

**Understanding Healthcare Pathways of Patients with Diabetes: Insights from an
Exploratory Study in a Government Sub-district Hospital of Bangladesh**

Final Report of Summative Learning Project (SLP) presented to the
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Abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
DGHS	Directorate General of Health Services
DM	Diabetes Mellitus
ESP	Essential Service Package
HCP	Healthcare Provider
IDI	In-depth Interview
IHD	Ischaemic Heart Disease
LMIC	Low- and Middle- Income Country
NCD	Non-communicable disease
NGO	Non-governmental Organisation
PHC	Primary Health Care
POC	Point Of Care
T2DM	Type 2 Diabetes Mellitus
UHC	Upazila Health Complex
WHO	World Health Organisation

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Abstract

Introduction: The prevalence of diabetes mellitus in Bangladesh was 13.75% in 2018. The healthcare system of Bangladesh makes it challenging to deliver integrated non-communicable disease service. There is a lack of resources at the primary healthcare level, a difficult pluralistic healthcare system to navigate, and limited evidence on diabetic care pathways in the context of Bangladesh. As diabetes mellitus is a leading cause of morbidity and mortality, understanding these pathways is vital for developing an equitable healthcare system tailored to chronic disease management.

Methods: This facility-based qualitative exploratory study was conducted at the Upazila Health Complex in Keraniganj, Dhaka, Bangladesh. By applying convenient sampling, a total of 22 in-depth interviews were conducted with respondents visiting the NCD corner of the UHC, from November 22, 2024 to December 11, 2024. Descriptive statistics about the respondents were evaluated using STATA V17. Thematic analysis of the interviews were done.

Results: The majority of the respondents were aged 40-69 years (81.8%) and female (68.2%), married (86.4%), Muslim (91%) and living in peri-urban areas (91%). 45.5% of the respondents had no formal education, 72.7% were unemployed and most household incomes were generally less than 15,000 BDT. 59% of respondents have lived with diabetes for 2-5 years and 77.3% had other comorbidities too. Respondents navigated complex care pathways, involving both formal and informal healthcare providers, with the longest pathway having five points of care. Most participants delayed seeking care due to attributing symptoms to other diseases, minimal perceived severity, or beliefs about diabetes, with many managing symptoms through home remedies. Delays were longest among women. Triggers that prompted seeking care were worsening symptoms, advice from social networks, or referrals from providers. The common initial points of care were private providers and drug-sellers, with UHCs generally becoming the final care provider by the third point of care. UHCs were preferred for their affordability, accessibility, and ability to manage comorbidities. Most respondents rated UHC services as good, yet unavailable essential medicine or diagnostic tests, short consultation times, disrespectful behavior, and insufficient privacy impacted patient experiences. Elderly and women with children struggled with access to distant hospitals. Private care was expensive and often led to discontinuation, while informal providers were chosen for affordability. One respondent took service from parallel providers. Expenses, especially for those with comorbidities, caused financial strain, often forcing difficult decisions between managing diabetes and other health conditions.

Conclusion: Respondents with diabetes navigated complex care pathways and encountered various categories of healthcare providers. While PHC facilities serve as critical hubs, there is a need to address challenges such as inconsistent medicine supply, unavailability of diagnostic facilities, inadequate consultation practices, and the financial burden of respondents to create equitable, patient-centered care for diabetes chronic diseases in resource-limited settings.

Keywords: Pathways, Care pathways, Noncommunicable diseases, Primary healthcare, Diabetes Mellitus, Bangladesh

Introduction

A **Care Pathway** is a systematic approach for attaining the planned and integrated provision of care for patients with specific diagnoses over an extended period (Schrijvers et al., 2012; Vanhaecht et al., 2007). It encompasses the sequence of activities, decisions, and medical encounters that a patient experiences from the onset of symptoms to the diagnosis, treatment, and continuing care of a medical problem. Care pathways aim to enhance patient and provider outcomes. This entails but is not limited to – quicker diagnosis, consistent treatment, fewer errors, cost reduction, and improved job satisfaction for healthcare providers (Schrijvers et al., 2012). Moreover, these pathways can identify the challenges patients face in their medical encounters, which contribute to understanding the factors influencing their care decisions, and assess their overall experiences within the healthcare system for specific conditions. This approach is particularly crucial for long-term illnesses like non-communicable diseases (NCDs), whose management necessitates ongoing, coordinated care across multiple providers and settings. Through this study we explore the care-pathways of patients with diabetes mellitus, in the context of Bangladesh.

Literature review

NCDs have emerged as the major cause of global mortality. Global deaths from NCDs increased from 61% in 2000, to 74% in 2019, making NCDs one of the most pressing public health challenges of this century (WHO, 2023). In the South Asian region, NCDs account for a third to two-thirds of all deaths and disabilities (Siegel et al., 2014). In Bangladesh, NCDs account for 63% of the total years lost to disability and early death (World Bank, 2019).

Among these NCDs, diabetes mellitus (DM) stands out as a significant contributor to high morbidity and mortality rates. In 2019, the International Diabetes Federation estimated that 465 million people worldwide were living with diabetes. By 2045, this statistic is projected to rise by 200 million more (Saeedi et al., 2019; Cho et al., 2018). Type 2 diabetes mellitus (T2DM) is now the third leading cause of mortality worldwide. Almost 80% of cases of T2DM are in low and middle-income countries (LMICs), and approximately 60% of these are concentrated in Asia (Guariguata et al., 2013). DM is a significant public health concern in Bangladesh as well, and a growing challenge for its health systems.

In Bangladesh, the prevalence of diabetes and pre-diabetes is increasing in both urban and rural areas, driven largely by lifestyle changes (Chowdhury et al., 2018). A comparison of

the Bangladesh Demographic and Health Survey data revealed that diabetes prevalence among adults aged ≥ 35 years increased from 10.95% in 2011, to 13.75% in 2018 (Chowdhury et al., 2022). Despite the high prevalence, the awareness about prevention, control and management of this condition are alarmingly low (Fottrell et al., 2018).

Bangladesh's pluralistic healthcare system further complicates the situation. The healthcare system comprises government, private, and non-governmental organization (NGO) services, alongside poorly regulated informal providers. Due to inadequacies in government healthcare facilities, many patients are redirected to private healthcare services which exacerbates the growing financial burden. Patients primarily try to seek services from informal sectors, especially the disadvantaged (Ahmed et al., 2009) and when their needs remain unmet, patients turn to formal healthcare providers (HCP). This fragmented structure makes it challenging to deliver integrated non-communicable disease services effectively (Ahmed et al., 2024).

While there is a national policy and strategy for NCD care in Bangladesh (DGHS, 2018) it is often inadequate to meet patient needs. As the first referral health facility at the primary level, 'Upazila Health Complexes' (UHCs) ensure that individuals have access to essential medical care close to home (Islam et al., 2020). As of today, according to the DGHS Facility Registry there are more than 400 UHCs in Bangladesh, with five of these UHCs in the Dhaka District alone. These facilities are designed to meet the population's healthcare needs by offering an Essential Service Package (ESP), which includes dedicated 'NCD corners'. Since its introduction in 2012, NCD corners have offered an ideal window for management of certain NCDs, and preventive services for some cancers. However, like many other over-stretched government facilities, the NCD corners' success is impeded by a lack of trained staff, equipment (Ahmed et al., 2024), and the supply of essential medicines (Kabir et al., 2022). This disjointed healthcare system leads to suboptimal health outcomes and a substantial economic burden on NCD patients.

Globally, a number of studies on pathways to care of psychiatric patients have been conducted (Gater et al., 1991). In Bangladesh, however, there is a scarcity of literature on care pathways for diabetes mellitus. Our review revealed some literature focusing on care pathways for mental health disorders (Nuri et al., 2018 and Giasuddin et al., 2012), preeclampsia and eclampsia (Dempsey et al., 2021), myocardial infarction (Chowdhury et al., 2021), tuberculosis (Shatil et al., 2018) and only one qualitative study on hypertension (Naheed et al., 2021) in the context of Bangladesh. Most studies around diabetic respondents tend to focus on knowledge and are based in tertiary care facilities (Siddique et al., 2017; Sultana et al., 2013). There is

limited research on access and quality of diabetes services in Bangladesh. We identified one mixed-methods study on care-seeking and managing diabetes, in the context of rural Bangladesh (Jennings et al., 2021). One relevant qualitative study was identified (Lewis & Newell, 2014) to understand diabetic patients' needs, perceptions and experiences, however healthcare pathways were not delineated. We have found that limited data exists for prevalent NCDs, and pathway studies for diabetes mellitus, which accounts for a substantial burden of disease and mortality in the country.

Justification

Given that NCDs have a particular chronicity, rising prevalence and the current NCD interventions at the primary healthcare (PHC) level are often insufficient to manage them fully (Ahmed et al., 2024), it is therefore crucial to understand the care pathways that patients navigate throughout their lives to manage this disease. This study aims to understand the care pathways of diabetic patients, particularly considering the healthcare providers consulted, factors influencing the choice, challenges in the pathways, and the impacts of these encounters. The findings can help design an equitable healthcare system tailored to the unique needs of chronic disease patients, particularly in low- and middle-income settings.

Conceptual Framework

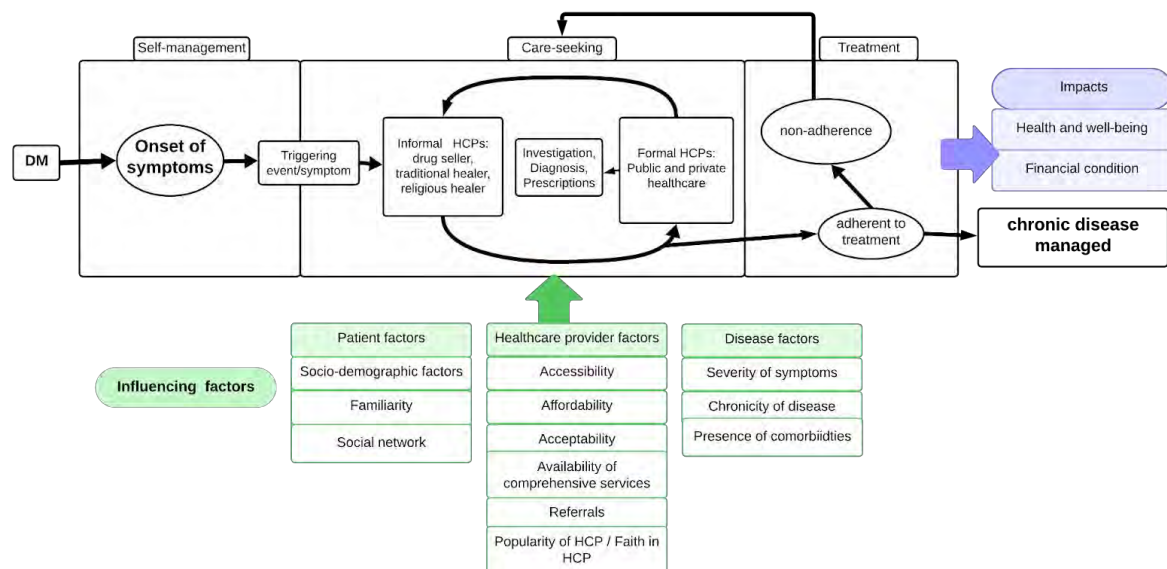


Figure 1: Care Pathways of diabetic patients, influencing factors and its impacts, adapted from The Model of Pathways to Treatment (Scott et al., 2012), with insights from the study on hypertensive patient pathways and perceptions (Naheed et al., 2018).

This study's **Patient Care Pathway Framework** is adapted from The Model of Pathways to Treatment (Scott et al., 2012), a validated model for analyzing patient-reported pathways to diagnosis and initial treatment. It also draws from insights from the framework employed for the study on patient pathways and perceptions of hypertension treatment, management, and control in rural Bangladesh (Naheed et al., 2018).

According to this framework, the diabetic patient will experience the first symptom(s) of diabetes, prior to diagnosis and subsequent medical treatment. The presence of this symptom will first be managed by the patient themselves without medical intervention, in this **self-management interval**. However a **triggering event**, which could also be the worsening of the symptom(s), will prompt the patient to no longer delay seeking care. This will lead the patient to encounter different delivery delivery points in the **care-seeking interval**. These delivery points could be formal healthcare providers such as a physician of a government facility, non-governmental organisation or private facility. It could also be informal healthcare providers, which comprises drug-sellers, traditional healers, religious healers in the context of Bangladesh. The service delivery points will provide a treatment for the patients' condition, but only registered physicians can confirmedly diagnose the patient's condition. Patients may navigate between different providers during this interval. Some patients adhere to the prescribed treatment, while others may not. Additionally, patients who initially adhere to treatment may later become non-adherent, restarting the care-seeking process. Various influencing factors shape the care pathway, including **patient factors** (e.g., age, gender, socioeconomic status, familiarity with the service delivery point, their social networks etc.), **healthcare provider factors** (e.g. affordability, accessibility, acceptability, etc.) and **disease-related factors** (e.g. the severity and chronicity of the disease; the presence of other comorbid conditions). These factors play a significant role in determining the service points. The pathways navigated by patients can significantly affect their health outcomes and financial imperatives, shaping their overall well-being.

The research questions and specific objectives that will guide our study are as follows:

Research Questions

1. What are the care pathways encountered by patients with diabetes in a selected sub-district government healthcare facility in Bangladesh and what are the main service delivery points in these care pathways?

2. What are the various factors influencing care pathways of patients with diabetes?
3. What are the impacts of these pathways on treatment outcomes of the patients?

Objectives

General: To explore the patient care pathways, identify the main service delivery points, factors influencing the pathways and its impact on diabetic patient outcomes in a selected sub-district government healthcare facility.

Specific:

1.1 To understand the care pathways diabetic patients have to navigate to seek treatment.

1.2 To identify the different service delivery points in the diabetic patient care pathways where they sought treatment

2.1 To explore the various factors that influence care pathways of diabetic patients.

2.2 To determine the time needed from the beginning of the illness to reach a particular service delivery point in the care pathways, including underlying factors of such journeys.

2.3 To explore their experiences at different points of the care pathways.

3.1 To explore the impact of the care pathways encountered on their health and well-being, including financial imperatives.

Methods

Study design

This study was a facility-based qualitative exploratory study. Exit interviews were conducted with eligible respondents. to explore the care pathways and experiences of diabetic patients.

Study site and settings

The study was conducted at an Upazila Health Complex in Keraniganj, in Malancha, Dhaka, Bangladesh. Data collection took place from November 21, 2024, to December 11, 2024. Keraniganj is a sub-district or ‘Upazila’ of Dhaka District (See Annex 2, for area map). It is situated on the southern outskirts of the capital city of Dhaka, separated by the Buriganga River. The area is well-connected by roads and waterways. This proximity to Dhaka makes

Keraniganj a blend of urban and rural, also making it a gateway for people traveling between Dhaka and nearby rural areas. The healthcare landscape of Keraniganj has a mix of government-run health facilities, such as the UHC, private clinics, and informal healthcare providers. The UHC, since its establishment in 1984, serves as a vital primary HCP for this population. For these characteristics, and for the study team's convenience, this facility had been chosen.

