Are there differences in perceptions, preferences and attitudes towards disclosure of genetic testing for Stroke? A qualitative study among stroke-free SIREN-SIBS genomics study participants

Oyedunni Arulogun, PhD,[a] Michelle Nichols, DrPH,[b] Carolyn Jenkins, DrPH,[b] Adekunle Gregory Fakunle, PhD,[c,d] Onoja Akpa, PhD,[e,f] Fred S. Sarfo, PhD,[g] Albert Akpalu, MBChB,[h] Kolawole Wahab, PhD,[i] Reginald Obiako, PhD,[j] Morenikeji Komolafe, MBBS,[k] Lukman Owolabi, PhD,[l] Godwin O. Osaigbovo, MBBS,[m] Akinkunmi Paul Okekunle, PhD,[c,n] Joshua Akinyemi, PhD,[e] Godwin Ogbole, MBBS,[o] Benedict Calys-Tagoe, MPH,[h] Adeniji Adeleye, MBBS,[p] Yaw Mensah, PhD,[g] Osahon Jeffery Asowata, MSc,[e] Abiodun M. Adeoye, MSc,[c] Lambert Appiah, PhD,[g] Arti Singh, PhD,[g] Philip Adebayo, MBBS,[q] Donna Arnett, PhD,[r] Hemant K. Tiwari, PhD,[s] Daniel Lackland, DrPH,[b] Philip Ibinaiye, MD,[j] Wisdom Oguike, MSc,[j] Chimdinma Melikam, BSc,[j] Adeniyi Sunday, BTech,[h] Abiodun Bello, MBBS,[i] Okechukwu Ogah, PhD,[c] Rufus Akinyemi, PhD,[c,t,v] Bruce Ovbiagele, MD,[u] and Mayowa Owolabi, DrM[c,v], on behalf of SIREN

Objective: This study explored perceptions, preferences and attitudes towards disclosure of genetic testing results for stroke among stroke-free controls (and their family members) in the SIREN-SIBS Genomics Study, healthcare providers and policymakers. *Materials and Methods:* We conducted a qualitative thematic analysis of key informant interviews with 61 participants recruited from community advisory boards (30) and health care providers (31) across seven sites in Nigeria and Ghana. *Results:* Major findings illustrate differences in the knowledge of genetic testing with superior knowledge among health care

---

From the [a]Department of Health Promotion and Education, University of Ibadan, Nigeria; [b]College of Nursing, Medical University of South Carolina, South Carolina, USA; [c]Department of Medicine, College of Medicine, University of Ibadan, Nigeria; [d]Department of Public Health, Osun State University, Osogbo, Nigeria; [e]Department of Epidemiology and Medical Statistics, University of Ibadan, Nigeria; [f]Institute of Cardiovascular Diseases, College of Medicine, University of Ibadan, Nigeria; [g]Department of Medicine, Kwame Nkrumah University of Science and Technology, Ghana; [h]Department of Medicine, University of Ghana Medical School, Accra, Ghana; [i]Department of Medicine, University of Ilorin Teaching Hospital, Ilorin, Nigeria; [j]Department of Medicine, Ahmadu Bello University, Zaria, Nigeria; [k]Department of Medicine, Obafemi Awolowo University Teaching Hospital, Ile-Ife, Nigeria; [l]Department of Medicine, Aminu Kano Teaching Hospital, Kano, Nigeria; [m]Jos University Teaching Hospital Jos, Nigeria; [n]Department of Food and Nutrition, Seoul National University, Seoul, Korea; [o]Department of Radiology, University of Ibadan, Nigeria; [p]Department of Medicine, Federal Medical Centre, Abeokuta, Nigeria; [q]Aga-Khan University Dar es Salaam, Tanzania; [r]College of Public Health, University of Kentucky, USA; [s]The University of Alabama at Birmingham, Birmingham, Alabama, USA; [t]Neuroscience and Ageing Research Unit, Institute for Advanced Medical Research and Training, College of Medicine, University of Ibadan, Nigeria; [u]Weill Institute for Neurosciences, University of California San-Francisco, USA; and [v]Center for Genomic and Precision Medicine, College of Medicine, University of Ibadan, Nigeria.

Received September 21, 2022; revision received December 30, 2022; accepted January 4, 2023.

Corresponding author at: Mayowa O. Owolabi, MBBS, MD, DrM, FAAN, FANA, FRCP, FAMedS, FAS, FAAS, Department of Medicine and Center for Genomic and Precision Medicine, University of Ibadan, 200284, Ibadan, Nigeria. E-mail: mayowaowolabi@yahoo.com.

1052-3057/$ - see front matter

https://doi.org/10.1016/j.jstrokecerebrovasdis.2023.106978

professionals. Relatives and religious leaders were opined as the best to receive the disclosure as they would be able to break the news to the patient in a culturally sensitive manner to reduce the likely resultant emotional outburst. Poor level of awareness of national guidelines for disclosing genetic results exist. Key facilitating factors for disclosure are education, enabling environment, involvement of religious and community leaders, campaigns, and possible treatment options. Disclosure inhibitors include inadequate information, fear of marital break-up or family displacement, fear of stigmatization, fear of isolation, religious beliefs, health worker attitude, and lack of preparedness to accept results. *Conclusions:* These necessitate culturally sensitive interventions for continuing education, increased awareness and sustained engagement to equip all stakeholders in genetic testing disclosure process.

