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Knowledge and attitudes about genetic counseling in patients at a major hospital in Addis Ababa, Ethiopia

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Abstract

Previous work at St. Paul's Hospital Millennium Medical College (SPHMMC) in Addis Ababa, Ethiopia, demonstrated a need for genetic counseling (GC) services, with 4% of pediatric, neonatal intensive care, and prenatal patients identified as having indications for genetic evaluation (Quinonez et al, 2019). The aim of this study was to investigate SPHMMC patients' familiarity with, knowledge of, and attitudes toward GC services. Surveys were adapted from previous work in North America populations (Riesgraf et al, 2015 and Gemmell et al, 2017) and administered to 102 patients, and results were compared to North American populations using Student's *t* test. 30% of respondents reported at least some familiarity with GC, primarily via the media or healthcare providers. Patients had generally positive attitudes toward GC, reporting they would trust information provided by a genetic counselor and that GC is in line with their values. Knowledge of GC showed similar trends overall when compared to results from North American populations. Our work indicates limited exposure to GC in this population, but generally positive feelings toward GC. Patients' attitudes toward GC were comparable to rural North American populations surveyed using the same tool on most items; however, cultural differences including views on abortions and directiveness of healthcare providers could account for discrepancies and are important considerations when implementing genetic services globally.

KEYWORDS

attitudes, beliefs, genetic counseling, global health, noncommunicable diseases

1 | INTRODUCTION

Low- and middle-income countries (LMICs) are experiencing a rapidly changing landscape of disease with a decrease in morbidity and mortality caused by communicable diseases, nutritional deficiencies, and maternal and neonatal delivery complications (Murray & Lopez, 2013). With the improved care of these conditions, there has been an increase in the impact of noncommunicable diseases (NCDs) with congenital anomalies and genetic diseases, the most common NCDs affecting pediatric-aged populations, now the fifth leading cause of morbidity and mortality in children under 5 and in older children and adolescents (Global Burden of Disease Child & Adolescent Health Collaboration, 2017; GBD 2015 Child Mortality Collaborators, 2016016). Congenital anomalies and genetic conditions affect 7.9 million children worldwide, and it is estimated that 70% of deaths related to NCDs occur in LMICs, with 94% of all births affected with congenital anomalies occurring in LMICs (GBD 2015 Child Mortality Collaborators, 2016016; Christianson & Modell, 2004; Hunter & Reddy, 2013). The United States and other high-income countries previously experienced a similar decrease in communicable conditions with a resulting increase in relative impact

of NCDs in the 1950s and 1960s, causing public health initiatives to shift their efforts to the identification, diagnosis, and treatment of NCDs (Christianson & Modell, 2004). Increased focus on congenital anomalies and genetic disease resulted in well-established medical genetics services such as prenatal screening, genetic counseling, carrier detection, and newborn screening which are now in place in many high-income countries.

As the relative impact of NCDs increases, equipping LMICs with the necessary medical genetics capacity to diagnosis, treat, and prevent NCDs will become increasingly important (Christianson & Modell, 2004; Kingsmore et al., 2012; Tekola-Ayele & Rotimi, 2015). Genetic counseling, the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease, has been shown to be an effective method of reducing a country's incidence of congenital anomalies and genetic disease (Christianson & Modell, 2004). Genetic counseling officially became a profession in the United States in 1969 and has expanded internationally over the past 30 years (Abacan et al., 2019; Heimler, 1997). As of 2018, it was estimated there were almost 7,000 genetic counselors in 28 countries where the profession was established or developing, with more than 60% of these individuals practicing in North America (Abacan et al., 2019). A review of genetic counseling services worldwide found some form of medical genetics services are available in many countries in Africa; however, South Africa is the only country with formal genetic counseling training programs and services (Abacan et al., 2019). In sub-Saharan Africa, targeted genetic counseling has been successfully utilized in Cameroon and Kenya to address prenatally diagnosed congenital anomalies and retinoblastoma, respectively (He et al., 2014; Wonkam et al., 2011).

