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Awareness, experiences and perceptions regarding genetic testing and the return of genetic and genomics results in a hypothetical research context among patients in Uganda: a qualitative study

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ABSTRACT

Background Genetic testing presents unique ethical challenges for research and clinical practice, particularly in low-resource settings. To address such challenges, context-specific understanding of ethical, legal and social issues is essential. Return of genetics and genomics research (GGR) results remains an unresolved yet topical issue particularly in African settings that lack appropriate regulation and guidelines. Despite the need to understand what is contextually acceptable, there is a paucity of empirical research and literature on what constitutes appropriate practice with respect to GGR. The study assessed patients' awareness, experiences and perceptions regarding genetic testing and the return of GGR results in a hypothetical context.

Methods This cross-sectional study employed a qualitative exploratory approach. Respondents were patients attending the medical outpatient unit of Mulago National Hospital. Three deliberative focus group discussions involving 18 respondents were conducted. Data were analysed through thematic analysis.

Results Three main themes and several subthemes were identified. Most respondents were aware of genetic testing, supportive of GGR and receiving results. However, only a few had undergone genetic testing due to cost constraints. They articulated the need for adequate information and genetic counselling to inform decision-making. Privacy of results was important to respondents while others were willing to share results.

Conclusion There was general awareness and support for GGR and the return of results. Stigmatisation emerged as a barrier to disclosure of results for some. Global health inequity impacts access and affordability of genetic testing and counselling in Africa and should be addressed as a matter of social justice.

INTRODUCTION

Genetics and genomics research (GGR) and testing present unique ethical, legal and social challenges for research and clinical practice particularly in low-resource settings.[1–4] To address such challenges, context-specific understanding of ethical, legal and social issues (ELSI) is essential. Such knowledge is useful in the process of developing appropriate ethics frameworks for genetic testing. The return of results following GGR, and testing remains topical but unresolved particularly in the African setting due to lack of appropriate regulatory frameworks.[1 2] Additionally, literature on what constitutes appropriate practice in a particular context is limited.[5–13] Although existing international GGR-specific ethics guidelines can be used to inform policy development in research, adequate understanding of the local clinical context is essential.[1 14] In Uganda, some literature has been generated to guide the process.[4–6] However, most studies are related to genetics or other research contexts, capturing views of research participants or researchers.[4–7] The clinical context and patient views have not been explored in the Ugandan setting neither are there any publications on patient views even though patients are the usual consumers of many diagnostic, therapeutic and public health interventions. Such patients tend to be more familiar with genetic testing, rather than genomics which is used mainly in research or for pathogen genomics testing. A significant amount of genetic testing particularly for clinical diagnosis like sickle cell disease, forensic identification and paternity testing is conducted in the country. Forensic examination is usually handled by the government, while the other tests to a great extent are paid for privately by the individuals tested or their family. In the case of research, genetic and genomic testing will be funded by the study, with no costs to the participants. Yet many ethical and legal issues associated with genetic and genomic testing and research remain a challenge even in resource rich settings.[15–18] Exploring perceptions of different stakeholders can help identify such issues to guide formulation of culturally appropriate approaches and ethics frameworks for GGR testing and return of results. There is a need to capture views from a wide range of stakeholders and generate data that are representative of the relevant clinical healthcare settings.

This study assessed patients' awareness, experiences and perceptions regarding genetic testing and the return of results in a hypothetical GGR context.

METHODS

Study design and setting

This was an exploratory cross-sectional study that employed qualitative methods of data collection. The study was conducted by a multidisciplinary team of researchers comprising social scientists, bioethicists and medical scientists with experience in qualitative research. JO a male MD, BK a

female PhD sociology academic of more than 20 years and JB a male PhD Philosophy academic led the focus group discussions (FGDs). They were assisted by a male and female research assistants with masters-level bioethics training. Respondents were Ugandan patients recruited from the medical outpatient unit of Mulago hospital. The hospital was purposively selected for being a national referral hospital that attends to patients from across the country. Three deliberative FGDs involving 18 respondents were conducted. Respondents were recruited from predetermined hospital units. Respondents were not known to the researchers and were contacted and recruited during their clinic attendance.