The UHC in which the study was conducted is a 50-bed government hospital offering outpatient, inpatient, emergency, and surgical services, pathology, pharmacy, and ambulance support. These facilities are designed to cater to the health needs of the population by providing an Essential Service Package (ESP), which includes an NCD corner where the research team was able to reach potential diabetic respondents from diverse demographic backgrounds.

Study population

Diabetic patients who visited the UHC's NCD corner on the days of data collection and completed service uptake were part of the sampling frame. They were included in the exit interview if they fulfilled the inclusion criteria for the study.

Inclusion criteria

- Patients above the age of 18 who can give their consent.
- Patients who have been diagnosed with T2DM.
- Patients who have had a consultation at the NCD corner on the day of the data collection and are about to exit the UHC premises.
- Patients who agreed and gave consent to participate in this study.

Exclusion criteria

- Diabetic patients who appear to be severely ill.
- Diabetic patients who were advised for urgent admission to the hospital but had refused, which also signifies that they are severely ill.
- Diabetic patients of the same household.
- Gestational Diabetes Mellitus in pregnant women as they may have the disease of interest which might resolve when the gestation period has ended.
- Patients with any disability, as it is not possible to explore their special needs to healthcare access within the limited scope of this study.
- Patients under 18 years of age who cannot provide consent .
- Patients who are unwilling to participate.

Sample size and sampling

Using convenient sampling, 22 eligible respondents were interviewed. One to two interviews, spanning 30-45 minutes each, were conducted for each day, within the eighteen days of data collection. Due to time and budgetary constraints, and a high non-response rate from eligible patients, twenty-two respondents were interviewed at the end of the data collection period.

Data collection process

The study team collected data from the UHC from 10 AM until 2 PM on weekdays and Saturday, as the NCD corner closed at 2 PM. Patients were first identified as having taken consultation at the NCD corner, as they would generally have the NCD corner patient book (a green book to record clinical sign symptoms, findings, the prescription, and date for the next follow-up visit), on their being. Then they would be identified as being diabetic when it was seen that they would be receiving the anti-diabetic medication from the UHC pharmacy which was on the same floor as the NCD corner. These patients were approached as they exited the NCD corner after collecting their medication. Patients willing to participate were then interviewed primarily in a room within the UHC, and otherwise in the seating area adjacent to the NCD corner, or a nearby spot close to their home or workplace which was easily accessible by the study team (See Annex for interview locations), after respondents had provided consent and met the eligibility criteria for the study. The interviews would span 35-40 minutes each. Attendants were allowed to be present at the time of the interview, if that was more comfortable for the respondent. At the end of the interview, the respondents were given a copy of the information sheet (with details of the study, and study team's contact information) and a signed copy of their consent form.

Data collection tool

Exit interviews were conducted using a data collection tool having both open-ended and close-ended questions. The open-ended questions were part of the IDI guide (See Annex 3). The guide focused on the onset of symptoms, respondents' self-management practices before seeking healthcare, influences on their choice of HCP, experiences at each point of care, impact the pathway had on their health, well-being and financial imperatives.. The close-ended questions were used to collect some quantitative data (e.g., socio-demographic information, duration of illness, duration of treatment under each provider, satisfaction with present point of care). Both qualitative and some quantitative data were collected with this tool in order to comprehensively visualise the data.

Development of tool

The tool was developed in line with concepts of other pathway studies (Nuri et. al, 2018) and this study's Patient Care Pathway framework (Figure 1). The major domains of the tool included respondent's (i) perception of their health condition, (ii) factors influencing their choice of healthcare provider, (iii) experience with the service delivery points, (iv) impact on health, well-being and financial imperatives, and (v) their expectations for better care for diabetes from the service delivery points. The tool was developed in English and translated into Bangla by native Bangla speakers. The data collection tool was piloted with individuals at the study setting, and necessary adjustments were made.

Data quality assurance and management

To ensure data quality, debriefing sessions were held after each day's data collection. Interviews were transcribed on the same day they were conducted. To reflect on the interviewer's reflexivity and positionality, the study team reviewed the Consolidated Criteria for Reporting Qualitative Research (COREQ) Checklist's Domain 1 (See Annex 10). Reflexivity refers to the researcher's self-awareness and acknowledgment of how their own background, experiences, and beliefs, might influence the research process. Positionality involves recognizing how aspects such as gender, class, education, and professional status affect the research and interactions with participants. By acknowledging these, the research team can contribute to a more ethical and credible body of qualitative knowledge. At the time of writing the report, this 32-item tool was again reviewed, to assess and ensure reporting on this qualitative study comprehensively (Tong et al., 2007). The data was stored securely on password-protected laptops and encrypted servers at the BRAC James P Grant School of Public Health, as well as in internal cloud storage. The signed consent forms were kept in a locked storage area accessible only to the study team.

Data analysis

Quantitative data collected by the questionnaire in Bangla, was directly entered into an English format, and descriptive statistics about the respondents were evaluated using STATA V17.

During the study, interviews were conducted in Bangla and audio-recorded with prior written consent. All interviews were transcribed directly into English. The study team familiarised themselves with the data. A codebook (See Annex 6) had been created with initial *a priori* codes drawn from existing literature and the questionnaire, and new inductive codes emerging from the interviews were added. Transcripts were coded using the software Dedoose.

Using a combination of inductive and deductive codes, patterns and themes were identified and organized into a data display matrix (See Annex 7). Themes were developed through a thematic analysis approach (See Annex 8), as was done by Nuri et al. (2018) in their study on care pathways for Bangladeshi mental health patients, as well as the IDI guide and this study's Care Pathway framework (Figure 1).

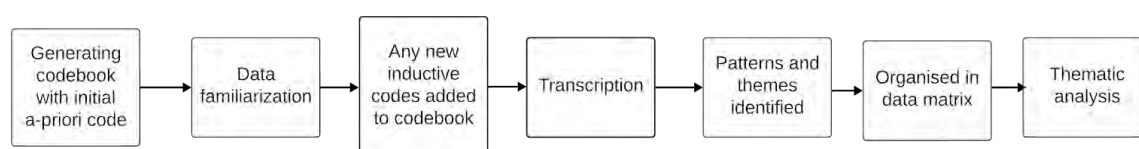


Figure 2: Qualitative data analysis plan

Ethical consideration

Ethical clearance was obtained from the IRB of BRAC James P Grant School of Public Health. Written permission was obtained from the Civil Surgeon Office and also secured from the Upazila Health Complex through the Residential Medical Officer. During the study, interviewers read informed consent forms (See Annex 5) in Bangla to all respondents. Participants were recruited after providing written informed consent (by signing the consent form or providing a thumbprint) for participation and audio recording. Participants were ensured that they could refuse to answer any question and withdraw from the study at any time without repercussion. Confidentiality was maintained using pseudonyms.

Results

A combination of quantitative and qualitative data was obtained and our findings have been presented below.

Sociodemographic profile of the respondents

The twenty-two respondents were in the age range of 32 to 89 years. The majority of the respondents were aged 40-69 years (81.8%) and female (68.2%) (Table 1), with most being married (86.4%), Muslim (90.9%) and living in peri-urban areas (90.9%). Slightly less than half of the respondents had no formal education (45.5%). None of the respondents pursued education beyond secondary school. Most were not engaged in employment (16; 72.7%), and a significant proportion (18; 81.8%) did not or could not share their monthly income, though most household incomes were generally less than 15,000 BDT (9 out of 22). Only one

respondent's average household monthly income was above 20,000 BDT. Households typically had fewer than 5 members (77.3%), one household had 10 or more family members, and around half of the respondents (54.5%) identified themselves as household heads. More than half of the respondents (59%) have lived with diabetes for 2-5 years and a significant portion (17; 77.3%) had other comorbidities too.

Table 1: Respondents' Sociodemographic Characteristics (n=22)

Variable	N=22	Percentage (%)
Age (in years)		
25-39	3	13.6
40-54	9	40.9
55-69	9	40.9
70-84	1	4.5
Sex		
Male	7	31.8
Female	15	68.2

Variable	N=22	Percentage (%)
Marital Status		
Married	19	86.4
Ever married ¹	3	13.6
Religion		
Islam	20	90.9
Hinduism	2	9.1
Residence		
Rural ²	2	9.1
Periurban ³	20	90.9
Education		
No formal education	10	45.5
Less than primary	3	13.6
Primary	8	36.4
Secondary	1	4.5
More than secondary		
Employment status		
Currently working ⁴	6	27.3
Not working ⁵	16	72.7
Present monthly income (in BDT)		
Less than 5000	2	33.3
5,000-10,000		
11,000-15,000	1	4.5
16,000-20,000	1	4.5
More than 20,000		
Cannot/Could not share ⁶	18	81.8
Average household monthly income (in BDT)		

Variable	N=22	Percentage (%)
Less than 5000	3	13.6
5,000-10,000	3	13.6
11,000-15,000	4	18.2
16,000-20,000	2	9.1
More than 20,000	1	4.5
Cannot/Could not share ⁶	9	40.9
Number of household members		
1-5	17	77.3
6-9	4	18.2
10 and above	1	4.5
Relation to household head		
Self	12	54.5
Spouse	8	36.4
Parents	2	9.1
In-laws		
Duration of illness		
Under 1 year	1	4.5
2-5 years	13	59.1
6-10 years	5	22.7
More than 10 years	3	13.6
Comorbidities⁷	17	77.3

¹ Separated/Divorced/Widowed

² Rural areas are typically characterised by low population density, agricultural or natural landscapes, and limited infrastructure.

³ Peri Urban areas are transitional zones between urban and rural areas, where rural and urban features overlap.

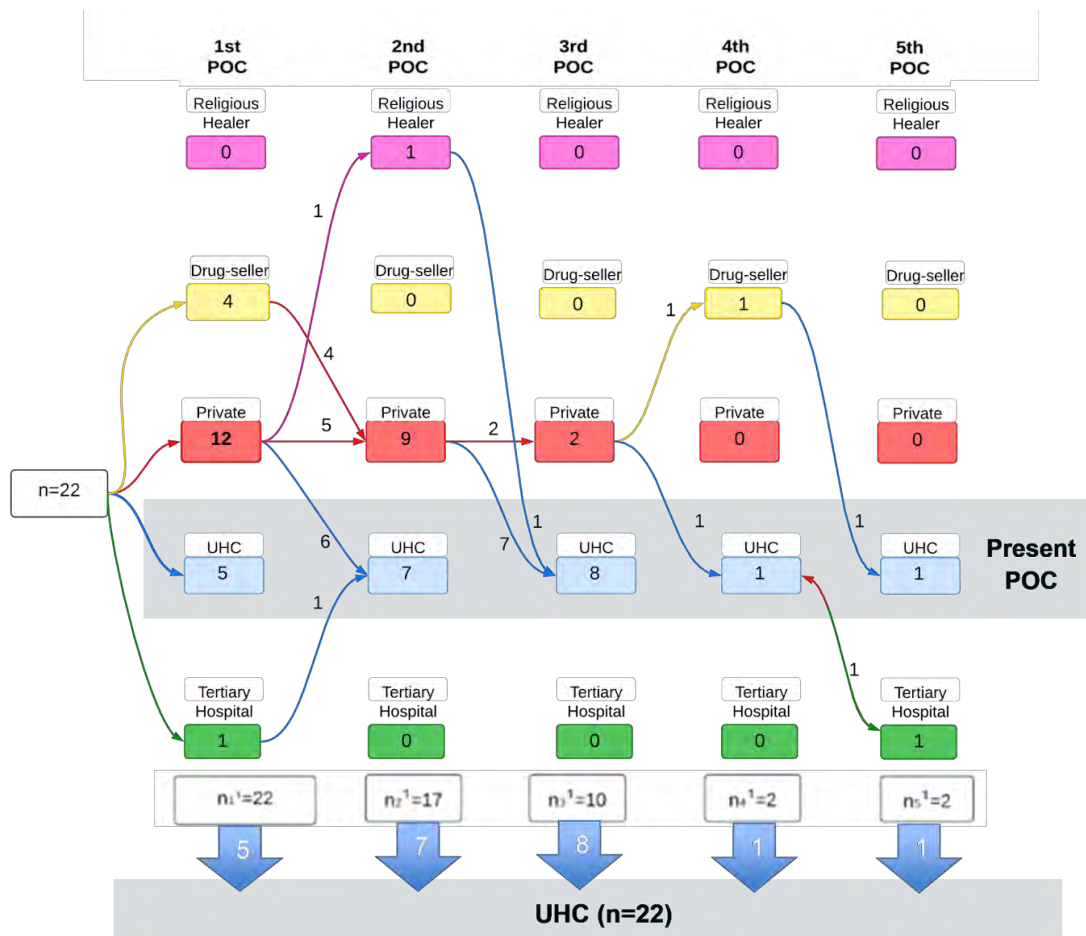
⁴ Auto rickshaw puller, carpenter, farmers, day-labourers, persons in business and trade, and others

⁵ Individuals who are not involved in any income-generating activities including homemakers, and retired persons

⁶ Cannot share: Respondent does not want to share. Could not share: No fixed income, cannot recall or not earning.

⁷ Presence of comorbidities like: diabetes, hypertension, cerebrovascular disease, ischaemic heart disease, chronic kidney disease, thyroid disorders and others.

Pathways of Care



¹ n_{1-5} refers to the total number of respondents in each point of care

Figure 3: Healthcare pathways of diabetic patients visiting the UHC across all points of care (Reconstruction of the pathways presented by Nuri et al. (2018)). Numbers within coloured boxes represent the total number of patients for that provider category, in its respective point of care (POC) column. Numbers near arrows depict the number of patients moving from the provider of one POC to the consecutive POC.

Figure 1 shows care pathways up to the point the respondent arrived at UHC. The pathway's starting point was the first healthcare provider they sought out and the endpoint was the present point (the UHC) at which care was being continued. Among the 22 respondents interviewed from the UHC, which was their present point of care, the length of their diabetes care pathways varied. The longest pathway involved five points of care till the UHC was reached, while the shortest had only one point (Figure 3). However, an exception was one respondent who received care simultaneously from both the UHC (as the 4th point of care) and then, a government tertiary hospital (as the 5th point of care). The number of respondents for the 1st, 2nd, 3rd, 4th, and 5th POC was 22, 17, 10, 2, and 2, respectively. Among these, those who continued using UHC services (n=22) were 5, 7, 8, 1, and 1, respectively, for each of the five POC.

First Point of Care

Among the participants (n=22) who sought care for diabetes, five respondents initially went to the UHC, where they started and completed their care pathway, without seeking additional points of care. Out of the remaining participants (17), more than half of the respondents (12; 54.5%) initiated their care with a private provider. Four respondents had gone to a drug seller at the pharmacy, and one respondent had consulted a provider at a government tertiary hospital.