While effective in these settings, genetic counseling and other novel interventions require careful consideration prior to their introduction due to varying practice settings with different cultural, religious, ethical, logistical, and legal factors (World Health Organization, 2011). In Ethiopia specifically, previous work has identified differences between Ethiopian and North America in healthcare settings. Physician/provider training in Ethiopia includes more hospital-based training in high-volume hospitals rather than outpatient settings due to the structure of their healthcare system (Gossa et al., 2019). There is also limited access to services and medical equipment, which affects care delivery (Defaye et al., 2015). It is also known Ethiopian patient perceptions regarding causes of genetic conditions differ from most North American-based patients; specifically, Ethiopians have reported beliefs in supernatural, natural, and societal causes contributing to the development of disease (Kahissay et al., 2017). Additionally, limited information is available on the concept of facilitated decision-making in Ethiopia (Kebede et al., 2020). There has been to date no work focused on the introduction of genetic counseling services in Ethiopia. All available information that covers the tenets of genetic counseling, such as facilitated decision-making, has been derived from fields largely unrelated to genetic counseling and medical genetics. Prior to the introduction of genetic counseling services in Ethiopia, we aimed to identify the public's attitudes toward genetic counseling.

What is known about this topic

Previous work identified that 4% of pediatric, neonatal intensive care, and prenatal patients at a large hospital in Addis Ababa, Ethiopia, have indications for genetic evaluation including genetic counseling. No formal genetic counseling services are available in Ethiopia, and physicians at this same hospital have indicated a desire for more education regarding genetics and genetic disease.

What this paper adds to the topic

This is the first paper that reports the views of the Ethiopian public on genetic counseling. This patient perspective is an important consideration as genetic services including genetic counseling are introduced in Ethiopia and other sub-Saharan African countries.

St. Paul's Hospital Millennium Medical College (SPHMMC) is the second largest public hospital in Ethiopia and is located in the capital city of Addis Ababa, where only approximately 4% of the country's population lives. Patients travel from around the country to obtain health services in Addis Ababa, and SPHMMC predominantly serves patients with lower socioeconomic status with approximately 75% of its services being provided free of charge. SPHMMC has recently increased their capacity to prenatally screen for and diagnose congenital anomalies and genetic disease through the use of ultrasound and in-country genetic testing facilities. Previous work at SPHMMC showed that the burden of congenital anomalies and genetic disease is similar to that seen in public hospitals located in high- and middle-income countries, with 4% of pediatric, neonatal intensive care, and prenatal patients who completed a family history assessment screening positive for an indication for which genetic evaluation is recommended (Quinonez et al., 2019). Additionally, pregnant patients at SPHMMC surveyed previously expressed broad interest in prenatal testing and termination of pregnancy for many common congenital anomalies and genetic diseases, particularly those that are associated with a shortened lifespan (Brooks et al., 2019). While the capacity to diagnose congenital anomalies and genetic disease increases at SPHMMC and throughout Ethiopia, only a minority of physicians feel their medical genetics knowledge is sufficient for their practice and the majority are interested in additional genetics education (Quinonez et al., 2019). Prior work at SPHMMC found that 64% of providers reported being asked about congenital disorders/genetic disease multiple times per month, while only 8% stated they were never asked about this by patients/families (Quinonez et al., 2019). While future training of healthcare providers in genetic counseling is planned, Ethiopian patients have no experience with genetic counseling and their attitudes toward genetic counseling warrant consideration prior to training initiation. Attitudes have

been shown to predict intention to act with regard to many health behaviors, including genetic counseling and testing, indicating that an assessment of SPHMMC's population could identify how receptive they would be to receiving this service (Cyr et al., 2010; Fishbein et al., 2003).

