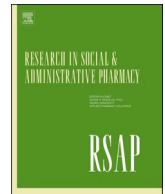


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Factors associated with continuity of care in hypertension and type 2 diabetes among forcibly displaced persons in the Bidibidi refugee settlement in Uganda: Protocol for a cross-sectional, mixed-methods study

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ABSTRACT

Background: Non-communicable diseases in humanitarian settings are generally under-researched, particularly in Africa and have been called a neglected crisis. Little is known about factors affecting access to and (dis)continuity of care for chronic conditions, such as hypertension (HTN) and type 2 diabetes among forcibly displaced persons (FDPs) in Uganda.

Aim: To investigate factors affecting access to and (dis)continuity of HTN and/or type 2 diabetes care among FDPs in the Bidibidi refugee settlement, Uganda.

Methods: A sequential explanatory mixed-methods design incorporating methodological and investigator triangulation will be conducted. The study aims to employ a community-based participatory research approach to equitably engage community members, researchers, and other stakeholders in the research process, recognising and maximising their diverse contributions. In phase 1, the quantitative arm of the study, 960 FDPs with HTN and/or type 2 diabetes will be interviewed about their sociodemographic characteristics, health status, migration experiences, social capital, and awareness, treatment, and control of these diseases. Participants will be purposively recruited from phase 1 as well as village health teams, healthcare providers, and policymakers to participate in phase 2, the qualitative study, in order to gain more insight into how mobility and social factors affect (dis)continuity of care among FDPs with HTN and/or type 2 diabetes.

Discussion: The findings from phase 1 and phase 2 of the study will be integrated through a triangulation process to provide a more holistic and comprehensive insight into the factors affecting access to and (dis)continuity for HTN and/or type 2 diabetes care among FDPs. Understanding these factors is expected to pave the way for conceptualizing health-enabling environments and strengthening health systems for FDPs with chronic conditions. It is anticipated that the study will generate baseline evidence that might be beneficial in developing and implementing HTN and diabetes care models for FDPs in the region.

1. Background

Globally, there are an estimated 89.3 million forcibly displaced persons (FDPs), including 53.2 million internally displaced persons,

27.1 million refugees, 4.6 million asylum seekers, and another 4.4 million forcibly displaced outside their country.¹ These forced displacement situations are driven by armed conflicts, persecution, disasters, and economic and social pressures. FDPs have a high risk for

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many adverse health outcomes, such as communicable diseases, chronic diseases, accidents, injuries, mental illness, and violence due to compromised access and continuity of healthcare in host nations. Uganda is the largest refugee-hosting nation in Africa with over 1.5 million refugees in 2022, with more than 2,46,000 living in the Bidibidi settlement near the South Sudan border.²

Despite acute infectious communicable diseases remaining a priority in Uganda, non-communicable diseases (NCDs) have become an increasing threat in recent years. Statistics from recent population-based national surveys in Uganda show that the prevalence of hypertension (HTN) among adults aged 18 years or older is 26.4%³ and type 2 diabetes among adults aged 18–69 years is 1.4%,⁴ and both chronic conditions are among the top 20 causes of outpatient hospital admission, mortality, and attendance in Uganda.⁵ The rising burden of NCDs in Uganda suggests chronic conditions may also be common among FDPs,⁶ highlighting the need for a greater understanding of these conditions among this population.

An approach to monitoring the effectiveness of long-term chronic disease management is to examine the continuum of care: the continuum of screening, diagnosis, treatment, and control. The approach was originally developed to evaluate HIV care⁷ but has now been expanded to NCDs, including HTN⁸ and type 2 diabetes⁹ in an attempt to shift healthcare delivery from episodic acute care to long-term, comprehensive care. Migration and mobility may interrupt care and service provision for people with HTN or type 2 diabetes and providing continuity of care to mobile populations present particular challenges.¹⁰

Mobility is a complex phenomenon, where time, space, motivation, and social factors act together to inform the final individual decision to move. For instance, the back-and-forth seasonal movements of people in Uganda or South Sudan can be attributed to security issues, rainfall patterns, and the beginning or end of academic years.¹¹ The spatial mobility of people has also increased in Uganda with people arriving from different places in South Sudan and taking different routes to Uganda.¹⁰ Likewise, push and pull factors are major motivating factors for mobility, with push factors being forces that pressure people to leave their place of origin, whereas pull factors induce people to move to a new specific place because of the availability of care or better quality of care for chronic or other diseases.¹² Moreover, food insecurity and hunger are also among main the motivations driving displacement to Uganda, particularly among the estimated 650,000 food-insecure people living along South Sudan's border with Uganda, specifically the West, Central, and Eastern Equatorial States.¹¹

On the other hand, social factors, such as social networks, may help people with HTN or type 2 diabetes stay connected with health professionals, relatives, friends and others who have the same conditions, which may improve their quality of life.¹³ Relatedly, social capital, has been shown to affect HTN detection, and better control of type 2 diabetes and cardiovascular risks.¹⁴ Mobility may affect social capital in two ways. Mobility may either contribute to a breakdown in social capital, as people are forced to leave behind their social networks, or it may strengthen social capital, as people move to locations with stronger support networks. To inform interventions targeting FDP living with HTN and/or type 2 diabetes, it is crucial to understand how social and mobility-related factors converge in different and complex ways to shape continuity of care.

