

BMJ Open Reasons for referral and referral compliance among Congolese and Burundian refugees living in Tanzania: a community-based, cross-sectional survey

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To cite: Enumah ZO, Rafiq MY, Manyama F, *et al*. Reasons for referral and referral compliance among Congolese and Burundian refugees living in Tanzania: a community-based, cross-sectional survey. *BMJ Open* 2022;**12**:e058778. doi:10.1136/bmjopen-2021-058778

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-058778>).

Received 01 November 2021
Accepted 26 April 2022



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ABSTRACT

Objectives In order to prevent overburdening of higher levels of care, national healthcare systems rely on processes of referral, including for refugee populations which number 26 million globally. The goal of this study is to use data from a population-based household survey to describe patterns of referral services among a population of Congolese and Burundian refugees living in Tanzania.

Design Cross-sectional survey using cluster randomised sampling.

Setting Nyarugusu refugee camp, Kigoma, Tanzania.

Participants 153 refugees.

Primary outcome Referral compliance.

Secondary outcomes Proportion of referrals that were surgical; proportion of referrals requiring diagnostic imaging.

Results Out of 153 individuals who had been told they needed a referral, 96 (62.7%) had gone to the referral hospital. Of the 57 who had not gone, 36 (63%) reported they were still waiting to go and had waited over a month. Of the participants who had been referred (n=96), almost half of the participants reported they were referred for a surgical problem (n=43, 45%) and the majority received radiological testing at an outside hospital (n=72, 75%). Congolese refugees more frequently had physically completed their referral compared with Burundians (Congolese: n=68, 76.4% vs Burundian: n=28, 43.8%, p<0.001). In terms of intracamp referral networks, most refugees reported being referred to the hospital or clinic by a community health worker (n=133, 86.9%).

Conclusion To our knowledge, this is the first community-based study on patterns of referral healthcare among refugees in Tanzania and sub-Saharan Africa. Our findings suggest patients were referred for surgical problems and for imaging, however not all referrals were completed in a timely fashion. Future research should attempt to build prospective referral registries that allow for better tracking of patients and examination of waiting times.

INTRODUCTION

Referral healthcare is a key component of any high functioning healthcare system. WHO has outlined a number of key processes and

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Cross-sectional survey with most records obtained from cluster randomised sampling.
- ⇒ Active surveillance methodology to obtain estimates and patterns of referral healthcare rather than relying on passive surveillance using hospital records.
- ⇒ Potential bias that completion of survey may have led some respondents to believe they would get a referral for a medical or surgical problem.
- ⇒ Potential for recall bias.

definitions as it relates to referral, which is defined

as a process in which a health worker at a one level of the health system, having insufficient resources (drugs, equipment, skills) to manage a clinical condition, seeks the assistance of a better or differently resourced facility at the same or higher level to assist in, or take over the management of, the client's case.¹

In order to prevent overburdening of higher levels of care and appropriate utilisation of lower level centres, national healthcare systems rely on processes of referral.^{2–5} More specifically, surgical referrals often require advanced radiographic imaging (eg, CT scans, echocardiography) that are not available at lower level primary healthcare facilities. In addition to imaging needed for diagnosis, many surgical conditions also require referral because they must be managed by specialist surgeons at the district, regional or national level.⁶

Recent research has highlighted a number of challenges in executing referral in low-income and middle-income countries including a lack of protocols, poor adherence

to protocols and other communication delays and issues.⁵⁷ Referral healthcare is a critical part of a functioning health system. Some countries have developed national health planning programmes and protocols, such as the recent adoption of the National Surgical Obstetric and Anaesthesia Plans to assist in strengthening health infrastructure. A number of these factors may relate to referral, but national health planning programmes do not always include refugee populations who also often must access national healthcare services in their countries of asylum, including in Tanzania.⁸

Globally, there are approximately 26 million refugees, and Tanzania has hosted refugees for over six decades with a current population of close to 300 000.^{9,10} A significant body of literature focuses on refugee health.^{11–15} But, a smaller body of literature focuses on access to health services with regard to referral healthcare.^{16,17} In 2009, the United Nations High Commissioner for Refugees (UNHCR) published guidance on referral healthcare for refugees that offers guidelines primarily for providers and humanitarians on how and when to refer patients.¹⁸ Similarly, there are guidelines to guide referral healthcare for refugees in northwestern Tanzania.¹⁹ Studies that address referral often focus on patients that present to hospitals using passive surveillance methods.^{4,6} To our knowledge, there has never been a community-based surveillance study on utilisation of referral among refugees in any sub-Saharan African country, including Tanzania. The goal of this study is to use data from a population-based household survey to describe patterns of referral services among a population of Congolese and Burundian refugees living in Tanzania.