Previous works assessing patient attitudes and knowledge of genetic counseling have been reported in a rural Midwestern population in the United States (Riesgraf et al., 2015) and in the Hutterite population in Manitoba, Canada (Gemmell et al., 2017). To our knowledge, no similar work has been performed in a LMIC. Here, we report for the first time the assessment of the Ethiopian public's attitudes toward and knowledge of genetic counseling. As genetic counseling is primarily based on Western values, we also compared the results from Ethiopia to those from the previously reported studies.

2 | METHODS

2.1 | Instrumentation

Surveys (Supplementary Materials and Methods) were adapted from previous work surveying populations in a Midwest rural area in the United States (Riesgraf et al., 2015) and in the Hutterite population in Canada (Gemmell et al., 2017). The demographic response options for ethnicity and religion were modified from the original survey to be reflective of those commonly found in Ethiopia. Surveys were translated into Amharic, the official language of Ethiopia, and administered verbally by Ethiopian physicians. The administered survey consisted of three sections; familiarity, knowledge and attitudes, and demographics. The first assessed both familiarity with genetic counseling and the source of familiarity, if applicable. The second section consisted of a brief description of genetic counseling which was identical to that used by Riesgraf and Gemmell: 'Genetic counseling is the process of providing information and support to families who may be at risk for a variety of genetic or inherited conditions. Genetic counselors identify families at risk, investigate the problem present in the family, interpret information about the condition, analyze inheritance patterns and risk of recurrence, and review available options with the family'. This definition was adapted from a description on the National Society of Genetic Counselors' website under 'Genetic Counseling as a Profession' (2009) (Riesgraf et al., 2015). After this description was read in Amharic to the patients, 15 statements about genetic counseling that were accurate or inaccurate ($n = 13$) or that assessed attitudes toward genetic counseling ($n = 2$) were read aloud. Participants were asked to rate their agreement with these statements on a Likert scale from 1 to 4 (1 = disagree, 2 = somewhat disagree, 3 = somewhat agree, and 4 = agree). The third section collected demographic information, including sex, nationality, ethnicity, religion, marital status, whether the individual has children, and educational level. The two prior studies from which our instrument was adapted also included a fourth section querying whether respondents had used genetic counseling services and whether there were any circumstances under which they would consider using these services. This section was omitted from our survey given the lack of genetic counseling services in Ethiopia. Following survey administration, it was identified that the original question 'Genetic counseling helps expecting couples to *choose* the sex of their child' may have been translated to read 'Genetic counseling helps expecting couples to *know* the sex of their child', which changes the accuracy of the statement. Given this inconsistency, this question was omitted from analysis and only 14 of the original 15 items were included for data analysis.

3 | PARTICIPANTS AND PROCEDURES

We aimed to survey 25 adults from four different departments (Internal Medicine, Surgery, Pediatrics, and the Maternity/Gynecology ward) with the goal of obtaining a total of 100 surveys. Institutional Review Board approval was obtained from both SPHMMC and the University of Michigan. Informed consent was obtained from participants. Participants were enrolled over a one-week period in May 2018 by five medical residents at SPHMMC. These residents were recruited by the Ethiopian physician members of our study team (AYW, AK, DB) based on their prior experience with the residents. Multiple residents were recruited to ensure coverage of four different target departments and approached patients in their respective departmental waiting rooms. Residents administered the consent and survey verbally to patients. As part of the survey, the definition of genetic counseling was read to participants before beliefs and attitudes regarding genetic counseling were assessed, but after familiarity with genetic counseling was queried.

4 | DATA ANALYSIS

Data analysis was completed using two-tailed Student's *t* tests to compare our population's mean responses to those from rural North American populations from prior work. For the purposes of analysis, a mean response of <2.5 indicated disagreement with a statement while >2.5 indicated agreement with the statement. Responses were considered correct if participants disagreed with inaccurate statements or agreed with accurate statements.

