

ARTICLE OPEN



Gender bias within a diabetic retinopathy screening programme in Tanzania

Charles R. Cleland^{1,2,6 ⋈}, Cristovao Matsinhe^{3,6 ⋈}, William U. Makupa^{4 ⋈} and Heiko Philippin^{2,5 ⋈}

© The Author(s) 2022, corrected publication 2022

BACKGROUND: The Kilimanjaro Diabetic Programme has been running since 2010 and screens persons with diabetes for diabetic retinopathy (DR). It was noted that women were less likely to attend follow-up appointments compared to men. The aim of this study was to explore gender biases amongst persons registered with the screening programme.

METHODS: A prospective mixed-methods study was carried out using a questionnaire of closed-ended questions and a semistructured interview guide.

RESULTS: Of the 300 participants included in the quantitative component of the study, 193 (64.3%) were female and 107 (35.7%) were male. Females were significantly less educated (p < 0.001) and self-reported as less likely to attend the tertiary hospital if referred (p = 0.022). Of the married participants, on multivariate analysis, men were significantly more likely to make both financial decisions in the household (p = 0.001) and to decide if, and when, family members should attend hospital compared to women (p = 0.0048), independent of age, education level and whether they were from an urban or rural area. Qualitative analysis of the 33 interviews revealed a good understanding of the threat to vision from DR, but limited appreciation of disease chronicity. A common theme was that men are regarded as the head of the household and therefore make the financial decisions; this was especially true in less educated families.

CONCLUSION: As screening and treatment facilities for DR are developed in SSA, it is important that strategies are employed to reduce the burden of blindness and visual impairment from the under-utilisation of diabetic eye care services by women.

Eye (2022) 36:33-39; https://doi.org/10.1038/s41433-022-02004-7

INTRODUCTION

Diabetes in sub-Saharan Africa (SSA) is predicted to more than double by 2045, which is the highest increase worldwide [1]. Diabetic retinopathy is the commonest cause of blindness in people of working age, which has compounded consequences on the individual, family and wider society [2].

Typically, screening for diabetic retinopathy (DR) is performed annually and patients who need further management or an intervention are referred to the respective eye care centre. However, there are often limited screening and treatment programmes for DR particularly in SSA. As diabetes and its sequelae become more prevalent in SSA it is important these are developed.

Globally, 56% of the blind are female [3]. There are several reasons for this, not least that women live longer than men. Furthermore some blinding conditions are more likely to affect women than men, for example, trachoma and cataract [4, 5]. However, another key factor is that women do not access eye care services as often as men [6].

The Kilimanjaro Diabetic Programme (KDP) has been running since 2010 and screens eyes of persons with diabetes across the Kilimanjaro region of northern Tanzania in diabetic clinics.

Of concern, only 42% of patients referred to the tertiary eye hospital (Kilimanjaro Christian Medical Centre) for treatment after screening attended [7]. It was noted that women were significantly less likely to attend a follow-up appointment at the tertiary eye hospital when referred. The aim of this study was to explore gender biases amongst persons registered with the KDP to help better understand why women access diabetic eye care services less than men.

METHODS

This prospective study was carried out between September 2014 and February 2015. All patients registered with the Kilimanjaro Diabetic Programme (KDP) were considered eligible.

A questionnaire of closed questions and a separate semi-structured qualitative interview guide (Appendix 1) were developed by a team of eye care professionals involved in screening and management of patients with diabetes. The questionnaire and guide were piloted with 10 patients prior to the start of the study to ensure adequate understanding.

Quantitative component

307 patients were selected from the KDP database through random number generation to take part in the study.

¹Moorfields Eye Hospital, London, UK. ²International Centre for Eye Health, London School of Hygiene & Tropical Medicine, London, UK. ³Eye Department, Provincial Hospital of Pemba, Pemba, Mozambique. ⁴Department of Ophthalmology, Kilimanjaro Christian Medical Centre, Moshi, Tanzania. ⁵Eye Centre, Medical Centre, Faculty of Medicine, University of Freiburg, Freiburg, Germany. ⁶These authors contributed equally: Charles R. Cleland, Cristovao Matsinhe. [⊠]email: Charles.Cleland@lshtm.ac.uk; cristovaomatsinhe@gmail.com; makupauw@yahoo.com; Heiko.Philippin@lshtm.ac.uk

Once the participants were identified, they were consented for participation in the study with an explanation of what this would involve. The questionnaire was then administered in Kiswahili, by a native speaker.