A number of studies have examined various health challenges for FDPs,¹⁵ however little is known about factors affecting access to and (dis)continuity of care for HTN and/or type 2 diabetes among this population in Uganda. Furthermore, developing a knowledge foundation for innovative chronic disease care models in Uganda that consider the lived experiences of FDPs is urgently needed to understand and respond to HTN and/or type 2 diabetes burdens among FDPs. The main research question guiding the study is: 'What are the factors affecting access to and (dis)continuity of HTN and/or type 2 diabetes care among FDPs in Bidibidi refugee settlement, Uganda?'

2. Objectives

The study was designed to investigate the following objectives.

1. To determine the sociodemographic and health-related characteristics of FDPs with HTN and/or type 2 diabetes.
2. To estimate awareness, treatment, and attainment of HTN and/or type 2 diabetes control among FDPs.
3. To investigate the association between mobility-related factors and (dis)continuity of care among FDPs with HTN and/or type 2 diabetes.
4. To investigate the association between social factors and (dis)continuity of care among FDPs with HTN and/or type 2 diabetes.
5. To explore the effects and consequences of mobility on the control of HTN and/or type 2 diabetes in FDPs.
6. To explore stakeholders' and FDPs' perception of the (dis)continuity of care for HTN and/or type 2 diabetes.

3. Methods

3.1. Study design

The proposed study will apply a sequential explanatory mixed-methods design, drawing from both quantitative and qualitative methods and analysis.¹⁶ In general, explanatory designs are used when researchers need qualitative data to extend or explain their quantitative findings, or when quantitative results are needed to guide the selection of participants for qualitative studies.¹⁶ Implementing the qualitative research steps after the initial quantitative phase will help to develop an understanding of quantitative analysis outcomes, potential variations in outcomes, and ways in which context will influence outcomes. Phase 1 involves the collection and analysis of quantitative data (objectives 1,2,3 and 4) while phase 2 involves the collection and analysis of qualitative data (objectives 5 and 6). Phase 2 comprises theory-based qualitative interviews to gather more detailed information from participants. The findings from phase 1 and phase 2 of the study will be integrated, triangulated, and synthesised to provide a more holistic and comprehensive insight into the factors affecting (dis)continuity of HTN and/or type 2 diabetes care among FDPs. In addition, the study aims to employ a community-based participatory research (CBPR) approach in which community members are equitably involved in all phases of the research process, such as defining the research problem and designs, collecting data, analyzing data, and implementing results to address community concerns.¹⁷ The study will identify and involve peer researchers as part of this approach. They will represent a mix of individuals with HTN and type 2 diabetes. As a result of the mixed methods design, the reliability, credibility, trustworthiness, and validity of the research are expected to increase by corroborating evidence from a variety of sources and methodologies.

3.2. Study setting

The study will be conducted in the Bidibidi refugee settlement, which is located in the West Nile area of Uganda. The settlement is home to 246,312 residents and 42,783 households, and it is the second-largest refugee settlement in the world.¹⁸ There are five administrative zones in the settlement, 75 villages, and 15 Health Facilities (HFs). Zone 1 has three HFs, zone 2 has three HFs, Zone 3 has three HFs, Zone 4 has four HFs, and Zone 5 has only two HFs (Fig. 1). According to the latest available statistics, approximately 25,000 people aged 36 and over are currently living in the settlement.¹⁸

3.3. Study population

Study participants will be selected from all five zones in Bidibidi refugee settlement. The current population of the FDPs by zone is shown