5 | RESULTS

One hundred two surveys were administered and one patient declined to participate, for a response rate of 99%. The 101 participants who consented and completed surveys were from four different units: Internal Medicine (24, 23.8%), Surgery (27, 26.7%), Pediatrics (25, 24.8%), and Maternity/Gynecology ward (25, 24.8%). Seventy-four respondents were female (73%), and most reported their ethnicity as either Oromo (35, 35%) or Amhara (35, 35%). A majority of respondents were married (80, 79%), and most had children (83, 82%). Most respondents reported an educational level of secondary

school or lower (83, 82%) including 7 (7%) with no education at all. Only 10 (10%) reported having received a university degree. The percentage of respondents in our population who had post-secondary education (12%) was significantly different than respondents in the Midwestern United States population (76%, $p < 0.0001$), but similar to those in the Hutterite Canadian population (16%, $p = 0.1164$). Other demographics are shown in Table 1. Based on available census data, the percentages of each religious group within our population were representative of those in Ethiopia, but our respondent group included more females and educated individuals relative to the national population (Central Statistical Agency, 2007).

Previous experience with genetic counseling is detailed in Table 2. 70 (69%) respondents reported little/no familiarity with genetic counseling, and one individual (1%) did not answer this question. Of the 30 participants who reported being somewhat familiar (14, 47%), familiar (12, 40%), or very familiar (4, 13%) with genetic counseling, most reported they had heard about genetic counseling in the media (14) or at a health center/hospital (9). Others reported hearing about genetic counseling in school (6), from friends (5), from family (2), and one reported having received genetic counseling services themselves. Several respondents indicated they were familiar with genetic counseling via more than one method. There were significant differences between the percentage of our total respondents who had undergone genetic counseling previously (0.99%) compared to both North American populations, in which 16.5% (Midwestern United States population) and 10.8% (Hutterite Canadian population) of individuals reported receiving genetic counseling ($p = <0.0001$ and $p = 0.0014$, respectively).

TABLE 1 Demographics of study population ($n = 101$)

	Number	Percentage
Gender		
Male	26	26%
Female	74	73%
Prefer not to answer	1	1%
Ethnicity		
Oromo	35	35%
Amhara	35	35%
Gurage	22	22%
Other	8	8%
Unknown	1	1%
Religion		
Ethiopian Orthodox	54	53%
Muslim	23	23%
Protestant	18	18%
Other	4	4%
Unknown	2	2%
Relationship status		
Single	19	19%
Married	80	79%
Divorced	1	1%
Unknown	1	1%
Children		
Yes	83	82%
No	16	16%
Unknown	2	2%
Education		
Less than high school	47	47%
Some high school	36	36%
University, received degree	10	10%
Other (technical/vocational, university no degree, diploma, unknown)	8	8%

TABLE 2 Previous experience with genetic counseling

Familiar with genetic counseling ($n = 101$)		
Yes (somewhat familiar, familiar, or very familiar	30	30%
No (little/no familiarity)	70	69%
No response	1	1%
How heard of genetic counseling[a] ($n = 30$)		
Media	14	47%
Through health center/hospital	9	30%
School	6	20%
Family/friend	7	23%
Have received services	1	3%

Includes responses only from those who were familiar with GC, some individuals selected more than one answer.[a]

Mean participant responses were correct in 8/12 (66.7%) knowledge-based questions. There were statistically significant differences between the SPHMMC population and the North American populations in mean responses on multiple items (Table 3), although most of the Ethiopian population's mean answers were consistent in directionality when compared to the prior studies. The most significant difference between our group compared to the North American groups was in response to the statement 'Genetic counselors advise women to get abortions when there is a problem', an inaccurate statement with which most of our respondents agreed (mean = 3.41) but the Hutterite and Midwestern populations did not (means = 1.41 and 1.59, respectively). Significant differences were also noted on the item 'The goal of genetic counseling is to keep genetic problems out of society', an inaccurate statement, which significantly more SPHMMC participants agreed with (mean = 3.36) compared to the Hutterite and Midwestern populations (means = 2.99 and 2.29, respectively), although within the Hutterite Canadian population on average there was overall agreement with this statement as well.