Data collection

The FGDs were conducted privately in a spacious meeting room away from non-participants. Data collection entailed face-to-face FGDs conducted in the local language (Luganda), lasting about 90–120 min, in strict adherence to COVID-19 protocols. The FGDs were conducted using a guide adopted from related work.[19] Respondents were assessed about their perspectives in a hypothetical GGR setting. Initially, participants were asked general questions on awareness and knowledge about genetics, this was followed by an explanation/educational session on genetics, genes, DNA, genome, genetic testing and feedback of results lasting about 30 min. The educational session was followed by the discussion according to the FGD guide. Key aspects addressed included understanding of genetics and genomics, experience with genetics testing, feedback of results in a hypothetical research context and any other considerations. Data were collected between June and July 2021. The discussions were audiorecorded, complemented by note taking.

Data management and analysis

Recorded data were transcribed verbatim, checked for accuracy and later translated into English. Thematic analysis was conducted manually using a comprehensive thematic matrix that included identifying codes and categories to identify common patterns arising from the narratives. The coding conducted by JO and BK was done both deductively based on predetermined themes and inductively based on emerging themes. JO was involved in applying and confirming application of codes across all transcripts and disagreements were resolved by cross checking with the recorded data. Qualitative information is presented as narratives and quotes.

RESULTS

The age range of the 18 respondents was 19–60 years and 12 were female. They attended various clinics including those treating rheumatology, haematology, diabetic, cardiology and hypertensive conditions. All respondents expressed willingness to participate in GGR testing as part of clinical care and feedback of test results. Many had awareness of genetic testing, and a few had undergone testing. They observed the need for adequate information, genetic counselling and privacy during GGR. Concerns about affordability of such testing services post-research were raised.

Analysis of data identified three themes: (1) awareness and experiences of genetic testing; (2) perspectives on hypothetical GGR and feedback of results and (3) potential for stigma associated with disclosure of results and several subthemes (table 1).

Table 1 Summary of themes and subthemes

No	Theme	Subtheme
1.	Awareness and experiences of genetic testing	Experience following genetic testing of other family members
		Experiences of genetic testing and sharing results with the family
2.	Perspectives on hypothetical GGR and feedback of results	Role of the doctor
		Public and individual education and information
		Genetic counselling
3.	Potential for stigma associated with disclosure of results	

GGR, genetics and genomics research.

Awareness and experiences of genetic testing

Although none of the respondents had GGR participation and experience, most had knowledge about DNA-related testing. Some respondents had undergone genetic testing for diagnostic purposes, others had experience from testing of a family member for DNA related to paternity conflicts while others had learnt about DNA testing through the media such as television and radio.

> I had a genetic test done because I would fall sick [frequent attacks of sickness] but they couldn't establish what I was suffering from till they checked my DNA and established what I was suffering from. **FGD 002 Respondent 2**
>
> My uncle died and the family was not sure if the children belonged to him. They took samples and tested for paternity. This testing took place in South Africa. **FGD 001 Respondent 4**

Respondents felt that the process for genetic testing should consider aspects like adequate information sharing and informed consent to facilitate understanding and preparedness.

> Doctor has to counsel you and tell you how your results would affect you **FGD 001 Respondent 2**

Experience from other family members

Some of the respondents' awareness was based on experiences of family members who had been tested for diagnostic, treatment and paternity confirmatory purposes.

> Our aunty delivered our cousin when she was still schooling. He grew up with his grandfather …This boy did not have a sibling, so they took a sample from one of our close uncles and discovered that the percentage of relatedness was very high. **FGD 002 Respondent 6**

Experience with genetic testing and sharing genetic results with family

Although respondents had not participated in GGR, some who had been tested in the clinical setting shared their genetic test results with close family members, while others went further to include members of the extended family to raise awareness concerning their genetic condition and to encourage others to test.

> For me I took a picture of my test results and shared them on the family WhatsApp group, **FGD 001 Respondent 2**

I desire that all people be informed…. I can tell them that I am in such and such a state in order to protect others… **FGD 001 Respondent 4**

The role of the government

Several challenges were highlighted that could make GGR and genetic testing difficult in the Ugandan setting. Some respondents were concerned about the prohibitive costs associated with the testing, which limits demand and poststudy access for such services. Hence, the call for government intervention to subsidise costs for genetic testing in the clinical context to facilitate community benefit from the outcomes of GGR. Other aspects included the long time it takes to receive such results.