Second Point of Care

As five of the respondents had finished their pathway at the UHC, the remaining seventeen participants moved to their second point of care. All four respondents who had started with a drug seller switched to a private provider at the 2nd POC. Similarly, five of the twelve respondents who took service from a private provider at the 1st POC, switched to another private provider at the 2nd POC. By doing so, slightly more than half of the participants (9 out of 17; 52.9%) had again opted for a private provider at this stage. Only one respondent transitioned from a private provider to a religious healer (i.e. a *Pir*). Seven respondents had finally reached the UHC at this point – five had transitioned from a previous private provider, and one from the tertiary level hospital.

Third Point of Care

As seven of the seventeen respondents had already completed their pathway at the UHC, ten participants continued their healthcare journey to the third point of care. Of these, eight eventually reached the UHC—seven transitioning from a private provider and one from a *Pir*. This stage marked the highest number of UHC users in the care pathways. Notably, no respondents sought care from non-medical or informal providers at this stage.

Fourth Point of Care

Among the two participants who reached this stage, one respondent opted for care at the UHC and the other respondent had visited the drug-seller. However, both of their pathways continued to the fifth point of care.

Fifth and Final Point of Care

In this point of care, one respondent finally concluded their path at the UHC, having previously taken treatment from a drug seller. The remaining respondent had previously gone to the UHC, but also began to take services simultaneously from a government tertiary hospital from a parallel healthcare provider.

Steps taken to reach the UHC

A total of five respondents sought out the UHC as their first point of care (5 out of 22; 22.7%) in their care-seeking pathway, followed by seven respondents (31.8%) in the second point, eight (36.4%) in the third point, one (4.5%) in the fourth stage, and one (4.5%) in the fifth and final point of care. Notably, one respondent received care simultaneously from both the UHC (as the 4th point of care) and a tertiary hospital (as the 5th point of care).

Number of respondents consulting each provider category

We calculated the total number of respondents who consulted each healthcare provider category at all points in their care-seeking pathway (Table 2). The majority of the respondents sought treatment from more than one healthcare provider. Formal providers included the UHC, government tertiary hospitals, and private practitioners, while informal providers comprised religious healers and drug sellers. After the UHC where the interview took place, the majority had sought care from a private practitioner for diabetes in the past. Among informal care-providers, drug sellers were most common.

Table 2: Number of respondents consulting each provider category in any point of care in their care pathway

Healthcare provider category	Number of respondents (N ¹)
UHC ²	22
Private provider	16
Drug seller	4
Tertiary hospital	2
Religious healer	1

¹ Multiple responses per respondent was collected

² Respondents had sought care from the medicine outpatient department and the NCD corner of the UHC

Duration of care

We tabulated how long patients consulted a particular provider (Table 3). Duration of care was explored to understand their continuity of care. Majority (10 out of 22; 91%) of the respondents had been receiving care for more than one year from the UHC. More than half of the respondents (13; 59%) had been taking treatment from the UHC for 1-2 years. Private providers were commonly consulted for short-term care (56.5%), often only for a few visits, but a significant proportion also sought a longer term care (>2 years; 26.1%). For diabetes, drug sellers and religious healers were exclusively sought for short-term care (<1 year). Tertiary hospitals (n=2) showed a mix of short-term and long-term care usage.

Table 3: Duration of care received at each service delivery point

Healthcare providers	Duration of care					
	<1 years		1-2 years		>2 years	
	N=13	%	N=18	%	N=14	%
UHC ¹ (n=22) ²	2	9.1%	13	59.1%	7	31.8%
Private facility (n=23) ²	13	56.5%	4	17.4%	6	26.1%
Tertiary hospital (n=2) ²	1	50.0%			1	50.0%
Drug seller (n=5) ²	5	100%				
Religious healer ³ (n=1) ²	1	100%				

¹ Respondents had sought care from the medicine outpatient department and the NCD corner of the UHC

² Number of respondents who take services from this healthcare provider

³ *Pir*

Perception of health condition

This section provides a comprehensive picture of the diabetic respondents' perceived initial symptoms, self-management practices, delay in care-seeking, triggering events that led them to seek care from healthcare providers, and the subsequent process of diagnosis.

Perceived initial symptoms and self-management practices

Self-management here refers to the actions the respondents took to manage or alleviate their symptoms independently, without direct intervention from a HCP for diabetes specifically. Before initiating their healthcare pathway with service providers, many respondents had opted for self-management (16 out of 22). These symptoms generally included feeling easily fatigued, dizziness, increased thirst, increased hunger, increased urination, weight gain and weight loss. Only one participant reported slow-healing sores. Another 32 year-old female talked of multiple blister-like lesions on her scalp, which she attributes to diabetes, as her diabetic father had experienced the same in the past.

The self-management period ranged from 15 days to 1 year, among the respondents who could recall their average duration self-care. The three persons who managed their symptoms for around one year with self-care were all women. Males generally did not wait over a few months to seek care. One of these respondents, a 65 year-old widow whose husband

died 9 years back, has been taking treatment for her diabetes from the UHC for the last one and a half months. Her initial symptoms were dizziness, weight loss and fatigue. The dizziness continued for more than half a year, during which time she poured water or rubbed oil on her head as a remedy.

An exception to these practices are some respondents who went without any self-management (5 out of 22), generally due to being **asymptomatic**, and prior to an **incidental diagnosis**, and thus did not feel the need to administer any self-care practices.

The most reported self-care practices to manage these initial symptoms were using home remedies of taking sour-drinks, for traditional care of increased blood pressure, as both hypertensive and non-hypertensive respondents attributed their condition to high blood pressure. One normotensive, diabetic middle-aged woman used to drink sour tamarind juice for her dizziness, as she believed her blood pressure rose from worrying about her husband's cancer treatment. One hypertensive respondent talked about how for over two weeks he would become uncharacteristically easily fatigued while walking. During this period, he adhered to his anti-hypertensive medication but without any alleviation of his symptoms. One comorbid respondent explained her confusion while self-managing as:

“I couldn't understand why this was happening, and I had been dealing with this for one month. I thought it might be due to my high blood pressure and so I used to take sour drinks. But why was I feeling this way? I couldn't say.” (A 35 year-old female, suffering from both hypertension and diabetes mellitus for 14 years.)

Other self-care practices mentioned were increased physical activity, and changing food habits to counter tiredness. Of the two respondents who changed their food habits one increased intake of meat and fish, while the other stopped taking these items. Pouring water, or rubbing oil onto the head to alleviate dizziness were also practiced.

Reasons for delays in care-seeking

We grouped the respondents' statements by reasons for delay in seeking out a healthcare provider for their diabetic symptoms. The most recurring reasons were as follows.

A. Before any diagnostic test:

1. Believing their symptoms were not severe enough to require medical attention.

2. Attributing their symptoms to other causes (such as a comorbid condition or stress).
3. Not believing they could have diabetes.

B. Even after a diagnostic test indicated elevated blood sugar levels:

1. Assuming that diabetes would resolve on its own or could be managed without any medical intervention.

The **severity of the perceived initial symptoms**, certain **beliefs about diabetes** and attributing symptoms to other causes (such as **comorbidities**) as reasons for delay in help-seeking were commonly surfaced themes.

Another individual didn't believe it could be diabetes as he led a physically active lifestyle. He had mentioned that he had walked a lot, and rarely relied on transport. A 55 year-old male respondent also believed he could manage diabetes with an active lifestyle, without any medical consultation. He continued delaying care in this manner for three months. One of the participants who found out her blood sugar was raised during a free medical camp three years back, delayed her treatment for one year while taking sour food at home, as she did not understand the severity of her condition. She believed her diabetes would resolve on its own, as illustrated below:

"After being checked, they told me my 'diabetes' (blood sugar) was high. I thought diabetes was a simple disease, like a fever, and it would go away on its own...They (neighbours taking treatment for diabetes) told me to come to take treatment at the UHC but I didn't come for a long time, because I didn't understand." (A 52 year-old diabetic female.)

Events that triggered the journey on to the healthcare pathway

Followed by self-care, usually a certain event triggered the patients to end self-management at home in order to seek healthcare (at the 1st POC) and initiate their healthcare journey. An exception to this are the respondents who were asymptomatic, and then had an **incidental diagnosis** while taking treatment for another disease such as a cold, or during a follow-up for ischaemic heart disease or hypertension. Events that prompted respondents to seek care may have been symptoms that became too severe to manage with self-care alone. This push may also have been an advice to seek care, from their **social network**. Many participants reported their family members, neighbours giving them information about why

and where they should seek care. This information may have come from a **referral (formal or informal)** for another disease condition too, as illustrated in the following quotes:

“A man sits outside the medical hospital, who measures diabetes and pressure there For 30 taka. I went to measure my pressure as I was feeling bad but when I talked about my symptoms, he told me to measure my diabetes. I did a test, and by pricking my finger, I found out I had diabetes. He told me to go to the hospital.” (A 40 year-old female, with diabetes diagnosed two and a half years ago.)

“ I used to feel really hungry. I used to weigh a lot more than you are seeing right now. I went to see a doctor at a private chamber for my cold. He listened to all my problems, and told me to get tested for diabetes.”(A 32 year-old woman who has been diabetic for 4 years.)

Some triggering events were a blend of these reasons too (symptom severity and referral). For instance, a respondent sought care from a drug-seller after injuring his foot at work, but the medication proved to be ineffective as his sore did not heal. After which, the drug-seller advised him to see a diabetes specialist. The event was described as below:

“I was given medicine again for the cut on my foot, and like this 15 (more) days passed. Still, it didn't heal. The side of my foot began to harden, but the centre still did not heal. Then I was told (by the drug seller) to do a diabetes test. It was high, around 14.2 or 14.6. I was told to consult with a diabetes doctor.” (A 52 year-old man, with diabetes for 8 years.)

Oftentimes, other than oneself, the decision to seek healthcare was dependent on worried well-wishers or the respondents' autonomy. For some respondents, the **decision** to go to the first point of care had been made by the respondents' spouse, family members, parent, or children.

None of the respondents knew that it was possible to manage diabetes from the NCD corner of the primary healthcare facilities, prior to their diagnosis. Similarly, none of the respondents were aware of diabetes or its symptoms from any sort of community-based awareness programs. Therefore, the PHCs played no role in triggering respondents to seek care for diabetes.

Process of diagnosis of DM

The methods of diagnosis among the respondents were found to be: (a) finger-prick test for blood sugar at non-hospital settings such as pharmacy/roadsides/medical camps (3 out of 22), (b) self-referral to diagnostic centres (2 out of 22), and (c) diagnosis by a formal healthcare provider (17 out of 22).

Factors influencing the respondent's choice of healthcare provider

We had asked respondents what was the driving factor(s) behind their choice of HCP (Table 4) and their decision to transition to another HCP, from which we derived some 'push and pull factors'.

Table 4 : Factors influencing the respondent's choice of healthcare provider

Variables¹	UHC	Private facility	Tertiary hospital	Drug seller	Religious healer
	N	N	N	N	N
Accessibility	20	1		5	
Affordability	21	3		5	
Acceptability				2	1
Availability of comprehensive care	8	1	1		1
Social Network²	6	4	1		
Referral	1				
Familiarity	5			1	
Popularity of HCP/Faith in HCP		2			1

² ¹Total responses will exceed 22 as there are multiple responses

²Social network refers to the relationships and interactions among individuals and groups in a community built through shared activities and/or communication.

Accessibility, including distance, travel time, and costs, was a significant factor driving the choice of UHC (20), and drug sellers (5), but it played a minor role for private facilities (1) and religious healers (1). Similarly, affordability heavily influenced decisions for UHC (21) and, to a lesser extent, private facilities (3), while other provider types were less affected by cost considerations. Two participants found the drug-seller to be an acceptable first POC, and one sought out a religious-healer for this reason. UHC was frequently chosen for its availability of comprehensive care in individuals who also had hypertension (8), and a similar driver was seen for tertiary hospitals (1) and religious healers (1). Social networks impacted choices for UHC (6), private facilities (4), and tertiary hospitals (1). Familiarity due to previous experience at that facility was a moderate factor for UHC (5) and private facilities (3). Referrals/ advice from HCPs to seek a doctor had also been a driving factor, but only one of these informal HCPs had mentioned a particular facility (i.e. the UHC).

Accessibility

Accessibility to healthcare emerged as a significant driving factor, and consisted of distance, time, and travel cost. Many respondents chose nearby healthcare services for these reasons. When it came to selecting the UHC this was a major factor, as many participants mentioned that the UHC was close to home and transport was easily available. Most respondents accessed UHC services using auto rickshaws (19 out of 25), with travel costs ranging from 20 to 80 BDT for a round trip. A few walked or used CNG, incurring no or higher travel costs.

Similarly, lack of accessibility emerged as a reason to transition to other HCPs too. One elderly female respondent mentioned that although a certain private hospital's treatment for her diabetes was satisfactory, it was difficult for her to travel away from Keraniganj, unaccompanied. Similarly, a 32-year old female mentioned that going to a further away private hospital, while leaving children unattended at home was what drove her to shift to another nearby private facility. Two elderly males mentioned that in their old age, it was not possible to travel to Dhaka City to seek better care. Accessibility issues with hospitals farther from home were commonly reported by elderly individuals, women, and mothers with young children.

Affordability

The cost of the services was one of the most important factors for choosing a certain service provider. Almost all the respondents who took service at the UHC mentioned that they

had gone to this facility for the free essential medicine for diabetes. Among private hospital service-users, some reported it was the discount on medicine, investigations or visiting fee, and yet it was these same costs for most of those who went to private hospitals, which caused their discontinuation from private facilities. Drug-sellers were another cheap resort for care. One retired respondent with a comorbidity, who takes service from the UHC and is tense about the financial condition of his family is quoted as :

“I don’t work anymore. I need to buy 2000-2500 taka worth of medicine monthly. But if I get free medicine here, then my children will be ‘safe’. Thinking about how to keep my children ‘safe’ I came here for treatment. The ticket is 3 taka, sometimes I don’t pay for the ticket, because I have some person I know there. Sometimes I even give 10 taka for the ticket, voluntarily.” (A 65 year-old man, with diabetes for 5 years.)

When it comes to affordability at tertiary government hospitals, an additional expenditure reported by one respondent was that towards ‘dalals’ or medical brokers who hamper satisfactory care at the hospital until an amount is paid to them.

Acceptability

Respondents found it more acceptable to go to a drug-seller for what they perceived to be ‘minor symptoms’. It did not seem necessary to go to a hospital for such an issue. When the symptoms worsened, they would change this provider. One respondent found it the most acceptable to consult a *Pir* for all ailments, as it was a part of his religious belief.

Availability of comprehensive care

As seventeen of the respondents (n=22) were co-morbid (Table 2), the UHC seemed to them a good choice to manage both their hypertension and diabetes in one consultation. Similar care was taken at private and tertiary-level facilities for other comorbid conditions like IHD. One follower of a *Pir* took care for diabetes here as he believed the *Pir* to have the power to heal every illness.