METHODS

Study setting and overview of referral healthcare for refugees

Nyarugusu refugee camp is home to approximately 130 000 refugees and is the largest refugee camp in Tanzania.²⁰ Refugees are primarily from the Democratic Republic of the Congo (DRC) and Burundi, with a major influx of Burundian refugees coming in 2015. Recently, repatriation efforts have reduced the number to the current population by about 20 000 persons. Nyarugusu refugee camp is considered a protracted refugee camp, as it was first created in 1996.²¹ The healthcare services are run primarily by a humanitarian organisation and are free to all refugees and Tanzanians. The total catchment population (including Tanzanian citizens served by the health centre) is approximately 200 000 people.

When medically or clinically necessary, refugees in Tanzania are referred to higher level hospitals in the Tanzania healthcare system (eg, district, regional, zonal or national hospitals) in accordance with global and local guidance and standard operating procedures. Camp-level physicians may write a referral for a refugee, and the referral must be approved by the Medical Referral Committee (MRC). Finally, a permit must be issued by the Ministry of Home Affairs (MHA). Refugees are not

legally permitted to leave the camp without a permit. The MRC meets approximately monthly and reviews and approves cases for referral. The process may take weeks to months for a refugee's referral case to be presented and approved and for the patient to physically be transferred to a higher-level care facility.

Data collection

This project was part of a larger study on the surgical burden of disease among refugees in western Tanzania, where 3944 unique records were collected of which 153 reported they had been told they needed a referral and were available for analysis for this study.²² The parent study used cluster randomised design. Nyarugusu refugee camp is divided into 14 administrative zones which are further divided into villages, clusters and households. Out of the identified 1472 clusters in the refugee camp, 132 were randomly selected in two stages. All households in a cluster were pursued for sampling and two members of each household were randomly selected to complete the survey. Additional records that we included were from clusters not originally in the random sample were also included for the sake of completion. Finally, additional information on sampling is noted in the parent study.²² The response rate of the parent study was 99% (3574/3610).

The data come from an adapted version of the Surgeons Overseas Assessment of Surgical Needs (SOSAS) tool.²³ The SOSAS tool has been validated and used in many other low-income and middle-income countries to date including in one refugee population in the Middle East.²⁴ We adapted this tool to ask additional questions focused on referral healthcare. The data reported here are part of a larger project examining burden of surgical disease among refugees of which referral is a major part. A high functioning surgical healthcare system requires a well-functioning referral system. Since questions on referral were not a focus of the original SOSAS survey, we sought to elicit information reasons for referral and fill a gap in the literature on general referral outcomes for refugees. The adapted survey was administered in Kiswahili language. Data were collected in an offline fashion with mobile tablets using REDCap Mobile, screened for quality and subsequently uploaded daily to the secure Johns Hopkins University REDCap data server. Data were collected by trained refugee community healthcare workers who are well known and respected throughout the different zones of the camp. The language of the survey was Kiswahili (see online supplemental files 1 and 2 for Kiswahili version and English translations, respectively). Upon final deployment of the Kiswahili version, minor changes were made for translation and clarity.

Data analysis

We used Stata V.16 (StataCorp, College Station, Texas, USA). Descriptive analysis was performed. Continuous variables were reported as means with SD and categorical variables were presented as total number and relevant

percentages. T-tests were used to compare continuous variables and χ^2 tests were used to compare categorical variables between the two populations (Congolese and Burundian refugees). A p value of <0.05 and a 95% CI were used for statistical significance. Missing data were also excluded from individual proportion calculations for categorical variables, but missing data were relatively minimal.