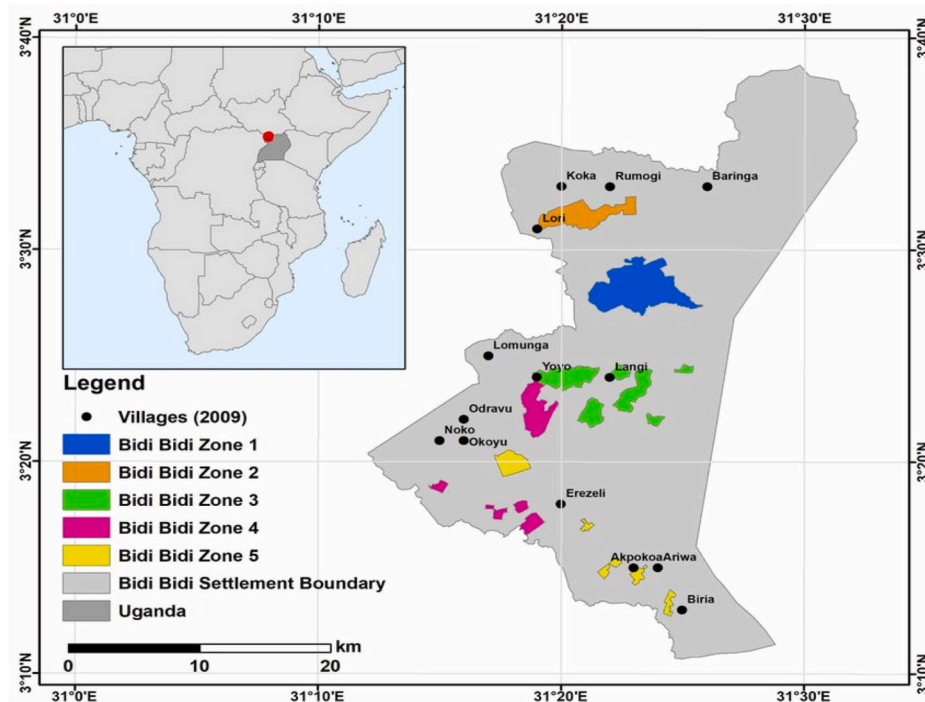


Fig. 1. Maps of Africa and Uganda showing the location of the Bidibidi refugee settlement and the 5 zones.²

in Table 1. Zone 3 has the highest population with 58,524 people followed by zone 2 with 54,162, zone 5 has 52,336 and zone 1 with 47,461 people. Zone 4 has the smallest population with 33,811 refugees (Table 1).

3.4. Inclusion and exclusion criteria

To be included in the study, participants must be: a) South Sudanese who are refugees, asylum seekers, or undocumented migrants in Uganda; b) 40 years old or above¹⁹; c) have HTN and/or type 2 diabetes; d) have a valid respondent-driven sampling (RDS) coupon from the researcher (the coupon will include key information such as location, expiration date, contact information and serial numbers to track recruitment information); and e) able and willing to provide written informed consent. Individuals who are unwilling or incapable of providing written informed consent will be excluded from the study. Refugees are defined as people who fled South Sudan and cannot return due to fear of persecution and have been given refugee status; asylum seekers are South Sudanese who have left their home countries as political refugees and made an application for asylum in Uganda, but their application status has not yet been finalized; and undocumented migrants are defined as those residing in Uganda without the legal right to do so.¹ Participants are classified as having HTN if their average systolic blood pressure is ≥ 140 mm Hg and/or their average diastolic blood pressure is ≥ 90 mm Hg, and/or if they have self-reported previous diagnosis of HTN by a healthcare provider, and/or if they reported being on regular anti-hypertensive therapy.²⁰ Participants are considered to

have type 2 diabetes if they had previously been diagnosed by a physician and/or will be on antidiabetic medications and/or had fasting blood glucose ≥ 7.0 mmol/L (126 mg/dL) and/or HbA1c ≥ 48 mmol/mol (6.5%).²¹

4. Sampling and recruitment

4.1. Phase 1: Quantitative study

We will conduct context analyses between February 2023 and March 2023. The proposed study period for the quantitative analysis is from April 2023 to December 2024. Since there is no sampling frame available for individuals with HTN and/or type 2 diabetes (some with both conditions) in the study area, eligible participants will be recruited using an explorative RDS strategy. The RDS is a network sampling methodology designed for hard-to-reach populations where sampling frames are not available.²² The RDS method is based on the principle that initial members of people living with HTN and/or type 2 diabetes termed “seeds” refer other members of the same population to participate so that the sample is established by successive generations of recruitment referrals. The RDS will be implemented in five stages. First, five initial and eligible seeds who are well connected to other individuals living with HTN and/or type 2 diabetes will be invited to participate in the survey by reviewing medical records from local health centres and with the assistance of village health teams (VHTs). The VHTs are community volunteers selected from within their communities to provide health information, and primary healthcare support, and are considered the first point of contact between community members and primary healthcare centres across the country.²³ Written informed consent will be obtained from them. Second, each seed will be given a personal identification number and will be enrolled as a participant. Third, each seed will receive three RDS coupons and will be invited to refer three additional individuals living with HTN and/or type 2 diabetes in the study area. Each seed will be expected to extend up to three to six “recruitment waves” at each site. If the initial seeds are unable to recruit participants or if the enrollment has been halted because all recruitment chains have ‘dried up’ (i.e., stopped recruiting), additional seeds will be

Table 1
Bidibidi Refugee statistics by zone January 2022.¹

Sn	Zone	No of household size	Population	No of health facilities
1	Zone 1	7455	47,461	3
2	Zone 2	8455	54,162	3
3	Zone 3	11,216	58,524	3
4	Zone 4	6074	33,811	4
5	Zone 5	9583	52,336	2
	Total	42,783	246,294	15

selected based on the inclusion criteria. Finally, recruited individuals will be provided the same opportunity as seeds to recruit other individuals living with HTN and/or type 2 diabetes in the study area. Recruitment will continue until eligible participants have been sampled. The network members will return to the study site with the coupon, and if eligible, will be enrolled and asked to complete study assessments. If RDS appears to function as an effective sampling method in identifying FDPs living with HTN and type 2 diabetes, this approach will have further implications for potential use in identifying FDPs with similar types of chronic conditions which otherwise will be hard to reach in order to improve continuity of care.