During the interviews, data were entered on paper forms and later entered into Microsoft Access (2007). STATA version 13 was used for statistical analysis.

Qualitative component

A total of 33 participants, selected through random number generation, underwent semi-structured qualitative face-to-face interviews from 7 diabetic clinics in the Kilimanjaro region. No participant took part in both the qualitative and quantitative components.

The interviews were conducted in Kiswahili and were recorded, after consent from the participants. They were later transcribed into Microsoft Word (2007) and translated into English by a bilingual speaker. NVIVO version 12 was used for data management.

Ethics approval

The study was approved by the Kilimanjaro Christian Medical College University ethics committee. Informed written consent was obtained from all participants.

RESULTS

Quantitative component

A total of 307 persons were interviewed. 7 participants were excluded due to incomplete questionnaire forms. The remaining 300 participants had a median age of 61 years (IQR 55–69 years). 193 (64.3%) were female and 107 (35.7%) were male with a median age of 58 years (IQR 53–67 years) and 65 years (IQR 56–73 years) respectively (p=0.002). The mean duration of diabetes was 6.76 years (SD 5.5 years), with no significant difference between men and women.

Table 1. Socio-demographic details of participants and self-reported compliance with referral recommendation split by gender.

Variable	Male (%)	Female (%)	
Education*			
No formal education	2 (1.89)	24 (12.4)	
Primary	42 (39.6)	122 (62.2)	
Secondary education or higher	62 (58.5)	47 (24.6)	<i>p</i> < 0.001
Will attend KCMC if referred			
Yes	102 (95.3)	168 (87.1)	
No	5 (4.7)	25 (13.0)	P = 0.022
Health Insurance*			
Yes	68 (63.6)	111 (57.8)	
No	39 (36.5)	81 (42.2)	P = 0.332
Marital Status**			
Married	97 (91.5)	132 (71.7)	
Not married	1 (0.9)	20 (10.9)	
Widowed	8 (7.6)	32 (17.4)	p = 0.024

^{*}Data available for 299 participants.

Of the included 300 participants, 252 persons (84%) had been screened for DR through the regional screening programme. Of the 252 screened persons, 75 persons (29.8%) were referred to KCMC and of the 75 persons referred 29 (38.7%) attended the referral appointment. 55.2% of men referred to the specialist eye clinic attended their follow-up appointment compared with 44.8% of women; however, this difference was not significant (p = 0.422).

Table 1 shows details of the education level, insurance status and the self-reported answer given when asked whether the participant would attend KCMC (the tertiary hospital) if referred, split by gender. Females were significantly less educated (p < 0.001) and self-reported as less likely to attend the tertiary hospital if referred. There was no significant difference in rates of health insurance between men and women.

Data were available on 290 participants concerning marital status with 10 preferring not to say. A significantly higher proportion of females were not married or widowed compared to men (Table 1).

There was a good level of understanding regarding diabetes, DR and the need for DR screening, with no significant difference between men and women. Of the 300 participants, 96% understood that it is important to attend hospital appointments for diabetes even if one is asymptomatic and, similarly, 96% knew that DR can cause blindness. 94% and 87% of participants respectively had heard of DR and understood the need for screening even if one has no visual complaints.

Sub-analysis of the married participants showed that females were less likely to make independent financial decisions compared to men (Table 2). Females were also significantly more likely to depend on their spouse when deciding if, and when, they, or family members, should attend hospital appointments compared to men (Table 2). There was no significant difference between education level and whether individuals made financial decisions. However, the more educated were more likely (p = 0.016) to decide if family members should attend hospital.

On multivariate analysis, men were significantly more likely to make both financial decisions in the household and to decide if, and when, family members should attend hospital compared to women. This was independent of age, education level and whether the participants were from an urban or rural area (Table 3).

