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ORIGINAL RESEARCH

Early Nephropathy Screening as a Health Seeking Behavior Among Type 2 Diabetes Mellitus Patients: A Phenomenological Study in Southwestern Uganda

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Background: Nephropathy screening is vital in type 2 diabetes mellitus (T2DM) management to prevent complications, yet uptake remains low in resource-limited settings like Southwestern Uganda. This study explored the barriers and facilitators influencing screening among T2DM patients and providers at the diabetic clinic of Mbarara Regional Referral Hospital.

Methods: A qualitative cross-sectional study guided by a phenomenological approach to explore lived experiences around nephropathy screening was conducted. Fifteen adult T2DM patients in care for ≥12 months and five healthcare providers (doctors, nurses, and a laboratory technician) were purposively sampled. Semi-structured, in-depth interviews were conducted. Data were analyzed using an inductive approach. Socio-demographics; including age, sex, education, and employment were collected. All interviews were audio-recorded, transcribed verbatim, and thematically analyzed using Dedoose (version 10.0.25). Study reporting adhered to the COREQ 32-item checklist.

Results: Patients described diabetes as a burdensome and life-altering condition. Key barriers to nephropathy screening included financial constraints, lack of transport, limited awareness, and dissatisfaction with care. Despite these challenges, facilitators such as proactive provider encouragement, community outreach, and availability of free testing motivated screening uptake. Providers emphasized their critical role in educating patients and detecting nephropathy but reported systemic constraints, including staff shortages, equipment failures, limited knowledge on new disease trends and screening protocols. Both groups highlighted the need for routine integration of nephropathy screening into diabetes care and greater support from the health system.

Conclusion: Nephropathy screening behaviors among T2DM patients are influenced by perceived disease severity, provider communication, and systemic barriers such as cost and infrastructure. While both patients and providers recognize the value of early detection, sustained screening is hindered by resource limitations and inconsistent implementation. Strengthening institutional capacity, integrating screening into routine care, and enhancing patient-provider engagement are essential to reducing the burden of diabetic nephropathy in the study setting.

Keywords: type 2 diabetes, nephropathy screening, health-seeking behavior, barriers, facilitators, qualitative study, Uganda

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Introduction

Type 2 Diabetes Mellitus (T2DM) poses a significant and escalating public health challenge, particularly in low- and middle-income countries (LMICs).[1,2] As of 2021, approximately 589 million adults aged between 20 to 79 years were living with diabetes worldwide, with over 80% residing in LMICs.[2,3] The prevalence of diabetes has been rising more

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rapidly in these regions compared to high-income countries for example, projections indicate the number of adults with diabetes in Africa will increase by 142% by 2050, compared to a 10% increase in Europe.[2]

Diabetic nephropathy (DN), a common complication of T2DM, is the leading cause of end-stage kidney disease globally, accounting for approximately 20–50% of all cases.[4,5] Studies indicate that up to about 50% or more of individuals with T2DM may develop diabetic nephropathy during their lifetime.[5–7] A systematic review of primary studies reported the prevalence of CKD among T2DM patients in LMICs to be high ranging from (11% to 83.7%).[8] Early detection through routine screening allows for the prompt initiation of kidney-protective therapies such as SGLT2 inhibitors, ACE inhibitors/ARBs, which can prevent or delay the progression of nephropathy;[9,10] however, many patients with T2DM in resource-limited settings do not participate in recommended screening practices.[11,12]

In Uganda, T2DM prevalence has been on the rise due to changing lifestyles, urbanization, and limited access to diabetes care services.[13] Current estimates indicate that approximately 1.4 million adults are living with diabetes in Uganda, with a national prevalence of 2.2% as of 2024.[14] Furthermore, the burden of diabetes complications is high; a study at Jinja Regional Referral Hospital in eastern Uganda, found that over 56.9% of 784 T2DM patient records reported microvascular complications, of which 25.9% had renal complications.[15]

Mbarara Regional Referral Hospital (MRRH) serves as a key health facility for diabetes management in Southwestern Uganda, offering specialized care at its Diabetes Mellitus (DM) clinic. Despite the availability of nephropathy screening services at MRRH, the uptake among T2DM patients remains suboptimal with age of the patient and waiting time at the clinic being key factors affecting the ultimate uptake of services provided at the DM clinic of MRRH.[16] Other contributing factors to low uptake remain unexplored. Moreover, healthcare workers' perspectives on screening can influence patient behaviors, either encouraging or hindering screening practices.

The cost implications of advanced kidney disease are particularly severe in Uganda, where access to tertiary care is limited. Without early screening and intervention, diabetic nephropathy can progress to end-stage kidney disease (ESKD). Treatment options for ESKD, such as regular dialysis or kidney transplantation, are prohibitively expensive and largely inaccessible for most of the population.[11,17] For instance, the ongoing cost of dialysis alone can create catastrophic health expenditures for families.[18] Crucially, kidney transplantation, often the optimal long-term treatment, is extremely rare in Uganda due to high costs and infrastructural challenges.[19] Therefore, early screening and intervention represent not just a clinical imperative but the most viable and cost-effective strategy to prevent progression to a fatal and financially ruinous outcome.

Our study aimed to fill a knowledge gap using a qualitative approach to assess the barriers and facilitators to early nephropathy screening as a health seeking behavior among T2DM patients at the DM clinic in MRRH. This study focuses specifically on nephropathy due to its particular severity, cost, and the critical importance of early detection. Specifically, we sought to explore how personal, social, and healthcare system factors influence health-seeking behaviors related to nephropathy screening among patients and health workers. With the perspectives of both patients and their healthcare workers, the study generated evidence that can inform targeted interventions to enhance screening uptake, aiming to reduce the financial and health burden associated with advanced kidney disease in high-risk populations.

Materials and Methods

Study Setting

The study was carried out at Mbarara Regional Referral Hospital (MRRH), situated in Mbarara City in southwestern Uganda. This facility serves patients from surrounding districts and neighboring countries such as Tanzania, Rwanda, and the Democratic Republic of Congo. As a government-run institution, MRRH offers free healthcare services, though it also has a private wing for paid services. The hospital functions as the teaching hospital for the Mbarara University of Science and Technology Medical School.