Patient and public involvement

We did not involve patients or the public directly in the study design, execution or analysis apart from the dual roles that study team members may also have played as members of their respective communities.

RESULTS

A total of 153 participants were included for analysis. The mean age (SD) of the study population was 34.2 (20.0) years. The majority of participants were female (n=97, 63.4%). Education level was heterogenous: no formal education (n=51, 33.6%), primary school (n=48, 31.6%), secondary school (n=49, 32.2%) and higher education (n=4, 2.6%). Most participants were unemployed (n=79, 51.6%), with farmer being the most common occupation thereafter (n=27, 17.6%). Almost half of the participants were married (n=70, 45.8%) and approximately one-fourth were unmarried (n=39, 25.5%). The majority of participants were Christian (n=140, 91.5%) and literate (n=95, 62.1%). There were no significant differences in demographic factors between Congolese and Burundian refugees with the exception of education, where Congolese refugees more frequently had obtained secondary school education compared with Burundians (Congolese: n=37, 41.6% vs Burundian: n=12, 19.0%) with respect to all other education levels (p<0.001) (table 1).

Out of 153 individuals who had been told they needed a referral, 96 (62.7%) had actually gone to the referral hospital and 57 (37.3%) had not gone. Of the 57 who had not gone, 36 (63%) reported they were still waiting to go. All 36 reported they had been waiting for over a month (data not shown). Most refugees reported being given a referral slip when being referred (n=68, 71%). Almost half of the participants reported they were referred for a surgical problem (n=43, 45%) and the majority received radiological testing at an outside hospital (n=72, 75%). Approximately one-in-three were referred for an urgent condition (n=33, 34%). More than half had waited over a month to be referred (n=56, 59%), 27 (28% of total) of whom had been waiting >3 months. The most common duration of treatment at the outside hospital was 1–3 days (n=35, 37%) with 1–2 weeks being the second most common duration (n=20, 21%). Less than half reported getting better after the referral (n=46, 48%) and the majority reported they did not get better (n=50, 52%) with most refugees reporting the problem was still ongoing (n=73, 74%).

There were few significant differences between the Congolese and Burundian refugees regarding referral patterns and outcomes. Congolese refugees more frequently had physically completed their referral compared with Burundians (Congolese: n=68, 76.4% vs Burundian: n=28, 43.8%, p<0.001). Globally, Burundian refugees had shorter length of stay at the outside hospital and were more likely to have gotten better after the referral (table 2). Congolese refugees were more frequently referred for a surgical problem (n=35, 52%) than Burundian refugees (n=8, 29%), and were more frequently referred for an urgent condition (Congolese: n=28, 41% vs Burundian: n=5, 18%), but neither were statistically significant, (p>0.05) (table 2).

Intracamp referral

In terms of intracamp referral networks, most refugees reported being referred to the hospital or clinic by a community health worker (n=133, 86.9%). Only two participants (1.3%) reported being referred to a traditional healer by a community health worker. Several participants (n=17, 11.3%) reported being referred from a traditional healer to the clinic or hospital. A minority of participants reported being referred from the hospital to a traditional healer (n=6, 3.9%). The only significant difference between Congolese and Burundian refugees was with regard to being referred from a traditional healer to the hospital, where more Congolese refugees (n=14, 16.1%) were referred than Burundian refugees (n=3, 4.7%, p=0.028) (table 3).

DISCUSSION

To our knowledge, this is the first community-based study on patterns of referral healthcare among refugees in Tanzania and sub-Saharan Africa. Strengths of this study include use of a household-based survey and a high response rate in the parent study. While in most cases this would not be an efficient design to target those who are referred for care, we used an existing dataset from a cross-sectional study to obtain community-based estimates of referral among refugees. This allowed us to capture those patients in the community setting who may not repeatedly present or ever present to the hospital setting, where other studies of referral often based their findings on hospital-based populations through passive surveillance.^{4 5 25} Similarly, our population was representative of the population in Nyarugusu refugee camp itself. Our results suggest a few key themes on referral patterns for refugees in Tanzania.