The government should first help us concerning money; it is too much. The poor cannot afford such costs. **FGD 002 Respondent 1**

Perspectives on hypothetical GGR and return of results

Respondents observed that appropriate GGR and return of results requires a clear process that would mitigate possible negative implications. They proposed several roles for the key actors including the central government, health workers and highlighted the need for education and information on genetics, genomics as well as genetic counselling.

Role of the doctor

Most of the respondents felt that return of GGR results should be done by the doctor/researcher, who should ensure privacy while sharing the results. Other respondents expressed the need for the presence of a close family member to provide moral support.

I would want to be told when there are other people around because you may collapse but if there is somebody to comfort you, you may not be so overpowered. **FGD 002 Respondent 4**

They felt that the doctor should be able to disclose all the necessary information to the individuals tested to facilitate understanding and decision-making. Hence, the need for disclosure of the potential positive and negative outcomes for the GGR test.

I think that doctors have to sit down the patient and explain to them that they are not the first… they need to encourage the patients. **FGD 002 Respondent 2**

Public and individual information and education on genetics

Respondents felt that since genetic information is relatively new to most communities, it would be important to sensitise the public and create awareness on genetics, GGR, its importance and the return of results. Other aspects should help the communities appreciate what GGR entails and its implications. Such education would prepare individuals for any future GGR and testing. Respondents observed that such public preparedness is feasible since it has been achieved regarding testing for HIV/AIDS.

We should first be taught about possible outcomes and the implications. Such a study would be good. **FGD 002 Respondent 4**

Respondents stressed the need to understand GGR, the return of results and their implications, to facilitate informed decision-making on testing and receipt of results. Such informed consent facilitates appreciation of the risks and benefits of the research study.

Receipt of results was useful. Now I swallow my medicine since I know what I am suffering from. **FGD 002 Respondent 2**
I think that they should educate us. In case of sickle cell anaemia, they should find a way of talking to the whole family and encourage them to get tested. **FGD 002 Respondent 3**

Appropriate genetic counselling

Respondents highlighted the need for genetic counselling to help individuals understand GGR, the nature of the genetic test, its benefits and risks. Such counselling was considered important both before the test and at the time of sharing the results.

I think the doctor should first counsel you to be strong, they should inform clients about the possibility of treatment. **FGD 002 Respondent 1**
Before being tested I would need counselling, in case they find that I have the disease. **FGD 001 Respondent 3**

Respondents felt that counselling would prepare the individual psychologically for any implications. They stressed the need to highlight the positive and negative outcomes of the proposed GGR, and available treatment or preventive measures.

What I know is counselling before they even start testing. I have to be told the bitter truth … to prepare me for the results. **FGD 002 Respondent 6**

Respondents opined that genetic counselling should ensure privacy. Adequate time and attention should be dedicated to the clients.

I wouldn't want the results to be disclosed in the presence of other people. When they discover that I have sickle cells, I need to be counselled alone. **FGD 002 Respondent 6**

Potential for stigma associated with return of results

The need for privacy and confidentiality concerning GGR and the return of results was highlighted as an important aspect to minimise the potential for stigma. Hence the disclosure of results, especially those concerning diseases should be restricted to the patient and in some cases a trusted person, otherwise they should remain confidential.

Apart from the doctor, I only want one other person to know the results. I would ask the doctor to explain to my sister that would have accompanied me … other people may indiscreetly share the results. **FGD 001 Respondent 1**

The fear of stigma and its negative implications such as gossip, and mockery is a major deterrent to wider disclosure of GGR results.

They should be kept between me and the doctor, I would not want anyone else to know them. **FGD 003 Respondent 2**
Wherever you pass people would gossip about you saying 'there she is, the sick one', which is not good. **FGD 003 Respondent 1**

Stigma contributes to isolation, psychological torture and a low self-esteem. This was perceived as being harmful to one's health.