Qualitative component

Thematic analysis was used to interpret the qualitative data. The results from the qualitative interviews are presented in two sections. Firstly, the perceived need for DR screening and themes relating to the poor follow-up rates seen within the Kilimanjaro Diabetic Programme. Secondly, the results focus on the family dynamics between husband and wife in regards financial decision making.

Perceived need for diabetic retinopathy screening

Most interviewees had a good understanding of the potential for diabetes to affect the eyes and lead to a reduction in, or loss of, vision, with no difference between men and women. This is consistent with our results from the quantitative section of the study that also showed no significant gender difference in the understanding of the threat to vision from diabetes and the need for regular DR screening.

Table 2. Intra-family and financial decision-making practices split by gender amongst married participants (n = 229).

Variable	Male (%)	Female (%)	
Participant makes financial decisions in household over spouse	45 (46.4)	28 (21.1)	<i>p</i> < 0.001
Participant makes decision if family members attends hospital over spouse	56 (57.7)	52 (39.4)	p = 0.006

SPRINGER NATURE Eye (2022) 36:33 – 39

^{**}Data available for 290 participants.

Table 3. Univariate and multivariate logistic regression analysis assessing the association between financial decision making and intra-family decision making and socio-demographic factors amongst married participants (n = 229).

	Univariate analysis			Multivariate analysis		
Variable	OR	95% CI	p value	OR	95% CI	p value
Participant makes financial	decisions in hou	sehold over spouse				
Male gender	1.92	1.18-3.10	0.008	3.00	1.58-5.65	0.001
Age	1.00	0.98-1.02	0.71	1.00	0.97-1.03	0.84
Education level	1.28	0.88-1.88	0.20	1.20	0.69-2.06	0.51
Urban/Rural dwelling	1.21	0.68-2.15	0.51	1.41	0.69-2.88	0.34
Participant makes decision if/when family members attend hospital over spouse						
Male gender	1.93	1.19–3.11	0.008	1.81	1.01-3.27	0.048
Age	0.98	0.96-1.00	0.13	1.00	0.97-1.02	0.64
Education level	1.69	1.15-2.47	0.01	1.60	0.97-2.63	0.07
Urban/Rural dwelling	0.73	0.35-1.49	0.38	1.19	0.61-2.34	0.62

However, despite a good level of understanding of the risk to vision from diabetes, the rates of follow-up for those referred after DR screening remain poor. The interviews identified several themes potentially explaining this, including: cost of treatment and transport to and from the hospital, fear of treatment and a cultural lack of understanding and appreciation of chronic disease.

The majority of participants interviewed (n = 30) were aware that diabetes could affect vision and that screening was important in the absence of symptoms:

 "Definitely! Because they say diabetes runs slowly to the eyes so it's important to check frequently."

When asked why a lot of patients do not comply with follow-up recommendations, financial concerns were most commonly cited:

 "...it could be due to the cost, because KCMC is very far. Noone does not want treatment Doctor. The problem is money!"

The costs incurred included not only the cost of treatment, but the cost of transport, accommodation and the loss of income through missed work, which was particularly cited as a factor for men. An escort, which is often required, doubles the cost of travel and accommodation. In addition to their transport and accommodation costs, some escorts were reported as asking for payment to accompany the patient:

 "...you must find someone to escort, get treatment pay for transport for two people and others will say pay me if you want me to escort you."

Several patients commented on the cultural relationship with disease and a limited appreciation of the chronicity of diabetes. There was, amongst some participants, a lack of understanding the concept of being "sick" without any symptoms:

 "Most Africans don't have the habit of checking our health status until we get sick."

Family dynamics with regard to financial decision making in households

Men were cited as acting as head of the household (n = 14) and making financial decisions most commonly; thereby determining access to healthcare:

 "Of course father is the final decision maker! Because he is the head of the family. And all family members depend to him!" There were some participants who stated that, even when the male household member is absent, a female household member is unable to make decisions and must wait until the man household member returns:

"...no one, even a wife can make decision in my absence. Without my permission she cannot decide!"