Social Network

Many respondents mentioned how it was the information of HCPs they got from their community, which led them to a certain facility. A few respondents mentioned seeing a neighbour’s diabetic patient book from the UHC, which made them choose this facility. Three respondents mentioned having acquaintances working at the facility they went to, one of which

had been for a private facility. None mentioned any sort of community-awareness program, or any promotion of the NCD corner, as their information source.

Familiarity

Respondents generally felt comfortable taking treatment from a place they had been to previously for other concerns (such as colds, for their antenatal check-up, etc.).

Popularity of HCP/Faith in HCP

Sometimes respondents would consult a HCP based on their popularity or ardent faith. One respondent is quoted as:

“He is a very powerful man with the treatment for everything. My cousin's daughter has cancer...she first went to a private doctor, but I believe if she went to the Pir first, she would have been cured.” (A 65 year -old man with diabetes for 5 years, and other comorbidities).

Experiences at all service delivery points

This section outlines respondent's experience throughout their healthcare pathways. It highlights their experience at each service delivery point.

Drug seller

Although not qualified to dispense medicine without a prescription, the drug seller was a popular choice among the respondents, as it was usually affordable, close to home, and it seemed acceptable to visit this HCP to manage less severe symptoms. One respondent received anti-diabetic medication, namely Gliclazide, from the drug-seller, but others did not. Many respondents recounted measuring their blood sugar at the drug-stores from time to time. Sometimes, drug-sellers would do counselling. A few respondents mentioned that it was the drug-seller that implored them to seek care, and one drug-seller had advised the respondent to seek care from the UHC for their symptoms.

A 79- year old male respondent with diabetes for three years, initially took treatment for increased urination at the drug-seller, where he was dispensed medication without any proper diagnosis. It was when this medication failed, that he was referred to the UHC. Similarly, another 52 year old male respondent was taking treatment for a cut from a drug-seller who knew how to dress wounds. The drug-seller also dispensed antibiotics to the respondent, without any prescription. After noticing that even after two weeks the wound did

not heal, the drug seller referred the respondent to a doctor, and also mentioned that slow-healing wounds could be due to diabetes.

During the 2020 lockdown due to COVID-19, a respondent consulted a nearby drug-seller with his previous prescription from a private hospital, as he was afraid to travel during the pandemic. The drug seller encouraged him to continue taking the medication he was already prescribed.

Pir

Only one of the respondents was a lifelong follower of a popular Pir, who hails from Chattogram. The respondent was offered a one-time *tobarok* or offering to cure his illnesses. He believed it to have cured his symptoms, but still transitioned to the UHC after sometime to continue diabetic treatment. The respondent still continues to take yearly pilgrimages, from Keraniganj to Chattogram, to meet the *Pir*.

Tertiary hospital

A respondent had been admitted at the tertiary hospital to treat a stroke. It was here that his diabetes was incidentally diagnosed as well. One of the challenges he recounted here was having to pay 200 taka to a “medical broker” or dalal.

Private provider

One respondent stated that the smooth queues were a reason for why they preferred a certain private hospital.

“The service at a certain private hospital was very good. Fine, there's a serial - there could be a long queue everywhere! But here there were rules and regulations for maintaining the queues.” (a 35 year old-woman with diabetes for 14 years.)

The same respondent, who has poorly controlled diabetes, mentioned that if she were financially better off, she could have continued to take treatment from this hospital for specialised care. She believed that the classes, and disciplined lifestyle encouraged by this hospital could have kept her health in a better condition.

On the other hand, a 65 year-old male respondent with diabetes for over 5 years, considered the service of that same private provider to be the worst because of an HCP's

behaviour. Despite perceiving the service to be bad, he had continued treatment there till his financial condition no longer allowed it. He is quoted as:

“Service at a certain private hospital was not good. Doctors these days...they don’t understand compassion, you see. Even if I’m still paying for it, and even if their behaviour wasn’t good, I still had to keep on going there for my treatment.”

Other challenges respondents mentioned were rude behaviour from the HCPs and staff at private facilities, cost of the investigations, and accessibility difficulties to private hospitals (such as travel costs, leaving housework and children unattended, and difficulty traveling in old age). Two respondents mentioned how lucrative it seemed when private facilities offered discounts on consultation fees, but were then disappointed by the high prices of investigations or medication.

A respondent who shifted from one private provider to another, had quoted the following challenge which led to the transition:

“But it got difficult taking treatment from that private hospital...leaving my children alone, and standing in queues...and it’s far from where I lived. Then I thought another private hospital is close and a doctor from this hospital also works at that one.. let’s see how the treatment is.” (A 35-year old housewife with diabetes for more than a decade.)

UHC

In our study, the final point of care was the UHC, where the respondents received their last consultation. It is important to explore the respondents’ satisfaction with this primary healthcare facility to understand their adherence with this point of care, and also to identify the obstacles faced at the level of PHC.

Three of the respondents said they were happy with “whatever they received”. One of these respondents taking treatment from the UHC is quoted as:

“We are happy with whatever we get....Nai mama theke kana mama bhalo (better to have something than nothing at all)” (a 42 year-old woman, who has struggled with diabetes for 2 years.)

Another respondent, who is doing odd jobs, echoed the same sentiments and mentioned that the financial aspect of services must be taken into account when determining which service provider was the best. For many of the respondents a trade-off, or a lack of alternative, is mentioned when it comes to experiences around primary healthcare facilities.

The most recurring challenge for twenty-one respondents (n=22) had been the cost of services. The affordability-factor influenced respondents choosing to go to the UHC. Yet at the UHC, additional expenditure arose from purchasing the unavailable prescribed essential medicine that they had to buy from other pharmacies, and the cost of investigations for which there were no diagnostic services available at the facility.

One of the respondents expressed his woes about not getting free essential medicine as:

“Today they gave me medicine for 15 days, not even 15 days, as I take it three times a day, it will finish in 10 days...So coming to the hospital gave me no benefit. Now it seems...When I go to buy a pack of medicine from outside, it costs 80 taka. If I go to the hospital and ultimately buy the medicine then what is the need for a hospital? Now see... for the last 6 to 7 months See (respondent is showing the NCD corner book) they don't give me medicine. It's the same (phrase) again and again: “There's no medicine, there's no medicine.” (A 70 year-old man with diabetes for 3 years.)

Table 5: Satisfaction with quality of care at last consultation at UHC

Variable	N	Percentage (%)
Perception of Quality of care		
Excellent	4	18.2
Good	15	68.2
Poor	3	13.6
Duration of consultation (in minutes)		
< 2	8	36.4
2-5	10	45.5
6-10	2	9.1
> 10	2	9.1
Perception of consultation duration		
Adequate	10	45.5
Not adequate	12	54.5

Variable	N	Percentage (%)
Feeling respected by the HCPs	18	81.8
Privacy was maintained during the consultation	4	18.2

We had asked respondents to rate the service at their final point of care. Most rated the UHC's quality of care as **Good** (68.2%), with 18.2% rating it as **Excellent** and 13.6% as **Poor** (Table 6). This perception is mainly based on the interaction with the healthcare provider at the consultation, as illustrated by the following quote:

“There is a doctor who behaves like we are at a private hospital. It is very good, he understands patients and explains very nicely to them. It feels like I’m actually going to the doctor, the previous doctor here treated patients as if we were beggars.” (A 48 year old woman with diabetes for over a year.)

Those who quoted the service to be poor, often pinned it on the HCP's unwillingness to address the patient's health. One such respondent mentioned:

“Did not ask me a single thing! They just see my book and write the medication. I asked for an investigation but they didn't give it to me.” (A 68 year old-woman with diabetes for 4 years)

One 39 year old female respondent who rated the HCP's service to be excellent did so by saying:

“He talked really well to us. He talked very nicely. He did well. I could rate him 100 out of 10!”

Consultation durations were generally short, with 36.4% lasting less than 2 minutes and 45.5% lasting 2–5 minutes, while only 18.2% extended beyond 5 minutes. Over half of the respondents (54.5%) felt the consultation duration was inadequate, although 45.5% found it sufficient.

A respondent who received 5 minutes of consultation stated that such short times were enough for those hailing from a “middle” socioeconomic class. Another person who received

less than 5 minutes of consultation, but considered it adequate as well also stated that it was understandable that the HCP could not talk freely when there was a long queue of patients to attend to. There is a recurring notion among respondents that regardless of the short time of consultation, it is adequate given the busy circumstances of the NCD corner.

On a positive note, 81.8% of respondents reported feeling respected by healthcare providers, which is again depicted by this quote:

“When I'm standing, he said “Aunty, please sit.” So this is a sign of respect, right? This is a way to talk beautifully right? They write the slip for medicine beautifully, and sometimes tell me “yes, I wrote the medicine you asked about.” (A 52 year-old woman with diabetes for three years.)

However, **privacy** during consultations was maintained for only 18.2% of respondents, indicating a significant gap in confidentiality.

Expectations from the UHC

Availability of essential medicine for diabetes, including insulin : Many respondents suggested that the UHC and government should look into the unavailability of essential medication for diabetes. Again, among the essential medicine that is unavailable, insulin unavailability was a recurring challenge for those who needed the intravenous medication. The UHC pharmacy had informed us that the supply was not ongoing for insulin. Six of the respondents talked about their difficulty in availing insulin. Two of the respondents believed there is corruption going on through the UHC pharmacy, which is why they are unable to avail their necessary medication, underscoring a need to address this. One of them described how their complaint was not considered by the UHC authority as:

“I’ve seen how medicine is given to some patients discreetly, even after telling other patients that the medicine is unavailable. It is done through cash hidden in the card, which is then handed over to the UHC pharmacy...I left a complaint about it in the complaint box too, but it was never addressed. I have seen the medicine being sold off

in front of my eyes. This is very inhumane.” (A 45 year old woman with diabetes for 2 years.)

Availability of medicine for other comorbid conditions: Other challenges respondents mentioned were inability to receive free medication for comorbidities (such as IHD and dyslipidemia) or complications of diabetes at UHC’s NCD corner.

Availability of the prescribed investigations within the UHC: Respondents mentioned that they are prescribed tests which are unavailable in the UHC. It becomes a hassle to get tested outside the UHC, as it is costlier.

Improved doctor-patient communication: Respondents highlighted that privacy was a concern, and that the consultation durations were short. Although most of the consultations were under five minutes, and there was a level of dissatisfaction expressed, many respondents were compelled to accept it because of a lack of alternative options.

Case Study: Rani’s Chase for Insulin

Rani, a housewife in her 30s, has struggled with diabetes for over 14 years. Despite taking insulin, her blood sugar remains poorly controlled. After her family fell into debt, they sold their five-story house and moved to a smaller one in Malancha, an area in Keraniganj, Dhaka which is walking distance from the UHC. With her husband unemployed, her sons help her financially whenever they can.

Rani has traversed five points of care in her complex care pathway. She recounted to us how she reached the fourth point of care– the UHC. After two years at the UHC, she suddenly sought further treatment at a tertiary government hospital.

A few months ago, Rani developed a skin condition on her thighs and back. When she went for her follow-up at the NCD corner, she felt uncomfortable due to the lack of privacy. Multiple patients had been ushered into the consultation room at the same time. There were male and female patients, as well as male and female doctors. Yet, she had to tell the doctor tending to her about her itchy skin condition. When she explained her skin condition, the doctor asked her to expose the affected area, which she refused. The doctor then asked her to bring photos on her next visit, but the prescribed medication didn’t help. She described the event at the UHC as follows:

“I had an itching issue...the area where this itching occurs...it's not possible to show it. It was on my back and on my thighs. The doctor told me quite rudely to show where it itches. How will I show it? Male and females all sit together in that room, both doctors and patients, and make 4 people at a time enter the (consultation) room. Then the doctor told me to come with a photo

of those places next time. Then that's what I did, and they wrote some "halka-patla" (insignificant) medication for that."

As the skin condition showed no signs of improving, Rani decided to seek specialised care at the tertiary government hospital. It was here that she found out that her skin condition was a by-product of uncontrolled diabetes. The physician had also seen Rani's prescription from the UHC, and told her that her diabetes could not be controlled with the oral medication she is being given. Following this, a prescription for insulin was given to her, and she was also told that the medicine prescribed from the UHC would be ineffective

"I went with Malancha's prescription to 'a certain tertiary government hospital'. I was told that it (the itching) was due to my diabetes, and I had to start insulin. I told the doctor there about the prescription I was following, and the doctor told me that these are very "low power" medicine and I should stop taking these medicines as my diabetes will never come under control with these."

The physician also noted that the oral medications she was taking were too weak to control her diabetes and prescribed insulin instead. Rani returned to the UHC for insulin, but the supply had been unavailable for months. She mentioned that others in her neighbourhood had also stopped coming to the NCD corner for follow-ups due to the lack of insulin, forcing them to buy it on their own. Rani's blood sugar is now 10 to 14. She is also contemplating on taking this path.

Effect of the care pathways navigated

Effect on health and well-being

We explored how the healthcare pathways affect the respondents health, and well-being. A lot of the worrying stemmed from knowing that diabetes is a life- long condition, and the expenditure of the treatment. There were reported effects on **health-seeking behavior** too. One 35- year old female respondent has stopped taking medicine for a week as they are afraid of what their family member might say about the added expenditure. For four of the respondents, a lot of their health and well-being was tied to spirituality. One such quote illustrating how the participant believe diabetes and its outcomes are closely linked to her faith are illustrated as follows:

"Maybe it was written in my fate, that's why diabetes happened to me. There were times I didn't take medicine for 4 or 5 months because of all this tension. I used to

think if God wants me to be sick, then I'll stay sick...what's the use of taking medicine? Now I tell myself to believe in God. Whatever God does, it's probably for something good.” (A 35-year old woman with poorly controlled diabetes.)

Effect on financial imperatives

Out of all the respondents (n=22), twenty-one stated that they felt the treatment of diabetes to be a financial burden. One respondent mentioned that regardless of the choice of service, treatment is only received if there is money.

Four of the respondents talked of how this financial burden affects their domestic life, yet they must continue treatment. One such quotes is as follows:

“I have a low earning...so should I eat or buy 100 taka's worth medicine? But I have to take medicine, or else my life won't be good. If I don't take the medicine, my head will spin, I'll fall sideways while walking....I always have 'a tension'. I have to go through "him-shims" (ups-and-downs). I need the money I now use for buying medicine, for my domestic life.” (A 47 year old woman with diabetes for over 2 years.)

Three respondents had to loan money, or take out installments to avail their medicine. Five of the respondents expressed how difficult it was to juggle the cost of more than one **comorbidity**. One such respondent has to choose between treating his heart disease or managing his diabetes. In such instances he opts to put more importance on his heart disease medication (which has to be purchased), and tries to manage diabetes with diet and activity. He also works to make ends meet although he has been advised to rest, because he has to pay back some loans he took out for his medication. He is quoted as follows:

“A lot of money is spent taking treatment for my heart disease, that's why there are those gaps of a few months where I don't visit the UHC, but I take my medicine for diabetes regularly...What my son earns is not enough to get by. The doctor has advised me to be at rest, yet I am still working at this tea-shop. Even a few days ago, I had to take out some installments. It has to be given back every week, and it gets difficult. If it's late, they shout at me.” (A 65-year old man with diabetes for three years.)

