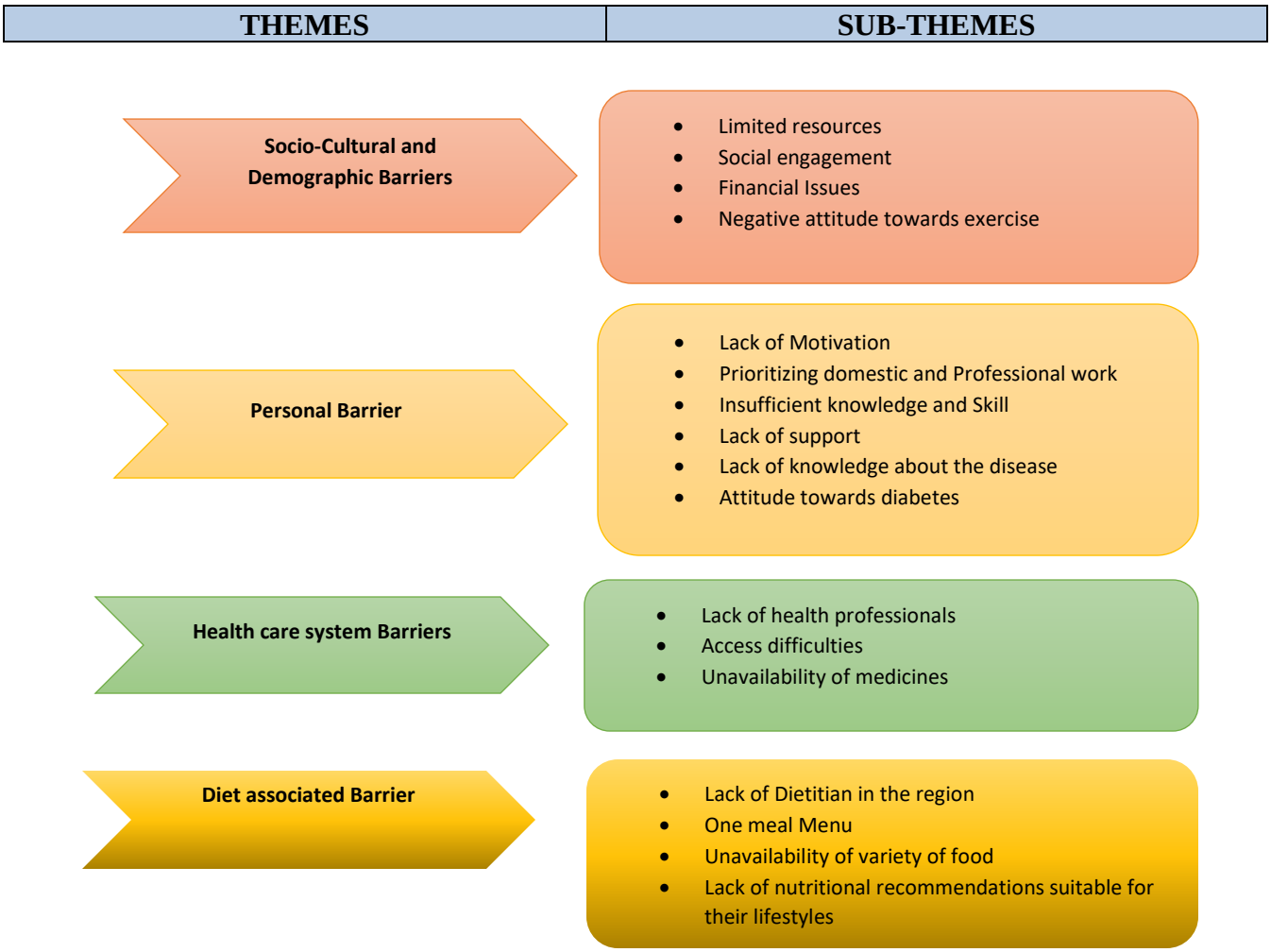

Fig (1): Themes and sub-themes of barriers to managing type 2 diabetes highlighted by the study cohort.

1. SOCIO-CULTURAL AND DEMOGRAPHIC BARRIER

Four sub-themes emerged under this theme.