To adjust for the complexity of RDS, the sample size was computed using the following formula: $n = DE^* Z^2 * Var(Y) / P^2$, where DE is the Kish's design effect,²⁴ Z is the value from standard normal distribution corresponding to desired confidence level, $Var(Y)$ is the variance of the variable under study and is the acceptable width of the confidence interval. To apply this formula to our case we first had to set the unknown parameters $Var(Y)$ and DE . In order to have sufficient numbers of observations for all situations, we decided to choose the highest possible variance for a dichotomous characteristic for $Var(Y)$. As the variance of a dichotomous characteristic is $Var(Y) = P(1 - P)$, with P being the proportion of "successes" for the dichotomous characteristics. The maximum variance is $0.5*(1-0.5) = 0.25$.²⁵ For the unknown parameter DE , we followed the majority of RDS samples by setting $DE \approx \widehat{DE} = 2$.²⁶ This means that we strived for a sample size two times the size of a simple random sample. Finally, we set to the common 5% level and stipulated the acceptable width of the confidence interval to be $\pm 2.5\%$, leading to $\alpha = 0.05$. For high precision, the power of 80% at α is 0.05. Using the settings just described, we initially arrived at a target sample size of 768. To account for incompleteness or loss of information, we increased the number by 20% to have a total of 960 respondents.

4.2. Phase 2: Qualitative study

The qualitative study will involve the four participants groups, including a) FDPs with HTN and/or type 2 diabetes, b) VHTs, c) primary healthcare providers (primary care physicians, medical officers, primary care nurses), and d) policymakers (specialist doctors and nurses from the Ministry of Health). We aim to conduct 5 focus group discussions (FGDs) - 2 with FDPs and 3 with VHTs, 12 photovoice interviews²⁷ with FDPs, 6 in-depth interviews with primary healthcare providers, and 4 with policy makers. During the in-depth interviews, open-ended questions will be used by peers researchers to encourage participants to discuss issues pertinent to the research question. The FGD is a group interaction, which encourages participants to explore and clarify their individual perspectives and share them. Photovoice is a visual participatory method in which participants use photographs to explore their perceptions about specific topics and represent community conditions and other phenomena. We will purposively invite participants from phase 1 as well as VHT, healthcare providers, and policymakers to participate in phase 2. Due to unequal health staff-to-population ratios in the five zones, both under- and overserved will be represented to get rich, relevant, valid and generalizable information. All the interviews will be carried out until data saturation is achieved. The proposed start date for the qualitative study is January 2025, the end date for interviews is July 2025, and the qualitative analysis will be finished by December 2025.

5. Study instruments

5.1. Phase 1: Quantitative study

Blood pressure will be measured using a digital automatic blood pressure monitor (Omron HEM-7130-HP OMRON Corporation, Kyoto, Japan). Three readings for the systolic and diastolic blood pressure will be taken with 5-min rest between each reading. The mean systolic and

diastolic blood pressure from the second and third readings will be used for analysis. Participants will be classified as hypertensive if their average systolic blood pressure is ≥ 140 mm Hg and/or their average diastolic blood pressure is ≥ 90 mm Hg, or if they reported being on regular anti-hypertensive therapy.²⁰

Fasting blood glucose for the participants will be estimated using a standardized digital glucometer, using the capillary finger prick method (fasting being defined as no caloric intake for at least 8 h). Prior to the test, VHTs will remind participants to fast overnight (including giving up smoking or drinking tea in the morning). Participants will be considered to have type 2 diabetes if they had previously been diagnosed by a physician and/or will be on antidiabetic medications and/or had fasting blood glucose ≥ 7.0 mmol/L (126 mg/dL) and/or HbA1c ≥ 48 mmol/mol (6.5%). The cut-off values will be based on the 2006 World Health Organization (WHO) guidelines.²¹ A laboratory technologist will collect venous blood from patients with reported fasting blood glucose higher than 7 mmol per and use it to determine the HbA1C of each participant to confirm diabetes without repeating the fasting blood glucose level. The HbA1c will be repeated after 6 months to monitor the blood glucose levels of patients confirmed with diabetes.

Continuity of care will be the outcome variable of the study and is defined as the sequence of steps in long-term care for HTN and/or type 2 diabetes: screened, diagnosed, treated, and controlled. Participants is deemed screened if they ever have their blood pressure and blood glucose checked. Being diagnosed with HTN and/or type 2 diabetes is defined as having received a previous diagnosis by a healthcare worker or health professional. Being treated for HTN and/or type 2 diabetes is defined as having a diagnosis and self-reported current use of antihypertensive or antidiabetic drugs. Being controlled for HTN is defined as currently using antihypertensive drugs and having an average systolic blood pressure <140 mmHg and an average diastolic blood pressure <90 mmHg, while being controlled for type 2 diabetes is defined as using antidiabetic drugs and having an HbA1c < 48 mmol/mol (6.5%).