Discussion

The findings of this study highlight the complexities of diabetes care pathways in Bangladesh's fragmented healthcare system.

Patient's journey through a complex care pathway and delays in seeking care

Many respondents delayed care-seeking due to symptom perception, misconceptions about diabetes, or attributing symptoms to comorbidities. Self-management, lasting from a few weeks to many months, was common, with longer durations of self-care (i.e. one year) particularly practised among female respondents. The exceptions are those who had been incidentally diagnosed while taking treatment for another disease, usually hypertension. T2DM can have a prolonged asymptomatic period where the condition remains undetected for years (Ramachandran, 2014). Hypertension is a common comorbidity among individuals with diabetes, and T2DM and hypertension frequently coexist (Petrie et al., 2017).

Respondents sought care when they experienced worsening symptoms, received advice from social networks, referrals from HCPs that were consulted for other disease conditions, rather than awareness they already had about diabetes, or information about the NCD corner. The majority of the respondents had been diagnosed by formal HCPs, which is similar to a 2018 study on hypertension pathways by Naheed et al.

Our study on twenty-two respondents found the longest care pathway involved five points of care till the UHC was reached, which is close to the number of points of care in Nuri's 2018 study on healthcare pathways for psychiatric patients, i.e. four points. The shortest pathway had only one point of care (Figure 3). However, an exception was one respondent who received care simultaneously from both the UHC (as the 4th point of care) and then, a government tertiary hospital (as the 5th point of care), as the UHC could not address a concern related to her privacy. Parallel care seeking was also found in 29% of the respondents in another Bangladeshi study (Giasuddin et. al, 2012). The primary healthcare facility was reached by the majority by the third-point of care.

Respondents in this study had sought out formal HCPs (from the UHC and tertiary level government hospital) as well as informal providers (drug-sellers and religious healer). Over half of the respondents initiated care with private providers, while others turned to informal care such as drug sellers or religious healers. UHCs emerged as the most common sustained care provider, as it was where the interviews were held. Private providers emerged as the second-most common provider, but one with the shortest duration of care. Informal providers,

such as drug sellers and religious healers, were exclusively used for short-term care, reflecting their role as temporary or supplementary options rather than long-term solutions.

Multiple factors influence the choice and decision of healthcare service utilisation

UHCs were preferred for their affordability, accessibility, and ability to manage comorbidities in one consultation. The UHC's location and transport availability made it an accessible choice. Accessibility to farther away hospitals were difficult for the elderly and women with young children. Tertiary hospitals were inaccessible to certain groups due to the distance. Cost considerations strongly influenced provider selection. Although the UHC was more affordable, respondents were still having to pay out of pocket for unavailable essential medicine, prescribed tests, and medication for other comorbid conditions. At tertiary hospitals, healthcare brokerage or 'dalali' was a barrier to care, which is a well-documented phenomenon in low-income country healthcare settings (Zaman & Van Der Geest, 2020). Respondents frequently began their care-seeking journey over a short-term course with private providers until they were financially unable to continue, or with informal providers, such as drug sellers. Access to appropriate treatment being restricted by availability and costs of services has been highlighted in the 2014 study by Lewis and Newell as well.

At the final POC, the UHC, respondents were generally satisfied with the services. Some patients reported that the brevity of the consultation period was to be expected and felt they had received adequate care as long as they would receive the medication they had come for. There were a few instances reported of rude behavior from HCPs towards patients, corruption at the UHC pharmacy, and privacy concerns. The rude behavior and privacy concern had made one respondent consult a parallel provider too. This signifies the importance of provider-patient relationships and communication in NCD treatment and management. Similar studies have reported this too for hypertension care (Schoenthaler et al., 2008).

The challenges of inadequate essential medicine supply, especially for insulin, at this primary health care facility indicate critical gaps in service quality. The unavailability of essential medication for diabetes, which has been reported in many UHCs (Kabir et al., 2022). Inadequate supplies for NCD treatment was also reported by Naheed et. al (2018), in a hypertension pathway study.

The role of drug-sellers in LMIC-settings for dispensing medicine has been well-documented (Azhar et al., 2009), including in Bangladesh where drugstores are poorly regulated. In a WHO report on Bangladesh in 2015 for mental health disorders, the main factor influencing the choice of an informal healthcare provider in general over a formal provider was

easy access, low-cost of treatment and availability of the provider on demand. Similarly in our study, the most popular among the informal healthcare providers, the drug-seller, was sought out due to their affordability. Informal care options were seen as acceptable for managing mild or initial symptoms. Referrals to formal healthcare providers were also done by drug-sellers, which was advice taken by the respondents. This shows the role that informal healthcare providers have on a patient's decision-making while navigating the care pathways.

Only one respondent went to a religious healer, who are often chosen by lifelong followers, indicating the influence of cultural and spiritual factors in healthcare decisions. Familiarity with the healthcare provider, or facility, social networks and the popularity of the HCP were important factors too. Similarly, evidence from other settings has mentioned the importance of trust in decision making about care (Burridge et al., 2015). Cultural and social influences, such as reliance on advice from social networks, and spiritual beliefs, further shape care pathways, indicating the scope for community-based interventions.

None of the respondents had received information about diabetes or its symptoms through community awareness programs or NCD corner promotions. While UHCs were valued for long-term care and managing comorbidities, they played no role in raising awareness or triggering initial care-seeking for diabetes, and rarely was it the first point of care. This underscores a missed opportunity to integrate community outreach and preventive strategies into their services.

Impact of complex care pathways on patient's health and financial imperatives

Respondents expressed anxiety and worry upon learning about their diabetes, viewing it as a life-long burden. The study also emphasizes the financial burden faced by participants, impacting not only their healthcare decisions but also their household stability. Furthermore, the study reveals that financial burdens, compounded by the cost of medication and investigations, significantly impacted respondents' ability to access sustained treatment. Expenses were particularly challenging for all, specially those with comorbidities, often forcing difficult trade-offs between managing diabetes and other conditions. These findings align with existing literature which emphasize the role of socioeconomic factors in shaping healthcare access and utilization in LMICs (Braveman & Gottlieb, 2014).

The act of 'doctor-shopping' for treatment of chronic conditions can lead to a loss of continuity of care, inappropriate treatment and add to financial burdens. While a study in India found doctor-shopping to empower patients to navigate their illness journey to address tailored needs (Mendenhall et al., 2016), our study shows that patients often have to navigate these

complex pathways as fulfilling service is not received at any one-point, the primary healthcare facility is seldom the first choice, and again the final point of care (the UHC) is often a trade-off.

Strengths

- The study mainly employs qualitative methods, providing insights into the care-seeking behaviors and pathways of diabetic patients.
- The study setting allowed for a diverse demographic sampling.
- Having complimentary quantitative and qualitative data helps to comprehensively visualise the data.

Limitations

- As the study was conducted at a primary healthcare facility, there may have been a selection bias that influenced the types of respondents engaged in the study.
- A facility-based study does not take into account the healthcare pathways of those in the community who never visited the UHC, or any facility for treatment.
- The study includes only 22 respondents due to the time constraints, limiting the generalizability of the findings across broader populations or settings.
- The study primarily focuses on the demand side (patients), leaving out insights from healthcare providers that could offer a more balanced view of the challenges and potential solutions.
- Potential recall bias: respondents may not accurately recall all details of their care pathways, particularly about past providers or durations of care.
- The Hawthorne effect due to the presence of researchers might have changed the quality of services and may not reflect the usual conditions.
- Respondents and their attendants were unwilling to provide the sufficient time to the researcher, which might have resulted in losing eligible respondents. In some cases, respondents withdrew their consent in the middle of the interview. Consequently, we missed the opportunity to gather more insights.

Addressing these limitations in future research could enhance the robustness and applicability of the findings.

Conclusion

The study provides valuable insights into the complex care pathways of diabetic patients in a PHC setting at sub-district level in Bangladesh. Multiple factors that influence the choice of healthcare service have been identified. The study also found reliance on informal providers such as drug-sellers, a short-term usage of private providers until financial constraints arose, and the choice UHC as the present point of care due its accessibility, affordability and availability of medicine for other comorbid conditions such as hypertension. However, UHC was often seen as a compromise rather than a preferred option, making it rarely the first choice for many individuals. The findings highlight barriers to sustained treatment such as medication unavailability, lack of facilities for investigation, inadequate consultation practices at the PHC-level and the impact of the complex pathways on the patient's health and financial imperatives. As PHC facilities should serve as vital hubs for diabetes management, addressing these challenges is critical to ensuring equitable, effective, and patient-centred care for chronic diseases in resource-limited settings.

Recommendations

The findings suggest several actionable recommendations for improving diabetes care pathways.

1. At facility-level:

- Ensure consistent supply of essential medicines, including insulin at the UHC.
- Ensure available diagnostic services of nominal fee, for diabetes, at the UHC
- Improve privacy during consultations to foster trust and comfort among patients.
- Introducing medication for other comorbidities such as heart disease, so patients can receive comprehensive care from one service point, from the NCD corner.
- Ensure citizens are aware of the availability of treatment for diabetes at the UHC.

2. For informal care providers: Capacity building of the informal sector, such as drug sellers, and then integration from community based care, to streamline referrals to appropriate care at PHC facilities.

3. At the community-level:

- a. Implement financial assistance programs for low-income patients by exploring subsidized care packages and insurance schemes to alleviate out-of-pocket expenses for low-income households.
- b. Improving patient education by developing community-based awareness programs to reduce delays in seeking care and educate patients on the importance of early diagnosis, proper self-care for diabetes, and sustained treatment.

References

- Ahmed, S. M., Hossain, M. A., & Chowdhury, M. R. (2009). Informal sector providers in Bangladesh: how equipped are they to provide rational health care? *Health Policy and Planning*, 24(6), 467–478. <https://doi.org/10.1093/heapol/czp037>
- Ahmed, S. M., Krishnan, A., Karim, O., Shafique, K., Naher, N., Srishti, S. A., Raj, A., Ahmed, S., Rawal, L., & Adams, A. (2024). Delivering non-communicable disease services through primary health care in selected south Asian countries: are health systems prepared? *The Lancet Global Health*, 12(10), e1706–e1719. [https://doi.org/10.1016/s2214-109x\(24\)00118-9](https://doi.org/10.1016/s2214-109x(24)00118-9)
- Akhtar, S., Nasir, J. A., Sarwar, A., Nasr, N., Javed, A., Majeed, R., Salam, M. A., & Billah, B. (2020). Prevalence of diabetes and pre-diabetes in Bangladesh: a systematic review and meta-analysis. *BMJ Open*, 10(9), e036086. <https://doi.org/10.1136/bmjopen-2019-036086>
- Azhar, S., Hassali, M. A., Ibrahim, M. I. M., Ahmad, M., Masood, I., & Shafie, A. A. (2009). The role of pharmacists in developing countries: the current scenario in Pakistan. *Human Resources for Health*, 7(1). <https://doi.org/10.1186/1478-4491-7-54>
- Barua, U. K., Saha, S. K., Ghosh, D. K., & Ruble, M. M. K. (2013). Epidemiological study on bronchial asthma at shaheed suhrawardy medical college hospital, Dhaka. *Journal of Shaheed Suhrawardy Medical College*, 5(2), 77-80.

- Braveman, P., & Gottlieb, L. (2014). The Social Determinants of Health: It's Time to Consider the Causes of the Causes. *Public Health Reports*, 129(1_suppl2), 19–31. <https://doi.org/10.1177/00333549141291s206>
- Burridge, L. H., Foster, M. M., Donald, M., Zhang, J., Russell, A. W., & Jackson, C. L. (2015). Making sense of change: patients' views of diabetes and GP-led integrated diabetes care. *Health Expectations*, 19(1), 74–86. <https://doi.org/10.1111/hex.12331>
- Chowdhury, I. Z., Amin, M. N., Chowdhury, M. Z., Rahman, S. M., Ahmed, M., & Cader, F. A. (2021). Pre hospital delay and its associated factors in acute myocardial infarction in a developing country. *PloS one* 16(11), e0259979. <https://doi.org/10.1371/journal.pone.0259979>
- Chowdhury, M. A. B., Islam, M., Rahman, J., Uddin, M. J., & Haque, M. R. (2022). Diabetes among adults in Bangladesh: changes in prevalence and risk factors between two cross-sectional surveys. *BMJ Open*, 12(8), e055044. <https://bmjopen.bmj.com/content/12/8/e055044>
- Chowdhury, S. R., Islam, M. N., Sheekha, T. A., Kader, S. B., & Hossain, A. (2023). Prevalence and determinants of non-communicable diseases risk factors among reproductive-aged women: Findings from a nationwide survey in Bangladesh. *PloS one*, 18(6), e0273128. <https://doi.org/10.1371/journal.pone.0273128>
- Cho, N., Shaw, J., Karuranga, S., Huang, Y., Da Rocha Fernandes, J., Ohlrogge, A., & Malanda, B. (2018). IDF Diabetes Atlas: Global estimates of diabetes prevalence for 2017 and projections for 2045. *Diabetes Research and Clinical Practice*, 138, 271–281. <https://doi.org/10.1016/j.diabres.2018.02.023>
- Directorate General Health Services. (2018). Multisectoral Action Plan for Prevention and Control of Noncommunicable Diseases 2018-2025.

https://old.dghs.gov.bd/images/docs/Publicaations/NCDC_multisectoral_action_plan_2018_2025.pdf

DGHS | Facility Registry. (n.d.). <https://hrm.dghs.gov.bd/public/facility-registry/facilities/70/profile?tab=detailed-information>

Dempsey, A., Sripad, P., Sultana, K., Kirk, K., Hossain, S. M. I., & Warren, C. (2021). Pathways to service access for pre-eclampsia and eclampsia in rural Bangladesh: Exploring women's care-seeking. *PloS one*, 16(2), e0245371. <https://doi.org/10.1371/journal.pone.0245371>

Fottrell, E., Ahmed, N., Shaha, S. K., Jennings, H., Kuddus, A., Morrison, J., Akter, K., Nahar, B., Nahar, T., Haghparast-Bidgoli, H., Khan, A. K. A., Costello, A., & Azad, K. (2018). Diabetes knowledge and care practices among adults in rural Bangladesh: a cross-sectional survey. *BMJ Global Health*, 3(4), e000891. <https://doi.org/10.1136/bmjgh-2018-000891>

Gater, R., Sousa, D. B. a. E., Barrientos, G., Caraveo, J., Chandrashekar, C. R., Dhadphale, M., Goldberg, D., Kathiri, A. H. A., Mubbashar, M., Silhan, K., Thong, D., Torres-Gonzales, F., & Sartorius, N. (1991). The pathways to psychiatric care: a cross-cultural study. *Psychological Medicine*, 21(3), 761–774. <https://doi.org/10.1017/s003329170002239x>

Giasuddin, N. A., Chowdhury, N. F., Hashimoto, N., Fujisawa, D., & Waheed, S. (2012). Pathways to psychiatric care in Bangladesh. *Social psychiatry and psychiatric epidemiology*, 47(1), 129–136. <https://doi.org/10.1007/s00127-010-0315-y>

Hashimoto, N., Fujisawa, D., Giasuddin, N. A., Kenchaiah, B. K., Narmandakh, A., Dugerragchaa, K., Tamrakar, S. M., Adhikari, S. R., & Sartorius, N. (2015). Pathways to mental health care in Bangladesh, India, Japan, Mongolia, and Nepal. *Asia-Pacific*

journal of public health, 27(2), NP1847–NP1857.

