# Perspectives of patients with type 1 and type 2 diabetes on barriers to diabetes care: a qualitative study

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## Abstract

**Background** Diabetes care incorporates multiple integrated elements like self-care practices, patient education and awareness, societal support, equitable access to healthcare facilities and trained healthcare professionals, commitment from the diabetes associations and government policies. There is a dearth of research exploring the barriers experienced by both People with Type 1 diabetes (PwT1D) and People with Type 2 diabetes (PwT2D) in accessing the holistic elements of diabetes care. This study thus aimed at exploring the perceived barriers among PwT1D and PwT2D in accessing diabetes care services in urban and rural areas of Nepal.

**Method** This study was a qualitative research using phenomenological approach where an in-depth interview with 23 participants on insulin was conducted. This included 15 PwT1D and 8 PwT2D, residing in the capital and rural areas and attending the hospitals and clinic in the urban and semi-urban regions in Nepal. A semi-structured questionnaire was used for the interview. The interviews were transcribed verbatim and deductive thematic analysis was done.

**Results** Majority were female participants and most had received a formal education and were visiting the hospitals located in capital city. Mean age for PwT1D was (27.86 ± 1.85) years whereas the median age for PwT2D was [47.5 (IQR, 16.5)] years. Seven themes were generated from the study representing key barriers from patient's perspective. These were: Theme (1) Double stigma: Diabetes diagnosis and insulin use, Theme (2) Non-adherence to insulin and Self-Monitoring of Blood Glucose (SMBG), Theme (3) Logistic challenges in rural areas: Scarcity of healthcare professionals and other healthcare facilities, Theme (4) Dissatisfaction with healthcare services, Theme (5) Patients seeking alternative treatment strategies over allopathic treatment, Theme (6) Limitations of health insurance scheme and Theme (7) Limited role of national diabetes organizations.

**Conclusion** There is a need in raising awareness among general public especially on T1DM to address the issue of diabetes stigma. An effort in implementation of policies supporting diabetes care and refinement of National Health Insurance Scheme is equally essential. Similarly, strengthening of Health Care System by ensuring availability of insulin, laboratory facilities and trained healthcare professionals in rural areas should be focused to address the inequity in access to healthcare in rural and urban sectors.

**Keywords** Diabetes care, Type 1 diabetes mellitus, Type 2 diabetes mellitus, Insulin, Barriers, Perspectives

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## Background

Type 1 and Type 2 diabetes are the two main types of diabetes mellitus-a rapidly rising non communicable disease (NCD). It is estimated that Type 1 diabetes will affect between 13.5 and 17.4 million people worldwide by 2040 [1] whereas Type 2 diabetes is projected to impact 643 million individuals by 2030 globally [2]. While both Type 1 Diabetes Mellitus (T1DM) and Type 2 Diabetes Mellitus (T2DM) bears adverse impact on individuals, society and the entire health care system [3, 4], T1DM compared to T2DM is understudied, particularly in Low Middle Income Countries (LMICs) such as Nepal [5]. The prevalence of T2DM in Nepal is reported at 8.5% [6] whereas T1DM prevalence remains largely unknown [5]. Data on incidence of both T1DM and T2DM in youth in LMIC remains limited [7].

T1DM differs from T2DM in terms of its' etiologies, management [8, 9] as well as patients' experiences of living with diabetes [10]. T1DM is characterized by the autoimmune destruction of pancreatic cells, requiring insulin therapy [8], while T2DM is marked by insulin resistance, with insulin being used primarily to manage cases of uncontrolled hyperglycemia [9]. Experiences and needs of PwT1D also varies from that of PwT2D in terms of early onset, requiring continuous supply of insulin and blood glucose monitoring supplies, increased risk of morbidity and mortality and less public awareness of the disease [5]. Although timely diagnosis remains a challenge in both the types [11, 12] it is more prominent in T1DM as it demands certain level of sophisticated laboratory facilities that can detect the serological markers of the autoimmune ongoing process in T1DM [8]. Availability of such facilities in only selected tertiary care centers and the associated cost often lead to late diagnosis of T1DM in South East Asian countries which can further lead to complications [5].

Besides this, barriers to diabetes care can span multiple levels ranging from an individual level, interpersonal or societal level and health system level. These barriers impede patients from achieving desired clinical outcomes which can cause further progression towards diabetes related complications [13]. For example, on an individual level, failure to follow structured self-care practices for diabetes has been linked to uncontrolled glycemic range (HbA1C > 7%) [14]. Some of the self-care practices include adherence to medicines and Blood Glucose Monitoring (BGM). Barriers at an individual level for both PwT1D and PwT2D on insulin include cost of therapy [15, 16], patients' lack of knowledge on medication [17] and on use of glucometer [18]. Forgetfulness [19], fear of injection [20] and fear of pricking [18] are other factors influencing compliance to insulin and BGM respectively. Besides, an individual's role, adhering to self-care activities in chronic diseases like diabetes also demands social support and lack of such support can also be a barrier to self-care practices [21]. Similarly stigmatization felt or experienced by People with Diabetes (PwD) can also impede patients' health seeking behavior and their adherence to medication [22]. Owing to the chronic and complex nature of the disease, support from an interwoven matrix of both societal and health care system level are incumbent elements of diabetes care [23].

An essential element in the diabetes management is the provision of unceasing and viable delivery of healthcare services to individuals with diabetes [24]. This serves as the cornerstone in chronic disease management. Hence, in addition to an individual's role and societal role, diabetes care provision incorporates a complete integrated picture of the healthcare system in the country. This comprises of diabetes programs, patient education and awareness, availability and affordability of laboratory tests and access to diabetes care services. Furthermore, receiving timely diagnosis and continuity of care, healthcare professionals training, patients' adherence, ensuring availability of insulin and other required medicines also play an important role in diabetes management. The policies set by the government and the efforts of diabetes organizations can also influence diabetes management [25, 26].