Differences in directionality were also identified in response to 'Genetic counseling can help cure a genetic problem', with a mean of 2.86 in the SPHMMC population and means of 2.28 and 2.37

TABLE 3 Means, standard deviations, and medians for responses to 12 knowledge and two attitude assessment statements included in analyses and comparisons to populations from prior work using same survey

Purpose, scope, and practice of genetic counseling	SPHMMC			Hutterite Canadian population (Gemmell et al., 2017)					Midwestern United States population (Riesgraf et al., 2015)				
	Mean	*SD*	Median	Mean	*SD*	Median	*p*-value	*d*-value	Mean	*SD*	Median	*p*-value	*d*-value
Genetic counselors must receive a lot of special training to do their job. *Accurate*	3.86	0.61	4.00	3.47	0.96	4.00	0.0012	0.49	3.59	0.61	4.00	0.0003	0.45
Genetic counselors give people emotional support. *Accurate*	3.77	0.75	4.00	3.38	0.82	4.00	0.0024	0.50	3.25	0.84	3.00	<0.0001	0.66
Genetic counselors advise women to get abortions when there is a problem. *Inaccurate*	3.41	1.10	4.00	1.41	0.83	1.00	<0.0001	2.05	1.59	0.83	1.00	<0.0001	1.87
The goal of genetic counseling is to keep genetic problems out of society. *Inaccurate*	3.36	1.16	4.00	2.99	1.14	3.00	0.0058	0.32	2.29	1.05	2.00	<0.0001	0.96
Genetic counseling can help cure a genetic problem. *Inaccurate*	2.86	1.38	4.00	2.28	1.24	2.00	0.0007	0.44	2.37	1.07	2.00	0.0009	0.40
Genetic counseling is confidential. *Accurate*	2.85	1.40	4.00	3.48	0.90	4.00	<0.0001	0.54	3.64	0.69	4.00	<0.0001	0.72
Genetic counseling may be helpful for someone with cancer in their family. *Accurate*	2.72	1.37	4.00	2.85	1.18	3.00	0.5120	0.10	3.46	0.69	4.00	<0.0001	0.68
Genetic counseling is a service mainly for pregnant women. *Inaccurate*	2.18	1.37	1.00	1.20	0.42	1.00	<0.0001	0.97	1.73	0.86	1.00	0.0008	0.39
Genetic counselors require people to have genetic tests. *Inaccurate*	2.14	1.35	1.00	2.93	1.21	3.00	<0.0001	0.61	2.57	1.05	3.00	0.0034	0.35
Genetic counseling helps expecting parents choose the eye color of their child. *Inaccurate*	1.88	1.27	1.00	1.09	0.37	1.00	<0.0001	0.85	1.41	0.79	1.00	0.0001	0.45
Genetic counseling is only useful to a small group of people with rare diseases. *Inaccurate*	1.77	1.22	1.00	1.53	0.88	1.00	0.1496	0.23	1.72	0.86	1.00	0.6922	0.05
Seeing a genetic counselor could cause someone to lose their job. *Inaccurate*	1.37	0.94	1.00	1.21	0.69	1.00	0.1190	0.20	1.56	0.83	1.00	0.0821	0.21
Attitudes about genetic counseling													
I would trust the information provided by a genetic counselor	3.84	0.48	4.00	3.49	0.69	4.00	<0.0001	0.59	3.19	0.66	3.00	<0.0001	1.12
Genetic counseling is in line with my values	3.59	0.92	4.00	3.42	0.82	4.00	0.0881	0.19	2.88	0.82	3.00	<0.0001	0.81

Note: Scale: 1 = Disagree, 2 = Somewhat Disagree, 3 = Somewhat Agree, 4 = Agree.

in the Hutterite and Midwestern populations, respectively. Finally, SPHMMC patients were less likely to agree with the statement 'Genetic counselors require people to have genetic testing' with a mean response of 2.14, while individuals surveyed in the Hutterite and Midwestern populations had mean responses of 2.93 and 2.57, respectively.