> Mockery can rob one of peace and can hasten the advancement of disease. It would be good to keep results confidential, restricted to the client and the doctor or the spouse, such that others don't get to know. **FGD 003 Respondent 4**
>
> It is painful because people will not want to associate with you, it may be a strange disease and they discriminate against you. So, at times you may not want people to know. **FGD 001 Respondent 2**

DISCUSSION

The study assessed patients' awareness, experiences and perceptions regarding genetic testing and return of results in a hypothetical GGR setting. Findings show that most of the respondents had general awareness of DNA-related genetic testing, were supportive of GGR, genetic testing and feedback of results, although relatively few had undergone genetic testing and no participation in GGR. They highlighted the challenge of access to genetic testing services when such research ends and, this could have increased the supportive attitude to GGR where genetics and genomics testing would occur as part of the research study and would have no cost implications. The important role of genetic counselling during consent processes in GGR was highlighted. Furthermore, the potential for negative implications of inadvertent disclosure of results to family members during research was highlighted and constitutes a potential research related risk.

Most of the respondents had some knowledge concerning genetic testing. The media, particularly television, has played a major role in creating awareness concerning genetic testing particularly that associated with paternity and forensic identification following disasters like school fires. Television has also been considered effective in disseminating scientific information, raising awareness in HIV and facilitating empowerment of women.[20–22] However, only a few respondents had been tested which is due in part to genetic testing being a relatively new but expensive practice in the Ugandan clinical setting.

Respondents expressed willingness to participate in hypothetical GGR, undergo genetic testing and receive results, which was considered essential for decision-making concerning personal and family health. However, in the research context, results may not always impact on personal or family health. The need for feedback of results is stipulated in national and international ethics guidelines as an obligation in research, generally,[23 24] and should be part of the informed consent process, though this is still unresolved in GGR.[14] Return of GGR results could potentially improve confidence in the research process and build trust within the research community but is not always possible, especially if results are not specific, predictive or actionable. Feedback of results in the clinical setting is less of a challenge than in research, since it is usually diagnostic, and therefore, expected that results will be returned. Related work in Uganda highlighted the need to provide feedback of GGR results by researchers and grassroots communities.[4 19 25] Researchers in Uganda supported only the return of results that are considered actionable/beneficial in keeping with recommendations from the American College of Medical Genetics and Genomics, the European Society of Human Genetics, the Global Alliance for Genomics and Health and the H3Africa consortium.[14 26–29] However, grassroots communities expressed the need to receive all their interpretable results because it was considered useful health information. The need for feedback has also been observed by genomics research participants in other related settings.[6 10]

However, for such feedback of research results to be meaningful and safe, it has to be conducted appropriately in accordance with contextualised ethics guidelines based on socio—cultural norms. Feedback is an ethical requirement that forms part of the informed consent process as stipulated by local and international research ethics frameworks.[23 24]

Although participation in GGR and testing was acceptable, respondents were concerned about the possible high cost of genetic testing in the clinical setting which would limit utilisation of the outcomes of such research. For example, paternity testing (a common test in the country) costs US$60–US$400 at private facilities. The lack of government funding for genetic testing limits access and affordability of such services as well as societal benefits from such research. Hence the call for government intervention to make genetic testing affordable and accessible to ordinary citizens. However, in a research context, genetic and genomic testing is usually free. In settings where genetic and genomic testing is expensive and not easily accessible, research studies could serve as an easier way to access such testing. Access to genetic and genomic testing could even be considered an unfair inducement to research participation if clinically actionable results are returned to participants in Low and Middle Income Countries (LMICs). The issue of GGR affordability of genetic testing has also been raised in a related study involving grassroots communities in Uganda that proposed the use of meaningful and beneficial community engagement to address the gaps and facilitate poststudy access.[19] The fears concerning the cost of genetic testing is worsened by the fact that African populations retain more genetic diversity yet are tremendously under-represented in genetic studies. Limited genetic data and testing services on the continent as a consequence of global health inequity remains a social justice challenge.[30–34]

Several considerations were proposed for both GGR and feedback of results including the need for appropriate genetic counselling and meaningful information sharing as part of the consent process. The requirement for informed consent is an ethical obligation both in clinical care and research and pivotal to patient decision-making. Informed consent for genetic or genomics testing in research should be a process that occurs before testing and continues to the time of communicating results and beyond.[4–6 19 25] To enhance comprehension, consent should be sought in a language understood by the participant, written in simple terms and participants should be allowed enough time to understand the complex scientific information.[7] However, genetics is challenged with unfamiliar terminologies and vocabulary that may be very difficult to translate into local languages. Hence the need to devise appropriate mechanisms, including audio-visual aids and contextualised language translation, to facilitate individuals' understanding.