- Limited Resources

The participants reported limited resources as a barrier to manage diabetes. Limited resources included lack of transportation, limited income, lack of insurance coverage, lack of glucometer and lack of hospital in the village.

"I try to manage my sugar level by exercise and walk but my husband's income is not enough to fulfil my diabetic needs". (Female, 49).

"I want to test my blood glucose level but for that I have to go to the nearby village because I do not have glucometer at home, and I do not know how to do it." (Female, 53).

"We don't have much choices here and the food routine is monotonic like the most used food is potato and wheat because it is available due to our own hard work….." (Male, 50).

- Interaction at Social and Cultural Events

The transcribed data showed most of the participants commented that social interactions and consuming traditional dishes high in fats and carbohydrates at various events such as religious rituals and wedding etc.

"We have one or other events going on in the village and participating in them is necessary. I just cannot sit alone and follow my diabetic routines because social inclusion is necessary, and you know village life is all about interaction and gatherings." (Female, 49)

"Social gatherings disrupt the dietary routine even if I want to set it because our community and village life is inclusive, and every member is part of the gatherings." (Male, 38).

- Negative attitude towards exercise

To control and prevent non-communicable disease particularly diabetes, physical activity and exercise plays important role. Despite this, very few participants who had positive attitude towards exercise, the data showed that majority of the participants have negative attitude towards exercise. Some participants stated that they think their daily house chores and other activities constitute exercise.

"It's really difficult to allocate time for exercise after doing all the domestic chore and working in the fields because no one does exercise in my surrounding, everyone is busy in their…." (Male, 48).

"I do all the domestic works along with working in the field and I think that is enough exercise for me." (Female, 52).

"I lack the confidence to do any exercise because if I do any I don't know what others will think about me. Also, I don't know exercise that is culturally appropriate for me…" (Female, 50).

- Attitudes of Family and Relatives

Family members and close relatives play a vital role in looking after a person especially when one has health issues. Two of the participants stated that their children were conscious about their health and would take care of their diet and help in managing diabetes. Whereas, for majority of the participants, family members were not taking care of their diabetic schedule and diet due to personal reasons.

"My wife is busy doing all the outdoor works which is why cooking is often neglected and we usually have a snack during meals." (Male, 49).

"I go out with my friends and eat every kind of food because my friends think that nothing happens because whatever is God's will happen and one cannot stop it." (Male, 51).

"It is not easy for me to change my behavior and lifestyle while continuing to look after my kids and keep my husband happy." (Female, 50).

2. PERSONAL BARRIERS

Some participants mentioned that they lack the motivation to manage diabetes and other commented that do not have time to keep the diabetic schedule sustained and lack the skills and knowledge. Some patients also shared that they prioritize their professional work over taking care of their health.

- Lack of motivation

For various reasons, the participants were not motivated to self-manage their disease; some felt like they will have it forever and there is no point in managing it.

"I am not sure about the effectiveness of the medicines and influence of diet on diabetes and my health outcomes." (Female, 48).

"Living with diabetes for the past seven years, I have got myself down to the fact that diabetes is never going to end, and I don't see any benefit in managing it." (Male, 56).

"I am motivated to do some exercise and take care of my diet to control my sugar level but, I don't get enough time due to my busy schedule of work and domestic chore." (Male, 38).

- Prioritizing other social and professional work

"Honestly speaking, I don't have time for myself because If I started focusing on my diabetic routine, who will do other office and domestic work." (Male, 54).

"With me personally, I have no spare time to do my exercise and follow a diet plan because of a lot of household work which is stressful and energy-draining." (Female, 47).

- Lack of knowledge and skill

"I do not know how to monitor diabetes at home and if my children make me learn, I forget it the next day, I forget the normal range and I hardly remember to do it before meal." (Female, 56).

3. HEALTHCARE SYSTEM BARRIERS

Three sub-themes emerged under this theme. Lack of health professionals in the region, Access issues and unavailability of medicines. Participants reported different difficulties to access healthcare centers such as transportation, lack of a person to take them to the hospital, and lack of manpower at the hospital.

- Lack of health professionals

"I want to monitor my blood glucose level but when I visit the hospital I find no doctor there. We have only one hospital in the village you know, and it has only one doctor who is bound to see all types of patients and when we visit there either he is absent, or he is preoccupied." (Female, 49).