Inequity in healthcare access, centralization of healthcare facilities, which leads to a skewed distribution of services between rural and urban areas, present a major challenge to Nepal's healthcare system. In addition, inadequate resources, lack of trained workforce and resilient healthcare infrastructure, poor disease awareness are the other challenges [27]. However the impact of such challenges on PwT1D and PwT2D using insulin in Nepal remains unexplored. In our research, Rapid Assessment Protocol for Insulin Access (RAPIA) framework was used for the assessment of health system barriers for diabetes care in addition to general questions for assessment of barriers at individual and interpersonal level. RAPIA has been widely used in different resource constraint countries to give a holistic picture of the barriers to diabetes care existing at health system level. It is a multi-level assessment of the different components that bear an impact on the patient's insulin access and diabetes care in a given country. It is used to identify barriers with regard to diabetes care at macro (Ministerial), meso (Health care centers) and micro (Health care workers and patients) level of health care system [25]. This paper is a part of a broader scope of our research work which focuses only on the patients' perceived barriers in accessing diabetes care.

Barriers to diabetes care perceived by PwT1D and PwT2D remains largely unexplored in Nepal.

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Understanding the perspectives of both PwT1D and PwT2D in receiving diabetes care is essential to comprehend how the patients are being impacted at an individual, societal and healthcare system level. Such an understanding of the perspectives of patients is necessary to provide patient-centered care, effective diabetes management [28] and provide recommendations on bringing necessary changes in policies governing diabetes care. Hence this study aimed to explore the perceived barriers among PwT1D and PwT2D in accessing diabetes care services in urban and rural areas of Bagmati Province in Nepal.

## Methodology

### Study design and study site

This study was a qualitative research that used phenomenological approach to explore the barriers to diabetes care from the lens of PwT1D and PwT2D residing in the capital (Kathmandu), semi-urban (Dhulikhel and Banepa) and rural sector (Sindhupalchowk). The study site included hospitals (government, private and community hospitals) and clinics providing services to diabetes patients. Patients residing in Kathmandu, Dhulikhel, Banepa, Sindhupalchowk and visiting Tribhuvan University Teaching Hospital (TUTH), Grande Hospital, Kathmandu Model Hospital, Kathmandu Diabetes and Thyroid Centre, Scheer Memorial Hospital and Dhulikhel Hospital were enrolled in the study.

### Study participants, their recruitment and data collection process

The study participants were individuals diagnosed with T1DM and T2DM of age 18 years and above and on insulin therapy for at least 3 months. Participants who met the inclusion criteria were recruited using the purposive sampling method. Most participants were identified and approached during their regular Outpatient Department (OPD) visit and their diagnosis was confirmed from their OPD cards. The researcher communicated with the participants for building rapport. A total of three patients were selected from the list of PwD provided by the doctors. These patients were contacted through phone calls. However, only one of these patients selected from the list agreed to participate while the other two participants denied their participation. The reason for denial was lack of time and interest. The researcher collected the patient's name, location, phone number, their tentative date of next OPD visit and asked the participant's permission to contact them for an in-depth interview at a location convenient to them. The researcher then contacted the participants via phone calls in between to strengthen the rapport and to confirm the date of appointment. Date, time and place of visit was fixed verbally and face

to face interviews were conducted by the first author SS(a). The researcher was a female PhD scholar and also a faculty at Kathmandu University, Nepal who was prior involved in qualitative research. However, her identity as a faculty was not disclosed to the patients as this we believed could affect the response given by them. The informed consent form noted that the researcher was a PhD scholar and that the research was part of the PhD work. The interviews were conducted in restaurants, parks, patients' residence and hospital periphery only in the presence of the interviewer and interviewee. All the interviews were audio-recorded using an interview recorder and field notes were taken after the interviews. Interviews were conducted from July 2023 to September 2023. Each interview ranged from 30 to 45 min. Data collection was stopped after interviewing 23 patients as no new responses appeared which indicated the achievement of data saturation particularly code saturation.

### Data collection tool

A semi-structured questionnaire [Supplementary file I] was used to conduct the interviews. After taking permission from the first author, a semi- structured questionnaire was developed based on the RAPIA (Rapid Assessment Protocol for Insulin Access) framework. RAPIA is a multi-level assessment tool developed with an effort of International Insulin Foundation (IIF) to explore the different elements that bear an impact on the provision of diabetes care and patient's access to insulin [25]. The questions were contextualized to our local context. In addition to the questions in the framework, few other questions were added to reflect upon the barriers to diabetes care existing at an individual and societal level. These included questions on impact of diabetes on patients' lives, adherence to insulin and SMBG, family support, disclosure of diabetes and insulin use and preference of alternative treatment strategies. After finalization of the semi-structured questionnaire, pilot testing was conducted. No major modification was needed.

### Data analysis

The data were analyzed following the Braun and Clarke's recommended process [29]. The process contains six steps namely familiarizing with data, coding of transcripts, looking for themes through deductive coding, reviewing the themes, naming the themes and generating the report. Familiarization with the data was done by transcribing verbatim all the audio-recorded interviews. Transcription was done concurrently with the data collection so as to gain acquaintance with the pattern of emerging data. The transcripts were read multiple times by the first author and the other team members to familiarize with the data. Coding of the transcripts was done

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where two authors SS(a) and KA coded the data manually, across the entire transcript assigning words or relevant phrases. No major discrepancies were observed in the codes. In case of minor discrepancies, a third member did the coding and discrepancy was settled with discussion. This was followed by translation of the coded extracts in the transcripts into English. A quality check was done by back translating some random extracts into Nepali. Since no significant differences was noted in the translated and back translated versions, the translation was deemed appropriate. Looking for themes from the deductively derived codes from six transcripts was done, visualizing them through branching technique, and the pattern of the emerging themes were created based on the codes. The codes were clustered to generate potential themes and sub-themes. The remaining seventeen interviews were coded and thematized by SS (a). Reviewing of all the themes and sub-themes from the seventeen and earlier six transcripts was done. Naming and defining the themes was done where the themes were given a suitable name to reflect the value it captured and then each theme was defined. Finally, a report was prepared detailing the themes and sub-themes.

Scientific trustworthiness of the research was established by ensuring accomplishment of the following measures namely credibility, transferability, dependability and conformability [30]. Credibility was ensured by building a good rapport with the participants through multiple interactions (OPD visit, phone calls in middle and interview) which resulted in proper understanding of their perspectives. Transferability was ensured by providing a detailed contextual description in the manuscript regarding participants, methods and sampling strategies. Dependability was ensured by providing a detailed documentation of methodology and keeping an audit trial. Conformability was ensured through member checking where some of the participants were given the transcriptions to ensure correct representation of their perspectives and experiences. The participants confirmed correct reflection of their views and experiences [30]. The consolidated criteria for reporting qualitative research (COREQ), a 32-item checklist was used in reporting the study [Supplementary file II].