To assess the experience of HTN and diabetes-related distress in the study population, we will use the Problem Areas in Diabetes Scale (PAID)-5.²⁸ Unlike other tools such as the Diabetes Distress Scale,²⁹ the PAID-5 specifically focuses on emotional concerns related to coping with diabetes and diabetes complications. The PAID-5 has demonstrated high sensitivity and specificity and has already been used in a low-income setting.³⁰ The PAID-5 consists of 5 items pertaining to worrying about the future and the risk of complications, feeling scared or feeling depressed when thinking of diabetes, feeling diabetes is taking up too much mental and physical energy, and coping with complications. The items are measured on a 5-point Likert scale, scoring from 0 to 4 in which 0 stands for "not a problem" and 4 stands for "a serious problem." A higher score indicates more diabetes distress. A cut-off score of 8, out of a maximum of 20, will be used to indicate elevated diabetes distress. The PAID-5 will be translated into the Ugandan version and will be validated in the local context.

Quality of life will be measured by the World Health Organization Quality of Life Brief Version Questionnaire (WHOQOL-BREF).³¹ The WHOQOL-BREF has been validated cross-culturally and has been used previously in Uganda.³² The instrument consists of 26 items measuring four domains: physical health, psychological health, social relationships, and environment. Each individual item of the WHOQOL-BREF is scored from one to five on a response scale. The scores are then transformed linearly to a 0–100 scale. Higher scores indicate a better quality of life.

Information on socio-demographics (age, sex, income, marital status, educational level, occupation, country of origin, tribe), history of migration, history of the disease, self-reported severity of diseases, involvement in diagnostic and treatment options focusing on access to treatment, care and follow-up, adherence to medication, access to continuous blood pressure and blood glucose monitoring, support received from family and community, knowledge and practice of self-management of diseases, involvement of informal caregivers and their support in disease care, and mobile phone use and access, specifically

whether participants can track their health-seeking behavior with a text message will be collected.

5.2. Phase 2: Qualitative study

The development of semi-structured interview questions and discussion guides will be based on results obtained from the quantitative survey, literature review, and expert input and will be tailored to elicit responses from study participants regarding their lived experience with HTN and/or type 2 diabetes and factors affecting (dis)continuity of care for these conditions. Furthermore, participants will be asked to share their individual pictures, notes, or audiotaped materials to document their experiences. To give structure to the factors likely to influence (dis)continuity of care, we will develop a conceptual framework that is based on a mobility theory,³³ social capital theory,³⁴ and the cascade of care (CoC) framework.^{35,36} According to the mobility theory, migrants' mobilities are constructed and reconstructed by temporality (time), spatiality (space), as well as push and pull factors.³⁷ In other words, the meanings of time (how fast, how many times, when and how it stops, back and forth: rhythm, historically the migration patterns) and space (routes taken, momentum, destinations, places FDPs come from, and the places they stop along the way, health, and other services on their route) matter to their migration experiences. The pull and push theory views human mobility as associated with specific factors that either cause individuals to migrate (pull factors) or prevent them from staying in their habitual residences (push factors).³⁷ Putnam defines social capital in five critical aspects: (a) community and personal networks; (b) civic networks and participation; (c) local networks (i.e., sense of belonging); (d) reciprocity and norms of cooperation; and (e) community trust.³⁴ Similarly, the CoC framework outlines the sequential steps involved in long-term and uninterrupted care (screening, diagnosis, treatment, follow-up treatment, and control) that are needed to achieve a successful outcome.^{35,36} The CoC is a very useful tool to identify the characteristics of people lost at each stage of the care continuum, quantify losses, understand where the health system or social support structures have failed, and also identify interventions to enhance health literacy.

6. Data collection

6.1. Phase 1: Quantitative study

A structured, interviewer-administered, questionnaire survey will be conducted using android tablets installed with Open Data Kit software. In case of a breakdown of electric power or IT access, we will have paper backups or USB sticks for questionnaires. We will recruit peer researchers for data collection. The peer researcher is someone who represents the target group and is living with HTN and/or type 2 diabetes. They will receive a 3-day training on how to collect data using a structured questionnaire and blood pressure and blood glucose measurements. The training will be provided by the project coordinator at the local District Health Office and the principal investigator. Before data collection, an advisory group, consisting of community leaders, community members, a representative from local health centres and the United Nations High Commissioner for Refugees, a university researcher, and a VHT will be established. The group will participate in study context analysis, recruitment of peer researchers and VHTs, implementation of the study, and dissemination of the study results. They will meet regularly before, during, and after data collection to discuss and plan these components. The group will recruit a total of 8 peer researchers, including four males and four females from the study area. Similarly, a total of 20 VHTs (5 from each of the 5 zones i.e., 1 from each cell or village) from the study area will be recruited by the advisory group and trained on the data collection process as well as on screening HTN and type 2 diabetes. Moreover, the study participants will participate in the research. They will be invited to a recruitment centre where they will be provided with information about the study and asked if they

would consent to participate in it. Participants who provided informed consent will be eligible to take part in the study.