"One of the major problems I face to manage my blood glucose level is lack of the concerned professional." (Male, 51).

- Access issues

Not every village in the region has hospitals and if they have a dispensary they don't find manpower there. In case of their health issues, participants have to travel to another village.

"For my checkups I have to go to Gulmit, which is 2 hours away from where I live. Sometimes I have someone from home to accompany me there but when I have no one home I cannot go there because I have to travel through public transport." (Female, 53).

- Undersupply of Medicines

"I fear the side effects of medications (Diabetic medicines) and I do not take it daily because I feel like whenever it is needed I will take it. There have been days like you know when I needed the medicine because my blood glucose level was high, I didn't find the medicine in the store." (Male, 51).

4. DIET ASSOCIATED BARRIERS

Four sub-themes emerged under this theme including lack of dietitian in the area, one meal menu, unavailability of variety of food and lack of culturally suitable nutrition and diet plan. The traditional diet of Hunza is typically high in saturated fats which is from dairy products like ghee, yogurt, and milk. Both men and women find it difficult to sustain their diabetic diet during social gathering, events, and social visits.

"After coming home from a whole day work in the fields, the easy food is either yogurt or milk with local bread… because you know one have no energy left to cook special food after a whole day or work." (Female, 51).

I get hungry often and I cannot control my eating habits, I mean I just eat whatever is cooked and I

have not been able to find a dietitian who could help me with a diet plan and guidance of which food to avoid and which is to be taken." (Male, 52).

"I am a farmer and I grow crops and vegetables, but such food is available in summer and for winters we have very monotonic diet because there are only few foods that we can preserve for winters… so like due to seasonal food availability, we don't get many choices and variety when it comes to food." (Male, 57).

"You know our region has most of its people dependent on agriculture and livestock and most of our work is outdoor, we do all the work and come back home and take one meal menu because we do not know what nutritional diet plan culturally and socially suits us." (Female, 59).

DISCUSSION

The evidence provided by the study cohort highlight that they all perceive barriers which impede the self-management of their type 2 diabetes. From the conversations, four distinct themes presented which included cultural and sociodemographic barriers, personal barriers, diet-associated barriers, and healthcare system barriers.

This study highlighted limited resources as a major barrier to self-managing diabetes. This mirrors the observations of other studies which have demonstrated socioeconomic factors, including financial difficulties in continuing medication and appropriate diet, which prevent the patient from maintaining a routine where their diabetes is well-managed [16,17].

Previous studies have demonstrated a lack of awareness of exercise and its importance in managing diabetes [16]. In this study, participants displayed a negative attitude towards exercise, indicative of low perceived benefits and high social and cultural barriers.

This study also reveals that in rural settings, patients with diabetes engage in social events and activities, in the same manner as healthy individuals, due to the fear of social exclusion. Hunza, where conventional food is high in fats and dairy products, and traditional foods are cooked and served during social and cultural events, is not conducive to good diabetes self-management. It is consistent with a previous study that showed that feelings of social exclusion and embarrassment influence diabetes mellitus self-management practices [18]. Cultural norms and the unaffordability of certain medications, and an unhealthy diet impede healthy eating practices in Pakistani culture [19]. The present study echoes the finding of a study showing that diabetic patients eat whatever is cooked at home [20]. The finding of this study showed that social interaction, engagement, and participation in social gatherings such as marriages and deaths in the village are a barrier to self-management practices of diabetes because the traditional food served during such events is not suitable for people with diabetes. A previous study has shown that conventional and traditional food is a significant barrier that impedes the management of diabetes [21]. This is closely linked to the diet-associated barriers conveyed by participants, which noted a lack of dietitians in the area, one meal menu, unavailability of a variety of food, and lack of nutritional recommendations that suit their lifestyle.

A significant perceived personal barrier faced by the participants was a lack of motivation to manage diabetes for various reasons. Some participants reported that diabetes is a lifetime disease and can never be controlled, so they do not feel any benefit from self-management practices. This finding aligns with a previous study showing a lack of motivation to alter their routine activities and schedule to manage diabetes [22].