First, a referral rate of 3.9% (153 referrals made out of total 3944 records from the parent study), is likely an underestimate of the true referral rate in the camp for patients who present to the hospital. Our estimate using cluster random sampling is based on household surveys among people who may not be sick or have ever been sick, but it already is slightly higher than other referral rates documented in similar, but hospital-based contexts,

Table 1 Demographic profile of study population

	DRC N=89	Burundi N=64	Total N=153	P value
Age, mean (SD)	34.9 (20.4)	33.3 (19.7)	34.2 (20.0)	0.63
Age category (years)				0.67
Under 18	17 (19.1%)	15 (23.4%)	32 (20.9%)	
18–29	22 (24.7%)	12 (18.8%)	34 (22.2%)	
30–44	23 (25.8%)	19 (29.7%)	42 (27.5%)	
45–59	12 (13.5%)	11 (17.2%)	23 (15.0%)	
60 or older	15 (16.9%)	7 (10.9%)	22 (14.4%)	
Sex				0.59
Male	31 (34.8%)	25 (39.1%)	56 (36.6%)	
Female	58 (65.2%)	39 (60.9%)	97 (63.4%)	
Education				0.004
None	31 (34.8%)	20 (31.7%)	51 (33.6%)	
Primary school	19 (21.3%)	29 (46.0%)	48 (31.6%)	
Secondary school	37 (41.6%)	12 (19.0%)	49 (32.2%)	
Higher education (eg, college degree)	2 (2.2%)	2 (3.2%)	4 (2.6%)	
Occupation				0.20
Unemployed	50 (56.2%)	29 (45.3%)	79 (51.6%)	
Farmer	11 (12.4%)	16 (25.0%)	27 (17.6%)	
Small business	4 (4.5%)	2 (3.1%)	6 (3.9%)	
Self-employed	7 (7.9%)	3 (4.7%)	10 (6.5%)	
Mother of the home	8 (9.0%)	3 (4.7%)	11 (7.2%)	
Other	9 (10.1%)	11 (17.2%)	20 (13.1%)	
Marital status				0.64
Married	42 (47.2%)	28 (43.8%)	70 (45.8%)	
Unmarried	24 (27.0%)	15 (23.4%)	39 (25.5%)	
Divorced	4 (4.5%)	6 (9.4%)	10 (6.5%)	
Other	19 (21.3%)	15 (23.4%)	34 (22.2%)	
Religion				0.93
Christian	82 (92.1%)	58 (90.6%)	140 (91.5%)	
Muslim	5 (5.6%)	4 (6.3%)	9 (5.9%)	
Other	2 (2.2%)	2 (3.1%)	4 (2.6%)	
Literacy				0.93
No	34 (38.2%)	24 (37.5%)	58 (37.9%)	
Yes	55 (61.8%)	40 (62.5%)	95 (62.1%)	

DRC, Democratic Republic of the Congo.

including in Tanzania, using passive surveillance.^{6 26} Understanding outward referral rates is important because too high a referral rate could be indicative of overburdening of higher level health centres.^{4 5} Too low a referral rate could imply overuse of local health services or poor or complex processes at the level of the health system to support an adequate referral system.¹⁸

Second, our results confirm that of other findings that surgical problems and need for specialised equipment are common reasons for referral.^{4 27} In our study, a majority

of patients reported they underwent radiological testing at the referral centre. Nyarugusu refugee camp has only ultrasound as an imaging modality, so many patients are referred to higher levels of care for basic radiography. Not all individuals who are given a referral complete it, and our findings of approximately 63% completion rate are in line with what has been seen elsewhere in this literature. Despite approximately one-third of patients reporting their condition was urgent, 70% took longer than 3 days to be referred and up to 30% waited at least