Keywords: Genetic test disclosure—Perception—Preference—Attitudes

Introduction

In the last few years, genomics studies have taken center stage in the understanding of genetic interactions and disease outcomes in the human body, these studies have spurred great advancements in medicine and technology revealing risk information in diseases such as stroke, heart disease, cancer to mention a few such information should help the patient/individual achieve better health outcomes. Evidence in best practice for risk disclosure is sparse.[1, 2] A much deeper understanding of genetics testing will shed light on more than just hereditary risks by revealing the basic components of cells and, consequently, examining how the various elements involved work together to affect the human body in both health and disease, for both the medical professionals and the patient.[3] For the patient, this understanding becomes impossible if disclosure of genetic test is hampered by other unprecedented factors. Informed decisions cannot be made if attitude towards and perception of disclosure are wrong. It points to a far bigger issue; health outcomes might not change. Healthcare professionals and policymakers in Europe reportedly are struggling to find effective strategies to communicate genetic risk information and, at the same time, to enhance individual empowerment and shared decision making in this field.[4] A considerable number of studies have investigated the level of knowledge, attitudes, and ability to manage genetic information among general practitioners[5-9] and the interest of people in genetic testing in many European countries.[10-18] They attempted to provide a global view of the general public's predisposition to consider and undergo genetic testing, but studies to correlate these trends with specific psychological tendencies associated with health are sparse.[19-21] In Sub-Saharan Africa, little is known about people's perception and attitude about genetic test result disclosure and how this can push the adoption of the process. A disease such as stroke can have different outcomes through genetic testing, but it is the attitude towards disclosure that will determine if the test has any effect on the disease outcomes. Perception and attitude towards disclosure of genetic test results for stroke may or may not be due to individuals' previous interaction with the disease.[3] It is important to emphasize that people have the right to know the outcomes of their genetic testing and to decide if they want this information shared with them. But the question here is what will be individuals' perception and attitude towards disclosure among stroke-free individuals where knowledge is limited. Furthermore, there is a paucity of literature in this field for studies conducted among Sub-Saharan Africans. Consequently, there is the need to investigate stroke-free individuals' perception, preferences and attitudes towards disclosure of results of genetic testing for stroke among SIREN-SIBS Genomics stroke-free study participants (controls), their family members, healthcare providers and policy makers, as these individuals have not experienced first-hand a stroke at the time of study participation and may have unique insight into disclosure of genetic test results given their naïve personal experience with stroke.

Methodology

Design

We used a qualitative design using focus group discussions to capture the variation in perceptions, preferences and attitudes towards disclosure of genetic testing for stroke which is well suited for exploring how attitudes and opinions are formed and for researching sensitive topics, as the setting among peers can create a safe and encouraging environment for participants.[22] The focus group format allows subjects to express themselves in their own vocabulary and elaborate on each other's statements through interactive dialogue.[23] The method minimizes the influence of the facilitator and is advisable in settings where there is a gap between professionals and target audiences or power differential between respondents and decision-makers.[24]

Key informant interviews which are qualitative in-depth interviews with persons who know what is going on the community were used. The purpose was to collect information from a wide range of people in this case health care professionals and Community Advisory Board (CAB) members who had first-hand knowledge about the subject of inquiry. The key informant interview guide allowed participants to express themselves in their own vocabular. The study was approved by the Institutional Review Boards of the participating institutions in Nigeria and Ghana.

Participant selection

Participants were recruited through non-probability sampling from CAB members from seven project sites in Nigeria and Ghana and health professionals involved in management of stroke. The study sites have been previously described elsewhere.[25] Healthcare provider participants included primary care physicians/stroke physicians/geneticists, social workers/ethical committee members, and nurses. Individuals identified by the research team were approached with a request for participation and information with contact details to the research team was provided if needed. A time and date were scheduled to suit the participants.

Data collection

An interview guide was developed to capture a) approaches to disclosure genetic test results; and b) perceived facilitators and hindrances to result disclosure. The guide had 8 questions based on literature review and input from research team (Table 1). Prior to the interviews, study team members provided a brief overview of the study and how genetic testing result can be disclosed, specifically within the context of stroke. The interview started with very broad statement on why participants have been invited to reflect their opinions regarding genetic testing and disclosure, and how they think the results should be disclosed. The facilitator used probing questions to elaborate and clarify statements if needed. Towards the end of the sessions, the facilitator reiterated a summary of the discussed topics to confirm the understanding. Interviews were held in a neutral meeting room in office-like administrative premises at the participating hospitals and homes/offices of CAB members. The duration of the interview ranged between 25 and 35 minutes (median = 31 minutes). The interviews were held in English language for the health care professionals and the local language of the communities (Yoruba, Hausa, Akan and Ga languages) for the CAB members in Nigeria and Ghana. The main facilitator with experience in qualitative methodology led all sessions assisted by a second colleague who collected consent forms and managed the audio equipment. Interviews were audio recorded, transcribed verbatim, cross-validated with audio and anonymized. Incentives, in terms of transport fare, were used in this study.

Data analysis

The dataset was analyzed using qualitative thematic analysis. Transcripts were read several times to establish a sense of the whole. The identified meaning units related to the research objectives were condensed and descriptive codes were applied. Related sub-categories were then grouped and interpreted to form main categories. The objectives were divided into themes extracted from the transcripts. The themes were further developed into sub-themes and codes.