## Results

The demographics of the participants are presented in (Table 1).

Seven themes emerged from the study: (1) Double stigma: Diabetes diagnosis and insulin use (2) Non-adherence to insulin and SMBG (3) Logistic challenges in rural areas: Scarcity of healthcare professionals and other healthcare facilities (4) Dissatisfaction with healthcare services (5) Patients seeking alternative treatment strategies over allopathic treatment (6) Limitations of Health Insurance Scheme (7) Limited role of national diabetes organizations [Table 2].

### Theme 1: Double stigma: diabetes diagnosis and insulin use

The theme summarizes the stigma experienced by PwD particularly T1DM, the experience often being linked to the diagnosis of diabetes and use of insulin which made them feel vulnerable.

Some PwT1D linked their experience of stigma which led to fear after diagnosis of the disease particularly because of their young age: A 24 year old girl expressed her fear of being shoved into the "Not Normal" category which inflicted psychological and emotional anguish upon her and contributed to her reluctance to unravel among her peers: "...they [Friends in village] will say *"Oh!.you have such a disease, which makes me feel very low and I feel I have this disease that is not normal....So, I even hide it from my friends."* [P1, T1DM]. Another 23 year old girl also shared her experience of being labelled as "Sick and Vulnerable" in the family (by grandparents) and in the community: *"People said, "She caught sugar at such young age... ... who is going to look after such sick person...everyone behaved differently... This hurt a lot..."* [P21, T1DM].

Need of insulin further added to the experience of the stigmatization among the patients. One participant verbalized her experience of how being on insulin was perceived as synonymous with a "Near- deathbed" condition within the community. This further led her to deny insulin use for an entire year in spite of medical need: *"...people said ... insulin is the last stage!...now you won't live long!...I denied using insulin for a whole year and stayed on tablets....my sugar level refused to go down ...eventually I started insulin."*[P11, T1DM]. Another person shared how embarrassment in injecting insulin in public led to fluctuation in timing of insulin shots: *"I felt awkward to inject insulin in front of other people. So, there used to be fluctuations in timing of my shots"* [P5, T1DM].

The absolute reliance of PwT1D on insulin for sustaining their lives added to the vulnerability experienced by them. A participant expressed *"I once left insulin... but I got very sick. So, I continued it again...if not it would mean death for me."* [P1,T1DM].

Another participant shared, *"Sometimes I feel very irritated because of regularly injecting insulin but I have to live with it everyday. We have to accept this fact but I feel its' difficult for most people to accept it."* [P10, T1DM].

However, none of the PwT2D in our study reported confronting such experiences.

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**Table 1** Demographic characteristics of patients

| Characteristics | T1D Participants *n* (%) | T2D Participants *n* (%) |
|---|---|---|
| **Age (Years)** | Mean ± SD [27.86 ± 1.85] | Median (IQR) [47.5 (IQR,16.5)] |
| **Gender** | | |
| Male | 5 (33.3) | 4 (50) |
| Female | 10 (66.6) | 4 (50) |
| **Education** | | |
| No formal education | 0 (0) | 2 (25) |
| Primary Level | 1 (6.6) | 1 (12.5) |
| Secondary Level | 6 (40) | 4 (50) |
| Higher Secondary | 1 (6.6) | 0 (0) |
| Undergraduate and above | 7 (46.6) | 1 (12.5) |
| **Occupation** | | |
| Employed (Pharmacist/Staff nurse) | 2 (13.3) | 0 (0) |
| Student (Pharmacy/Nurse) | 2 (13.3) | 0 (0) |
| Student (Other) | 2 (13.3) | 0 (0) |
| Employed (Other sectors) | 4 (26.6) | 3 (37.5) |
| Retired/ Unemployed/ Housewife | 5 (33.3) | 5 (62.5) |
| **Duration of diagnosis (Years)** | | |
| Median | 6 | 11 |
| Interquartile Range (IQR) | 5.5 | 15 |
| **Type of regimen prescribed** | | |
| Insulin only | 14 (93.3) | 0 (0) |
| Insulin + OHA | 1 (6.6) | 8 (100) |
| **Temporary Residence** | | |
| Rural | 1 (6.6) | 4 (50) |
| Semi-Urban | 6 (40) | 0 (0) |
| Capital/Urban | 8 (53.3) | 4 (50) |
| **Location of hospital Visited** | | |
| Capital | 7 (46.6) | 5 (62.5) |
| Semi-urban | 8 (53.3) | 3 (37.5) |

**Table 2** Themes and subthemes

| Themes | Subthemes |
|---|---|
| 1. Double stigma: Diabetes diagnosis and Insulin use | |
| 2. Non-adherence to insulin and SMBG | 1.Costliness of insulin and glucometers |
| | 2. Unavailability of insulin and glucometers |
| | 3. Forgetfulness |
| | 4. Other factors |
| 3. Logistic challenges in rural areas: Scarcity of healthcare professionals and other healthcare facilities | |
| 4. Dissatisfaction with healthcare services | 1. Dissatisfaction with counseling services |
| | 2. Dissatisfaction with switching of doctors |
| 5. Patients seeking alternative treatment strategies over allopathic treatment | |
| 6. Limitations of health insurance scheme | 1. All insulin are not covered by Health Insurance |
| | 2. Lack of uninterrupted availability of insulin covered by Health Insurance |
| | 3. Long waiting time after implementation of Health Insurance |
| 7. Limited role of national diabetes organizations | |

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**Theme 2: Non adherence to insulin and SMBG**
The theme outlines the reasons for not adhering to insulin and SMBG and the challenges experienced in maintaining their adherence to insulin, as expressed by PwD.

*Subtheme 1: Costliness of insulin and glucometer*
All the PwD, both T1DM and T2DM mentioned the "high cost of insulin" as their major concern surrounding diabetes management. There were instances where some participants rationed their insulin due to its' steep price. One participant reported trying self-management measures such as exercise and diet over insulin whereas some deliberately skipped insulin doses: *"Due to financial reason (insulin cost) I thought of controlling my sugar level with exercise and dietary restriction. ...I left insulin for 1 month ......I had to get admitted in the hospital."* [P4, T1DM].