Mbarara Regional Referral Hospital has a capacity of 350 beds and provides a wide range of services, including inpatient, outpatient, and specialized care. These services encompass a diabetic clinic, a nephrology unit, medical wards, an eye care center, and other specialized clinics. Annually, the hospital attends to approximately 500–600 type 2 diabetes mellitus patients, with about 10% being newly diagnosed T2DM cases. A previous study conducted at this clinic found the prevalence of diabetic nephropathy to be at 22.9% out of the 140 T2DM patients who were sampled.[20]

Study Design

We used a qualitative cross-sectional design. To gain rich, contextual insights into the lived experiences, perceptions, and attitudes of both patients and healthcare providers involved in diabetes care. The study was guided by a phenomenological methodological approach, which emphasizes understanding individuals' lived experiences and the meanings they assign to them.[21]

Study Participants

The study targeted two main groups of participants: T2DM patients attending the DM clinic at MRRH and healthcare workers involved in their care.

Patients

The inclusion criteria were adult males and females out-patients diagnosed with T2DM who were regular or irregular attendees of the diabetes mellitus clinic. Participants were required to have been under care for at least 12 months. This duration ensured that participants had at least three clinic visits, reflecting a level of engagement with the healthcare system. Patients without a documented history of diabetes care or those visiting the clinic for the first time to establish a diagnosis were excluded.

Healthcare Workers

Participating healthcare providers were those working at the diabetic clinic of MRRH, consultant physicians, senior house officers (residents), medical officers, nurses, and laboratory technicians. Eligible participants had to have at least six months of experience managing diabetes patients at MRRH, ensuring that they had adequate exposure to patient care dynamics relevant to nephropathy screening at the study site. Five health care providers met this criterion and were included as study participants.

Sampling and Recruitment

Sampling was conducted with the aim of capturing variation in age, gender, education, and clinical background among healthcare provider participants. We determined our sample size a priori by aiming to interview approximately 5 healthcare providers, who make up the core team at the MRRH diabetic clinic and 15–20 patients recommended for phenomenological qualitative studies. However, the final sample size for patients was guided by the principle of thematic saturation. We operationally defined saturation as the point where three consecutive interviews yielded no significant new themes or sub-themes related to the research question. For healthcare workers, sampling aimed for completeness by interviewing all five members of the clinic's core team. To assess saturation, the research team held iterative coding meetings after every 3–4 interviews. Transcripts were coded and discussed, and a running list of themes was maintained. After 15 patient interviews, the team's consensus was that saturation had been reached for patient-related themes.

Eligible participants were approached by a research assistant with prior experience of 3 years in conducting qualitative interviews in the clinic who provided them with information about the study. Participation was voluntary, and whoever was not able to participate, we left them and looked for another willing and eligible participant. All participants were compensated for their time with modest fee of 50,000 Ugandan shillings (~14 USD) and provided with refreshments during the interview process.

The interviewer, a research assistant with a Master's in Public Health, had no prior relationship with participants and maintained a neutral stance throughout the interviews. All interviews were conducted in the private rooms within the hospital to ensure confidentiality and comfort. Only the interviewer and participant were present during each session. Socio-demographic and specified clinical data, such as, age, sex, education level, employment status, and diabetes duration were collected to contextualize participants' responses.

Framework

The study's conceptual framework integrated the Health Belief Model with contextual factors specific to the T2D patient population at Mbarara Regional Referral Hospital (MRRH). This framework visually represented the interplay of individual, social, and healthcare system factors influencing nephropathy screening behavior. It highlighted the relationships between perceived barriers and facilitators and their impact on patients' health-seeking actions.

Data Collection

Semi-structured interview guides were developed using the Health Belief Model (HBM)[22] for patients and the Theory of Planned Behavior (TPB)[23] for providers, shown in Figures 1 and 2 respectively, which served as sensitizing frameworks to inform the development of questions without constraining participant responses. Study reporting adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines which provide a 32-item checklist that we customized to fit this study (Supplementary File 1: COREQ Checklist).

Prior to the actual data collection exercise, the interview guides (Supplementary File 2: Interview guides) were translated to Runyankole language (local dialect) and were informally pilot tested on 3 patients and 2 providers at another diabetic clinic of a Health Center IV Hospital in Mbarara district to remove ambiguous questions and improve on clarity.

Thereafter, a trained interviewer collected data through in-depth, semi-structured interviews each lasting 30 to 60 minutes. The transcripts were not returned to participants for verification since interviews were conducted as single encounters and no repeat interviews were done.

For patient participants, the interviews explored their experience having diabetes, understanding of long-term complications such as kidney disease, and routine clinic visit practices. Questions also addressed patient perceptions of kidney disease risk, awareness of screening, and perceived benefits of early detection, barriers to screening, including socio-economic factors (eg, cost, distance, health literacy), cultural influences (eg, stigma, beliefs), and health system-related challenges (eg, service availability, provider attitudes). Interviews also probed facilitators to screening, such as family or peer encouragement, past experiences with care, and communication factors that would influence willingness to be screened. Lastly, patients were invited to suggest practical strategies that could improve the accessibility and acceptability of nephropathy screening services.