Results

Demographic Information of studied participants

A total of 30 CAB members and 31 health care professionals from the SIREN sites in Nigeria and Ghana participated in the interviews (Table 2). The mean age of CAB members (49.5 ± 11.9 years) was slightly higher than the health professionals (45.5 ± 7.6 years), with a higher proportion of males; 66.7% and 77.4%, respectively. Most of the CAB members (73.3%) and health professionals (74.2%) were married. The CAB consists of community leaders (23.3%), community traders (20.0%), religious leaders (20.0%), community nurses (20.0%), and media representatives (16.7%), while the health care professionals were made up of medical doctors with experience in stroke care (51.6%), medical laboratory scientists (12.9%), health services administrators (16.1%), public health educators and ethics committee members (9.7%).

Knowledge on genetic test and the types

Respondents had appreciable knowledge on genetic testing, but healthcare providers had more extensive knowledge of genetic testing compared with CAB members. Several types of genetic tests were identified by both healthcare providers and CAB members. Types of genetic testing identified include: cytogenetics, genotype testing, cancer oncogenes, short tandem repeat (SRT), karyotyping, trinuclear type repeat for stroke, and molecular testing.

> “. . .we do what is called karyotyping because we want to know about the distribution of chromosomes in certain inherited diseases.” - Paediatrician, Ibadan

> “If I am not mistaken when you talk about blood group, genotype, I think those ones fall in line with genetic test.”- Pastor, Abeokuta

> “Stroke is one of the diseases that you can do a genetic test, yes.” - Community Leader, Accra

Approach to disclosure of genetic test result

When respondents were faced with who genetic test results should be disclosed to, members of both groups

Table 1. *Key informant interview guides.*

Domain	Community advisory board	Healthcare provider
Interviewee Practice	Q1. Please describe what your work is/what you do. Q2. How often do you come in contact with people who have had brain related illnesses in your job?	Q1. Can you describe what your work is/what you do? Q2. How many patients who have had brain related illnesses do you see in a given month? Q2a. What is the average number of times you see these patients in a given month? Q3. How many years have you been a practitioner for patients in this [Name of hospital]?
Approach to Disclosure of Genetic Test Results	Q1a. Please name and describe any genetic tests that you may have heard of. Q1b. Describe anything or any approach to disclosure of genetic test results to individuals. Q2. Are you aware of any current national guideline recommendations for genetic test disclosure? If yes, are you aware of how they are implemented? Q3. What systems are currently in place for enhancing genetic testing and what are the capacities/resources available for genetic testing? Q4. In your estimation, what percentage of people you know are aware of genetic testing and would be willing to undergo genetic testing?	Q1a. Please name the genetic tests that you may order for your patients or that they receive from other physicians. Q1b. Tell us about your current approach to disclosure of genetic test results to patients in this hospital. Q2. Are you aware of current national guideline recommendations for genetic test disclosure in your area of expertise? If yes, are you aware of how they are implemented at this [Name of hospital]? Q3. Are you aware of any systems currently in place at this [Name of hospital] for enhancing genetic testing? Q4. If yes, what are the capacities/resources available within the hospital for genetic testing? Q5. In your estimation, what percentage of patients that you encounter are aware of genetic testing and would be willing to undergo genetic testing?
Perceived barriers and facilitators to disclosure of genetic test results?	Q1. What do you think are barriers to disclosure of genetic test results among people within your community? Q2. What do you think are facilitators to disclosure of genetic test results among people within your community? Q3. What would you like to see happen or change related to disclosure of genetic test results and why would you like to see this change?	Q1. What do you think are barriers to disclosure of genetic test results among the patients you see? Q2. What do you think are facilitators to disclosure of genetic test results among the patients you see? Q3. What would you like to see changed related to genetic test results and why would you like the change?
Action plans toward practice of genetic testing and disclosure of genetic test results	Q1. What actions would you recommend related to sensitizing people about genetic testing in your community? Q2. What action steps do you recommend for disclosing genetic test results to persons and their caregivers or significant other and who would you want to disclose the results? Q3. Do you think people's sensitization about genetic tests and the various methods of disclosing genetic test results could improve uptake and practice of genetic testing? Please expatiate on your response.	Q1. What actions would you recommend related to sensitizing patients and caregivers about genetic testing at this [Name of hospital]? Q2. What action steps do you recommend for disclosing genetic test results to patients and caregivers at this [Name of hospital] and who should disclose the results? Q3. Do you think patient and caregiver sensitization about genetic tests and the various methods of disclosing genetic test results could improve uptake and practice of genetic testing among patients?
Additional Comments	Q1. What do you suggest should be done to promote willingness towards the uptake of	Q1. What do you suggest should be done to promote willingness towards the uptake of

Table 1 (*Continued*)

Domain	Community advisory board	Healthcare provider
	genetic testing among people in Ghana/Nigeria? Q2. What other information can you share that you help providers, patients, caregivers, and the community to better understand and improve willingness to use genetic testing to improve health?	genetic testing among patients and caregivers in Ghana/Nigeria? Q2. What other information can you share that you help providers, patients, caregivers, and the community to better understand and improve willingness to use genetic testing to improve health?