Following the interviews, trained peer researchers and VHTs will measure participants' blood pressure and fasting blood glucose levels following the updated WHO guideline.³⁸ Participants with the elevated blood pressure of higher than 140/90 mmHg and elevated blood glucose of higher than 7 mmol/l will be referred to the nearest health facility where they will receive further diagnosis and treatment.

Venous blood will be drawn from all those with fasting blood glucose higher than 7 mmol/l by the laboratory technologist at the health facility for measuring Glycated Haemoglobin (HbA1c). The concentration HbA1c is a surrogate measure for the average circulating glucose level over the previous 120 days (typical lifespan of a red blood cell) as well as a strong marker of complications associated with type 2 diabetes. It is also used as a clinical tool for monitoring glycaemic control in people with type 2 diabetes. The test will be done by an A1CNow + device, which has shown high agreement (over 90%) among negative tests and among participants with risk factors for type 2 diabetes (obesity, overweight, or HTN).³⁹ An HbA1c of 48 mmol/mol (6.5%) is recommended as the cut-off point for diagnosing type 2 diabetes.³⁸ After the screening, participants will be offered health education by health care workers and VHTs on self-management of HTN and/or type 2 diabetes, including how to modify their lifestyle considering the available aliment and possibilities for exercise. Participants who do not attend the recruitment centre will be interviewed and screened during the follow-up visits by VHTs.

6.2. Phase 2: Qualitative study

The study will use FGDs, IDIs, and the photovoice methods, offering the advantage of triangulating the data. A semi-structured topic guide containing prompt questions to elicit participants' perceptions on the factors affecting access to and (dis)continuity of HTN and/or type 2 diabetes care, such as 'Why did you decide to migrate from South Sudan to Uganda? What challenges did you face while travelling and getting treatment for type 2 and/or HTN from the health facility? How do you receive care and support for your type 2 diabetes and HTN? What kind of support are you receiving from your family and community? What do you think can be done to improve the continuity of care services to FDPs in chronic care?' Participants will be encouraged to freely express their own ideas, and researchers will make notes of each interview. All interviews will last for 30 min while FGDs between 30 and 45 min. The photovoice will raise participants' perspectives and concerns using an iterative and collaborative process. The method actively encourages participants to use their photographs to express the issues that are important to them or their community, then share and discuss their selected key photos with their peers, usually in small groups. Photographs and narratives are then used to mobilize research findings for policy, practice, or community changes. Data collection will be done together with peer researchers and supervised by experienced qualitative researchers. We will follow the procedure for conducting photovoice studies as outlined by Skovdal and Cornish (2015) and summarized in Fig. 2.²⁷

The steps of photovoice include a) sensitizing the community and recruiting the participants; b) introducing the participants to the project and establishing a safe social space; c) formulating a research question; d) speaking out through photography; e) introducing photography and the use of cameras; f) taking pictures; g) developing story and caption; h) analyzing stories and pictures; i) developing exhibition; and j) making dissemination material available to the target audience.