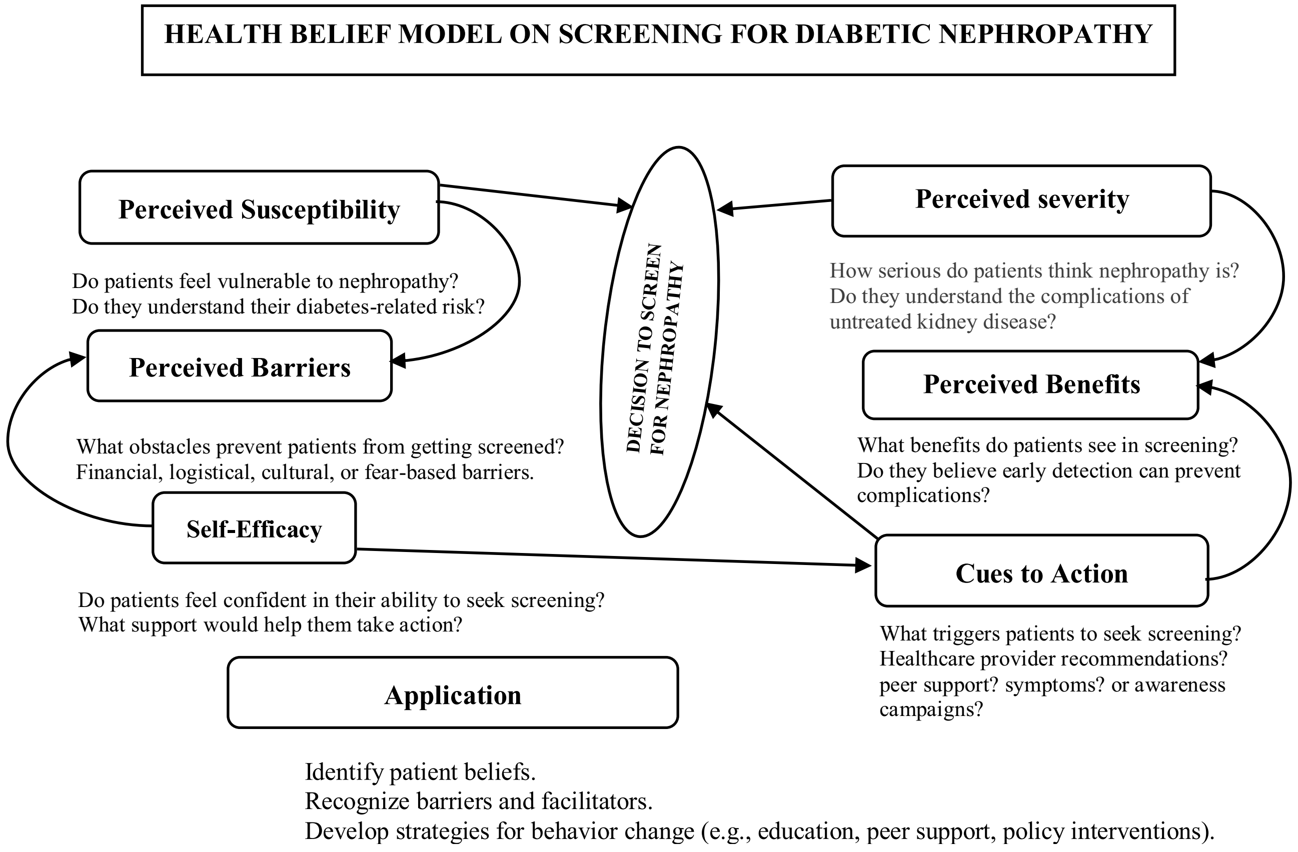

Figure 1 Application of the Health Belief Model to Nephropathy Screening Among Patients with Type 2 Diabetes Mellitus.

Notes: A framework that outlines how patients' perceptions of susceptibility, severity, benefits, barriers, self-efficacy, and cues to action shape their decision to screen for diabetic nephropathy. It identifies key psychological and contextual factors influencing health-seeking behavior.

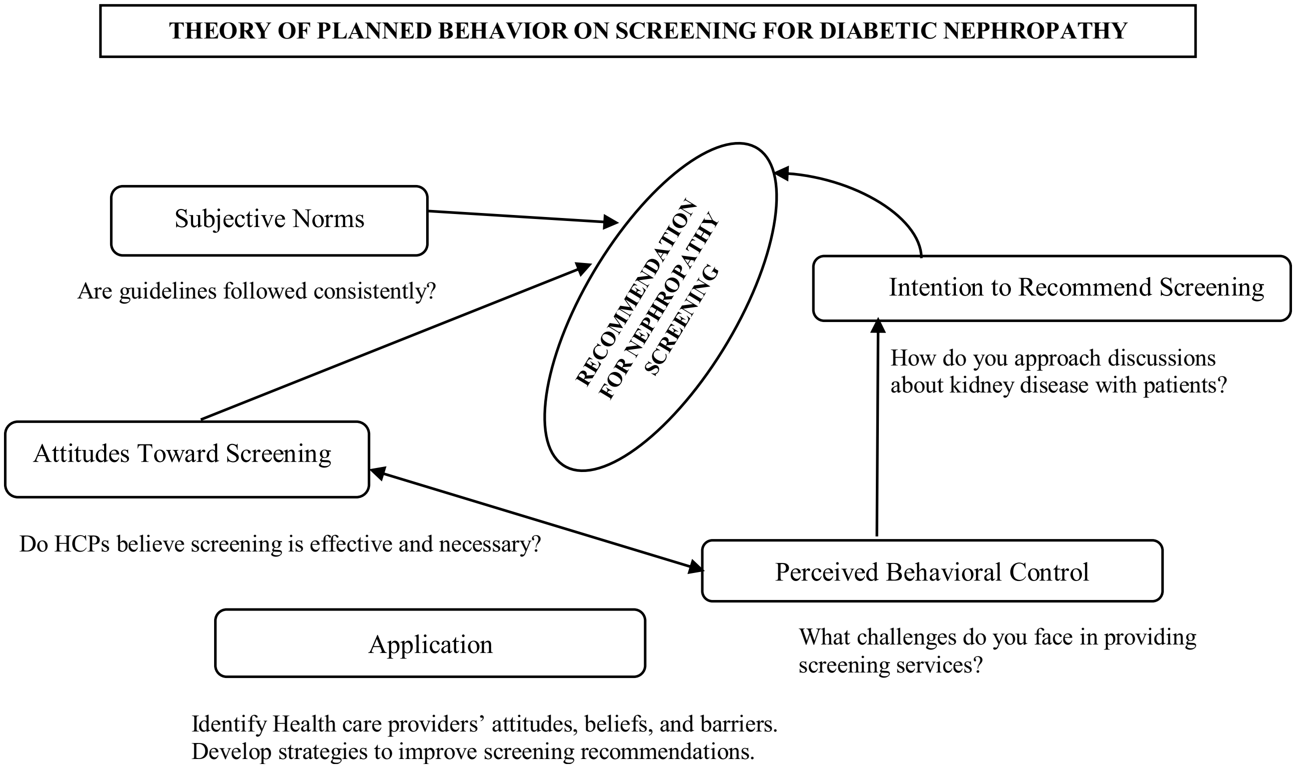

Figure 2 Application of the Theory of Planned Behavior to Nephropathy Screening Among Healthcare Providers.
Notes: A model which illustrates how providers' attitudes, perceived norms, and perceived behavioral control influence their intention to recommend nephropathy screening to diabetic patients. It identifies key barriers and facilitators related to clinical practice, system support, and provider beliefs.