Table 2. *Demographic characteristics of participants.*

Demographics	Variables	CAB Frequency (%); N = 30	Health professionals Frequency (%); N = 31
Site	***Nigeria***		
	Ibadan	4 (13.3%)	5 (16.1%)
	Abeokuta	4 (13.3%)	4 (12.9%)
	Ilorin	6 (20.0%)	5 (16.1%)
	Zaria	5 (16.7%)	5 (16.1%)
	Kano	3 (10.0%)	4 (12.9%)
	Ghana		
	Accra	5 (16.7%)	5 (16.1%)
	Kumasi	3 (10.0%)	3 (9.7%)
Age *(mean ± SD) years*		49.5 ± 11.9	45.5 ± 7.6
Sex	Male	20 (66.7%)	24 (77.4%)
	Female	10 (33.3%)	7 (22.6%)
Educational status	First degree	11 (36.7%)	2 (6.5%)
	PDG	3 (10.0%)	0 (0.0%)
	Master's degree	9 (30.0%)	6 (19.4%)
	PhD/Fellowship	7 (23.3%)	23 (74.2%)
Marital Status	Never married	7 (23.3%)	7 (22.6%)
	Married	22 (73.3%)	23 (74.2%)
	Separated/Divorced	1 (3.3%)	0 (0.0%)
	Widowed	0 (0.0%)	1 (3.2%)
Ethnicity	Yoruba	18 (60.0%)	14 (45.2%)
	Igbo	3 (10.0%)	2 (6.5%)
	Hausa	4 (13.3%)	10 (32.2%)
	Akan	1 (3.3%)	3 (9.7%)
	Ga/Adangme	4 (13.3%)	2 (6.5%)
Profession	Trader	6 (20.0%)	-
	Religious leader	6 (20.0%)	-
	Community leader	7 (23.3%)	-
	Journalist	5 (16.7%)	-
	Community Nurse	6 (20.0%)	-
	Health administrator	-	5 (16.1%)
	Medical laboratory Sci	-	4 (12.9%)
	Medical Doctors	-	16 (51.6%)
	Ethics committee member	-	3 (9.7%)
	Public Health Educator	-	3 (9.7%)

stated this would be the patient's prerogative and healthcare members shared examples of how these preferences are operationalized.

> "… I think it is important that the person involved should be the primary determinant of the disclosure of the result"- Pastor, Zaria

"We seek their consent first but the first contact is the woman if she wishes or she does not wish the husband to be around, we have to oblige her." - Gynaecologist Abeokuta

"If the patient wants the relative or any other person to be close it is allowed. If the patient wants to be left

> alone to hear the result alone, it is allowed. It depends on whatever the patient wants we do."- Community Nurse, Zaria.

There were varying opinions regarding who results should be shared with and whether others should be present. Respondents in both groups unanimously agreed that genetic test results could be disclosed to the patients' family members or spouses as this may prevent any potential shock as the family members will be able to break it to the patients softly.

> "So, when it comes to the disclosure, I believe the team lead would welcome the family and inform them that the results are in and tell them what the results are and ask them and explain the implication of the test results."- Pathologist Accra

Within both groups, some believed genetic test results should be disclosed only to the patients or that this was the practice within their facility.

> "So that is how I feel you must disclose to the person one on one in the best way that there will be no chaos."-Priest, Accra

> "In this hospital, as far as I know, the results are well communicated to the patients." -Pathologist Abeokuta

When this same question was asked among members of the community advisory board, some of the respondents believed that genetic test results should be disclosed to spiritual and traditional leaders, as this is a common route for some healthcare needs, especially when clinical services may be limited.

> "Like I have said earlier on we have spiritual leaders and we have traditional leaders and when there are issues like this occur when we don't have medicine being practice fully, they go to spiritual leaders or traditional leaders like herbalist"- Pastor, Ibadan

Who should disclose it

Respondents had different opinions on who should disclose the genetic test results to the patients or family members. Many believed the genetic test results should be disclosed by the person who ordered the test, trained health workers, spiritual leaders, experienced genetic counsellors, or a group of professionals.

> "I think the patients' primary care giver because there is a relationship or rapport at that point in time, so releasing the results to an already established rapport would be more comfortable for the patient to receive the results." - Senior Neurology Resident, Accra

> "So, the most experienced person in genetic counselling should do the disclosure." - Paediatrician, Ibadan

> "For the disclosure of the results I don't think it should be only one person who would do the disclosure. It should be a team approach."- Pathologist, Accra

> "Well, most times, people believe in their spiritual leader than their family because we have a way of breaking news."- Pastor, Ibadan.

Channels and modes of disclosure

Several channels of disclosure were proposed by the respondents of the community advisory board via which the genetic test results should be delivered to the patients. Some of these modes of disclosure include texts, emails, face-to-face, calls, and letters (enveloped safely). Some modes of disclosure discussed included ensuring confidentiality of results, obtaining prior consent, sharing information directly and privately, following medical ethics and protocols, incorporating counselling with adequate information, and considering inclusion of faith-based leaders.