Table 2 History and outcomes of referral

	DRC N=89	Burundi N=64	Total N=153	P value
Have you been told you need a referral and actually gone to another hospital?				<0.001
Yes	68 (76.4%)	28 (43.8%)	96 (62.7%)	
No	21 (23.6%)	36 (56.3%)	57 (37.3%)	
Are you still waiting to be sent to another hospital?				0.47
Yes	12 (57%)	24 (67%)	36 (63%)	
No	9 (43%)	12 (33%)	21 (37%)	
Have you been told you needed a referral but decided not to go?				0.83
Yes	5 (5.6%)	3 (4.8%)	8 (5.3%)	
No	84 (94.4%)	59 (95.2%)	143 (94.7%)	
If you did decide not to go, what was the reason?				0.45
Fear	3 (60%)	1 (33%)	4 (50%)	
Lengthy process	0 (0%)	1 (33%)	1 (13%)	
Too sick to travel	1 (20%)	0 (0%)	1 (13%)	
No transportation	1 (20%)	1 (33%)	2 (25%)	
Were you given a referral slip?				0.72
Yes	47 (69%)	21 (75%)	68 (71%)	
No	20 (29%)	7 (25%)	27 (28%)	
I do not know	1 (1%)	0 (0%)	1 (1%)	
Were you referred for a surgical problem?				0.075
Yes	35 (52%)	8 (29%)	43 (45%)	
No	31 (46%)	20 (71%)	51 (54%)	
I do not know	1 (1%)	0 (0%)	1 (1%)	
Did you have radiological testing (eg, X-ray, CT) performed at the outside hospital?				0.12
Yes	48 (71%)	24 (86%)	72 (75%)	
No	20 (29%)	4 (14%)	24 (25%)	
Were you referred for an urgent condition?				0.084
Yes	28 (41%)	5 (18%)	33 (34%)	
No	39 (57%)	22 (79%)	61 (64%)	
I do not know	1 (1%)	1 (4%)	2 (2%)	
How long did you wait to be referred (ie, to be sent to another hospital)?				0.57
<1 day	3 (4%)	1 (4%)	4 (4%)	
1–3 days	6 (9%)	6 (22%)	12 (13%)	
4–6 days	4 (6%)	0 (0%)	4 (4%)	
1–2 weeks	9 (13%)	4 (15%)	13 (14%)	
2–4 weeks	4 (6%)	2 (7%)	6 (6%)	
1–3 months	22 (32%)	7 (26%)	29 (31%)	
>3 months	20 (29%)	7 (26%)	27 (28%)	
How long were you treated at the outside hospital?				0.029
1–3 days	19 (28%)	16 (57%)	35 (37%)	
3–7 days	10 (15%)	5 (18%)	15 (16%)	
1–2 weeks	18 (27%)	2 (7%)	20 (21%)	
2–4 weeks	11 (16%)	1 (4%)	12 (13%)	
>1 month	9 (13%)	4 (14%)	13 (14%)	
Did you get better after being referred elsewhere?				0.012

Continued

Table 2 Continued

	DRC N=89	Burundi N=64	Total N=153	P value
Yes	27 (40%)	19 (68%)	46 (48%)	
No	41 (60%)	9 (32%)	50 (52%)	
Is the problem you were referred for ongoing?				0.42
Yes	53 (77%)	20 (69%)	73 (74%)	
No	16 (23%)	9 (31%)	25 (26%)	

DRC, Democratic Republic of the Congo.

1 month, suggesting significant delays in accessing care for this population. This is consistent with what others have found in western Tanzania that delays in referral are not uncommon.^{28 29} Our larger study of surgical burden in this refugee camp suggested approximately 28% of refugees have an ongoing or untreated surgical problem. Results from this subanalysis of patients who have required a referral suggest that up to three-fourths of all participants' problems remain ongoing. This is likely a consequence of both complex medical and surgical problems that require multiple follow-up visits and the availability of specialty care in the larger Tanzanian healthcare system. Moreover, a patient may initially be referred and only receive diagnostic testing and still require further interventions.