For healthcare providers, the interviews gathered data on their roles in diabetic care, experiences managing diabetes-related complications, and observations of nephropathy among patients. Providers shared insights into their communication practices, use of screening guidelines, and challenges encountered in delivering nephropathy screening services. Additional questions focused on institutional constraints, patient-related barriers, and recommendations to improve uptake. Suggestions included ways to support both patients and providers, as well as system-level strategies that could enhance screening coverage.

All interviews were conducted in private rooms within the DM clinic, audio-recorded following participant consent, and supplemented by hand written notes. Verbatim transcripts were produced for each interview to facilitate accurate thematic analysis.

Statistical Analyses

The analysis followed an inductive approach, which is suitable for exploring complex social phenomena and generating new insights from participants' perspectives, especially when existing theories are limited or not well-defined.

Data Preparation and Management

Data were collected through in-depth interviews with T2DM patients and healthcare workers, which were audio-recorded with participants' consent. The recordings were transcribed verbatim, and the transcripts were reviewed alongside the original recordings to ensure accuracy. The transcripts were then de-identified to maintain participant confidentiality and imported into qualitative data analysis software, to facilitate systematic coding and theme development.

Data Analysis Approach

The analysis employed thematic analysis, where we identified, analyzed, and reported patterns (themes) within the qualitative data based on the theoretical frameworks. The approach allowed for the direct assessment of the data, providing a bottom-up analysis that accurately reflected the participants' lived experiences and viewpoints. Data were analyzed using a predominantly inductive thematic approach, with key constructs from HBM and TPB applied deductively during interpretation. This hybrid analytical strategy enabled the identification of both theory-informed and emergent themes, capturing the multifaceted socio-behavioral and systemic factors influencing nephropathy screening in a resource-limited setting.

Familiarization with Data

The analysis began with a thorough reading of all transcripts to gain a deep understanding of the content. This initial step enabled us to become familiar with the data and identify preliminary insights.

Coding

Line-by-line coding was performed to identify significant statements, phrases, or words relevant to the study objectives. Coding was done iteratively done, with codes being refined and adjusted as patterns and relationships emerged within the data. Codes were then grouped into broader categories representing different aspects of the participants' experiences related to nephropathy screening.

Theme Development

Codes were systematically reviewed and grouped into overarching themes that captured the key barriers and facilitators influencing nephropathy screening. Themes were developed based on the frequency of codes, the significance of the data segments, and the relationships between different codes. Themes were continuously refined to ensure they were comprehensive and accurately represented the data.

Theme Interpretation

Each theme was analyzed in detail to explore the underlying meanings, relationships, and implications for health-seeking behavior toward nephropathy screening. The themes were linked back to the study's objectives and existing literature to contextualize the findings.

Methodological Rigor

To ensure the trustworthiness of the study findings, we employed the criteria of credibility, dependability, transferability, and confirmability as proposed by Lincoln and Guba.[24]

Credibility was achieved through in-depth, semi-structured interviews conducted by a trained and reflexive interviewer with expertise in qualitative health research. Interview guides were informed by the Health Belief Model (for patients) and the Theory of Planned Behavior (for providers), enabling a focused yet flexible exploration of participants' lived experiences. All interviews were audio-recorded with consent, transcribed verbatim, and analyzed using a predominantly inductive thematic approach, supported by Dedoose (version 10.0.25) software to ensure systematic data management. This process allowed for emergent themes to surface while grounding interpretation in participant narratives. To strengthen the analysis and minimize single-coder bias, we implemented a structured process for inter-coder reliability. The lead author developed the initial codebook based on a review of several transcripts. A second experienced qualitative researcher then independently coded a subset of transcripts (approximately 20%). The two coders met to compare their application of codes, discuss discrepancies, and refine the codebook definitions until consensus was reached. This calibrated approach ensured consistency before the lead author completed the coding of the remaining transcripts. Emerging thematic patterns were continually reviewed and discussed with the research team until consensus was reached.

Dependability was ensured through a consistent and transparent data collection process. A standardized interview protocol was used across all participants, and the interviewer maintained field notes to document contextual factors during data collection. The research team applied a coherent and replicable coding strategy, which was systematically documented to maintain an audit trail.

Transferability was supported through purposive sampling of patients and healthcare providers with diverse backgrounds in terms of age, gender, occupation, and clinical experience. Rich descriptions of the study setting and participant characteristics were provided to enable readers to assess the applicability of findings to other similar low-resource contexts.

Confirmability was strengthened through careful documentation of the research process, including interview transcripts, field notes, coding frameworks, and analytic decisions. The interviewer had no prior relationship with participants and maintained reflexive awareness of potential biases throughout data collection and analysis. The use of Dedoose software facilitated a transparent and traceable analytic process, reinforcing the objectivity of findings.

Results

Socio-Demographic Characteristics of the Participants

A total of 20 participants were included in the study, comprising 15 patients with Type 2 Diabetes Mellitus (T2DM) and five healthcare providers involved in their care at the Diabetes Mellitus Clinic of Mbarara Regional Referral Hospital. Among the patient participants, the median age was 53 years, with the majority (n=9) being female. Most patients were married (n=13), had completed primary or secondary education (n=14), and were engaged in informal or subsistence employment (n=12). The median duration of diabetes among participants was 9 years (IQR: 5.5–14.5 years). All the patient participants had received care at the DM clinic for at least 12 months.