<https://doi.org/10.1177/1010539510379395>

Islam, S. R., Rahman, F., & Siddiqui, M. M. R. (2014). Bangladesh is Experiencing Double Burden with Infectious Diseases and Non-communicable Diseases (NCD's): An Issue of Emerging Epidemics. *Anwer Khan Modern Medical College Journal*, 5(1), 46–50.

<https://doi.org/10.3329/akmmcj.v5i1.18844>

Islam, F., Rahman, A., Halim, A., Eriksson, C., Rahman, F., & Dalal, K. (2015). Perceptions of health care providers and patients on quality of care in maternal and neonatal health in fourteen Bangladesh government healthcare facilities: a mixed-method study. *BMC Health Services Research*, 15(1).

<https://doi.org/10.1186/s12913-015-0918-9>

Islam, M. Z., Zaman, F., Farjana, S., & Khanam, S. (2020). Accessibility to health care services of Upazila Health Complex: experience of rural people. *Journal of Preventive and Social Medicine*, 38(2), 30–37.

<https://doi.org/10.3329/jopsom.v38i2.47862>

Jennings, H. M., Morrison, J., Akter, K., Haghparsat-Bidgoli, H., King, C., Ahmed, N., Kuddus, A., Shaha, S. K., Nahar, T., Azad, K., & Fottrell, E. (2021). Care-seeking and managing diabetes in rural Bangladesh: a mixed methods study. *BMC Public Health*, 21(1).

<https://doi.org/10.1186/s12889-021-11395-3>

Kabir, A., Karim, M. N., & Billah, B. (2022). Health system challenges and opportunities in organizing non-communicable diseases services delivery at primary healthcare level in Bangladesh: A qualitative study. *Frontiers in Public Health*, 10.

<https://doi.org/10.3389/fpubh.2022.1015245>

Naheed, A., Haldane, V., Jafar, T. H., Chakma, N., & Legido-Quigley, H. (2018). Patient pathways and perceptions of hypertension treatment, management, and control in rural

- Bangladesh: a qualitative study. *Patient preference and adherence*, 12, 1437–1449.
<https://doi.org/10.2147/PPA.S163385>
- NCAER. (2023). Health Seeking Pathways in Four Indian States (4IS). In
<https://www.ncaer.org/project/health-seeking-pathways-in-four-indian-states-4is>.
- NIPORT. (2022). Bangladesh Demographic and Health Survey 2022 Key Indicators Report.
<https://www.dhsprogram.com/pubs/pdf/PR148/PR148.pdf>
- Nuri, N. N., Sarker, M., Ahmed, H. U., Hossain, M. D., Beiersmann, C., & Jahn, A. (2018).
 Pathways to care of patients with mental health problems in Bangladesh. *International journal of mental health systems*, 12, 39. <https://doi.org/10.1186/s13033-018-0218-y>
- Petrie, J. R., Guzik, T. J., & Touyz, R. M. (2017). Diabetes, Hypertension, and Cardiovascular
 Disease: Clinical Insights and Vascular Mechanisms. *Canadian Journal of Cardiology*,
 34(5), 575–584. <https://doi.org/10.1016/j.cjca.2017.12.005>
- Ramachandran, A. (2014, November 1). Know the signs and symptoms of diabetes.
<https://pmc.ncbi.nlm.nih.gov/articles/PMC4311308/>
- Saeedi, P., Petersohn, I., Salpea, P., Malanda, B., Karuranga, S., Unwin, N., Colagiuri, S.,
 Guariguata, L., Motala, A. A., Ogurtsova, K., Shaw, J. E., Bright, D., & Williams, R.
 (2019). Global and regional diabetes prevalence estimates for 2019 and projections for
 2030 and 2045: Results from the International Diabetes Federation Diabetes Atlas, 9th
 edition. *Diabetes Research and Clinical Practice*, 157, 107843.
<https://doi.org/10.1016/j.diabres.2019.107843>
- Sarker, M., Mohammad, D., Paul, S., Akter, R., Islam, S., Biswas, G., Hossain, A., & Islam, A.
 (2017). Lost in care pathway: a qualitative investigation on the health system delay of
 extra pulmonary tuberculosis patients in Bangladesh. *BMC health services research*,
 17(1), 240. <https://doi.org/10.1186/s12913-017-2181-8>

- Schoenthaler, A., Chaplin, W. F., Allegrante, J. P., Fernandez, S., Diaz-Gloster, M., Tobin, J. N., & Ogedegbe, G. (2008). Provider communication effects medication adherence in hypertensive African Americans. *Patient Education and Counseling*, 75(2), 185–191. <https://doi.org/10.1016/j.pec.2008.09.018>
- Schrijvers, G., Van Hoorn, A., & Huiskes, N. (2012). The Care Pathway Concept: concepts and theories: an introduction. *International Journal of Integrated Care*, 12(6). <https://doi.org/10.5334/ijic.812>
- Scott, S. E., Walter, F. M., Webster, A., Sutton, S., & Emery, J. (2012). The Model of Pathways to Treatment: Conceptualization and integration with existing theory. *British Journal of Health Psychology*, 18(1), 45–65. <https://doi.org/10.1111/j.2044-8287.2012.02077.x>
- Shatil, T., Khan, N., Yunus, F. M., Chowdhury, A. S., Reza, S., Islam, S., Islam, A., & Rahman, M. (2019). What Constitutes Health Care Seeking Pathway of TB Patients: A Qualitative Study in Rural Bangladesh. *Journal of epidemiology and global health*, 9(4), 300–308. <https://doi.org/10.2991/jegh.k.190929.00>
- Siddique, M. K. B., Islam, S. M. S., Banik, P. C., & Rawal, L. B. (2017). Diabetes knowledge and utilization of healthcare services among patients with type 2 diabetes mellitus in Dhaka, Bangladesh. *BMC Health Services Research*, 17(1). <https://doi.org/10.1186/s12913-017-2542-3>
- Sultana, Z., Ali, M. E., Akhtar, M. A., Uddin, M. S., & Haque, M. M. (2013). A Study of Evaluation for the Management of Diabetes in Bangladesh. *Pharmacology & Pharmacy*, 04(03), 355–361. <https://doi.org/10.4236/pp.2013.43051>
- Tong, A., Sainsbury, P., & Craig, J. (2007b). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International*

Journal for Quality in Health Care, 19(6), 349–357.

<https://doi.org/10.1093/intqhc/mzm042>

Vanhaecht, K., De Witte, K., & Sermeus, W. (2007). The impact of clinical pathways on the organisation of care processes (Doctoral dissertation). KU Leuven, Belgium.

World Bank. (2019). THE CONTINUUM OF CARE FOR NCDs IN BANGLADESH: The time to act is NOW!

<https://documents1.worldbank.org/curated/en/846731579019569888/pdf/The-Continuum-of-Care-for-NCDs-in-Bangladesh-The-Time-to-Act-is-NOW.pdf>

World Health Organization. (2007). WHO-AIMS report on mental health system in Myanmar.

World Health Organization. (2015). *Bangladesh health system review (Health Systems in Transition, Vol. 5, No. 3)*. <https://iris.who.int/handle/10665/208214>

World Health Organization. (2023). Advancing the Global Agenda on Prevention and Control of Noncommunicable Diseases 2000 to 2020.

<https://www.who.int/publications/i/item/9789240072695>

Zaman, S., & Van Der Geest, S. (2020). Brokers on the Ward. *Asian Journal of Social Science*, 48(1–2), 92–114. <https://doi.org/10.1163/15685314-04801006>

Annex

Operational Definitions

- i. **A Care Pathway** is a methodical strategy for attaining the planned and integrated provision of care for patients with specific diagnoses over an extended duration of time (Schrijvers et al., 2012). As defined by Vanhaecht et al. (2007), a care pathway should represent “ a complex intervention to enhance shared decision-making and coordination of a broad set of care

processes.” Care pathways, in general, aim to improve patient outcomes by ensuring safety, satisfaction, and efficient use of resources throughout the continuum of care.

- ii. **Diabetics** refers to those who have been diagnosed as having Diabetes Mellitus Type 2 by a physician.
- iii. **Traditional Healers** in the context of Bangladesh refers to healthcare providers of the informal sector which include but are not limited to Kabiraj, Polli Chikitschok etc.
- iv. **Religious Healers** in the context of Bangladesh refers to spiritual healers which include but are not limited to Pir, Imam etc.
- v. **Drug Sellers** or more commonly referred to as “pharmacies” by the Bangladeshi populace are retail medicine shops that provide symptomatic treatment by dispensing medication without a physician’s prescription.

Keraniganj map



<https://keraniganj.weebly.com/>

IDI Guide (English and Bangla)

Study title: Understanding Health Care Pathways of Patients with Chronic Diseases (Chronic Respiratory Disease, Hypertension, Diabetes): Insights from an Exploratory Study in a Sub-district Level Government Hospital of Bangladesh.

Data Collection Tool

Exit interview with IDI Guide

Date of interview	
Place of interview	
Interviewer	
Note Taker	
Interview start time	
Interview end time	

A. Socio-demographic profile:

Respondent Profile	
A1. What is your name?	
A2. What is your age?	years
A3. Gender?	Female.....1 Male.....2 Others.....99
A4. Where do you live(Area of residence)?	Urban.....1 Peri urban.....2 Rural.....3
A5. What is your marital status?	Married.....1 Unmarried.....2 Widowed.....3 Separated.....4 Divorced.....5
A6. What is your religion?	Islam.....1 Christianity.....2 Hinduism.....3 Buddhism.....4 Others.....99
A7. What is your educational background?	No formal education.....1 Below primary education.....2 Completed primary education (class 5)/ Ebtedayee.....3 Completed secondary education (SSC) /Dakhil.....4 Completed higher secondary education (HSC)/ Alim.....5 Completed Bachelor/Diploma/Fazil.....6 Completed Masters or higher/Kamil.....7

	Others (Specify).....99
A8. What is your current occupation?	Housewife.....1 Farming and agriculture.....2 Labor and construction.....3 Business and trade.....4 Govt Service holder.....5 Private Service holder.....6 Informal sector (Rickshaw puller, street vendor).....7 Retired.....8 Unemployed.....9 Others (Specify).....99
A9. What is your monthly income?	BDT
A10. What is the total number of people in your household?	
A11. What is your family income per month on average?	BDT
A12. Contact number	

B. IDI Guide

Domains	Questions	Response options	Probing
Perception of health condition	B1. Which one of these conditions are you seeking treatment for at the UHC today?	Hypertension.....1 Diabetes Mellitus.....2 Chronic Respiratory Disease (CRD) - COPD/Asthma.....3	- Why are you visiting the UHC today? - Why did you choose UHC for today's visit? Why not other service providers?
	B2: How long have you been suffering from this illness?	month/years	
	B3. What were the symptoms at onset? (Multiple answers can be selected for disease of interest)	Frequent urination.....1 Increased thirst.....2 Unexplained weight loss...3 Fatigue.....4 Blurred vision.....5 Slow-healing sores.....6 Asymptomatic7 Often asymptomatic.....8 Headaches.....9 Dizziness.....10 Shortness of breath, especially during physical activities.....11 Wheezing.....12 Chronic cough.....13 Chest tightness.....14 Others (Specify).....99	- How did the disease progress over time? - How did you manage your condition before seeking healthcare? (e.g. Self-care, suggestions from family members, neighbours?)? - What were those practices?
	B4. For how long did you manage this disease by yourself before seeking healthcare?	month/years	

	B9. How would you rate the expertise/skill/competence of the healthcare providers at the UHC facility?	Excellent.....1 Good.....2 Neutral.....3 Poor.....4 Very poor.....5	Why do you think so?
	B10. Did you feel respected and treated with dignity by the UHC healthcare providers?	Yes.....1 No.....2	Why do you think so?
	B11. During your consultation, was your privacy maintained at the UHC?	Yes.....1 No.....2	Why do you think so?
	B12. Did the healthcare provider explain the procedures and tests conducted during the consultation?	Yes.....1 No.....2	Why do you think so?
Impact on financial condition	B13. Can you list the expenditures for the following during the course of treatment at the UHC	For Medicine.....1 For Investigations.....2 Travel Fare.....3 Any other costs.....4	
	B14. How much is the total cost of your treatment till date?	BDT	
	B15. Has this been a financial burden to you?	Yes.....1 No.....2	- Why and how do you think this has been a financial burden? - Please describe the impact of your illnesses on your occupation, earnings, household expenditure and NCD treatment choices and plans.
	B16. Have you had to borrow money to aid your condition?	Yes.....1 No.....2	
	B17. Has the cost of your illness taken a toll on your household expenditure?	Yes.....1 No.....2	

Impact on health and well-being	B18. Do you think there has been any improvement in your health condition since you were first diagnosed?	Yes.....1 No.....2	Why do you think seeking healthcare has worsened these feelings?
	B19. Has this condition caused you feelings of anxiety or sadness?	Yes.....1 No.....2	
	B20. While seeking healthcare, have these feelings worsened?	Yes.....1 No.....2	
Recommendations	B21. Do you have any suggestions/Recommendations for the betterment of care in persons with the disease of interest?		- Do you have any suggestions/Recommendations for the betterment of care in persons with the disease of interest? - Why have you suggested these recommendations?