Extrapolating the 3.9% referral rate among refugees in Nyarugusu to the entire population, coupled with

the high number of referrals in each year, suggests that referral is very common for this population. Higher levels of care are hospitals in Tanzania's larger national health landscape—and are not refugee specific. Refugees in this context are incorporated into the national health landscape to use health services that are financed by the UNHCR and its partner institutions. Despite representing a substantial number of referrals seen regionally and numbering up to 280 000 as persons of concern in Tanzania, national health programmes often fail to incorporate or even mention refugees.^{8 10} In Tanzania, this creates a unique problem space for refugees because legally refugees are not allowed to leave the camp without a permit to seek healthcare independently. Our results suggest that some still do leave the camp to seek healthcare and realise their right to health through a process of self-referral without formal approval. The number of

Table 3 Referrals among healthcare stakeholders

	DRC N=89	Burundi N=64	Total N=153	P value
Have you ever been referred from a traditional healer to the clinic or hospital?				0.028
Yes	14 (16.1%)	3 (4.7%)	17 (11.3%)	
No	73 (83.9%)	61 (95.3%)	134 (88.7%)	
Have you ever been referred from the hospital or clinic to a traditional healer?				0.20
Yes	5 (5.6%)	1 (1.6%)	6 (3.9%)	
No	84 (94.4%)	63 (98.4%)	147 (96.1%)	
Have you ever been referred from a community health worker to go to a traditional healer?				0.81
Yes	1 (1.1%)	1 (1.6%)	2 (1.3%)	
No	88 (98.9%)	63 (98.4%)	151 (98.7%)	
Have you ever been referred from a community health worker to go to the hospital?				0.50
Yes	78 (87.6%)	55 (85.9%)	133 (86.9%)	
No	11 (12.4%)	8 (12.5%)	19 (12.4%)	
I do not know	0 (0.0%)	1 (1.6%)	1 (0.7%)	
Have you ever left the refugee camp to search for health services without a legal permit?				0.13
Yes	18 (20.2%)	7 (10.9%)	25 (16.3%)	
No	71 (79.8%)	57 (89.1%)	128 (83.7%)	

DRC, Democratic Republic of the Congo.

refugees in this cohort self-referring is lower than other averages seen in Tanzania, likely for sociopolitical reasons as documented above.

Currently, Tanzania does not have a systematic or national means to track referrals of patients. More specifically for refugees, how these referrals are tracked at outside hospitals remains complex, but tracking patient referrals and systematically assessing referral rates, time to completion of referral and other factors may provide valuable information on rate-limiting steps in the spectrum and process of referral. Caution should be taken on using a metric of referral rates in isolation, as this could have significant clinical and public health consequences that actually exacerbate health disparities for this population if clinical decisions are made simply on meeting a clinical metric.^{6 30 31} An example of the complexities of public health metrics is a recent focus on maternal mortality and the potential negative consequences of doing so.

In addition to building clinical capacity in more rural settings (eg, improving access to plain radiography), future work should build capacity to study referral in more depth (eg, building information technology infrastructure) and should focus on qualitative aspects of referral, such as patient and provider perceived barriers to referral compliance.³² Research should also attempt to build on retrospective registries of referral and pursue prospective referral registries that allow for better tracking of patients and examination of waiting times.³³ Additionally, such registries could help better document the process and outcomes of referral with a specific focus on specific barriers (eg, transportation), as many participants in our study waited over a month for a referral.³⁴ Additionally, future systems might harness mobile technology for improved communication, tracking, evaluating adherence to standard operating procedures, with the hope of expediting referrals especially for those conditions deemed urgent.

Limitations

Our study was not without limitations. While the parent study provided a large sample size of just under 4000 persons, those who reported a history of referral was relatively small. Nevertheless, this did allow us to report on population-based patterns of referral, rather than simply relying on hospital-based records which may introduce bias. Second, we used community health educators who based on our study results do have a strong history of referring patients to the biomedical health services in the camp. Our findings should be understood in a potential bias that may be present if there was an assumption that by answering the survey questions, a referral for a health condition may be given or expedited. Recall bias was also a possibility given the study design.

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Funding This Project was supported by Association for Academic Surgery Global Surgery Research Fellowship.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval The study was approved by the Johns Hopkins Medicine Institutional Review Board (IRB00258009). Research clearance was also obtained from the Tanzanian Commission on Science and Technology (2020-391-NA-2011-143). A permit to enter the refugee camp was granted by the Tanzanian Ministry of Home Affairs. Consent for participants was obtained orally by the participant if they were 18 years of age or older. For individuals younger than 18, assent was obtained orally by a parent or adult household member.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. Data are available on reasonable request to the corresponding author.

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