The healthcare providers included a consultant, a resident, a medical officer, a nurse, and a laboratory technician. Their years of experience in diabetes care ranged from 0.5 to more than 10 years. Four of the providers were female, and they reported routinely providing patient education on type 2 diabetes mellitus complications, including nephropathy. While all providers were aware of the importance of nephropathy screening, only three reported having access to clear facility-based guidelines to support systematic screening. The sociodemographic characteristics of patients and providers are summarized in Tables 1 and 2 respectively.

Coding Framework

From the 20 participants (patients and healthcare providers) interviewed, their transcripts were analyzed and categorized into broad themes and subthemes as shown in Table 3.

Table 1 Sociodemographic Characteristics of Participants (n = 15)

Variable	Response Category	Frequency (n)	Percentage (%)
Age (years)	Median = 53 (IQR: 47–59)	–	–
Gender	Male	6	40
	Female	9	60
Marital Status	Married	13	81.2
	Not Married (Single/Divorced/Widowed)	3	18.8
Highest Education Level	None	1	6.7
	Primary	7	46.7
	Secondary	7	46.7
Employment Status	Employed	12	80
	Unemployed	3	20
Duration Since Diabetes Diagnosis (years)	Median = 9 (IQR: 5.5 to 14.5)	–	–

Notes: This Table 1 presents the socio-demographic characteristics of patient participants (N=15) in the qualitative study. It includes age distribution, gender, marital status, education level, employment status, and the duration since Type 2 Diabetes Mellitus (T2DM) diagnosis. Medians and interquartile ranges (IQR) are reported for continuous variables, while frequencies and percentages are reported for categorical variables.
Abbreviations: T2DM, Type 2 Diabetes Mellitus; IQR, Interquartile Range; n, Number of participants; %, Percentage.

Table 2 Summary of Healthcare Provider Demographics (n = 5)

Variable	Response Category	Frequency (n)	Percentage (%)
Age (years)	25-34	2	40
	35-44	1	20
	45-54	2	40
Gender	Male	1	20
	Female	4	80
Professional Role	Consultant	1	20
	Nurse	1	20
	Senior House Officer	1	20
	Medical Officer	1	20
	Lab Technician	1	20
Years in Diabetes Care	0 to 2	1	20
	3 to 5	1	20
	6 to 10	2	40
	>10	1	20

Notes: This Table 2 summarizes the demographic and professional characteristics of healthcare provider participants (N=5) in the qualitative study. Variables include age group, gender, professional role, and years of experience providing care to patients with Type 2 Diabetes Mellitus (T2DM). Data are presented as frequencies and percentages for each category.
Abbreviations: T2DM, Type 2 Diabetes Mellitus; n, Number of participants; %, Percentage.

Table 3 Kidney Disease Coding Framework (Patients and Providers)

Study Participants	Broad Themes	Sub-themes (Child Codes)	Definitions/Examples
Patients	Experiences as a type 2 diabetes mellitus Patient	1. Journey with diabetes 2. Typical routine diabetic clinic visit 3. Knowledge of type 2 diabetes mellitus complications	Description of participant's journey with diabetes, how they first learnt and how it had been like managing the condition; description of typical diabetic clinic visit, and knowledge of other diseases that may result from diabetes including kidney disease perceived risk of developing complications for (him/her and others), concerns of developing kidney disease and if participant has already experienced some warning signs / symptoms
	Perceptions on checking for kidney disease	1. Concerns about kidney disease 2. Reasons and knowledge of screening 3. Benefits of screening for kidney disease	Any discussion around concerns of developing kidney disease among type 2 diabetes mellitus patients' if the participant has heard of a patient who developed kidney disease and their reaction; and benefits for screening kidney disease
	Barriers to getting checked for kidney disease	1. Encouragement/ invitation for kidney disease screening 2. Socio-economic barriers to screening 3. Cultural barriers 4. Health care system related barriers	Any discussion about the participant being encouraged by health care provider, family or friend to go for kidney disease screening, what the discussion was like and if they have not got the encouragement, if it would make a difference if they got it, challenges they have faced in accessing screening services such as social economic, cultural and health system related. Their experience with their doctor/health care provider the last time they went for screening.

(*Continued*)

Table 3 (Continued).

Study Participants	Broad Themes	Sub-themes (Child Codes)	Definitions/Examples
	Facilitators to Screening for Kidney Disease	1. Drivers for kidney screening without symptoms 2. Drivers/factors for kidney disease screening	Discussion around what may prompt type 2 diabetes mellitus patients to screen for kidney disease even without symptoms, factors patients may consider/reconsider for kidney disease screening and how the language used in communication affects their decision
	Suggestions and recommendations for change	1. Specific approach to kidney disease screening 2. Main obstacles to participation 3. Areas of improvement	Any discussion around specific approach to kidney, obstacles to participation by patients and areas of improvements by the health system.
Healthcare Providers	Experience as a Healthcare Provider	1. Role in caring for type 2 diabetes mellitus patients 2. Experience in managing complications 3. Assessment of the risk of Nephropathy 4. How often patients with kidney disease are seen	Any discussion around provider role in caring for type 2 diabetes mellitus patients, experience managing complications related to diabetes mellitus, how provider assess patient's risk of nephropathy, and how often they see patients with complications such as kidney disease.
	Awareness and Promotion of Kidney Disease Screening	1. Approach of kidney disease discussions 2. Factors for and against screening 3. Guides of protocols for nephropathy screening 4. Role of HCP in screening	Any discussion about hoe HCP approach discussions of kidney disease with patients, factors that may influence patients to screen or not screen for kidney disease, any guidelines or protocols for screening at the facility and if they are or not followed consistently and reasons why.
	Barriers to Screening for Kidney Disease	1. Biggest challenges in Nephropathy screening 2. Logistical and institutional barriers 3. Patient-related barriers	Any discussion around the biggest challenges to nephropathy screening, description of logistical and institutional barriers that make screening difficult and any patient-related barriers that impact on their willingness or ability to get screened.
	Strategies for Improvement	1. What can be done to improve rates? 2. Strategies that have worked 3. Support MoH can provide	Discussions about what can be done to improve Nephropathy screening rates, strategies that have worked; and how health care systems such as the MoH can support HCP.
	Suggestions and recommendations for change	1. Specific approaches to kidney screening 2. Main obstacles to participation 3. Areas of improvement	Any concluding discussion on specific approaches to kidney screening, main obstacles to screening and areas of improvement/ where changes can be made

Notes: This Table 3 presents the thematic coding framework developed from interviews with patients and healthcare providers regarding nephropathy screening among individuals with Type 2 Diabetes Mellitus (T2DM). Broad themes, sub-themes (child codes), and accompanying definitions/examples illustrate the dimensions explored in the qualitative analysis. Patient themes reflect personal experiences, beliefs, and behaviors related to kidney disease screening, while provider themes capture clinical roles, challenges, and suggestions for improving screening services.