However, a relatively large proportion of respondents (n = 11) stated that men and women make financial decisions together. This arrangement, whereby decisions are made collectively as a couple, seemed to be more common in educated families:

 "Both mother and father. My husband understands he was a medical assistant...for those who are not educated, the husband is deciding and sometimes those not educated take money and use for alcohol."

In those participants who reported female household members making decisions, the purchase of alcohol by their husbands was cited as a reason why women made financial decisions:

 "Father if given to make decision may use in bad manner like buying alcohol. But mother use for the benefit of the family like buying food and important things needed at home."

DISCUSSION

Men, in many areas of low- and middle-income countries, are twice as likely as women to access eye care services [8]. This study is the first to report and investigate reasons for gender differences in compliance with follow-up recommendations after screening for diabetic retinopathy (DR) in Africa.

World Health Organization (WHO) recognises regular and reliable follow-up of DR patients and timely treatment as key components in the effective management of the condition [9]. This is a particular challenge in low-income countries, such as Tanzania. There was a good level of understanding regarding the potential for sight loss from DR and on the importance of screening, yet follow-up remains poor. Financial challenges, fear of treatment and a lack of understanding of disease chronicity were cited as reasons for this. Similar themes pose challenges in the management of other chronic ocular conditions in SSA, such as glaucoma [10]. The reasons for poor follow-up of persons with DR are not well studied; however, are likely to be multi-factorial and not solely a consequence of financial challenges [11].

As with other eye health conditions, data from the Kilimanjaro Diabetic Programme (KDP) demonstrates that women are significantly less likely to comply with referral recommendations post DR screening than men [7]. As the number of persons with diabetes increases substantially over the next two decades in Africa [12], an understanding of why women access tertiary eye care services less than men, in relation to DR, and measures to address this will enable more effective screening and treatment facilities to be developed; potentially reducing visual impairment and blindness. For example, it is estimated that if women were to receive cataract surgery at the same rate as men, blindness and visual impairment from cataract in low and middle income countries could be reduced by up to 11% [8].

The results from this study suggest that women are significantly less likely than men to have financial independence and women more commonly rely on their spouse to make financial decisions within the household. The is irrespective of age and education. Moreover, women are significantly less likely than men to decide if household members should attend hospital, again irrespective of age and education. This provides insight into the social and family dynamics that may explain why women are less likely than men to access eye care services.

In African societies, it is typical for financial decisions to be made by male family members; women often do not have financial independence to make decisions regarding their own healthcare [13]. As seen in the KDP, this may contribute to women's reduced engagement with eye care services. This is likely to be particularly relevant for eye care services where the disease process is not always obviously apparent, such as DR.

There are no previous data on gender discrepancies within DR screening and treatment programmes in Africa. However, there are three strategies that have been shown to improve cataract surgical coverage for women in low- and middle-income countries: the use of outreach services, educating family members and using women to reach women [14, 15].

Outreach services could, for example, include the use of portable laser equipment to enable the treatment of DR at outreach clinics. This would help both the general low rates of follow-up, as seen in the KDP, as well as increase access to DR treatment services for women.

It is important to educate whole family groups on the detrimental effects of diabetes on eye health. As diabetic eye disease is not always obviously apparent and can be advanced and remain asymptomatic, it is important that male family members understand and appreciate the importance of compliance with screening and referral. This will help empower women to engage with eye care services.

The use of female healthcare workers to engage with family groups and women has been shown to be potentially beneficial in Egypt and Pakistan [14, 15]. In Egypt, for example, female health visitors were employed to educated family groups and particularly women on eye health. The intervention significantly improved blindness and visual impairment in women and reduced the prevalence of cataract and trachomatous trichiasis in women as well as improving engagement for men [14].

It is important that interventions such as those outlined above are audited as DR screening programmes are developed; data should be split by gender when published. This will allow an understanding of the challenges faced and analysis of the effectiveness of interventions on engaging women with eye care services.

In conclusion, women represent 56% of global blindness [3]. In low-income countries, there is reduced engagement with eye care services in women compared to men. As DR screening programmes are developed in low-income countries, strategies, such as the use of outreach screening combined with treatment services and using women to educate women and family groups, should be built into screening programmes, with audit data split by gender. This could help to alleviate the growing burden of blindness and visual

impairment from DR caused by the under-utilisation of eye care services by women.