> *"At times I do not have enough money to buy insulin. Last time I missed insulin for a whole month and my sugar level went up...."* [P9, T2DM].

However for most of the PwT1D, the fear of impaired glycemic control and negative impact on health motivated them to take insulin in spite of its' costliness. One participant stated: *".... Sometimes I feel like giving up on insulin, this is ridiculously expensive ...but I fear of getting gravely ill..."* [P5, T1DM]. Most of the patients adopted cost cutting strategies such as forgoing regular follow-ups or laboratory tests, a trade-off between insulin and other facets of medical care or borrowed money for insulin. Drawing on their experiences, some participants quoted: *"There are times when I miss my regular follow up because sometimes we run out of money.... But I have not missed out on my insulin...I manage by even borrowing money...."* [P1, T1DM].

> *"I have not compromised in buying insulin (due to financial reason). But I have cut down my follow up visits a few times....It's like I have to make a tradeoff between buying insulin and going on follow ups at times."* [P13, T1DM].

In regard to use of glucometers, some participants described cost of glucometer and strips to be the chief factors in avoiding its' use: *"...I don't have money to buy it [glucometer]..."* [P21, T2DM]. *"I neither have a fridge nor glucometer (due to unaffordability)."* [P22, T2DM]. *"...rather than availability issues, its' the affordability issues that I don't use glucometer."*[P8, T1DM].

*Subtheme 2: Unavailability of insulin and glucometer strips*
The issue of poor access to insulin particularly in the villages was highlighted by many participants. Most of the participants quoted insulin as something "Not readily available". They shared their stories of struggle with finding insulin at some point of time when visiting their villages ensuing in instances where they had to miss the doses. For example, some stated: *"...sometimes I have missed it (insulin) due to unavailability ... while going to my village."* [P6, T1DM].

> *"I have missed my insulin ... because...It's not available at my place [village] and I have to travel half an hour by bus to [place name]...if it's not available even there...I have to travel till Dhulikhel hospital... .I cannot take extra stocks ...I do not have refrigerator."* [P21, T1DM].

Some reported increased expenditure in travelling to city areas to get their regular supplies of insulin: *"To get a medicine supply worth Rs 900–1000 ($6.6 -$7.4), we need to expend Rs 5000 ($37) to come here [Dhulikhel] to get the medicine (insulin)."* [P22, T2DM]. One participant even reported migrating to Kathmandu (capital) due to unavailability of insulin in his village: *"...I migrated to capital for insulin"* [P7, T2DM].

Similarly use of glucometer was also found to be challenging in the villages due to unavailability of it's' strips: *"Glucometer, its' a little difficult to find the strips for it.... in my village"* [P2, T1DM].

*Subtheme 3: Forgetfulness*
Some participants with T1DM reported unintended medication non-adherence owing to forgetting their insulin shots during the outset of insulin therapy: *"I often used to forget my medicine [insulin] during starting days.... It was like...Oh! Do I have medication! ...."* [P3, T1DM].

*Subtheme 4: Other factors*

*Dread pricking and able to predict hypoglycemia*   Most of the participants who did not practice or reduced SMBG stated their fear of pain associated with frequent finger pricking as the chief factor: *"I have not bought glucometer in spite of doctor's recommendation. Earlier (during admission) I had been pricked multiple times. So I feel that anxiety will cause my blood glucose level to rise more and more..."* [P11, T1DM]. Some participants, on the other hand, reported their ability to identify the symptoms of blood glucose level fluctuations as reasons for cutting down on the use of glucometers: *"I used to check my blood glucose level very frequently...now I can feel the fluctuation ...so, I use glucometer in those times to confirm..."* [P5, T1DM].

**Theme 3: Logistic challenges in rural areas: scarcity of healthcare professionals and other healthcare facilities**

The theme "Logistic challenges in rural areas: Scarcity of healthcare professionals and other healthcare facilities" highlights the poor availability of doctors especially diabetes specialists and laboratory facilities in rural areas of Nepal.

Many participants originating from the villages pointed out to the scarcity of required laboratory facilities and healthcare professionals in the villages which resulted into delayed diagnosis in one of the rural participant. Majority expressed their dissatisfaction with having to rely on paramedics such as Health Assistants (HA) or Community Medical Assistants (CMA). Lack of endocrinologists was perceived as a scarcity of expertise by the participants which was a push factors for most of the rural residents to go to the city areas in search of proper medical care: *"In my village, I have not met specialist doctor. If such professionals were there, I would not have to come to Kathmandu (capital) …."* [P5, T1DM].

> *"There are no big [specialist] doctors in our village, there is not even a single proper tool for checkup at the health post. I had sugar but I didn't know that (could not be diagnosed) and it hit my kidney, eyes…."* [P22, T2DM].

> *Here (capital), various tests are available based on which the type of diabetes can be identified and accordingly the medication is instituted. The scenario in villages is different (lack of diagnostic facilities)"* [P6, T1DM].

However, one participant expressed his satisfaction on recent upgrade in laboratory facilities in the health posts: *"Earlier it was not there, but from this year, they have glucose testing facility at the health post…."* [P19, T2DM]. But for some this facility was not easily accessible: *"Currently there is blood test facility at Barabise [name of place], it takes an entire day on feet to reach that place."* [P22, T2DM].

**Theme 4: Dissatisfaction with healthcare services**

The theme "Dissatisfaction with healthcare services" reflects inconsistencies in counselling services provided in government and private hospitals as well as in the health care centers in rural areas. The theme also exhibits patients' dissatisfaction with frequent switching of doctors in government hospitals.

*Subtheme 1: Dissatisfaction with counseling services*

Participants' views on "Counseling services" was mixed. They expressed existence of variation in quality of counseling among various hospitals especially the private and government hospitals. This led to dissatisfaction among patients visiting government hospitals particularly due to lack of counseling on the dietary aspect. Few quotes explaining the subtheme are: *"I used to visit [government hospital]. There I did not receive any sort of counselling…not even on diet. I never properly understood how to inject insulin, the doctors never explained, so I never got better…. I went to see the specialist of sugar (private sector). There I received the diet plan."* [P4, T1DM].

> *"In the [government hospital], I was simply handed over a list of diet, there was no counselor. When I went to the [Private Hospital], the doctor sent me to a nutritionist where they told me what to eat and how to eat."* [P10, T1DM].