Abbreviations: T2DM, Type 2 Diabetes Mellitus; HCP, Healthcare Provider; MoH, Ministry of Health.

Patients

The following patients' results were obtained after the thematic analysis.

Experience with Diabetes

Participants described diabetes as a life-altering condition that affects multiple aspects of their lives. Delayed diagnosis, psychological distress, and socioeconomic burden were common experiences, indicating a perceived high severity and low initial awareness of the disease.

One participant mentioned that;

> I had lost a lot of weight and would urinate frequently. (50, Female)

Another also cited similar symptoms;

> Very frequent urination, feeling very thirsty. After diagnosis I was shocked. (55, Male)

Another mentioned limited awareness of symptoms:

> I got diseased with diabetes in 2010, but I did not understand the disease well until symptoms worsened. (53, Male)

Another confirmed the socio-economic burden associated with the disease;

> The disease is expensive to manage; I feel tired all the time, and I cannot do heavy work. (42, Male)

Perceptions and Concerns About Kidney Disease

There was strong awareness of the potential complications of diabetes, particularly kidney disease. Participants feared its consequences and valued early detection, recognizing the importance of screening despite limited information.

One participant narrated her screening encounter;

> They took my blood and told me I have a risk of kidney disease. (50, Female)

Another mentioned the utter shock that would befall her if she had not been screened and was later found with kidney disease;

> If I had the disease and didn't know, it could finish me. (53, Female)

Another recognized the multi-morbidity potential of diabetes;

> I now have high blood pressure, and I fear I may get kidney problems too. (42, Male)

Barriers to Kidney Disease Screening (Socioeconomic, Cultural, and Systemic)

Structural barriers such as poverty, distance, lack of awareness, and dissatisfaction with care hindered screening uptake. These issues compounded participants' vulnerability, especially those with limited support or income.

One participant mentioned transport fare to the clinic and social support as critical hindrances;

> Lack of transport fare and social support makes it hard to go for screening. (50, Female)

Another participant confirmed the transport challenge;

> You know these days' people don't have money to come for every test. (53, Male)

One participant noted the role of income in finding alternative remedies:

> Low income forces people to use herbs which are not always safe. (42, Male)

Another pointed out the impact of a poor turn-around time in establishing a diagnosis;

> Sometimes you test and wait long for the results; by the time they come, you have worsened. (55, Male)

Facilitators and Motivators for Screening for Diabetic Nephropathy

Health education, proactive counseling by healthcare workers, and community outreach motivated participants to undergo screening, even in the absence of symptoms. Participants were more likely to act when communication was clear and screening was made accessible.

One participant affirmed Health care provider (HCP) support to screen

> I wanted to know my status, and the nurse encouraged me. (53, Female)

Another participant also affirmed HCP support;

> They tell us to test for kidneys even if there are no symptoms. (55, Male)

> One participant mentioned free testing as a potential key driver to screening;

> If people hear on radio that testing is free, they will come. (53, Male)

Another participant suggested that screening should be made part of the routine services.

> Now that we are at the clinic, screening should be part of routine services. (50, Female)

Suggestions for Improvement

Participants emphasized the need for integrated, routine, and free kidney screening services. They suggested systemic improvements such as government involvement, better staffing, and tailored health communication.

One participant suggested that diabetic nephropathy screening tools and human resource should be prioritized;

> The government should provide testing kits and train health workers. (42, Male)

Another was hopeful that patients would respond positively to government aided initiatives targeting diabetic nephropathy screening;

> If people are told that kidneys are being checked for free, and it's from the government, they will respond positively. (53, Male)

One participant mentioned the preference of healthcare providers taking the lead on the screening initiative;

> Let the nurse test us automatically when we come. (53, Female)

Another participant had a similar view;

> Now that we are at the clinic, we should be checked automatically. (50, Female)

Healthcare Providers

The following providers' results were obtained after the thematic analysis.

Experiences in Managing Diabetes and Nephropathy Risk

Healthcare providers described their roles as spanning both diagnosis and longitudinal care for type 2 diabetes mellitus patients. They are responsible for not only initiating treatment but also monitoring for complications such as kidney disease.

The Laboratory technician mentioned his involvement in conducting tests.

> Diagnostics; Majorly it is diagnostics and we do quite a number of tests which include; for every diabetic patient we normally do urinalysis. We monitor the liver and the kidney tests because if you have diabetes for a long time it affects most organs. (32, Male)

Two health care providers, a medical officer and a senior house officer described their role in establishing a diagnosis and reviewing patients' medical records including key laboratory tests.

> My role is to make a diagnosis, follow up, doing investigations to aid follow up, to treat, to health educate and then. write to organizations asking for help. (46, Female)

> I see new patients and continuing patients that we educate and re-educate. we do certain tests like HbA1c, fasting blood sugar. the 3 monthly screening like RFTs. (30, Female)

On the other hand, the consultant handles patients who are suffering advanced disease.

> The patients are sent when they already have complications. health workers must reduce the progression of kidney disease. Once it has happened, it has happened. (47, Female)

Experience with Complications

Many providers had direct experience managing diabetes-related complications, particularly kidney disease, reinforcing their belief in the need for early intervention.

> These days [complications] are very common. 40% of the renal function tests we do show creatinine levels >3; some more than 20. the rate of kidney disease is growing. (32, Male)

> Most of the patients I have seen develop nephropathies. Actually, many are diagnosed with renal disease. (44, Female)

> During Christmas period we are overloaded with very sick people. relatives bring patients for one month's treatment then disappear. (46, Female)

Risk Assessment Practices

Providers reported assessing risk using available clinical indicators such as blood pressure and urine dipstick results, although comprehensive tools were limited.