Summary

What is known about this topic

- Women make up 56% of the global blind.
- In many low- and middle-income countries men are twice as likely as women to access eye care services.
- Diabetic retinopathy is an increasingly important cause of vision loss in low- and middle-income countries; however, follow-up within existing screening services is poor, particularly for women.

What this study adds

- The study highlights cost, fear of treatment and a lack of appreciation of disease chronicity as important reasons for the low rates of follow-up for those referred after screening for diabetic retinopathy.
- The study is the first to explore why women are less likely than men to access diabetic retinopathy treatment services after screening in Africa.
- Women were noted to have less financial independence than men and were less able to make independent decisions relating to access to healthcare than men in this region of Tanzania.

REFERENCES

- 1. International Diabetes Federation. Eighth edition 2017. IDF Diabetes Atlas, 8th edition. 2017.
- Rein DB, Zhang P, Wirth KE, Lee PP, Hoerger TJ, McCall N, et al. The economic burden of major adult visual disorders in the United States. Arch Ophthalmol. 2006;124:1754–60.
- Bourne RRA, Flaxman SR, Braithwaite T, Cicinelli MV, Das A, Jonas JB, et al. Magnitude, temporal trends, and projections of the global prevalence of blindness and distance and near vision impairment: a systematic review and meta-analysis. Lancet Glob Heal. 2017;5:e888–97.
- Cromwell EA, Courtright P, King JD, Rotondo LA, Ngondi J, Emerson PM. The excess burden of trachomatous trichiasis in women: a systematic review and meta-analysis. Trans R Soc Tropical Med Hyg. 2009;103:985–92.
- Lewallen S, Courtright P. Gender and use of cataract surgical services in developing countries. Bull World Health Organ. 2002;80:300–3.
- Courtright P, Lewallen S. Improving gender equity in eye care: advocating for the needs of women. Community Eye Health J. 2007;20:68–9.
- Cleland CR, Burton MJ, Hall C, Hall A, Courtright P, Makupa WU, et al. Diabetic retinopathy in Tanzania: prevalence and risk factors at entry into a regional screening programme. Trop Med Int Heal. 2016;21:417–26.
- 8. Lewallen S, Mousa A, Bassett K, Courtright P. Cataract surgical coverage remains lower in women. Br J Ophthalmol. 2009;93:295–8.
- World Health Organisation. Vision 2020 The Right to Sight Action Plan 2006-2011.
 World Heal Organ. 2007 (February 2000):14–7.
- Gilmour-White JA, Shah P, Cross V, Makupa W, Philippin H. Glaucoma awareness and access to healthcare: Perceptions among glaucoma patients in Tanzania. Postgrad Med J. 2015;91:373–8.
- Mtuya C, Cleland CR, Philippin H, Paulo K, Njau B, Makupa WU, et al. Reasons for poor follow-up of diabetic retinopathy patients after screening in Tanzania: a cross-sectional study. BMC Ophthalmol. 2016;16:115.
- International Diabetes Federation. Idf Diabetes Atlas 2017. Diabetes Atlas, six ed. 2014:1–14.
- UNDP. Africa Human Development Report 2016 Accelerating Gender Equality and Women's Empowerment in Africa. United Nations Development Programme. 2016
- Mousa A, Arab GEEI, Rashad E. Reaching women in Egypt: a success story. Community Eye Heal J 2009;22:22–3.
- Khan NU, Khan AA, Awan HR. Women health workers: Improving eye care in Pakistan. Community Eye Health J. 2009;22:26.

ACKNOWLEDGEMENTS

We thank the members of the Kilimanjaro Diabetic Programme for their help and support in this project. The Kilimanjaro Diabetic Programme was funded by CBM Australia in collaboration with AusAID.

FUNDING

The publication costs for this article were funded by The Queen Elizabeth Diamond Jubilee Trust through the Commonwealth Eye Health Consortium. The funding body did not participate in the design of the study, data collection and analysis, interpretation of data and writing the manuscript.

AUTHOR CONTRIBUTIONS

CRC, CM, HP and WUM, conceptualised the study. CM collected the data in the field. CRC and CM performed the statistical analyses. CRC and CM drafted the manuscript. All authors read and approved the final manuscript.