7. Quality assurance

7.1. Phase 1: Quantitative study

The questionnaire will be initially prepared in an English version,

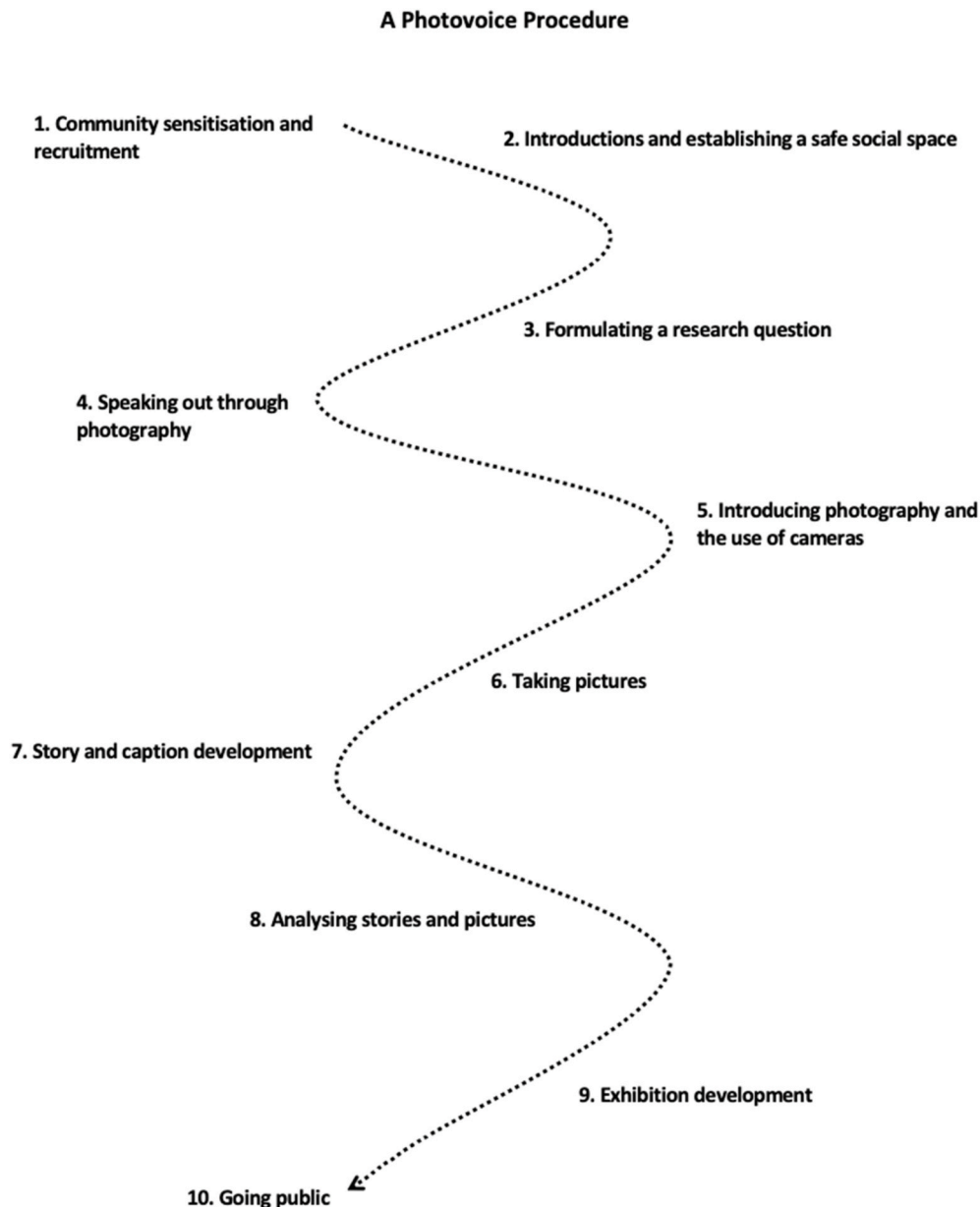


Fig. 2. Photovoice procedure.

which will later be translated into a Juba Arabic version (the language spoken by the vast majority of FDP in the study area), and then retranslated to English for analysis to ensure consistency. The peer researchers and VHTs will be trained in the data collection tools, and measurements of blood pressure and blood glucose levels using both the glucometer and the portable HbA1c machine for three days by the principal investigator and other health professionals. The instruments for the blood pressure and blood glucose apparatus will be calibrated before the actual procedure is performed. The content validity of the questionnaire will be determined by a team of specialists from the fields of public health, social sciences, medical laboratory science, epidemiology and biostatistics. The questionnaire will be pre-tested for appropriateness before major data collection in a nearby non-study area. Necessary revisions will be made to each questionnaire on the results of the pre-test. Furthermore, peer researchers will review their tablet data entries and give the tablets to the principal investigator to verify the completeness and upload data for analysis. Upon returning to the office, the data will be encrypted and uploaded over a Wifi connection to a central server. At least 10% of entered data will be double-checked by

the principal investigator for quality assurance. Only research staff will have access to computer-based data protected by passwords.

7.2. Phase 2: Qualitative study

The interview questions and guides will be initially prepared in English and translated into Juba Arabic in order to obtain the required information from the participants and will be back translated to English to check for any inconsistencies in the meaning of words. Interview questions and guides will be pre-tested before being used in the data collection. The peer researchers will also be trained in the qualitative study methods, tools, and ethics by the principal investigator. One of the researchers will randomly sample 10% of the translated transcripts and compare them with the original recordings during transcription. We will employ a range of strategies to ensure that our analysis is trustworthy and credible. Throughout the coding process, constant comparisons will be performed to ensure consistency. Transcripts will be paired for analysis by two researchers, who will check and refine the coding. Researchers will also discuss emerging findings with a wider research

group, explore various explanations, and refine coding and thematic analyses in order to enhance their reflexivity. The consolidated criteria for reporting qualitative research (COREQ) will be followed for this study.⁴⁰

8. Data analysis

8.1. Phase 1: Quantitative study

Quantitative data from the Open Data Kit tool will be exported into Microsoft Excel format and later coded using Stata statistical software version 17.0 for analysis purposes. Descriptive statistics such as frequency distributions, mean, median standard deviation, and interquartile range will be calculated to quantify the variables. Continuous variables and categorical data will be expressed as mean \pm standard deviation (SD) and percentage, respectively. A chi-square test will be conducted for comparing the proportions of categorical variables. Continuous variables will be tested for normality using histograms and described using the mean and SD if normally distributed or the median and interquartile range for skewed data. Bivariate and multivariable logistic regressions will be performed to identify factors associated with continuity of care. In the bivariate analysis, each explanatory variable will be tested for the presence of an association with the outcome variable, and using a threshold of $p < 0.20$ the significant variables will be subsequently included in the multivariate logistic regression model. Finally, a backward stepwise logistic regression will be used in the multivariate analysis to identify independent predictors of continuity of care using the adjusted odds ratio (aOR) and with 95% confidence intervals (95% CI). We will check for multicollinearity using estimates of the variance inflation factor (VIF) of the variables included in the model, and the VIF value below 10 is considered acceptable. All crude odds ratios (cORs) and adjusted odds ratios (aORs) of continuity of care with 95% confidence intervals (95% CIs) will be two-tailed and associations will be considered to be statistically significant for a $p < 0.05$ in the multivariate model.