> "Directly through a text message or email that is encrypted." – Pastor, Ilorin

> "The result will be enveloped and given to the person concerned person." - Lab Scientist, Zaria

> First one, it should be quite confidential, the person directly. You don't have to send it through the community head or somebody that the person knows; it should be the person personally then it should be from the doctor to the patient, no third party. - Journalist, Zaria

> It is faith-based [mode of disclosure]it is also going to add some value and confidence in people."- Imam, Ilorin

> "Disclose such with the assurance that the result is confidential, not that this thing they are telling you is like everybody already knows about it because that too may affect people." -Pathologist, Abeokuta

> "Well, we counsel them, we counsel before and after."- Neurologist, Abeokuta

Awareness of current national guidelines recommendations for genetic test disclosure

The majority of respondents in both groups were not aware of any current national guidelines pertaining to disclosure. A number of respondents who work in health institutions were not aware of any guidelines for genetic disclosure.

> "No, not aware of any current or national guideline recommended for genetic test disclosure, whether local, state or national, we use the guide we receive during training at the school."- Community Nurse, Kano

> "I don't think we have a standard approach, am not aware of, like an institutional approach."- Neurologist, Ibadan

> "I am not aware of any guideline for the disclosure of genetic test."- Community Leader, Kano

Systems and resources available for genetic testing

Respondents mentioned several systems and resources available for genetic testing. These include tertiary hospitals, testing centres, community advisory boards, stroke units, ethics committees, and research studies. Both groups also listed infrastructure type resources as testing equipment, finances, electricity, research institutes, storing facilities, and genetic units in hospitals, manpower, collaborations, necessary for genetic testing.

> "It is just like having ethics committee so which is very necessary."- Imam, Ibadan

> "Community Advisory Board, in collaboration with the stroke unit…; they did a lot of work in that arena just to make sure that people are educated and those that needs to go through the test."- Community Leader, Accra

> "Then secondly, electricity. We can't remove that away from it. If there is no light, how will you refrigerate it."- Teacher, Ibadan

> "The system currently in place for enhancing genetic testing are the equipment, i.e., the laboratories, machines, and the staff in the health facility to carry out tests." - Community Nurse, Kano

> "We have small vial repository where we are able to preserve samples before they are moved to the testing sit." -Medical Microbiologist, Abeokuta

Willingness to undergo genetic testing

Respondents unanimously agreed that the estimated number of people aware of genetic testing is low to very low. Willingness to undergo genetic testing received lower estimations. An example of this was where a pathologist from Accra reporting this willingness to be about 20%.

Factors related to disclosure of genetic test results

Barriers to disclosure

The participants enumerated some factors that might hinder the disclosure of genetic test results. These barriers were either from the patients or the health care provider. The factors that might be barriers highlighted by members of the community advisory board include inadequate information, lack of interest, ignorance, fear of marital break-up or family displacement, fear of stigmatization, fear of discrimination, fear of isolation, distance to testing facility, cost, lack of privacy, sociocultural beliefs, environmental factors, misconceptions, religious beliefs, health worker attitude, language barrier, time, readiness to accept results. Exemplary responses that corroborate these concepts are included in Table 3. Most barriers enumerated by the community advisory board were in line with those highlighted by the health care providers, some more barriers by the health care providers include poor training of health personnel and loss of patient's contact (Table 3).

Facilitators to disclosure

Participants identified factors that might facilitate genetic testing disclosure. These included clear guidance and legislation, having trained healthcare personnel and availability of genetic counsellors, use of a multidisciplinary approach, ensuring a private, comfortable environment for discussions, involvement of religious and community leaders, educational information, including possible treatment options, and confidence in medical personnel. CAB and healthcare team member exemplary quotes pertaining to facilitators of disclosure are noted within Table 3.

Suggestions on improving disclosure of genetic test

Respondents were asked what they would suggest in relation to sensitizing people about genetic testing, uptake and practice of genetic test disclosure, promoting willingness to undergo genetic testing and recommended changes related. These suggestions represent the perception of the respondents on how genetic testing should otherwise be carried out and disclosed. Suggestions from the CAB members towards improving uptake and practice of disclosing genetic test results include reducing cost of test, creating awareness, instituting infrastructures, freedom of expression, fighting against stigma, community campaigns, health workers' orientation, use of modern testing techniques, and provision of adequate information to patients. Participants responses to recommended changes related to disclosure of stroke genetic test results includes