Respondents reported positive attitudes toward genetic counseling, represented by high agreement with the statements 'I would trust the information provided by a genetic counselor' (mean = 3.83) and 'Genetic counseling is in line with my values' (mean = 3.59). Agreement with these statements was higher than in either of the North American populations from prior studies that used this survey (Table 3).

6 | DISCUSSION

Here, we show for the first time the public's perception of genetic counseling in a low-income sub-Saharan African country based on a survey completed by 101 Ethiopian patients assessing their familiarity with, knowledge of, and attitudes toward genetic counseling. When compared to previously reported participants from the United States and Canada, there were a number of similarities and differences important to consider prior to implementing genetic counseling in Ethiopia.

In general, Ethiopians held many of the same attitudes toward genetic counseling as participants in previous North American studies with clear exceptions. The majority of participants were not familiar with genetic counseling prior to study enrollment, though after being informed of the definition of genetic counseling, most participants agree with statements that they would trust the information delivered by a genetic counselor and felt genetic counseling services were in line with their values. This positive perception of genetic counseling is important to note as public misconceptions can be accounted for during genetic counseling curriculum design and instillation into healthcare systems but had participants not been open to counseling services, this would have raised important concerns that genetic counseling in its described form may not be appropriate for Ethiopians at this point.

7 | MISCONCEPTIONS

The most informative misconception held by Ethiopian participants centered on the perception that genetic counseling is used to eradicate congenital anomalies and genetic disease from society. In contrast to North American-based studies, the majority of Ethiopians agreed with the statements 'Genetic counselors advise women to get abortions when there is a problem' and 'The goal of genetic counseling is to keep genetic problems out of society'. While our study is limited to quantitative data, it is interesting to consider possible reasons for this belief. The concept of facilitated decision-making is relatively unheard of in Ethiopia; cultural norms dictate that a family member may make decisions on behalf of a patient, and often medical decisions are made based on physician recommendations at least partially due to limited medical literacy in patients and families (Kebede et al., 2020). This reason may well explain why Ethiopians were more likely to agree with the statement that 'Genetic counseling can help cure a genetic problem' compared to previously studied North American populations.

The finding that patients believe that the goal of genetic counseling is to eradicate genetic disease from society, yet still report that genetic counseling is in line with their values, may reflect on cultural and societal differences in the role of healthcare providers as well as in views on these conditions. Prior work in this population has shown that Ethiopians are interested in the option of termination for pregnancies affected by congenital anomalies and/or genetic disease (Brooks et al., 2019), and therefore may have favorable views toward providers they perceive as assisting in providing this service. The lack of access to adequate health care for some Ethiopians due to the distance needed to travel to obtain services and/or financial limitations may contribute to this preference, as having a child with congenital anomalies and/or genetic disease may place a large emotional and financial burden on the family (Brooks et al., 2019). Differences in some responses compared to the North American population may also in part be affected by previous perception of genetic counseling with approximately 50% of North Americans in the two previous studies familiar with genetic counseling at the time of survey administration while only 30% of the SPHMMC population reported familiarity with the profession.

While we have labeled 'incorrect' views on genetic counseling as 'misconceptions' held by this population, it is important to note that this survey was initially designed for and used in North American populations. Therefore, whether a statement describing genetic counseling is correct or incorrect is a judgment based on the North American definition and role of genetic counseling. Work by the Transnational Alliance of Genetic Counseling has shown there are differences in practice models globally and therefore suggests flexibility in the development and expansion of the profession to new countries to account for variations in culture and healthcare systems (Abacan et al., 2019). As genetic services are introduced in Ethiopia, it is likely the exact role of a genetic counselor in Ethiopia may differ compared to the North American definition. With time, it is possible that the term 'differences' will be used in place of the word 'misconceptions'.