For diabetic patients, it is essential to have a deep understanding of diabetes management as it is a predictor of self-care behavior [23]. Inadequate or lack of information is linked to a misconception about diabetes. Studies have shown that diabetes management is linked to performing self-

management practices of diabetes, including blood glucose monitoring and sustaining the daily medicine intake [24]. In this study, the respondents shared that they do not get sufficient time to manage their disease due to professional or social workloads. This finding echoes a previous study showing that diabetic patients, due to their daily work and busy schedule, do not care about their health.

Patients with type 2 diabetes substitute their household work with exercise when they are home from work [25]. This finding aligns with the previous finding that shows that their job natures which involved frequent traveling and long hours at work, make it difficult to adhere to healthy eating. Stress related to their workload impacts their blood glucose level [26].

Participants reported that a healthy diet is important, but the high cost impeded it. The finding echoes the studies showing that healthy food for diabetes control requires financial resources [27].

The respondents in this study also reported access to the healthcare system and issues with finding professionals and doctors who could help them when their blood glucose levels are mismanaged. This finding is consistent with a previous study showing that a lack of diagnostic equipment and expertise in the primary care units leads to higher costs for the patients who travel to a secondary and tertiary level clinic for treatment [28].

The undersupply of medicines was another barrier that hindered diabetes self-management because medicines were not reaching the rural settings timely due to affordability issues or availability problems. For example, medicines are available in the tertiary-level healthcare centers in Hunza, and drug availability issues are serious in the rural setting of Gilgit Baltistan.

The study also showed that women in the rural setting are preoccupied with household chores, looking after their children, and caring for their husbands, so they are left with no spare time to take care of themselves. A previous study has shown that insufficient support from family members is one of the major challenges in controlling the glycaemia of people with diabetes [29].

The present study's finding regarding inadequate knowledge about a healthy diet for diabetes as a barrier aligns with a previous study that showed that participants lack knowledge about foot care and a healthy diet [30]. The finding is also in line with a study conducted in India that showed that people with diabetes had low literacy and a healthy diet routine [31].

Spiritual beliefs play a significant role in managing various chronic diseases, including diabetes. Empirical evidence has shown that self-management of diabetes is significantly associated with lifestyle, food, resources and healthcare facilities [32, 34]. Various stresses, including financial, emotional, and physical trouble, the diagnosis of diabetes. The different coping strategies also involve exercise, diet, medication, and spirituality. Currently, the healthcare system is looking for ways to use various methods that help and assist compliance for people with diabetes to a healthy lifestyle, including spirituality where appropriate [35].

The practical implication of this study is that Pakistani healthcare providers should educate their patients about self-management practices through education and awareness sessions and involve dietitians in their teams to plan culturally and socially suitable diets for diabetic patients.

CONCLUSION

The present study provided a unique insight into the lives of the Wakhi ethnic group and explored their perception of barriers to managing diabetes mellitus. The diabetic patients reported inconsistency in their blood glucose level monitoring due to various barriers, including personal, social, cultural, diet and health system-related problems. Moreover, this qualitative study showed that the participants living in the rural setting have poor self-management of

diabetes due to household work and professional and social engagements.

The present study highlights the dire need for interventions and strategies to manage diabetes through health education, awareness programs, and health professionals focusing on changes in the behaviors of people with diabetes towards the disease. Considering the informational needs of people with diabetes, culturally sensitive and individualized diabetes management programs should be planned to achieve positive therapeutic outcomes. The interview findings suggest that improving education regarding the disease and its management could resolve such barriers among the Wakhi diabetic population. Basic knowledge could reap many advantages, including a broader knowledge of the disease, its management, how to access healthcare professionals and practitioners, and appropriate diet and exercise routine. The present study's findings may help develop culturally suitable self-management interventions for the rural setting of Northern Pakistan.

DECLARATIONS

The author confirms that all methods for the study were carried out in accordance with the relevant guidelines and regulations. All the experimental protocols were approved by the bioethical committee of the Institutional Review Board of the University of Agriculture, Faisalabad, Pakistan with reference number 3012/ORIC. Prior to the commencement of the study, informed consent was obtained from every patient.

Availability of data and materials: Demographic data of all patients is provided in supplementary table 1. The consent form and interview questions are provided in supplementary table 2 and 3, respectively. However, the complete data set and interviews conducted during the study are not publicly available due to intentions of ensuring anonymity of participants and agreement on confidentiality and privacy.

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