A number of participants indicated lack of appropriate counseling in the villages: *"We do not get such detailed information from the health post…. a person working in health posts does not know about diabetes."* [P17, T1DM].

*Subtheme 2: Dissatisfaction with switching of doctors*

A dissatisfaction among the patients was observed in terms of lack of provision for getting to see the same doctor in every follow up visit which they believed is an impediment to a proper healthcare delivery for chronic disease condition like diabetes. This also created a sense of skepticism among the patients in regard to the healthcare decisions made for them and a participant also reported it to be the chief reason for preferring the private healthcare facility over the government hospitals.

> *"If I could go to government hospital that would have been cost effective…but every time the doctor changes, that's' the problem…the service will not be good if the patient does not get to see a fixed doctor…"* [P10, T1DM].

> *"There is a lot of switching of the doctors…I am a pharmacy student so I titre the insulin dose myself. I don't go for regular follow up due to a lot of switching of doctors."* [P23, T1DM].

**Theme 5: Patients seeking alternative treatment strategies over allopathic treatment**

The theme underscores the existing practices apart from allopathic treatment, pursued for treating diabetes which included various healing practices pursued in our society ranging from Ayurveda, homeopathy, traditional home based remedies and going to faith healers. As compared to PwT2D, most of the PwT1D seemed to have a better understanding of the disease and its' dependence on insulin. These participants fostered skepticism to

any other traditional remedies which led some of them to deny its use whereas few tried it out of family members' request but with dubiousness. Few relevant quotes are: *"Some said if you go into Ayurvedic, you can get off the insulin but…I never tried any of those simply because I didn't believe it."* [P6, T1DM].

Although the impact of following alternative treatment strategies was neutral for many patients, some participants reported increased expenditure and negative impact on health following the alternative measures. For instance, few quotes are mentioned: *"I went to India 12 times…for ayurvedic treatment ….the expenses stood around Rs.40,000–50,000 ($296.7-$370.9), diet during travel was not suitable and my sugar level increased. It impacted me financially and mentally."* [P23, T1DM].

> *"I took in a lot of herbs in hope of getting cured…it affected my liver…." [P7, T2DM].*

Some participants also resorted to faith healers resulting into delayed diagnosis: *"My husband did not agree going to the doctor, he said: some evil force has harmed you…we went to faith healer [dhami jharkri]…later my sugar level was 650 when checked"* [P12 T2DM].

> *"My legs began to swell, I didn't know it was sugar. So we resorted to the faith healer…there was no improvement…." [P22, T2DM].*

### Theme 6: Limitations of health insurance scheme

The theme – "Limitations of Health Insurance Scheme" summarizes the mixed responses received from the patients on the National Health Insurance Scheme with a focus on the gaps for improvement highlighted by the participants. This included inadequate coverage of all types of insulin, inconsistency in availability of insulin in hospitals and long waiting lines in the hospitals offering health insurance services.

Remarks of participants on "National Health Insurance Scheme" of Nepal was heterogeneous. Most patients reported Health Insurance as a support in sharing cost of medicines and laboratory tests: *"Insulin is expensive, other medicines are expensive. But currently because of health insurance, it has become relatively easier (financially)"* [P7, T2DM]. But even though there were positive remarks, they were accompanied by some reservations.

### Subtheme 1: All insulins are not covered by health insurance

Majority of the PwT1D did not perceive any benefits of the Health Insurance as their insulin was not covered by the scheme. One participant stated: *"I have not done health insurance…. insulin is not there… (is not covered)"* [P6, T1DM]. Another participant quoted: *"I wish Health Insurance would cover all the medicines….insulin is the most expensive (and not covered)"* [P6, T1DM].

### Subtheme 2: Lack of uninterrupted availability of insulin covered by health insurance

Many among the enrollees commented on the lack of regular supply of insulin in the hospital in spite of its 'coverage by Health Insurance. This was also expressed by few as a misunderstanding of the previously covered insulin being taken off the Health Insurance Scheme: *"…. Currently health insurance is covering insulin too, it's like on and off"* [P7, T2DM].

> *"Insulin availability is irregular in the hospital under health insurance scheme. So I buy it from outside." [P17, T1DM].*

### Subtheme 3: Long waiting lines after implementation of health insurance

Participants regarded the upsurge in crowd and long waiting lines in the hospitals after implementation of the health insurance scheme as a sector requiring improvement.

> *"…the hospital, it's all swarmed with people and we end up waiting the entire day…We have to stand in line starting from the registration to taking the medicine." [P11, T1DM].*

> *"…I have to wait very long but because I am sugar patient, I have to take my meal in time for insulin… .I have to wait for hours to see the doctors…" [P9, T2DM].*

### Theme 7: Limited role of national diabetes organization

The theme "Limited role of national diabetes organization" outlines the current contributions and activities of diabetes organizations in fostering a positive environment for diabetes care. The theme also reflects the limited acquaintance of PwD with such organizations and their views on the potential role of these organizations.

Most of the participants were unacquainted with diabetes organizations. Among those involved, only two PwT1D were members of the diabetes association and were involved in awareness campaigns organized by the bodies: *"We established this organization, Type 1 diabetes Nepal. ….We conducted awareness programs for Type 1 diabetes patients on diabetes management earlier."* [P23, T1DM]. *"I am a life member of the "Nepal Diabetes Association"…we used to get free checkup. They conducted campaigns… oriented us on providing information on diabetes and spread these information in our regions."* [P17, T1DM].

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Only few PwT1D were acquainted with the support being provided by the International diabetes organizations to PwT1D. Insights on the support was obtained from 3 PwT1D. One of the patient, a pharmacy graduate mentioned about the provision of support for PwT1D from "International Diabetes Federation" (IDF) which provides free insulin, glucometer and strips for those under 25 years: *"IDF provides children and adults within age bracket of 25 years with insulin, glucometer, strips supply free of cost... till the age of 25 years ....There was a boy from [village] from a very poor economic background with diabetes... ...IDF has helped such people....and single mothers whose children suffered from diabetes."* [P23, T1DM].