গবেষণার শিরোনাম: ডায়াবেটিস রোগীদের কাছে থেকে চিকিৎসা পদ্ধতি বোঝা: বাংলাদেশের একটি উপজেলায় সরকারি হাসপাতালে অনুসন্ধানমূলক গবেষণা থেকে অন্তর্দৃষ্টি।

তথ্য সংগ্রহের সরঞ্জাম

প্রস্থান সাক্ষাৎকার প্রশ্নাবলী এবং নিবিড় সাক্ষাৎকার নির্দেশিকা

সাক্ষাৎকারের তারিখ:	
সাক্ষাৎকারের স্থান	
সাক্ষাৎকার গ্রহণকারী:	
নোট গ্রহণকারী:	
সাক্ষাৎকার শুরুর সময়:	
সাক্ষাৎকার শেষের সময়:	

A. সামাজিক-জনসংখ্যাগত

উত্তরদাতার প্রোফাইল

A1. আপনার নাম কী?	
A2. আপনার বয়স কত?	বছর

A3. লিঙ্গ	মহিলা.....১ পুরুষ.....২ অন্যান্য.....৯৯
A4. আপনি কোথায় থাকেন (বাসস্থানের এলাকা)?	শহর.....১ শহরতলী.....২ গ্রাম.....৩
A5. আপনার বৈবাহিক অবস্থা কী?	বিবাহিত.....১ অবিবাহিত.....২ বিধবা.....৩ বিচ্ছিন্ন.....৪ তালাকপ্রাপ্ত.....৫
A6. আপনার ধর্ম কী?	ইসলাম..... ১ খ্রিস্টান.....২ হিন্দু.....৩ বৌদ্ধ.....৪ অন্যান্য.....৯৯
A7. আপনার শিক্ষাগত যোগ্যতা কি ?	কোনও আনুষ্ঠানিক শিক্ষা নেই..... ১ প্রাথমিক শিক্ষার নিচে.....২ প্রাথমিক শিক্ষা সম্পন্ন (পঞ্চম শ্রেণি)/ ইবতেদায়ি.....৩ মাধ্যমিক শিক্ষা সম্পন্ন (এসএসসি)/ দাখিল.....৪ উচ্চ মাধ্যমিক শিক্ষা সম্পন্ন (এইচএসসি)/ আলিম.....৫ স্নাতক/ডিপ্লোমা/ফাযিল সম্পন্ন.....৬ মাস্টার্স বা তার উপরে/ কামিল.....৭ অন্যান্য (উল্লেখ করুন).....৯৯
A8. আপনার বর্তমান পেশা কী?	গৃহিণী..... ১ কৃষি ও চাষাবাদ.....২ শ্রমিক ও নির্মাণ.....৩ ব্যবসা ও বাণিজ্য.....৪ সরকারী চাকুরিজীবী৫ বেসরকারী চাকুরিজীবী.....৬ অনানুষ্ঠানিক খাত (রিকশাচালক, পথের বিক্রেতা).....৭ অবসরপ্রাপ্ত.....৮ বেকার.....৯ অন্যান্য (উল্লেখ করুন).....৯৯
A9. আপনার মাসিক আয় কত?	 টাকা

A10. আপনার পরিবারের মোট সদস্য সংখ্যা কত?	
A11. আপনার পরিবারের গড় মাসিক আয় কত?	 টাকা
A12. যোগাযোগ নম্বর	

B. সাক্ষাৎকার নির্দেশিকা

ডোমেইন	প্রশ্নসমূহ	প্রতিক্রিয়া	অনুসন্ধান
স্বাস্থ্য পরিস্থিতি সম্পর্কে উপলব্ধি	B1. আজ আপনি কোন সমস্যার জন্য উপজেলা স্বাস্থ্য কমপ্লেক্সে চিকিৎসা নিতে এসেছেন?	উচ্চ রক্তচাপ.....১ ডায়াবেটিস..... ২ দীর্ঘস্থায়ী শ্বাসযন্ত্রের রোগ (COPD/অ্যাজমা)..... ৩	- আপনি আজকে কেন উপদেলা স্বাস্থ্য কমপ্লেক্সে এসেছেন? - কেন আপনি আজকের জন্য উপজেলা স্বাস্থ্য কমপ্লেক্সে বেছে নিলেন? কেন অন্যান্য সেবা প্রদানকারী না?
	B2. আপনি কত দিন ধরে এ রোগে ভুগছেন?	মাস/বছর	

	B3. রোগের শুরুতে লক্ষণগুলো কী কী ছিল? (রোগ অনুযায়ী একাধিক উত্তর হতে পারে)	বারবার প্রস্রাব.....১ বার বার পানি পান করা২ ওজন কমে যাওয়া৩ ক্লান্তি.....৪ দৃষ্টি অস্পষ্ট.....৫ দীর্ঘস্থায়ী ক্ষত থাকা৬ কোনও লক্ষণ নেই.....৭ প্রায়শই লক্ষণহীন.....৮ মাথাব্যথা.....৯ মাথা ঘোরা.....১০ শ্বাসকষ্ট বিশেষত শারীরিক ক্রিয়াকলাপের সময়.....১১ শ্বাসের সাঁই সাঁই শব্দ.....১২ দীর্ঘস্থায়ী কাশি.....১৩ বুকে চাপ অনুভব.....১৪ অন্যান্য (উল্লেখ করুন).....১৯	• স্বাস্থ্যসেবা নেয়ার আগে আপনি কীভাবে আপনার শারীরিক অবস্থার যত্ন করেছিলেন? (যেমন স্ব-যত্ন, পরিবারের সদস্যদের বা প্রতিবেশীদের কাছ থেকে পরামর্শ?) • সে গুলো কি পদ্ধতি ছিল? • এ পদ্ধতি অবলম্বনের পর কি আপনার অবস্থার উন্নতি বা অবনতি হয়েছিল?
	B4. কত দিন আপনি এ রোগের জন্য নিজে নিজের যত্ন নিয়েছেন?	মাস/বছর	

প্রেরণাদায়ক কারণ, সমস্যা, খরচ এবং সেবার অভি জ্ঞতা	B5. এখন পর্যন্ত আপনি কোন কোন স্বাস্থ্যসেবা প্রদানকারীর কাছে গিয়েছিলেন?	ইউনিয়ন স্বাস্থ্য কমপ্লেক্স.....১ জেলা হাসপাতাল / মেডিকেল কলেজ হাসপাতাল.....২২ গ্রাম ডাক্তার/পল্লী চিকিৎসক.....৩ কবিরাজ.....৪৪ পীর/ফকির.....৫৫ ঔষধ বিক্রেতা.....৬ ৬ অনিবন্ধিত চিকিৎসক(ডিএমএফ/ স্যাকমো).....৭৭ কমিউনিটি ক্লিনিক.....৮ উপজেলা স্বাস্থ্য কমপ্লেক্স.....৯ এনজিও ক্লিনিক.....১০ বেসরকারি হাসপাতাল/চেস্বার.....১১ অন্যান্য (উল্লেখ করুন).....১১	• অনুগ্রহ করে ধারাবাহিক ভাবে বর্ণনা করুন যে আপনি কার কার কাছে থেকে চিকিৎসা নিয়েছেন? • এ সিদ্ধান্তের পিছনে কারণগুলি কি কি ছিল? • অনুগ্রহ করে আপনি প্রতিটি সেবা প্রদানকারীর কাছে থেকে প্রাপ্ত চিকিৎসা পদ্ধতি বর্ণনা করুন • এই সেবা প্রদানকারীর কাছে থেকে সেবা গ্রহণের ক্ষেত্রে আপনি কি কি সমস্যার সম্মুখীন হয়েছেন? • প্রতিটি সেবা প্রদানকারীর কাছে থেকে পাওয়া চিকিৎসা পদ্ধতিগুলোর মধ্যে আপনি কি কি ধরনের পরিবর্তন অনুভব করেছেন? • প্রতিটি সেবার সময়কাল কতছিল? • এই প্রতিটি সেবার
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উপজেলা স্বাস্থ্য কমপ্লেক্সে অভিজ্ঞতা			আনুমানিক খরচ কতছিল? - এ সকল পরিসেবার অভিজ্ঞতা কেমন ছিল? (ভালো বা খারাপ) - কোনটি সবচেয়ে ভালো চিকিৎসা পদ্ধতি ছিল এবং কেন আপনি তা মনে করেন? - কোনটি সবচেয়ে খারাপ চিকিৎসা পদ্ধতি ছিল এবং কেন আপনি তা মনে করেন? - সময়ের সাথে সাথে রোগটি কীভাবে বেড়েছে?
	B6. এ প্রতিষ্ঠানে আসার সিদ্ধান্ত কে নিয়েছেন? (একাধিক উত্তর হতে পারে)	নিজে..... ১ পরিবারের সদস্য.....২ প্রতিবেশী..... ৩ স্বাস্থ্যসেবা প্রদানকারী.....৪ অন্যান্য (উল্লেখ করুন).....৯৯	- উপজেলা স্বাস্থ্য কমপ্লেক্স থেকে চিকিৎসা নেওয়ার পিছনে কারণগুলি কী কী? - উপজেলা স্বাস্থ্য কমপ্লেক্সে রেফার করা হলে রেফারেল প্রক্রিয়া কী?
	B7. প্রতিষ্ঠানের এনসিডি কর্নার/বহির্বিভাগ এ কত বার গিয়েছিলেন?		

আর্থিক অবস্থার উপর প্রভাব	B8. আপনার রোগ বিষয়ে কোন প্রশ্ন জিজ্ঞাসা করতে এবং কোন বিত্রাস্তিগুলি পরিষ্কার করার জন্য আপনি কি উপজেলা স্বাস্থ্য কমপ্লেক্সে পরা মর্শের সময়কে পর্যাপ্ত মনে করেন?	হ্যাঁ.....১ না.....২	আপনি কেন এমন মনে করেন?
	B9. আপনি কিভাবে উপজেলা স্বাস্থ্য কমপ্লেক্সের সেবা প্রদানকারীদের দক্ষতা/গুণ/যোগ্যতা মূল্যায়ন করবেন?	অত্যন্ত ভালো.....১ ভালো.....২ সাধারণ.....৩ খারাপ.....৪ খুব খারাপ.....৫	আপনি কেন এমন মনে করেন?
উন্নতির জন্য পরামর্শ	B10. আপনার কি মনে হয়েছে যে উপজেলা স্বাস্থ্য কমপ্লেক্সের সেবা প্রদানকারীরা আপনার সাথে সম্মান ও মর্যাদার সাথে আচরণ করেছেন?	হ্যাঁ.....১ না.....২	আপনি কেন এমন মনে করেন?
	B11. সেবা নেয়ার সময় কি আপনার গোপনীয়তা রক্ষা করা হয়েছিল?	হ্যাঁ.....১ না.....২	আপনি কেন এমন মনে করেন?

	B12. সেবা প্রদানকারী কি আপনাকে চিকিৎসা পদ্ধতি এবং পরীক্ষা সম্পর্কে বিস্তারিত বুঝিয়ে বর্ণনা করেছিলেন?	হ্যাঁ.....১ না.....২	আপনি কেন এমন মনে করেন?
	B13. চিকিৎসার সময়ের খরচের জন্য নিম্নলিখিতগুলির খরচ তালিকা করতে পারেন? (শুধু উপজেলা স্বাস্থ্য কমপ্লেক্সের জন্য)	ঔষধের জন্য.....১ পরীক্ষার জন্য.....২ ভ্রমণের খরচ.....৩ অন্যান্য খরচ.....৪	
	B14. এখন পর্যন্ত চিকিৎসার জন্য আপনার মোট কত খরচ হয়েছে?	 টাকা	
	B15. এই ব্যয় কি আপনার জন্য আর্থিক বোঝা হয়েছে?	.হ্যাঁ..... ১ না.....২	• কেন আপনার কাছে এইটি একটি আর্থিক বোঝা মনে হয়েছে? • অনুগ্রহ করে আপনার পেশা, উপার্জন, পরিবারের ব্যয়ের উপর আপনার এ অসুস্থতার প্রভাব বর্ণনা করুন
	B16. আপনার পরিস্থিতি সামাল দিতে কি আপনাকে ঋণ নিতে হয়েছে?	হ্যাঁ.....১ না.....২	
	B17. আপনার অসুস্থতার খরচ কি আপনার পরিবারের ব্যয়ের উপর প্রভাব ফেলেছে?	হ্যাঁ.....১ না.....২	

B18. প্রথমবার যখন আপনার রোগ নির্ণয় হয়েছিল তখন থেকে এখন পর্যন্ত আপনার স্বাস্থ্যের অবস্থায় কোনো উন্নতি হয়েছে বলে আপনি মনে করেন কি?	হ্যাঁ.....১ না.....২	আপনি কেন মনে করেন যে স্বাস্থ্যসেবা গ্রহণ করার কারণে এই অনুভূতিগুলি আরও খারাপ হয়েছে?
B19. এই অবস্থার কারণে আপনার কি উদ্বেগ বা বিষণ্ণতার অনুভূতি হয়েছে?	হ্যাঁ.....১ না.....২	
B20. স্বাস্থ্যসেবা গ্রহণকালে কি এই অনুভূতিগুলি আরো খারাপ হয়েছে?	হ্যাঁ.....১ না.....২	
B21. আপনার মতো একই রোগে আক্রান্ত ব্যক্তিদের যত্নের উন্নতির জন্য আপনার কোনো পরামর্শ আছে কি?		- এ রোগে আক্রান্ত ব্যক্তিদের যত্নের উন্নতির জন্য আপনার কি কোনো পরামর্শ আছে? - কেন এ পরামর্শ দিচ্ছেন?

Information sheet and consent form (Bangla)

তথ্য পত্রক

ভূমিকা : শুভেচ্ছা, আমার নাম সাদাহ হাসান, এবং আমি ব্র্যাক জেমস পি গ্রান্ট স্কুল অফ পাবলিক হেলথ, ব্র্যাক ইউনিভার্সিটি থেকে এসেছি। আমরা ডায়াবেটিস রোগীদের স্বাস্থ্যসেবার পথ বোঝার উপর একটি সমীক্ষা পরিচালনা করছি: বাংলাদেশের উপ-জেলা পর্যায়ে হাসপাতালের একটি অনুসন্ধানমূলক গবেষণা থেকে অন্তর্দৃষ্টি।

লক্ষ্য : বাংলাদেশের একটি উপজেলা সরকারি স্বাস্থ্য সুবিধায় ডায়াবেটিস রোগীদের যত্নের পথ বোঝা।

অংশগ্রহণের ন্যায্যতা : আপনার অংশগ্রহণ অত্যন্ত গুরুত্বপূর্ণ। কারণ দীর্ঘস্থায়ী রোগের রোগী হিসাবে আপনার দৃষ্টিভঙ্গি এবং অভিজ্ঞতাগুলি স্বাস্থ্যসেবা খোঁজার ক্ষেত্রে জড়িত চ্যালেঞ্জ এবং প্রক্রিয়াগুলি সম্পর্কে মূল্যবান তথ্য প্রদান করে। এই অভিজ্ঞতাগুলি বোঝা আমাদের স্বাস্থ্যসেবা উন্নতির জন্য সহায়তা করে, যা ভবিষ্যতে একই রকম রোগীদের স্বাস্থ্যের অবস্থা ভালো করতে সহায়তা করতে পারে।

পদ্ধতি : আপনি অংশগ্রহণ করতে সম্মতি দিলে, আমরা প্রায় ৩০-৪৫ মিনিটের জন্য একটি মুখোমুখি সাক্ষাৎকার নিব। এই সাক্ষাৎকারের সময়, আমরা আপনাকে আপনার দীর্ঘস্থায়ী রোগের চিকিৎসার ক্ষেত্রে আপনার অভিজ্ঞতা এবং স্বাস্থ্যসেবা প্রদানকারীদের সাথে আপনার আলোচনা সম্পর্কে প্রশ্ন জিজ্ঞাসা করব। আপনার সম্মতিতে, সাক্ষাৎকারটি সঠিকতার জন্য অডিও-রেকর্ড করা হবে। আপনি স্পষ্ট অনুমতি প্রদান না করা পর্যন্ত কোন ছবি ও তোলা হবে না।