While there were statistically significant differences between how strongly participants agreed or disagreed with various statements compared to previous work, in general no other major differences were identified.

8 | PRACTICE IMPLICATIONS

Previous work has shown that Ethiopian patients are often not involved in decision-making for their own care due to both

provider- and patient-related factors (Kebede et al., 2020), which could present a challenge when attempting to assist patients in decision-making during a genetic counseling session. Limited work has been completed to determine how providers involve patients and families in decision-making in these challenging environments. Barriers to including patients in decision-making reported in a single study included time constraints, heavy workload, and lack of privacy to discuss sensitive information, all factors which providers noted made it difficult to discuss detailed health information and provide support to patients (Kebede et al., 2020). Providers in the same study reported patient-related factors including low health literacy, limited financial resources, language barriers, the stigma of disease, and reliance on traditional and/or religious treatments as barriers to providers involving patients in decision-making regarding their care. Patients may also have a family member act as a caregiver, who is then responsible for treatment decisions and may choose not to share news of a poor prognosis with the patient. Therefore, respect for this traditional role may prevent providers from involving patients in their own care. Importantly, though, pregnant women at SPHMMC have previously expressed interest in termination of pregnancies affected with congenital anomalies and genetic diseases independent of physician recommendation (Brooks et al., 2019). Similarly, in South Africa, 80% of older women offered genetic counseling request amniocentesis with a similar number accepting an abortion if the fetus was affected with a congenital anomaly (Viljoen et al., 1996). This indicates that patients may be open to a model with greater patient involvement in decision-making. This aspect of Ethiopian culture will be important to consider as genetic counseling training of providers expands in the future. Part of the role of genetic counseling involves respecting clients' beliefs, circumstances, family relationships, and cultural traditions (The National Society of Genetic Counselors, 2018), and this aspect of the profession is especially important when implementing this service for the first time in a country. If, and how, facilitated decision-making as well as other aspects of the North American view of genetic counseling is taught to providers will require future discussions with Ethiopian providers to avoid conflict with established cultural norms.

One item that was not addressed by our patient surveys is logistical challenges to the implementation of genetic services. Feedback from providers at SPHMMC in our group's prior work piloting a family history application indicated that time constraints were a barrier to collecting family history, even though all users noted the family history information took 10 min or less to complete per patient (Quinonez et al., 2019). Physician density in Ethiopia is 0.03 per 1,000, while the World Health Organization recommends 2.3 physicians per 1,000 individuals (Gossa et al., 2019). Informal interviews with Ethiopian prenatal and pediatric physicians at SPHMMC conducted as part of our work revealed nurses were considered ideal candidates to be trained in and provide genetic testing services based on their role in the healthcare system and greater availability of time to deliver news and provide emotional support to patients (author observations, unpublished data).

9 | STUDY LIMITATIONS

There were a number of relevant limitations of our study. It was restricted to one public institution in the capital city of Ethiopia resulting in a relatively narrow representation of the Ethiopian public. Based on census data, we know the gender, marital status, and education level of our population are not representative of the Ethiopian population as a whole, so our data are not reflective of the country's overall demographics. Because this was an exploratory study focused on the patient population at SPHMMC, the effect of demographics on perspectives on genetic counseling was not evaluated as part of this work, but it is possible these factors may affect willingness to use genetic counseling services. SPHMMC primarily serves patients of lower socioeconomic status, providing approximately 75% of services free of charge, but is still likely to represent a more urban population compared to hospitals in rural Ethiopia. Replicating this preliminary work in other regions of Ethiopia in the future will provide a more representative sample of the whole of the country's population, and inclusion of a broader population could also allow for elucidation of specific demographic factors that affect willingness to use genetic counseling services. This is especially important to consider given the many ethnicities and religions spread throughout Ethiopia. An additional limitation was the survey translation process. To confirm survey accuracy, a back translation identified one of the questions may have been incorrectly translated to study participants. While this did not significantly impact the findings of the study, future work will have to account for this possibility with increased attention to the translation process. Additionally, because the survey was delivered verbally by five different providers, there is the possibility of inconsistencies in delivery between providers. Attempts were made to control for this by the study team, specifically by meeting with each provider who would be delivering the survey and reviewing the content of the paper survey as well as requesting they read the content as written and not provide explanations to participants. However, the study team was not able to observe survey delivery and it is possible residents may not have asked the questions exactly as written or they provided further explanations if requested. At this time, Ethiopia has very limited access to medical genetics services with only one private laboratory offering MLPA-based genetic testing and no trained medical geneticists or genetic counselors in the country. Therefore, many aspects of the study relied on the training of Ethiopian providers with no ability to have an Ethiopian geneticist or genetic counselor to participate in the survey translation, consent process, or survey administration. While we are confident in the study's results, future inclusion of fully trained Ethiopian genetics professionals would improve all aspects of this and similar work.