> We assess risk based on blood pressure and urine tests when available. However, these are not sufficient to entirely rule out diabetic nephropathy among the T2DM patients. (44, Female)

Frequency of Nephropathy Among Patients

Nephropathy was commonly encountered, often in advanced stages, highlighting the lack of early detection.

> We see cases with renal complications quite often especially in advanced stages. Many patients usually present when they begin to experience discomfort or pain and unfortunately, this is usually late. (47, Female Provider)

Screening Practices and Promotion

Approaches to Educating Patients

Providers offered basic education on kidney disease during routine diabetes care. However, time constraints and clinic workload limited the depth and frequency of such counseling.

> Yes, we actually do some patient education whenever they come. (44, Female provider)

Perceived Facilitators and Barriers

Uptake of nephropathy screening was seen as closely tied to patients' understanding of its benefits and their ability to pay for tests.

> Many don't screen because they don't understand the risks or they can't afford it. Because this condition starts out asymptomatic, many patients wait until they have a certain form of discomfort or pain before they become proactive about screening. (46, Female)

Availability and Use of Screening Guidelines

Some healthcare providers referred to international guidelines like the 2024 CKD protocol,[25] but noted these are not widely adopted or supported at institutional level.

> I use the 2024 chronic kidney disease guideline, but many don't, probably because the guidelines are not fully incorporated into the Ministry of Health testing algorithm used at the clinic. (47, Female)

Perceived Role in Motivating Screening Uptake

Providers saw themselves as key influencers, often introducing the idea of screening during consultations, though their efforts were limited by systemic constraints.

> The Nurse Explained About Kidney Damage and That Helped Me Decide to Take the Test. (32, Male)

Challenges to Providing Nephropathy Screening

Institutional and Logistical Barriers

Common challenges included inconsistent availability of laboratory equipment, inadequate staffing, and long wait times.

> Sometimes we come and they say the machine is not working or the person operating the machine is not available on the day you have come for the diabetic clinic visit. (32, Male)

Patient-Related Barriers

Providers frequently noted patients' limited financial means and misconceptions about the value of screening.

> In most cases it is lack of money that stops them from screening. Many patients mention not having enough money to cater for their transport to the clinic and also be able to afford extra testing if recommended by the attending clinician. (46, Female)

Limitations in Existing Strategies

Although some interventions had been attempted, providers highlighted a lack of consistency and follow-through in implementation.

> Maybe putting a lab person dedicated to nephropathy screening would help tackle the issue of generalized care which is not intentional about the screening. (44, Female)

Strategies for Improvement and Support Needed

Practical Strategies That Have Worked

Awareness creation through targeted education and community engagement was cited as a useful approach.

> We actually do patient education in the morning; on all the complications of diabetes mellitus and nephropathy is among. Creation of awareness among diabetic patients has helped. (32, Male)

Suggestions for Improving Patient Access

Providers suggested integrating nephropathy screening into routine diabetes check-ups and improving patient follow-up.

> The ministry of health should ensure that people have the right information by sending supervisors to all health centers to ensure that people have access to right information; in all government health centers they should ensure that there is someone properly trained on the treatment and management of endocrine conditions. Putting a lab person at the clinic just for kidney checks might help. (44, Female)

System-Level Support Needed

There was a unanimous call for increased support from the Ministry of Health, especially in terms of training, supply chains, and infrastructure.

> I try to use the 2024 chronic kidney disease guidelines from ministry of health but you cannot follow them consistently for every patient because you manage the patient as they have come.
>
> The Ministry of Health should enhance screening capacity in regional hospitals. (46, Female)

Recommendations to Enhance Provider and Patient Engagement

Improving communication, standardizing messages about nephropathy risks, and building provider confidence were seen as key to strengthening uptake.

> We need to communicate risks better during visits or even on mass media. We could do radio talk shows or even TV talk shows about kidney disease, I never hear talk shows about kidney disease. (30, Female)

Discussion

We explored the lived experiences and perceptions of type 2 diabetes mellitus (T2DM) patients and their healthcare providers regarding nephropathy screening in a resource-constrained setting in southwestern Uganda. Our findings underscore the complexity of screening behaviors, shaped by a dynamic interplay of personal beliefs, social influence, and systemic challenges.

While prior research has documented general barriers to chronic disease care in LMICs,[26–29] our study offers a novel, dual-perspective qualitative analysis of the specific factors influencing nephropathy screening, a critical but often neglected aspect of diabetes management. The unique contribution of this work is threefold: (1) it simultaneously explores the lived experiences of patients and the operational realities of their healthcare providers within the same clinic system, revealing points of alignment and tension; (2) it identifies context-specific, actionable facilitators, such as the strong patient preference for automatic, integrated screening, that can be immediately leveraged for intervention; and (3) it provides rare empirical evidence from southwestern Uganda to inform local policy and clinic management, moving beyond broad regional generalizations.

The narratives of patients revealed that diabetes is not just a biological condition but a social and emotional burden. Participants described initial experiences marked by delayed diagnosis, unawareness of symptoms, and psychological distress. These experiences reflect findings from Hjelm's studies, which documented similar emotional responses and limited disease literacy among African type 2 diabetes mellitus populations in Uganda and Zimbabwe.[30–32] The consistent theme of fatigue, diminished productivity, and the economic toll of managing diabetes echoed literature that characterizes chronic diseases as significant contributors to household impoverishment in LMICs.[33–36]

Many patients noted they would be devastated to discover kidney disease late, reflecting the fear-based motivation that can prompt health-seeking behavior. Yet, the awareness of nephropathy risks coexisted with structural barriers that hindered follow-through. Poverty, long distances to health facilities, lack of transport, and the burden of user fees for tests emerged as dominant deterrents. Prior studies have identified similar barriers, noting that out-of-pocket payments and indirect costs such as travel, time off work remain key obstacles to preventive service uptake in rural Africa.[37–39]

Healthcare providers corroborated these barriers, noting that despite their efforts to educate patients and encourage screening, structural and institutional constraints impeded consistent implementation. They acknowledged encountering nephropathy frequently, often only in its advanced stages, highlighting a failure in early detection. This trend is supported by the global kidney health community, which has called attention to the "silent" progression of CKD and the need for proactive case finding in high-risk groups like diabetes mellitus patients.[40]

Providers also described their pivotal roles in managing T2DM, ranging from diagnosis to long-term monitoring, often under challenging conditions. Their accounts of multitasking, limited human resources, and equipment shortages mirror the burden borne by frontline health workers in LMICs and illustrate the implications of limited institutional support.[41] While some providers referred to guidelines such as the 2024 CKD protocol,[25] inconsistent dissemination and lack of localized adaptation reduced their practical utility.