COMPETING INTERESTS

The authors declare no conflict of interest.

APPENDIX 1 UNDERSTANDING GENDER IMBALANCES AT THE KILIMANJARO DIABETIC PROGRAMME IN TANZANIA

SOCIO-DEMOGRAPHIC INFORMATION		
Date of examination:// KDP number: District(wilaya):	Name (<i>Jina</i>): Year of birth(<i>mwaka wa kuzaliwa</i>): Ethnic group (<i>Kabila</i>)	
Urhan/rural	Education:	
Clinic(/kliniki): Type of diabetes: Duration of diabetes:	Occupation (kazi yako):Place of residence(mahali unapoishi):	-
Type of diabetes:	Place of residence(mahali unapoishi): Phone number	
Gender: 1. Male 2. Female	Referral to KCMC: 1. Yes 2. No	
First eye screening// Two last screenings// and	Date of referral to KCMC://	
FAMILY INFORMATION	Report to KCMC: 1. Yes 2. No Date of report to KCMC:/	
Q1	How many people are you living with? (Je, unaishi na watu wangapi?)	(in your house / in your compound)/(nyumbani kwako/kiwanjani kwako) Comments:
Q2	How far is your home from the diabetic clinic (approximately). (Kutoka nyumbani kwako mpaka kliniki ya kisukari kuna umbali kiasi gani)	Please, can you specify in Kms, transport fare and time you take. km: TSH: hours: (<i>Tafadhali elezea umbali ni Km ngapi na nauli in kiasi gani na muda unaotumia kusafiri</i>) Comments:
Q3	How far is your home from KCMC (approximately) (Kutoka nyumbani kwako mpaka KCMC kuna umbali kiasi gani)	Please, can you specify in Kms, transport fare and time you take. km: TSH: hours: (Tafadhali elezea umbali ni Km ngapi na nauli in kiasi gani na muda unaotumia kusafiri) Comments:
Q4	What is your household income per month? (kipato cha familia kwa mwezi ni shilingi ngapi?)	
Q5	How many meals, do you usually have per day? (unakula milo mingapi kwa siku?)	How many (Mili mingapi): Comments:
Q6	Do you have mobile phone?(Unayo simu ya mkononi?	1. Yes (Ndio) 2. No (Hapana)
Q7	If yes, Can your mobile phone play/stream videos? (Kama ndio simu yako unaweza kuangalia picha na video?)	1. Yes (Ndio) 2. No(Hapana)
HEALTH STATUS		
Q8	Do you have high blood pressure? (Je una presha ya kupanda?)	Yes(ndiyo) Last measurement: No(hapana) Medicine: I don't know(sijui)
Q9	Do you have any other different disease from diabetes? (unaun- gonjwa mwengine zaidi ya ugonjwa wa kisukari?)	1. Yes (ndiyo) 2. No (hapana)
Q10	If you have any other disease, please can you tell us which is? (Kama unaungonjwa mwingine, tafadhali elezea?)	
Q11	Do you have health insurance? (unahuduma ya bima ya afya?)	1. Yes (Ndiyo) 2. No (Hapana)
Q12	What is your marital status? (Hali yako ya mahusiano)?	Married (Nimeolewa) Single (Sijaolewa) Separated (Tumeachana kwa muda) Divorced (Mtalaka au tumeachana Widowed (Mjane)
Q13	If you are married where does your husband/wife live? (Kama umeolewa au umeoa)	In the same house (unaishi na mwenzi wako) In another town (e.g. work-related) (yuko mji mwingine mf. kikazi)
Q14	Who has a financial decision in your house? (ninani anamaamuzi kuhusu pesa nyumbani kwako?)	Yourself (mimi mwenyewe) Your husband/wife (mume/mke wangu) Son/daughter (kija/Binti) Other(specify)/(nyingine/tala):
Q15	Who makes a decision to go to hospital if someone is sick? (ni nani muamuzi kuhusu kutafuta huma ya afya)	Yourself (mimi mwenyewe) Your husband/wife (mume/mke wangu) Son/daughter (Kija/Binti) Other(specify)/(nyingine/tala):
KNOWLEDGE OF DIABETES IN EYE		
Q16	Is it important to attend hospital for some diseases if you feel well? For example high blood pressure or glaucoma (Ni muhimu kwenda hospitali hata kama unajisikia vizuri mfano BP na pressure ya macho?)	1. Yes (Ndio) 2. No (hapana)
Q17	ls it important to attend hospital for diabetes when you have no symptoms? (Je, ni muhimu kuuzuria hospitali kwa ajili ya kisukari hata kama huna dalili?)	1. Yes (Ndio) 2. No (Hapana)
Q18	Have you ever heard of DR? (Umewahi sikia ugoniwa wasukari unaharibu macho?)	1. Yes (Ndio) 2. No (Hapana)