Additionally, public sensitisation and education is a form of public/community engagement which is important and an ethics standard for community-based interventions and research. Meaningful community engagement facilitates community empowerment and participation in the concerned interventions as well as uptake of any new interventions proved to be effective. Community engagement has been recommended for genetics related research and testing that involves specific communities or populations. This need for community engagement has been stressed by participants in related studies involving genomic researchers and grassroots communities in Uganda.[4 12 27] However, public engagement for genetic testing in the clinical setting is also necessary.

Genetic counselling facilitates understanding of the complex nature of genetics, genomics, genetic results and their meaning as well as implications. A clear interpretation of the meaning of the findings is necessary because not all genetic predispositions

result in disease. Genetic counselling has been documented as an effective mechanism to address misconceptions associated with genetic testing and is essential in ensuring adequate understanding of testing and the implications in research and clinical settings.[4 35–39] However, qualified genetic counsellors are lacking in Uganda.[4 25] Hence, the suggestion by study respondents that the doctors who are considered knowledgeable and trusted by the population conduct genetic counselling. However, no evidence exists on doctors who have been trained as genetic counsellors in the country.[4 25] This finding has implications for medical and research training of doctors and researchers in Uganda. The need for capacity building in genetic testing, guidelines and policy development has also been highlighted by the Academy of Science of South Africa.[40]

Inappropriate handling of genetic information has potential for significant social and psychological harms to both the individuals tested, their families and sometimes the wider community.[36–43] Stigma and the ensuing discrimination after disclosure of an individual's genetic information is a major concern. Genetics results could be a basis for family breakups particularly following discordant paternity results or denial of insurance. Owing to the potential negative implications, genetic information should be handled with care to protect privacy and confidentiality. The need to observe privacy and confidentiality during GGR and return of results has been widely publicised but unresolved even in resource rich setting.[41–49] Additionally, although respondents highlighted the need for privacy, many also preferred the presence of a loved one at the time of consent and return of results, a trade off that people often make. But since the presence of a close one is permitted with express permission of the individual tested, this may not be a breach to privacy and confidentiality. However, researchers should be sensitised to how results are returned to participants, especially in cases of misattributed paternity.

Finally, most of the available literature on the ELSI associated with GGR in Uganda has been generated from individuals in research settings.[4–7 22] Our addition of patient perspectives on hypothetical GGR to the available literature widens the stakeholder knowledge base on GGR. We hope this will add useful data that can inform more inclusive ethics guidelines for genetic testing and feedback of results.

Limitations

Being a qualitative study and involving patients from only one hospital may not represent views of the population. Perspectives on return of results in a hypothetical research study could differ from perspectives elicited from patients who had participated in GGR previously. Consequently, some aspects of discussion around return of results in GGR may not be as nuanced coming from patients with limited or no exposure to research. However, related work has been conducted among different stakeholders to capture views from a wider stakeholder base.[4 19 23]

CONCLUSION

There was general awareness of genetic testing and support for hypothetical GGR, testing and feedback of results but this needs to be framed by appropriate guidelines and regulations to facilitate ethical practice. Stigmatisation emerged as a barrier to disclosure of results for some, and this fear can be mitigated by effective genetic counselling to reduce inadvertent disclosure of results during consent processes in research, observance of privacy and confidentiality as well as public education and engagement. Global health inequity impacts on access to and affordability of genetic and genomic testing and counselling in Africa and this must be addressed at both local and international levels if social justice is to be achieved in global health.

Contributors JO conceptualised this study; JO, BK and JB, developed data collection tools; JO, BK and JB collected data; JO and BK analysed data; KM and MM reviewed all transcripts and edited all drafts of the manuscript; JO guarantor. All authors provided substantive intellectual contributions to the study and manuscript and approve of its content.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants and ethical review and approval was obtained from the Makerere University School of Biomedical Sciences Research and Ethics Committee ref. SBS 787 and the Health Research Ethics Committee, Stellenbosch University ref. HREC 16853, followed by clearance by the Uganda National Council for Science and Technology (UNCST) ref. SS268ES. Participants gave informed consent to participate in the study before taking part.

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