Importantly, both patients and providers identified facilitators to screening. Proactive communication from health workers, the opportunity for free testing, and integration of screening into routine care were noted as positive drivers. These factors are supported by interventions in other LMIC settings where decentralizing screening services and integrating them into routine clinic visits has been shown to improve uptake.[42–44] Patients in this study favored automatic screening during routine visits, a strategy which not only normalizes preventive care but can also improve case detection and outcomes when paired with timely follow-up.

Several participants emphasized the importance of government support, particularly in providing screening supplies and training health workers. This reflects a broader consensus in global health discourse that scaling up healthcare services requires sustained political will, financing, and capacity building.[45] Providers also emphasized the need for task-shifting strategies, such as dedicating specific personnel to nephropathy screening within diabetic clinics, a recommendation that aligns with findings from studies on optimizing workforce distribution to strengthen primary healthcare in Africa.[46,47]

As recommendations, nephropathy screening should be institutionalized as part of routine diabetes care visits. Integrating kidney checks into existing clinic workflows using standardized protocols will help normalize screening behavior and improve early detection rates. This integration will reduce the need for patients to make additional visits, saving both time and cost. To minimize financial barriers, it is vital that kidney function tests are offered free of charge or at highly subsidized rates. Public health authorities and partners must prioritize the procurement and consistent availability of essential diagnostic kits and reagents in diabetes mellitus care clinics. Healthcare providers should receive regular in-service training on updated nephropathy screening protocols and effective patient engagement strategies. Building their capacity to assess risk, communicate clearly, and interpret test results will enhance the quality of type 2 diabetes mellitus care.

Support from the Ministry of Health in Uganda is essential. Clear policy directives mandating nephropathy screening for T2DM patients, accompanied by budgetary support and implementation oversight, are needed to achieve sustainable improvements. Monitoring and evaluation systems should be established to track screening coverage, identify gaps, and ensure follow-up care for patients diagnosed with early kidney damage. Data-driven feedback loops will help refine program strategies over time. Patient-centered models of care should be prioritized, focusing on respect, convenience, and responsiveness to patient preferences. Integrating feedback mechanisms into service delivery will promote greater trust and satisfaction among users. Finally, additional research is required to evaluate the impact of integrated screening models and to explore regional variations in screening barriers and enablers. This evidence will inform the design of context-sensitive interventions capable of achieving scale and equity.

Limitations

This study was not without limitations. First, the findings are based on qualitative data from a single hospital setting, which may limit the generalizability to broader populations across Uganda or other LMICs. Second, while purposive sampling ensured diverse perspectives among both patients and healthcare providers, the sample size especially among healthcare providers was relatively small, and some important viewpoints may have been missed. Furthermore, the gender composition of the healthcare provider participants (four females, one male) may have influenced the data, as gender dynamics can affect communication and the reporting of certain experiences. Thirdly, while the use of theory-informed interview guides (HBM and TPB) provided structure, it may have shaped the flow of responses, potentially constraining some participants' narratives. Lastly, due to resource constraints, transcript validation by participants (member checking) was not conducted, which could have enhanced the credibility of the findings. Despite these limitations, our study offers important insights that can inform future policy, program design, and research efforts aimed at improving nephropathy screening in diabetes mellitus populations at Mbarara Regional Referral Hospital.

Conclusions

Our qualitative study, drawing on the lived experiences of patients and healthcare providers, reveals that enhancing nephropathy screening in southwestern Uganda necessitates addressing a complex interplay of psychological, structural, and systemic factors. The data underscore a critical tension: while patients express a high perceived susceptibility to kidney disease, this fear is ultimately overwhelmed by tangible barriers such as cost, distance, and a fragmented healthcare system characterized by inconsistent guidelines, unreliable equipment, and overwhelming patient loads. This nuanced finding dictates that effective intervention must be both structurally sound and psychologically resonant. Therefore, policy and practice must be co-designed with these specific realities in mind: leveraging the strong participant-derived preference for automatic, integrated screening within routine visits; strengthening provider capacity with practical, localized training; and investing in appropriate communication to translate fear into actionable prevention. Ultimately, moving beyond a generic clinical mandate to address these deeply rooted barriers is essential for transforming current practice into a proactive, sustainable model of care that can avert end-stage kidney disease.

Abbreviations

T2DM: Type 2 Diabetes Mellitus; MRRH: Mbarara Regional Referral Hospital; DM: Diabetes Mellitus; CKD: Chronic Kidney Disease; HBM: Health Belief Model; TPB: Theory of Planned Behavior; COREQ: Consolidated Criteria for Reporting Qualitative Research; MoH: Ministry of Health; IDI: In-Depth Interview; USD: United States Dollar; UGX: Uganda Shilling.

Data Sharing Statement

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Ethical Approval and Consent to Participate

This study complies with the Declaration of Helsinki.[48] Ethics approval was obtained from the Mbarara University of Science and Technology-Research Ethics Committee (study number: MUST-2021-132). It was registered by the national research regulatory body in Uganda, the Uganda National Council of Science and Technology (study number: HS1941ES). Administrative clearance was obtained from the administration of Mbarara Regional Referral Hospital (MRRH) and the Head of department of the DM clinic. Informed written consent (in English and the local dialect) was obtained from each study participant prior to recruitment into the study. The participants' informed consent included publication of anonymized responses/direct quotes. We observed the ethical requirements related to conducting research involving human participants.

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The authors declare that they have no competing interests in this work.

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