Table 3. *Exemplary quotes pertaining to disclosure of genetic test results.*

Topics	Community advisory board	Healthcare providers/team members
Barriers	*Poor knowledge of people on what genetic test is the major barrier, talk less of disclosing the results for the test. -Imam, Kano* *I think people feel it is not something they should really do so that makes it difficult. – Journalist, Zaria.* *I think discrimination and people think that I won't get a husband or wife to marry if people know that these run in the family. - Health Services Administrator, Accra HS Admin., Accra* *Is cost intensive that people would think I don't have the money and that's also a barrier. -Health Services Administrator, Accra.* *Ignorance of the people on what genetic testing is the main barrier. - Community Leader, Kano.* *But in Africa, you know we are the kind of people that are very selective, once they know something, once they know you have a problem, it is going to be a talk on the town. People won't want to move closer to you. - Pastor, Ibadan* *At the same time, naturally as Muslim and Muslim scholar for that matter, we always look unto issues through Islamic juridentic way. How unlawful Muslim to subject himself or herself to that type of exercise, so it is a kind of an issue that we have been looking at. - Imam, Ibadan* *Another thing that I can see is an obstacle to disclosure of genetic test is the environmental circumstances. Let me just put it that way, where a lot of people are living, they may not even believe that such a thing is existing, at least those people that are living in rural area now. - Engineer, Ibadan.* *The way some medical workers like nurses, and some medical doctors too, the way they voice their mind on issues is derogatory to such issues to be accepted by ordinary person. - Imam, Ibadan.* *One of the barriers is the language. - Imam, Ilorin.*	*There are lots of barriers; fear of family displacement, breakup increase in marriages and divorce by husbands and wives. -Community Nurse, Kano* *Distance to testing facility. The distance, take for instance someone from maybe a rural area or whatever, you now ask such person to go and collect result from UCH [hospital in Ibadan]. - Public Health Nurse, Abeokuta.* *One of the barriers is that they have low understanding [ignorance]- Nurse, Ilorin.* *The readiness to accept result- readiness in the sense that even though you are telling the person that you have it and person keep telling you that I don't have it and the result now comes out and the person have it the fear of disclosing the result because the person will not accept the result. – Public Health Nurse, Ibadan.* *Something that will impede people from, impede the health worker from disclosing to the patient, like loss of contact. - Health Educator, Ilorin* *One is lack of proper training and I think if people have not been properly trained on how to disclose information that may evoke negative reactions by the hearers then that can be a problem. -Pathologist, Accra* *Well given the culture we have and our cultural background, one of the barrier is that people don't want to do anything to their health, many prefer to die than to know information about their health even if it is preventive, they don't want to hear that anything is wrong with them until it happens and they take it as their own faith. - Nurse Health Educator, Abeokuta*
Facilitators	*Legislation and then national framework or established systems that would buy into the necessity of this condition and then by virtue of that facilitate the provision of legislation, adequate resources. - Islamic Leader, Accra* *I think there needs to be an enlightenment campaign, advertisement that give people an idea on what it means and how beneficial it is to society. - Pastor, Zaria.* *Availability of testing facilities. When people have access to doing it on their own without being coerced, readily when they have some symptoms, they can readily go to the facility and say please check this things, me I want to know my status, and by the time they know, because they are the ones that volunteered, without any coerce to approach for testing, so disclosure will not be.- Imam, Ilorin*	*That ideally it should be a multi-disciplinary event because you need to talk about the consequence of what you want to do particularly when what you want to disclose is something that is palatable to the client, so you need some other expertise like multi-disciplinary approach. – Pediatrician, Ibadan* *What I think is that in any disclosure of any result, you have to create a very enabling environment. -Nurse, Ilorin.* *You do a type of rapport in between you and your client. - Nurse, Ilorin* *The education background of the client, studies have those that are well educated will want to do certain procedure investigation because of their background as educated person whereas those that are below average in term of education that could also be an impediment to them. -Nurse Health Educator, Abeokuta* *What I know is that once patients get the confidence of the doctor, you know, when they get the confidence of the doctor, and they know the doctor is really after*

Table 3 (*Continued*)

Topics	Community advisory board	Healthcare providers/team members
		their condition, there is no level that they cannot go in cooperating with whatever you want to do with them. — Pathologist, Ilorin *The only thing I will say is training, that is all, the more people have been trained in genetic counselling, it will go a long way to facilitate the disclosure of genetic test result. -Medical Microbiologist, Abeokuta* *Religious leaders can also be helpful in communicating this, even targeting churches, mosques and other places of worship to let people see the need for genetic testing - Neurologist, Ilorin*
Suggestions	*All the medical workers should be properly oriented; they should always mind their language when dealing with uninformed people. They shouldn't be that careless in passing negative comment regarding genetic researches. - Imam, Ibadan* *Creating good awareness campaign among the community members on health issues.- Community Leader, Kano* *We will first of all understudy who and who will be our gate keeper, that is number one, then after identifying them, they are the first people to be sensitized and convince their acceptance of the mission. - Imam, Ibadan* *Also, there should be a network of collaboration between state agencies like NCCE, Ministry of Health and Ghana Health Service in order to come down to the community to create these awareness.- Islamic Leader, Accra* *Peer influence too and the social grouping to be capitalized upon because they often get influenced by friends and socio group. - Imam, Ibadan.*	*Empathy should be shown when disclosing the results. -Neurologist, Kano* *I think possibly what I would look forward to see is an improve turnaround time in terms of ensuring that this result come out on time and having more of this available around. -Pathologist, Abeokuta* *We need an enabling framework, we need a legal backing, we need more awareness. -Neurologist, Abeokuta* *I will recommend that there should be national or worldwide education and we should have people to advertise this on national television, radio so that most people would be aware of it. - Community Health Nurse, Accra*

empathy, timeliness of result, disclosure of results by my managing physician, awareness, family involvement, availability of electronic results to clients, and to train health worker in local dialect.

Participant perceptions on how to sensitize people about genetic testing were identification and sensitization of community gate keepers, provision of free testing, testimony from experienced, advocacy, campaigns, training by professionals, use of religious gathering, financial incentives, use of social and peer groups, use of local languages, continuous education, follow up, involvement of community leaders, institution of a health committee, training of health educators, mass media education. Suggestions for enhancing disclosure of results from genetic testing from both community advisory board and healthcare team members are highlighted in Table 3.