Another pharmacy student participant though aware of this provision was unacquainted with the name of the organization and was not satisfied with the service offered by IDF: *"In (hospital linked with IDF), they give insulin free of cost to patients under certain age (less than 25 years) but ....It's in the syringe form,.... very inconvenient..."* [P10, T1DM]. Another patient with T1DM, previously a teacher, received help from a national organization "Nepal Diabetes Association" and was linked to the association by his physician (Pvt. Hospital). He quoted: *"An association "Nepal Diabetes Association" did provide us half the required amount of insulin on a monthly basis for 1 year due to the high cost of insulin"* [P17, T1DM].

Some participants also expressed their views on the potential roles of national diabetes organizations for benefit of people with diabetes. Participants shared that such organizations can serve as a common ground for PwD for expressing their emotions which can gestate a feeling of inclusion in the group and also serve as a fund assimilator to cater the treatment costs for economically disadvantaged PwD: *"...this gives a platform where people with diabetes can meet in a group and can share their feelings and experiences."* [P1, T1DM]. *"...when people may not be able to purchase their medications, in those times they may have some hope of receiving help from the organizations."* [P12, T2DM].

## Discussion
This study explored the perceived barriers among PwT1D and PwT2D in accessing diabetes care services. The key barriers identified by our study included diabetes stigma confronted particularly by the young people with diabetes. Factors leading to "Non-adherence to insulin and SMBG such as cost, unavailability of insulin and glucometer strips, forgetfulness, needle phobia were other barriers identified. Similarly frail availability of healthcare professionals and other healthcare facilities particularly in rural sectors, variation in the quality of counseling services and frequent switching of physicians in government hospitals also hindered diabetes care. Lastly, inclination to alternative treatment strategies, crevices in National Health Insurance Scheme and limited roles of national diabetes organizations were the others barriers recognized by this study.

## Double stigma: diabetes diagnosis and insulin use
Our findings reflect greater vulnerability of PwT1D to stigmatization as compared to PwT2D on insulin which is in congruence with a study by Nancy et al. [31]. This may be attributed to a preconceived notion that portrays diabetes as an old age disease [32]. This misconception tends to shift the PwT1D to a category atypical to the ideal norms that define young people. In close alliance to this interpretation, a study also reported PwT1D being considered as "monsters" or "strange" in China [33]. Studies have established an association between diabetes stigma and young age which further consolidates our findings [34]. Additionally being tagged as "Sick", "Weak", "Vulnerable", "Unable to work" were the other facets of stigmatization reportedly confronted by PwT1D in our study which is in alignment with other literatures [33, 35–37]. The lower prevalence of T1DM [33, 37] and prevailing unawareness among the general public on the same [31, 38–40] could be other contributing factors for the diabetes stigma. Being diagnosed with diabetes at an early age and using insulin were reflected as causes of stigmatization experienced by PwT1D. However, such types of experiences was not voiced by PwT2D in our study. Some literatures reflect PwT2D being blamed for self-inflicting the disease or facing discrimination in receiving opportunities [38, 41] which were not reported in our study. This might be attributed to the rising prevalence of T2DM in Nepal [42] which in the current scenario has become a common condition afflicting a large number of people [43] and also due to the age group of the participants in this study where T2DM is prevalent. Feelings of embarrassment can deter patients from timely administering of insulin as observed in our study or even lead to missing the doses as stated by researches [15, 28, 39, 40, 44]. Insulin in many instances has been linked with "Last resort treatment" within the community [45, 46]. So, its' initiation at an early age and lifelong reliance on insulin [34] places PwT1D in a situation akin to being on the brink of death in people's views [36, 40, 45], similar experience being expressed by some of our participants. Irrespective of the type of diabetes, diabetes associated stigma can have ripple effects such as non-disclosure [35, 36, 38, 39, 47, 48], internalization of the negative judgments which can further demean their self-esteem [43] as also shared by our participants.

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## Non-adherence to insulin and SMBG

Cost of insulin [15, 19, 20, 46, 49–52] and its unavailability or shortage [19, 46] particularly in the rural areas were found to be the principal barriers to insulin adherence [20, 49, 53, 54] as stated by both PwT1D and PwT2D in our study. Majority were well acquainted with pivotal role of insulin in management of their diabetes with PwT1D realizing its' absolute necessity for their survival which is in congruence with other literatures [15, 55]. However, the fact that insulin absorbed a significant expenditure of diabetes care can compel some patients to resort to rationing their insulin either by completely re-coursing to non-pharmacological alternatives, omitting the shots intermittently, self-adjusting the doses or switching to less expensive types [28, 56] as also reflected in some of our narratives. Nevertheless, majority reported being adherent to their insulin therapy. This reflects understanding of the patients in regard to the potential repercussions on health and health related expenditures that non-adherence to insulin can summon which is in congruence to findings of Elsayed H. et al. [57]. Similarly, findings by Shakya P. et al. depicted relatively higher adherence among PwD on insulin than those on OHA in Dhulikhel, Nepal [58] which further consolidate our results. Patients in our study reported buffering the high cost of insulin by compromising on the other aspects of care such as deferring regular follow-ups or laboratory tests which is in alignment with available literature [59].

Both PwT1D and PwT2D stated unavailability of insulin as a major problem thus impacting adherence particularly in the rural area as also evidenced by other studies [5, 13, 25, 60, 61]. Narratives of the patients residing in capital reflect their challenges of travelling to their villages due to unavailability of insulin whereas those of rural residents expressed the need to travel long distances to the town or capital to get their insulin supplies thus incurring additional cost as shown in another literature [13].

Forgetfulness as stated by some of our patients was a barrier to adherence which is consistent with other literatures [15, 19, 49, 50, 52]. However, this was quoted as a problem chiefly during the initial days of insulin therapy until the patients got habituated to their daily schedule of injection.

In spite of SMBG being an essential element of the self-care practices particularly for PwD on insulin [62] its' utilization is below optimum level [16] which is in consensus with our findings where majority of the PwT1D and T2D did not practice SMBG on a daily basis. This is also reinforced by another study highlighting perceptions and experiences of PwT2D in Nepal on SMBG [63, 64]. However, contradictory results are available from studies in Australia where above 80% of the patients on insulin practiced SMBG. This may be due to the discounts provided by the Australian government on blood glucose test strips and continuous glucose monitoring products through National Diabetes Services Scheme [65], a provision which does not exist in Nepal. Cost of glucometer and strips, fear of pain in finger pricking, unavailability of glucometer and strips particularly in the villages, patients' lack of understanding in regard to technical use of the devices and patients' ability to recognize symptoms of alterations in blood glucose level were found to be the barriers to SMBG in our study which is in alliance with other evidences [16, 18, 66–69]. Poor adherence to SMBG has been linked with higher healthcare costs due to increased expenditure associated with diabetes complications and hospitalizations [16, 70]. Hence, providing glucometers free of cost and introducing subsidies on the test strips and needles in Nepal is essential. Additionally stressing the significance of SMBG as an intricate component of diabetes management in counseling sessions could contribute in enhancing adherence of PwD on insulin to their SMBG practice.