8.2. Phase 2: Qualitative study

For qualitative data, all interviews will be digitally recorded by peer researchers. The peer researchers will transcribe the digital audio recordings verbatim in Microsoft Word and translate them into English. Both transcripts and captioned photographs will be uploaded in the NVivo 12 analysis software (QSR International Pty Ltd, Melbourne, Australia) for analysis. A thematic network analysis⁴¹ will be conducted, drawing on both inductive (i.e. data-driven) and deductive (i.e. based on pre-conceived ideas) approaches to analyse all interviews and photo-voice transcripts. The codes will be stored within nodes in the software.

9. Ethical considerations

This study will conform to the Helsinki Declaration. Ethical approval for the study will be obtained from Makerere University College of Health Sciences School of Medicine, Uganda, and Uganda National Council for Science and Technology. There will also be a letter of authorization from the Office of the Prime Minister. Written informed consent will be obtained from each participant before enrolling in the survey, in-depth interviews, and FGDs. If the participants are unable to write, then fingerprinting will be used. Participants will be assured verbally and in writing that all information provided will be kept strictly confidential and only used for the purpose of this study. As part of the photovoice, participants will be required to sign a photo release form granting us permission to use their photos. We will use pseudonyms for audio recordings, analysis, results reporting, and public exhibitions. Participants with high blood pressure and blood glucose readings will be immediately referred to the nearest health facility for further diagnosis and treatment. Furthermore, all participants will receive medical

counselling, health education in HTN and type 2 diabetes, and lifestyle advice from VHTs. Regarding data management and storage, both qualitative and quantitative data exported to the University of Copenhagen will be stored on safe drives in accordance with rules and regulations at the university and general data protection regulations. Participants will be reimbursed with an equivalent of 5 dollars to cover transport costs for a successful referral.

10. Discussion

This manuscript describes the protocol for a novel community-based participatory study to investigate factors affecting access to and (dis)continuity of care for HTN and/or type 2 diabetes among FDPs in the Bidibidi refugee settlement in Uganda. The lack of comprehensive evidence regarding the factors responsible for (dis)continuity of care for chronic conditions, especially in FDPs underlines the importance of implementing this study protocol. It is expected that the study will generate baseline evidence that might be beneficial in developing and implementing HTN and diabetes care models for FDPs. Understanding various factors is expected to pave the way for conceptualizing health-enabling environments and strengthening health systems for FDPs with chronic conditions. It is anticipated that the study will generate baseline evidence that might be beneficial in developing and implementing diabetes and HTN care models for FDPs in the region. Using the sequential explanatory mixed-methods design will help to strengthen the validity of our findings. Additionally, combining quantitative data with qualitative data will provide a better understanding of the research problem than either form of data alone.⁴² The findings from phase 1 and phase 2 of the study will be integrated through a triangulation process to provide a more holistic and comprehensive insight into the factors affecting access to and (dis)continuity for HTN and/or type 2 diabetes care among FDPs. Furthermore, the use of the CBPR approach will help to improve research processes, enhance research experience for both community members and researchers, increase sustainability, increase the efficiency of public health practice, and improve research outcomes.⁴³ It is also expected to directly benefit the people studied by actively involving them in the co-production of knowledge, including research design, data collection, reporting, and promoting the use of research results. This will also lead to an increased understanding of the social and economic status of individuals and the affected families; build trust between researchers and communities and help bridge culture gaps and improve the research process by making the research method more user-friendly and culturally appropriate.⁴⁴ As RDS is particularly helpful for the rapid recruitment of hard-to-reach populations that are socially connected, we anticipate that it will be an effective strategy for recruiting participants with HTN and/or type 2 diabetes in our study. While the potential for rapid recruitment of hard-to-reach populations is one of the advantages of using RDS as every participant becomes a recruiter, there is still the possibility that recruitment may be slow due to inadequate network size in the populations, resulting in unpredictable recruitment rates. Nevertheless, a new sampling strategy, measures, and scales used in this study are hoped to provide new ways of studying FDPs with HTN and/or type 2 diabetes in the region.

11. Dissemination

The results of this study will be disseminated through meetings organized by the advisory group, which will inform the participating community about the findings. Dissemination will also be done in scientific forums through academic seminars, conference presentations, and publications following appropriate discussions with the community.

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Author contributions

MS, DK, and TAD conceived the original idea behind the CONTINUITY study. BG and DR wrote the first draft of the manuscript and are the lead investigators of this study. TAD, DK, RN, EN, ICB, DWM, and MS were involved in reviewing and editing the manuscript. MS and DK were responsible for the acquisition of the financial support for the study leading to this publication. All authors have read and agreed to the published version of the manuscript.

Declaration of competing interest

The authors declare that they have no competing interests.

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