Discussion and conclusions

This report outlined the instinctive perceptions, preferences, and attitudes towards disclosure of genetic testing results among community advisory board members and health care professionals with a total of 61 participants. Both lay CAB members and healthcare team respondents noted similarities across barriers and facilitators of disclosure of genetic test results. Key factors for both groups included the lack of awareness or knowledge about genetic testing, the need for respecting individual and cultural preferences, through inclusion of family members or faith leaders in discussions, and recommendations for expanded oversight or legislation on genetic testing and increased education for all. While both groups highlighted the need to respect individual and cultural values, our findings noted variation between groups on who they felt should be included in discussions surrounding disclosure of genetic test results. Many of our participants felt strongly that spiritual and traditional leaders should be part of the discussion group. According to Akpinar and Ersoy,[26] issues such as that of privacy and confidentiality may arise during disclosure of genetic test results. Our results illustrate the disclosure dilemmas and highlight suggestions for improving the intention to disclose in a culturally sensitive way, which was a recommendation in a systematic review conducted by Vears et al.[27]

Our data corroborate previous findings that people indeed let quality and type of relationship govern attitudes and disclosure preferences. Limiting one's own perceived duty to inform only selected individuals could be interpreted as a compromise to escape the discomfort of conflicting moral duties, i.e., the duty to warn and the duty to protect from harm.[28] In a study by Hawranek, Hajdarevic and Rosén[29] participants raised concern about informing relatives and felt it was unnecessary to cause unrest by creating a scare of disease in the relatives. It is important to note that the preference to inform only selected relatives did not imply that our respondents wanted to relinquish the responsibility of risk disclosure altogether. The question was not about selecting one or the other mode of disclosure as the optimal approach but rather using a mix of both family-mediated, religion-mediated and healthcare-mediated disclosure efforts, preferably with healthcare taking the main responsibility. The findings show that background factors may predict attitudes about genetic information and intention to disclose. The impact of religiosity on disclosure is strong in this study as strong religious beliefs in Sub-Saharan Africa are associated with intention to inform relatives, which was not noted as heavily in similar research conducted in other geographic areas.

Our findings regarding the correlation between level of education, enabling environment, involvement of religious and community leaders, campaigns, and possible treatment options and intention to disclose are important considering the paucity of studies on the subject. According to Gilbar et al,[28] a high level of education will increase patient's acceptance and understanding of genetic test result disclosure and its implications on their health. A recent study indicates that higher education may predict a lower level of disclosure to relatives.[30] Furthermore, a better understanding of expectations between patients, healthcare and relatives, and a more collaborative approach towards disclosure might be a way forward in improving practice of disclosure of genetic results. Also, the findings provide justification for an evaluation of genetic testing disclosure that includes the patient in the decision making of the disclosure process.

Practice Implications

Our findings have important implications for clinicians in genetic counselling. Our study shows that personal, social and demographic characteristics affect attitudes towards disclosure to relatives. This may require clinicians to shape the encounters based on the patient's particular characteristics and discern the attitude of the patient to disclosure. Furthermore, our finding could shape the development of disclosure model that factors in that influence the perception, disclosure, reception of genetic testing for stroke. Such model may be scalable to other healthcare conditions in the African setting.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent

Informed consent was obtained from all individual participants included in the study prior to engaging in study activities.

Animal studies

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

Declaration of Competing Interest

The authors declare that they have no conflict of interest.

Acknowledgments: Our work is supported by The National Institutes of Health grants: SIREN (U54HG007479), SIBS Genomics (R01NS107900), SIBS Gen-Gen (R01NS10790002S1), African Neurobiobankfor Precision Stroke Medicine ELSI Project (U01HG010273), ARISES (R01NS115944−01), H3Africa CVD Supplement (3U24HG009780−03S5), CaNVAS (1R01NS114045-01), Sub-Saharan Africa Conference on Stroke (SSACS) 1R13NS115395-01A1 Training Africans to Lead and Execute Neurological Trials & Studies (TALENTS) D43TW012030

References

1. Roberts MC, Dotson WD, DeVore CS, Bednar EM, Bowen DJ, Ganiats TG, Green RF, Hurst GM, Philp AR, Ricker CN, et al. Delivery of cascade screening for hereditary conditions: a scoping review of the literature. Health Aff (Millwood) 2018;37:801-808.
2. Gaff CL, Clarke AJ, Atkinson P, Sivell S, Elwyn G, Iredale R, Thornton H, Dundon J, Shaw C, Edwards A. Process and outcome in communication of genetic information within families: a systematic review. Eur J Hum Genet 2007;15:999-1011.
3. Haga SB, Barry WT, Mills R, Ginsburg GS, Svetkey L, Sullivan J, Willard HF. Public knowledge of and attitudes toward genetics and genetic testing. Genetic Testing Mol Biomarkers 2013;17(4):327-335. https://doi.org/10.1089/gtmb.2012.0350.
4. Becker F, Van El CG, Ibarreta D, et al. Genetic testing and common disorders in a public health framework: how to assess relevance and possibilities. Eur J Hum Genet 2011;19(1):S6-S44.