অংশগ্রহণের সুবিধা: এই গবেষণায় অংশগ্রহণ করে আপনার সরাসরি কোনো সুবিধা নেই। তবে, আপনার উত্তরগুলো আমাদের গবেষণায় অবদান রাখবে যা আপনার মতো দীর্ঘস্থায়ী রোগে আক্রান্ত রোগীদের জন্য স্বাস্থ্যসেবা ডিজাইন উন্নত করতে সাহায্য করতে পারে, উপ-জেলা স্বাস্থ্য কমপ্লেক্সে সেবার মান উন্নতি করতে পারে।

ক্ষতিপূরণ: এই গবেষণায় অংশগ্রহণের জন্য কোন ক্ষতিপূরণ নেই।

ঝুঁকি: এই গবেষণায় অংশ নিলে শারীরিক বা মানসিক ক্ষতির কোনো ঝুঁকি নেই। কোন প্রশ্ন আপনাকে অপ্রস্তুত করে ফেললে আপনি সাথে সাথে এ সাক্ষাৎকার থামিয়ে দিতে পারবেন।

গোপনীয়তা এবং পরিচয় গোপন রাখা: আপনার কাছ থেকে সংগৃহীত সমস্ত তথ্য গোপন থাকবে এবং শুধুমাত্র গবেষণার কাজে ব্যবহার করা হবে। আপনার নাম এবং কোনো শনাক্তকারী বিবরণ এখানে অন্তর্ভুক্ত করা হবে না এবং সমস্ত উত্তর নামহীন করা হবে। শুধুমাত্র গবেষণা দলের কাছে প্রয়োজনীয় তথ্য থাকবে, যা নিরাপদে সংরক্ষণ করা হবে এবং পাসওয়ার্ড-সুরক্ষিত থাকবে। আমরা প্রতিবেদন বা একাডেমিক জার্নালে ফলাফল প্রকাশ করতে পারি; তবে, আপনাকে সনাক্ত করতে পারে এমন কোন তথ্য প্রকাশ করা হবে না।

অংশগ্রহণের প্রকৃতি: আপনার অংশগ্রহণ সম্পূর্ণ স্বৈচ্ছায়। কোনো নেতিবাচক পরিণতি ছাড়াই আপনি যে কোনো সময় প্রত্যাহার বা প্রত্যাহার করতে পারবেন। আপনি যদি ইন্টারভিউ শেষ হওয়ার পরে প্রত্যাহার করার সিদ্ধান্ত নেন, অনুগ্রহ করে দুই সপ্তাহের মধ্যে আমাদের জানান, এবং আমরা নিশ্চিত করব যে আপনার তথ্য বাদ দেওয়া হয়েছে।

যোগাযোগের তথ্য: গবেষণা প্রকল্প সম্পর্কে আপনার যদি আরও কোন প্রশ্ন থাকে, তাহলে অনুগ্রহ করে সাদাহ হাসান সাথে এই ফোন নম্বরের মাধ্যমে যোগাযোগ করুন +৮৮০১৭১৫৮৪৭০৫৩

নৈতিক উদ্বেগের জন্য, আপনি ইনস্টিটিউশনাল রিভিউ বোর্ডের সাথে যোগাযোগ করতে পারেন: +৮৮০১৯৯৩৩৭৯৫১২। ইমেল: irb-jpgsph@bracu.ac.bd

সম্মতি পত্রক

অধ্যয়নের শিরোনাম: ডায়াবেটিস রোগে আক্রান্ত রোগীদের স্বাস্থ্যসেবার পথ বোঝা: বাংলাদেশের একটি উপজেলা লেভেল সরকারি হাসপাতালের একটি অনুসন্ধানমূলক গবেষণা থেকে অন্তর্দৃষ্টি।

আপনি যদি এই গবেষণায় অংশগ্রহণ করতে সম্মত হন, অনুগ্রহ করে আপনার স্বাক্ষর/আঙুলের ছাপ রেখে নিশ্চিত করুন।

আপনার আন্তরিক সহযোগিতার জন্য আপনাকে ধন্যবাদ।

আপনি কি সাক্ষাতকারের অডিও রেকর্ড করার অনুমতি দেন? অনুগ্রহ করে মনে রাখবেন যে ইন্টারভিউ চলাকালীন যে কোন সময়ে, আপনি সাক্ষাতকারকে রেকর্ডিং ডিভাইসটি বন্ধ করতে বলতে পারেন।	হ্যাঁ	না
আপনি আপনার ফলাফল শেয়ার করার অনুমতি দেন?	হ্যাঁ	না
আপনি কি ছবি তোলার অনুমতি দেন?	হ্যাঁ	না
আপনি কি ছবি শেয়ার করার অনুমতি দেন?	হ্যাঁ	না
(আপনি যদি আবার উত্তরদাতার সাথে যোগাযোগ/ডাটা সংগ্রহ করতে চান, তাহলে এখানে উল্লেখ করতে হবে এবং অনুমতি চাইতে হবে...)		
আপনার কোন প্রশ্ন আছে?	হ্যাঁ	না
প্রশ্নটি জানান		

ইন্টারভিউয়ারের নাম:

উত্তরদাতার নাম:

ইন্টারভিউয়ার স্বাক্ষর:

উত্তরদাতার স্বাক্ষর/আঙুলের ছাপ:

তারিখ:

তারিখ:

Information sheet and consent form (English)

Information Sheet

Introduction: Greetings, My name is Sadah Hasan and I come from BRAC James P Grant School of Public Health, BRAC University. We are conducting a study on understanding health care pathways of patients with Diabetes: Insights from an Exploratory Study in a Sub-district Level Government Hospital in Bangladesh.

Serial no.: [Protocol number]

Aim: To understand the care pathways of patients with , Diabetes at a Sub-district Level Government Health Facility in Bangladesh.

Justification of participation: Your participation is crucial because your insights and experiences as a patient provide valuable information about the challenges and processes involved in seeking healthcare for chronic conditions. Understanding these experiences helps us to identify areas for improvement in healthcare access and delivery, which could benefit others with similar health conditions in the future.

Procedure: If you agree to participate, we will conduct a face-to-face interview lasting approximately 30-45 minutes. During this interview, we will ask you questions about your experiences in seeking care for chronic health conditions and your interactions with healthcare providers. With your consent, the interview will be audio-recorded for accuracy. No photographs will be taken unless you provide explicit permission.

Benefits of participation: There is no direct benefit to you from participating in this study. However, your responses will contribute to research that could help design healthcare interventions benefiting patients with chronic diseases like yourself, potentially improving care at sub-district health facilities.

Compensation: There is no compensation for participating in this study.

Risk: There is no risk of physical or mental harm from participating in this study. Some questions may touch on sensitive or personal issues related to your healthcare experiences. You have the right to skip any questions that make you uncomfortable, and we will respect your decision without any consequences.

Confidentiality and anonymity: All information collected from you will remain confidential and used only for research purposes. Your name and any identifying details will not be included in the study data, and all responses will be anonymized. Only the research team will have access to the data, which will be stored securely and password-protected. We may publish the findings in reports, presentations, or academic journals; however, no information that could identify you will be disclosed.

Nature of participation: Your participation is entirely voluntary. You are free to decline or withdraw from the study at any time, without any negative consequences. If you decide to withdraw after the interview has been completed, please inform us within two weeks, and we will ensure your data is excluded from the analysis.

Contact information: *If you have any further query about the research project, then please contact Sadah Hasan through this phone number + 8801715847053*

For ethical concerns, you can contact the Institutional Review Board: + 801993379512. Email: irb-jpgsph@bracu.ac.bd

Consent Form

Title of the study: Understanding health care pathways of patients with Diabetes :Insights from an Exploratory Study in a Sub-district Level government Hospital of Bangladesh.

If you agree to participate in this study, please confirm by putting your signature/thumbprint.

Thank you for your cordial cooperation.

(Note to investigator: Please note that the items below can vary from protocol to protocol)

Do you give permission for the interview to be audio recorded? <i>Please note that at any point during the interview, you can ask the interviewer to turn off the recording device.</i>	Yes	No
Do you give permission to share your findings?	Yes	No
Do you give permission to take photos (without face being shown in photos) ?	Yes	No
Do you give permission to share the photos?	Yes	No
<i>(If you need to contact the/collect data from the respondent again, need to state here and ask permission...)</i>		
Do you have any questions?	Yes	No
State the question		

Interviewer name:

Respondent's name:

Interviewer signature:

Respondent's signature/thumbprint:

Date:

Date:

Codebook

1. Care Pathway Stages

Code Name: Self-Management Practices

Short Definition: Strategies patients use to manage symptoms before formal care.

Long Definition: Refers to actions taken by patients to alleviate their symptoms independently, often guided by cultural beliefs or community advice, such as using home remedies, over-the-counter medications.

Code Name: Informal Care

Short Definition: Care from non-formal providers like drug sellers or healers.

Long Definition: Refers to healthcare services accessed through non-formal providers, including drug sellers and traditional healers.

Code Name: Formal Care

Short Definition: Care from healthcare facilities with registered physicians.

Long Definition: Refers to professional healthcare services received at formal healthcare facilities, including Upazila Health Complexes (UHCs), tertiary hospitals, and private facilities

2. Influencing Factors

Code Name: Accessibility

Short Definition: Ease of reaching healthcare providers.

Long Definition: Refers to geographical and logistical factors that determine how easily patients can access healthcare services. Includes proximity to providers, availability of transportation, and the time required to reach facilities.

Code Name: Affordability

Short Definition: Financial factors influencing care decisions.

Long Definition: Refers to the financial constraints faced by patients in accessing healthcare services, including costs of consultations, medications, diagnostic tests, and transportation, which often determine their choice of provider.

Code Name: Cultural Beliefs and Social Influence

Short Definition: Role of culture and community in healthcare choices.

Long Definition: Refers to the impact of cultural norms, traditional beliefs, and advice from family, friends, and community members on patients' decisions regarding care-seeking behaviors, often leading to reliance on informal providers or self-management practices.

3. Barriers and Challenges

Code Name: Delays in Diagnosis

Short Definition: Factors delaying Diabetes diagnosis.

Long Definition: Refers to systemic and individual barriers, such as lack of awareness, reliance on informal care, financial constraints, and inaccessible diagnostic facilities, that contribute to delays in diagnosing Diabetes.

Code Name: Healthcare System Gaps

Short Definition: Issues within healthcare facilities.

Long Definition: Refers to shortcomings in the healthcare system, including inadequate medicine supply, lacking diagnostic equipment, overcrowded facilities, and insufficient consultation times, which negatively affect patient care and outcomes.

4. Patient Outcomes

Code Name: Physical Impact

Short Definition: Physical effects of Diabetes on patients.

Long Definition: Refers to the physical health challenges experienced by patients due to Diabetes, such as poorly/uncontrolled diabetes and symptomatic diabetes.

Code Name: Emotional and Psychological Impact

Short Definition: Emotional challenges due to diabetes.

Long Definition: Refers to the mental health struggles faced by patients, including anxiety, depression, and feelings of helplessness, often exacerbated by the chronic nature of the disease and barriers to accessing timely and effective care.

Code Name: Financial Burden

Short Definition: Economic strain caused by pathways taken.

Long Definition: Refers to the financial difficulties encountered by patients due to ongoing expenses for medications, diagnostics, transportation, and follow-up care, often forcing them to prioritize healthcare over other basic needs.

5. Recommendations

Code Name: Awareness and Education

Short Definition: Importance of raising awareness about diabetes.

Long Definition: Refers to the need for community-based campaigns and educational initiatives to increase awareness about diabetes, its symptoms, and available healthcare services, including the role of NCD corners, to encourage timely diagnosis and treatment.

Code Name: System Improvements

Short Definition: Enhancements to healthcare facilities.

Long Definition: Refers to the need for systemic changes in the healthcare infrastructure, such as improving diagnostic and treatment capabilities at UHCs, ensuring a consistent supply of essential medicines, and addressing gaps in staffing and facility management to improve patient care and satisfaction.,

Data Matrix Display Portion

THEME	SUBTHEME	QUOTES
Factors influencing HCP Choice	Affordability of services	<i>"I am a poor person, I get free medicines from here. I remain well." (73 years old male, suffering from diabetes for 7⁸ years)</i>
	Accessibility (distance and travel cost)	<i>"Malancha medical is very close, I can take a rickshaw...or just walk there. I usually walk." – (35 year old with diabetes for 14 years)</i>

Themes and subthemes

Perception of health condition

1. Perceived symptoms
2. Preliminary or Self-management
3. Events that triggered the healthcare pathway
4. Diagnosis Process

Factors influencing the choice of HCP

1. Accessibility
2. Affordability
3. Acceptability
4. Availability of comprehensive care
5. Social Network
6. Familiarity

7. Popularity of HCP/Faith in HCP

Experience at all points of care

1. Drug seller
2. Religious healer
3. Private
4. UHC
5. Tertiary

Impact

1. Health and well-being
2. Financial

Images from study site



Study location: UHC, Keraniganj



Interview location 1 : a room at the UHC



Interview location 2: seating area adjacent to NCD corner



Interview location 3: In the community where respondent felt comfortable to give interviews

COREQ checklist

COREQ (Consolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in you where you consider each of the items listed in this checklist. If you have not included this information, either revise you accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description
Domain 1: Research team and reflexivity		
<i>Personal characteristics</i>		
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?
Credentials	2	What were the researcher's credentials? E.g. PhD, MD
Occupation	3	What was their occupation at the time of the study?
Gender	4	Was the researcher male or female?
Experience and training	5	What experience or training did the researcher have?
<i>Relationship with participants</i>		
Relationship established	6	Was a relationship established prior to study commencement?
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic

Interviewer who conducted the interview presented themselves as a student studying their Masters in Public Health, was female and had received training on how to conduct IDIs. The interviewer had established a relationship with the participant before interview commencement through rapport-building. The participant was made aware of the research purpose, and that the student researcher was carrying out the interview for their thesis.

Topic	Item No	Description	Reported on Page No.
Domain 2: Study design			

<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	11
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	11
Sample size	12	How many participants were in the study?	11
Non-participation	13	How many people refused to participate or dropped out? Reasons?	40
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	12
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	12
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	11
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	13
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	13
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	12
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			

Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	70
Derivation of themes	26	Were themes identified in advance or derived from the data?	14
Software	27	What software, if applicable, was used to manage the data?	14
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	71-72
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	71-72

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Timeline of study

Major Activities	M1	M2				M3				M4	
	Oct	Nov				Dec				Jan	
	W4	W1	W2	W3	W4	W1	W2	W3	W4	W1	W2
Development of ideas											
Protocol development											
IRB clearance											
Data collection											
Data entry											
Data analysis											
Report writing											
Dissemination											