## Logistic challenges in rural areas: scarcity of healthcare professionals and other healthcare facilities

Lack of diabetes specialists, other well trained health care professionals and poor access to healthcare facilities such as laboratory tests, diagnostic equipment and required medications make lives of PwD in rural areas an uphill battle [71] which has also been reported by most of the PwT1D and T2D. Advancements in service accessibility following enactment of policies by Ministry of Health and Population (MOHP) in Nepal represents a substantial effort towards fulfilling commitment outlined in Interim Constitution of Nepal, 2007, to provide free basic health care services to every citizen. However, report suggest distance to health centers posing significant challenge for rural population in utilizing the health care service [72, 73]. Our finding is in congruence with the reports of a study conducted in Bangladesh where patients in the rural and peri-urban areas lacked access to even the most fundamental medical care facilities within an accessible perimeter often landing up the patients on severe complications due to late diagnosis [74]. A prevalent issue mentioned by most of the participants was unavailability of doctors in the health post which was reportedly under the functioning of HA/CMA whose competency was distrusted by the patients. A plethora of evidence support our patient's statements reflecting urban/rural disparity of healthcare workforce especially doctors and nurses which is emblematic of Low Middle Income Countries (LMICs) [72, 75]. This can possibly be accounted to inadequate production, challenges in deployment to the rural sectors, difficulty in retention of health care workforce in

the country due to an imbalance in domestic push factors and international pull factors. Nevertheless, a close collaboration between the government entities and donor organizations and inception of rural staff support programs can be a viable solution. For instance, a program initiated in three districts of Nepal where scholarship along with service contract, comfortable temporary residence, increased salaries offered to the doctors willing to be a part of the program resulted in a notable rise in hospital service utilization [76]. As an option, embarking on the concept of task-shifting wherein alternative healthcare professionals are trained to undertake specific tasks typically performed by the physicians has been considered. This strategy could be targeted to provide health care services to individuals with NCDs such as diabetes which demands life-long care backed by adequate health care facilities and uninterrupted medication supply [77].

### Dissatisfaction with healthcare services

Most of our participants demarcated the quality of counseling received from private health care facilities and government hospitals expressing their dissatisfaction towards the counseling services in the latter. Patient's chief curiosity centered on the dietary plan which according to some of them was not provided timely. A gap in patient education on dietary aspect is portrayed in our context which can lead to inadvertent unhealthy eating habits. A significant association of dietary counseling received from healthcare providers with adherence to dietary recommendations has been found [78]. This often led patients to switch to private health care facilities where they claim to have received proper counseling. The situation was worse in rural sectors where according to our study participants, the healthcare personnel (HA or CMA) possess the least knowledge on diabetes and its 'management. Diabetes education is the cornerstone of diabetes management as it bears the strength to bring lifestyle, dietary and behavioral modifications in the patient's lives and make the patients in charge of their own health [58]. It improves treatment adherence among diabetes patients [58] and alleviates the possibility of complications thus saving the individual and the healthcare system as a whole from catastrophic cost burden [79].

### Patients seeking alternative treatment strategies over allopathic treatment

Ayurveda, homeopathy and other home based herbal remedies are rooted in the traditional healing culture of Nepal [46] as evidenced in majority of our patients' practices. However none of the patients discontinued their insulin while concurrently using the alternative therapies. This mirror their apprehension about potential adverse impact of discontinuing insulin therapy which is in contradiction to the findings of Hannah et al. where some of the traditional healers believed that their treatment would only be effective if the patient abstain from insulin and persuaded them in the same line [66]. Such beliefs held by the traditional healers can lead to fatal consequences for those on insulin especially the PwT1D whose survival rely on it. In spite of patient's decision to continue their insulin, a trend towards use of alternative treatments without consultation of doctors was seen which can lead to possible unwanted interactions or compromised efficacy of allopathic drugs. The historic and cultural values of herbs ingrained in Nepalese culture coupled with their easy availability, particularly in a close-knit rural communities, can lead individuals to experiment with various herbs based on word of mouth. Unfortunately, this can result in adverse health effects, as illustrated by one patient's firsthand experience, who nearly suffered from liver damage. Similarly, misconception that starting allopathic medicines will render the herbal remedies ineffective prevailed in some communities as expressed by some of our participants. Such false beliefs can detrimentally affect patients' health seeking behavior, abstaining them from seeking timely medical attention. In contrast to individuals with T2DM, those with T1DM appeared to possess a more scientifically informed understanding of their condition and the crucial role of insulin therapy. This inclination prevented many of them from turning to alternative treatments. This variance indicates a deeper comprehension of diabetes, its etiology, and its management among young adults, likely attributed to their education and access to diverse informational resources.

### Limitations of health insurance scheme

Patient's perception on National Health Insurance Program (NHIP) launched by Government of Nepal (GoN) in the fiscal year 2015/2016 was found to be heterogeneous. The chief grievance of the patients in our study revolved around the fluctuating availability of insulin in the hospital pharmacies or lack of coverage of all kinds of insulin under the health insurance scheme along with other medicines which they claimed to be expensive. This appeared as one of the reasons for declined attraction among PwT1D in getting enrolled in the scheme due to their absolute reliance on insulin. This corroborates conclusions drawn from researches conducted in Nepal, which revealed that a scarcity of medications and equipment acts as a barrier, reducing the appeal of the health insurance scheme to the general public [80–82]. This can further threaten its' sustainability as communicated by Sharma et al. where 34% of the household in Pokhara Metropolitan City dropped out of Social Health Insurance Program due to poor availability of drugs and

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healthcare services [83]. Furthermore, a need of re-evaluating and expanding the healthcare package to incorporate the essential medicines to a broader degree seems essential, aligning with recommendations from existing literature [82]. A common complaint articulated by the beneficiaries in our study was long waiting lines and delayed services in the hospitals partnered under health insurance program which is in agreement to the findings of Damaru et al. [80]. This has also come forth as a chief reason for dropping out of the scheme where 63% of the households terminated the scheme for the aforementioned cause [83].