5. Baars MJH, Henneman L, Ten Kate LP. Deficiency of knowledge of genetics and genetic tests among general practitioners, gynecologists, and pediatricians: a global problem. Genet Med 2005;7(9):605-610.
6. Challen K, Harris H, Kristoffersson U, et al. General practitioner management of genetic aspects of a cardiac disease: a scenario-based study to anticipate providers' practices. J Commun Genetics 2010;1(2):83-90.
7. Klemenc-Ketiš Z, Peterlin B. Family physicians' management of genetic aspects of a cardiac disease: a scenario-based study from Slovenia. Balkan J Med Genetics 2014;17(1):15-22.
8. Houwink EJ, Van Luijk SJ, Henneman L, Van Der Vleuten C, Jan Dinant G, Cornel MC. Genetic educational needs and the role of genetics in primary care: a focus group study with multiple perspectives. BMC Family Pract 2011;12.
9. Howard HC, Borry P. Survey of European clinical geneticists on awareness, experiences and attitudes towards direct-to-consumer genetic testing. Genome Med 2013;5 (5). no.article no. 45.
10. Cherkas LF, Harris JM, Levinson E, Spector TD, Prainsack B. A survey of UK public interest in internet-based personal genome testing. PLoS One 2010;5(10). Article ID e13473.
11. Vayena E, Gourna E, Streuli J, Hafen E, Prainsack B. Experiences of early users of direct-to-consumer genomics in Switzerland: an exploratory study. Public Health Genomics 2012;15(6):352-362.
12. Mavroidopoulou V, Xera E, Mollaki V. Awareness, attitudes and perspectives of direct-to-consumer genetic testing in Greece: a survey of potential consumers. J Hum Genet 2015;60(9):515-523.
13. Jallinoja P, Aro AR. "Does knowledge make a difference? The association between knowledge about genes and attitudes toward gene tests. J Health Commun 2000;5(1):29-39.
14. Hietala M, Hakonen A, Aro AR, Niemela P, Peltonen L, Aula P. Attitudes toward genetic testing among the general population and relatives of patients with a severe genetic disease: a survey from Finland. Am J Hum Genet 1995;56(6):1493-1500.
15. Vermeulen E, Henneman L, Van El CG, Cornel MC. Public attitudes towards preventive genomics and personal interest in genetic testing to prevent disease: a survey study. Eur J Public Health 2013;24(5):768-775.
16. Henneman L, Vermeulen E, vanEl CG, et al. Public attitudes towards genetic testing revisited: comparing opinions between 2002 and 2010". Eur J Hum Genet 2002;21 (8):793-799.
17. Panic N, Leoncini E, Di Giannantonio P, et al. Survey on knowledge, attitudes, and training needs of Italian residents on genetic tests for hereditary breast and colorectal cancer. Biomed Res Int 2014:7.. Article ID 418416pages.
18. Calsbeek H, Morren M, Bensing J, Rijken M. Knowledge and attitudes towards genetic testing: a two year follow-up study in patients with asthma, diabetes mellitus and cardiovascular disease. J Genet Couns 2007;16 (4):493-504.
19. Oliveri S, Renzi C, Pravettoni G. Toward an in-depth profiling of DTC users. Clin Genet 2015;88(5):505-506.
20. Oliveri S, Renzi C, Masiero M, Pravettoni G. Living at risk: factors that affect the experience of direct-to-consumer genetic testing. Mayo Clin Proc 2015;90(10):1323-1326. article no. 1101.
21. Oliveri S, Pravettoni G. The disclosure of direct-to-consumer genetic testing: sounding out the psychological perspective of consumers. Biol Med 2016;8. article 316.
22. Kitzinger J, Rosaline SB. Developing Focus Group Research. London, UK: SAGE Publications Ltd.; 1999.
23. Tausch AP, Menold N. Methodological aspects of focus groups in health research: results of qualitative interviews with focus group moderators. Glob Qual Nurs Res 2016;3:2333393616630466.
24. Morgan D. Successful Focus Groups: Advancing the State of the Art. Thousand Oaks, OK: SAGE Publications, Inc.; 1993.
25. Singh A, Jenkins C, Calys-Tagoe B, Arulogun OS, Sarfo S, et al. Stroke investigative research and education network: public outreach and engagement. J Commun Med Health Educ 2017;7:518. https://doi.org/10.4172/2161-0711.1000518.
26. Akpinar A, Ersoy N. Attitudes of physicians and patients towards disclosure of genetic information to spouse and first-degree relatives: a case study from Turkey. BMC Med Ethics 2014;15:39. https://doi.org/10.1186/1472-6939-15-39.
27. Vears DF, Minion JT, Roberts SJ, Cummings J, Machirori M, Blell M, et al. Return of individual research results from genomic research: a systematic review of stakeholder perspectives. PLoS One 2021. https://doi.org/10.1371/journal.pone.0258646.
28. Gilbar R, Shalev S, Spiegel R, Pras E, Berkenstadt M, Sagi M, Ben-Yehuda A, Mor P, Perry S, Zaccai TF, Borochowitz Z, Barnoy S. Patients' attitudes towards disclosure of genetic test results to family members: the impact of patients' sociodemographic background and counseling experience. J Genet Counsel 2016;25:314-324. https://doi.org/10.1007/s10897-015-9873-1.
29. Hawranek C, Hajdarevic S, Rosén AA. Focus group study of perceptions of genetic risk disclosure in members of the public in sweden: "i'll phone the five closest ones, but what happens to the other ten? J Pers Med 2021;11:1191.. 10.3390/jpm11111191.
30. Kegelaers D, Merckx W, Odeurs P, van den Ende J, Blaumeiser B. Disclosure pattern and follow-up after the molecular diagnosis of BRCA/CHEK2 mutations. J Genet Couns 2014;23(2):254-261.