Eye (2022) 36:33 – 39 SPRINGER NATURE

Table a. continued

Q19	Should you receive screening for DR if you have no visual problems? (Utakubali uchunguzi wa ugonjwa wa sukari machoni kama huna shida katika kuona?)	1. Yes (Ndio) 2. No (Hapana)
Q20	Do you know that diabetes can cause blindness?(je unajua kama kisukari kinaleta upofu)	1. Yes (ndiyo) 2. Perhaps (Labda) 3. No (hapana)
Q21	If yes, how do you know that diabetes can cause blindness? (Kama Ndiyo, je umejuaje kuwa kisukari kinaleta upofu?)	Probe: (told by physician, told by other patients, told by ophthalmologist, reading, saw other diabetic patients becoming blind) Comments:
Q22	Can DR be treated? (Je, Sukari inapoadhiri macho inatibika?)	1. Yes (Ndio) 2. No (Hapana)
Q23	Do you know of any ways to prevent blindness from diabetes? (Je	1. Yes (Ndio)
Q24	Unajua jinsi ya kuzui wa kisukari usiharibu Macho?) If yes, how can you prevent blindness from diabetes? (Kama ndio unazuiaje upofu unaosababishwa na ugonjwa wa kisukari?)	2. No (Hapana) 1. Control diabetes (kukontrol sukari) 2. Control blood pressure(Kukontrol Pressure) 3. Lose weight (kupunguza uzito) 4. Regular hospital follow-up (kuhudhuria clinic kama inavyotakiwa) 5. Other, please specify: Mengineyo;
Q25	How did you learn about diabetes, diabetic retinopathy and preventing eye problems? (Umejifunza wapi kuhusu ugonjwa wa kisukari unavoharibu macho na jinsi ya kuzui matatizo ya macho?)	1. Physician: Yes (Ndio) No(hapana) 2. KDP staff: Yes(Ndio) No (Hapana) 3. Leaflets: Yes(Ndio) No(Hapana) 4. Posters/cartoons: Yes(Ndio) No(Hapana) 5. Other diabetic patients: Yes Ndio No hapana 6. TV: Yes Ndio No Hapana 7. Radio: Yes Ndio NoHapana 8. Other: Please specify: Mengineyo
Q26	Of the above, which was the most useful way to learn about diabetes, DR and its complications? (Je kati ya hayo hapo jua ni njia gani ilikuwa rahisi kutumia kupata maelezo na matatizo ya ugonjwa wa kisukari?)	
Q27	Have you ever sought treatment other than from the modern sector? (Ulishawahi kutafuta matibabu kwingine tofauti na hospitali?)	1. Yes (Ndio) 2. No (Hapana)
Q28	If yes, mention please (Kama ndio, taja)	1. Religious prayers (Kwenye maombi) 2. Traditional healers (Tiba mbadala) 3. Herbal medicine (Mitishamba) 4. Other. If other, please specify: (kama kuna njia nyingine; taja)
ATTITUDE AND PRACTICE		
Q29	Have you ever had eye screening? If yes, when did you have your last eye screening? (Umeshawahi kupimwa macho? Kama ndiyo, ulipimwa mara ya mwisho lini?)	1. If yes, when? 2. I don't remember 3. No, never
Q30	lf you have had eye screening, why did you have? (Kama ulishapimwa macho, ni kwa nini ulipimwa?)	Probe: (told by physician, told by other patients, reading, saw other diabetic patients becoming blind) Comments:
Q31	lf you have never had eye screening, why? (Na Kama hujawahi kupimwa macho, ni kwa nini/ni kwa sababu gani?)	
Q32	Do you know how often you should have eye screening? If yes how often? (Je unajua ni kwa mara ngapi unatakiwa kupimwa macho? Kama Ndiyo, ni kwa mara ngapi?)	1. Yes (<i>Ndiyo</i>) 2. No (<i>hapana</i>) Comments:
Q33	Have you ever been at KCMC for further eye examination? (Je umeshawahi kufika KCMC kwa uchunguzi zaidi wa macho?)	1. Yes (Ndiyo) 2. No (hapana)
Q34	If you have been at KCMC, why have you been there? (Kama umeshafika KCMC, ni kwa sababu gani?)	Probe: (For regular follow-up, received a message, advised by physician, the vision dropped)
Q35	Have you ever been referred to KCMC? (Je umeshawahi kupewa rufaa ya kwenda KCMC?)	1. Yes (ndiyo) 2. No (hapana)
Q36	If yes, did you go? (Kama ndiyo, je ulikwenda?)	1. Yes (Ndiyo) 2. No (hapana)
Q37	lf you did not go, could you please tell us why? (Kama hukwenda tafadhali tueleze ni kwa nini/tafadhali tupe sababu?)	Why? (Lack of money, not feeling any problem with your eyes, Fear of treatment)
Q38	If you are referred to KCMC will go? If no why? (kama ukipewa barua ya kwenda KCMC utakwenda? Kama hapana kwa nini?)	1. Yes 2. No Comments:
EVALUATION OF SCREENING AND TREATMENT		
Q39	What kind of treatment did you receive at KCMC (Je ulipata matibabu gani KCMC?)	Laser treatment (matibabu ya mionzi) Surgery (upasuaji) Other(nyingine):
Q40	What do you think about receiving eye screening? (Je una mawazo gani juu ya kupokea huduma ya kupimwa macho?)	1. Probe: (not important, very important, don't know)
Q41	If you have received any kind of treatment, how are feeling? (kama ulishapata matibabu ya aina yoyote, unajisikiaje?)	Probe: (better, no change, worse, don't know)
EXAMINATION	· ,	
42	Weight(w) Kgs Height (h) m Abdominal circumference cm	Last Random Blood Sugar (RBG): mg/dl
	Blood Pressure mmHg	
	RE	LE