### Limited role of national diabetes organizations

Very few PwT1D and none of PwT2D were involved in diabetes association. Associating with diabetes association has been found to be a significant predictor of adherence to insulin therapy among PwD [54]. However, majority of our patients were completely ignorant of the diabetes organizations or associations in Nepal and their contribution in diabetes. Unacquaintance of most of the patients with awareness activities on diabetes both in urban and rural areas highlight the need for the organizations to widen their coverage for awareness campaigns. Awareness campaigns are reportedly one of the prime activities of various diabetes organizations in Philippines [84]. Nevertheless, few organizations in Nepal such as Nepal Diabetic Society (NDS), Nepal Diabetes Association (NDA) and ASTHA Nepal has been at the forefront of gearing the attempts towards prevention and control of diabetes. These organizations have been involved in raising awareness on diabetes and importance of seeking timely medical care [85, 86]. Astha Nepal is also a social organization that has been organizing awareness campaigns on diabetes [87]. Besides creating awareness, diabetes organizations as articulated by our participants can serve as a support group. International organizations such as American Diabetes Association (ADA), Diabetes Advocacy Alliance, Juvenile Diabetes Research Foundation (JDRF), etc. play a role in networking the patients with support groups with people on the same ride and experience of diabetes [88]. Literatures favor the utilization of support groups in chronic diseases where insights and experiences can be shared in a more equal and mutually beneficial manner without involvement of any hierarchical dynamic [89, 90]. Some of our PwT1D perceived one of the roles of diabetes organizations as fundraising and generating fund to cover the treatment expenses of diabetes patients needing financial assistance. Organizations such as ADA play a crucial role in accumulating funds and helping the people by networking them with appropriate resources needed for prevention and management of diabetes. ADA advocates for financial support from the government and pharmaceutical industries to promote impactful researches in field of diabetes and work towards campaigning for policies that favour prevention of diabetes [91]. Although NDS and NDA have provided complimentary medical tests and medications to financially vulnerable patients with diabetes to some extent, there is a recognized need to broaden their scope in line of organizations like ADA, reflecting the current demands. Moreover, the hospitals can serve to connect individuals with diabetes to the diabetes organizations.

### Strengths and limitations

The strength of the study is the inclusion of both PwT1D and PwT2D on insulin. We were able to delve into their perceived barriers to diabetes care and were able to incorporate multifaceted elements of diabetes care, which remains an unexplored topic in Nepal. Involvement of PwT1D adds to the strength of the study as research focusing on T1DM is very limited. We were able to include patients from different geographical regions and also highlight on the barriers to diabetes care faced by people in the rural areas.

The study's delimitation was that it included only individuals with diabetes who were 18 years of age or older. Hence the barriers to diabetes care from the perspectives of PwD below this age bracket could not be captured in the study. We recommend future studies to acknowledge this gap as researches focusing on T1DM and T2DM in young people in Nepal is very limited. Additionally, another limitation was that the study only included patients who visited hospitals and clinics. Consequently, patients with T1DM or T2DM living in rural areas who were unable to access these facilities were excluded. As a result, the study did not capture the barriers to diabetes care experienced by this group.

### Conclusion

Perceived barriers to diabetes care comprised of several factors, such as stigmatization related to diabetes and insulin use, as well as challenges that result in reduced adherence to insulin and SMBG. Compromised adherence to diabetes care was attributed to the high cost and limited availability of insulin and glucometer strips in rural areas. Additionally, the scarcity of endocrinologists and laboratory facilities in these regions hindered effective diabetes management. Inadequate counseling services, especially in rural health centers and government hospitals, along with frequent changes in doctors, were also seen as barriers. Other obstacles included reliance on herbal remedies and faith healers, as well as incomplete coverage of all insulin types under health insurance schemes. Unacquaintance of PWD to national diabetes organizations and its' limited role in

prevention of diabetes and assisting PwD in management of their disease were the other identified barriers. Hence, educating the general public on diabetes particularly T1DM is essential to end the stigma associated with it that can further lead to non-disclosure and compromised self-care practices. Government should consider extending the coverage of National Health Insurance Scheme to cover analogue insulin, glucometer and its' strips to enhance adherence to insulin therapy and SMBG practices. Government should also design and implement strategies to reduce disparity to healthcare access in the rural sectors.

## Abbreviations

| | |
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| ADA | American Diabetes Association |
| CMA | Community Medical Assistants |
| GoN | Government of Nepal |
| HA | Health Assistants |
| IDF | International Diabetes Foundation |
| JDRF | Juvenile Diabetes Research Foundation |
| LMICs | Low Middle Income Countries |
| MOHP | Ministry of Health and Population |
| NHRC | Nepal Health Research Council |
| NHIP | National Health Insurance Program |
| NDS | Nepal Diabetic Society |
| NCD | Non Communicable Disease |
| OPD | Outpatient Department |
| PwD | People with Diabetes |
| PwT1D | People with Type 1 diabetes |
| PwT2D | People with Type 2 diabetes |
| PHCCs | Primary Health Care Centres |
| RAPIA | Rapid Assessment Protocol for Insulin Access |
| SMBG | Self-Monitoring of Blood Glucose |
| TUTH | Tribhuvan University Teaching Hospital |
| T1DM | Type 1 Diabetes Mellitus |
| T2DM | Type 2 Diabetes Mellitus |

## Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-024-11925-w.

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Supplementary Material 1.

Supplementary Material 2.

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## Data availability
The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

## Declarations

### Ethics approval and consent to participate
Ethical approval was taken from the ethical review board of the Nepal Health Research Council (NHRC, Registration Number: 573/2022) and permission from the concerned authorities was taken before the study. The research was conducted in accordance with the "Declaration of Helsinki". Before data collection, the participants were informed about the purpose and objective of the study and written consent was obtained from each of them. The identity of the participant was kept confidential. The study was interview-based and did not consist of any human specimen.

### Consent for publication
Not applicable.

### Competing interests
The authors declare no competing interests.

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