10 | RESEARCH RECOMMENDATIONS

Here, we provide the first preliminary evidence that genetic counseling is in line with the Ethiopian public's values and the delivered

information would be trusted by Ethiopian patients. We additionally learned important aspects of the Ethiopian public's perceptions and misconceptions regarding genetic counseling that will be important to consider throughout implementation of training and services. Ethiopian cultural values and norms should also be considered in the ways in which this service may differ from delivery of genetic counseling in North America. This study, combined with our group's previous work, provides the first comprehensive Ethiopian medical genetics need assessment with information on patient and provider preferences, knowledge of medical genetics, and data on the epidemiology of congenital anomalies and genetic disease in the country (Brooks et al., 2019; Quinonez et al., 2019). Future efforts will focus on further evaluating the conclusions of our previous work and the design and implementation of medical genetics capacity-building strategies to include training programs, public education campaigns, and establishing diagnostic facilities. As with our previous work, our aim is to highlight the importance of genetics as a treatable cause of morbidity and mortality in countries not previously considered. Though the obstacles preventing the implementation of medical genetics services are easy to focus on, medical professionals should not lose sight of the realistic opportunity of medical genetics services to have a significant impact in the countries shouldering the highest burden of disease.

AUTHOR CONTRIBUTIONS

All authors contributed to this work using the criteria recommended by the International Committee of Medical Journal Editors. Michelle F. Jacobs, Bridget C. O'Connor, Abate Yeshidinber Weldetsadik, Atnafu Mekonnen, Delayehu Bekele, Erika Hanson, and Shane C. Quinonez all made substantial contributions to the conception or design of the study and/or the acquisition, analysis, or interpretation of data. The work was drafted by Michelle F. Jacobs, Bridget C. O'Connor, and Shane C. Quinonez and revised for important intellectual content by Abate Yeshidinber Weldetsadik, Atnafu Mekonnen, Delayehu Bekele, and Erika Hanson. Michelle F. Jacobs, Bridget C. O'Connor, Shane C. Quinonez, and Erika Hanson had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Michelle F. Jacobs, Bridget C. O'Connor, Abate Yeshidinber Weldetsadik, Atnafu Mekonnen, Delayehu Bekele, Erika Hanson, and Shane C. Quinonez will have final approval on the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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COMPLIANCE WITH ETHICAL STANDARDS

Conflict of interest

Michelle F Jacobs, Bridget C O'Connor, Abate Yeshidinber Weldetsadik, Atnafu Mekonnen, Delayehu Bekele, Erika Hanson, and Shane C Quinonez declare that they have no conflict of interest.

Human studies and informed consent

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. This study was approved by the SPHMMC and University of Michigan IRBs ([IRB#PM23/365] and HUM00146963, respectively). An informed consent document was prepared in Amharic, and verbal informed consent was obtained from all individual participants included in the study.

Animal studies

No nonhuman animal studies were carried out by the authors for this article.

Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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