SPRINGER NATUREEye (2022) 36:33 – 39

Qualitative Interview Guide

Mobility and activities in general

How easy is it for you to go to the hospital, market, farm and anywhere you wish to go? [Probe: And if you go, by which means do you go?]

What common activities do you do on a typical day? [Probe: Do you earn your own money?]

Cultural factors

What does your culture says concerning the decision making? [Probe: financial decision if one member of the family is sick]

Diabetes in general

What do you know concerning diabetes? [Probe: What are the causes of diabetes?]

In your opinion, are there any challenges for the diabetic patient to follow with the recommendations for the control and treatment of diabetes? [diet, medications, BP control, etc]

How diabetes interfere with your daily life?

Diabetes and eye

Do you think diabetic patient should have eye examination even without any eye complain? [Probe: why?]

What do you know concerning diabetes and eye? [Probe: can diabetes cause blindness?]

Many diabetic patients do not have eye examination, what do you think could be the reasons?

There are many women attending diabetic clinic than men, what do you think are the reasons?

Emotions and experience

Is there anything you want to share with us regards the diagnosis, treatment and control of the diabetes and eye examination?

ADDITIONAL INFORMATION

Correspondence and requests for materials should be addressed to Charles R. Cleland, Cristovao Matsinhe, William U. Makupa or Heiko Philippin.

Reprints and permission information is available at http://www.nature.com/reprints

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.



Open Access This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License.

which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, and provide a link to the Creative Commons license. You do not have permission under this license to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons license, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons license and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this license, visit http://creativecommons.org/licenses/by-nc-nd/4.0/.

© The Author(s) 2022, corrected publication 2022