Title

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Journal

AJOB Empirical Bioethics, 10(3)

ISSN

2329-4515

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Publication Date

2019-08-05

DOI

10.1080/23294515.2019.1645759

Peer reviewed

HHS Public Access

Author manuscript

AJOB Empir Bioeth. Author manuscript; available in PMC 2020 May 28.

Published in final edited form as:

AJOB Empir Bioeth. 2019 ; 10(3): 182–189. doi:10.1080/23294515.2019.1645759.

Exploring the role of shared decision making in the consent process for pediatric genomics research in Cameroon, Tanzania and Ghana

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Abstract

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Authors' contributions

M.J.T., J.M., K.O.F., S.M.C., J.D.V., K.A., and A.W. conceived the study, participated in its design, interacted with the participants, D.B., J.D.A., K.K.K., and C.M. performed interviews transcriptions, and translations; D.B. J.D.V., M.J.T and A.W. helped to draft the manuscript. All authors read and approved the final manuscript.

Ethics approval and consent to participate

Institutional review board (ethics) approval was obtained from all participating institutions. Informed consent was obtained from all study participants.

Consent for publication

Not applicable

Availability of data and material

The data set supporting the conclusions of this article, including raw transcript data, is available from authors on request.

Competing interests

The authors declare that no conflicting financial interests exist.

Background: It is customarily perceived that in Africa, decisions around research participation may be based not only on individual reflection but also on discussions with others. Some authors have argued that such decision-making is reflective of a more traditional communitarian African worldview; one critique of such a perspective is that it is lacking an empirical grounding. In this study, we explore decision-making around enrollment in sickle cell genomics research in three countries in Africa namely Ghana, Cameroon and Tanzania. Particularly, we focus on exploring the role of shared decision making with regard to participating in genomic studies.

Results: We involved 64 participants in 16 individual interviews or in 48 focus group discussions with research participants in rural and urban Tanzania (n=20), Ghana (n=30) and Cameroon (n=14). We used a vignette to explore decision-making around enrollment of children in sickle cell genomics research. Data were imported in Nvivo11 and analyzed using thematic content analysis. Our findings indicate that the majority of the participants from both rural and urban settings prefer to make their own individual decisions and not consult with extended family or community leaders. Shared decision making was only considered necessary for individuals who were perceived to be in some way vulnerable.

Conclusion: We found very limited support for shared decision-making as the primary process for decision-making about research participation. Whilst consultation was considered important to support individual decision-making, particularly when parents were perceived as vulnerable, there was no suggestion in our data that shared decision-making would be a more important or valuable means of seeking consent for research participation in the African research context.

Keywords

Genomics Research; Consent; Children; Research participation; Shared Decision Making; Africa

Introduction

Whilst informed consent is generally recognized as one of the pillars of research ethics and plays a key role in protecting the rights and interests of participants, some authors have questioned whether its strong reliance on autonomous and individual decision-making is appropriate in the African research context (IJsselmuiden and Faden 1992;Chima 2015;Chukwuneke et al. 2014;Chuwa 2014;DeCosta et al. 2004;Levine 1991;Marshall and Rotimi 2001;Vreeman et al. 2012;Azetsop 2011). In particular, these authors emphasize the importance of shared decision-making processes that are more reflective of communitarian worldviews (Louw 2010;Mboti 2015;Shutte 2001;van Loon and Lindegger 2009) and that should be taken seriously in the context of research enrollment. The argument is that shared decision making may be more appropriate than individual decision-making in the African context due to the nature of how family members interact with or relate to one another (Andoh 2011;Biko 1971;Chukwuneke et al. 2014). In this context, the connection between the individual and the community is emphasized, with a person's social identity considered largely shaped by community relationships.

Concerns have been expressed about whether shared decision-making in the context of such a communitarian worldview compromises autonomy and hence the validity of informed consent. For instance, Chukwuneke and colleagues have challenged the notion of decision-

making through consensus and argue that African societies should shift from communal to individual decision-making (Chukwuneke et al. 2014). Other critics have argued that in addition to understanding individuals in relation to their communities or social networks, it is just to acknowledge that every individual is different and that Africans are persons with or without the community (Mboti 2015). One exponent of this view, Mboti objects to the false dichotomy that casts all Westerners as individualists and all Africans as interdependent. Observing that the notion of communitarianism is rarely challenged, Mboti recommends that critical scholarly examination is needed regarding what an African ethics would entail and that discarding informed consent as a pillar of research ethics is premature. In a review, Coleman noted that the philosophical discussions around autonomy amongst African bioethicists have not been supported by empirical studies (Coleman 2017). In partial response to these critiques, others have proposed that the concept of 'respect for persons' should be central to the consent process in African settings as opposed to 'autonomy' (London et al. 2014).

The Human Heredity and Health in Africa (H3Africa) initiative affords the opportunity to advance the study of genomics and environmental determinants of common diseases in Africa (Rotimi et al. 2014). H3Africa has increased attention to a number of long-standing and emerging issues in genomic research, such as informed consent, privacy and confidentiality (Munung et al. 2016). Sickle cell disease (SCD) research within the context of H3Africa provides an unprecedented opportunity to grapple with these issues. There is growing empirical literature describing ethical considerations for genomics research in Africa. Studies in Ethiopia, Kenya and Nigeria that have examined the informed consent process show that shared decision-making with family members, community leaders and neighbors was highly appreciated by the participants (Marshall et al. 2006;Rotimi and Marshall 2010;Tekola et al. 2009;Marshall et al. 2014). Our study, having combined data from three African countries aim to provide a strong account of shared decision making in Africa. Qualitative or social science research on informed consent in Africa is critical to allow the identification of specific practical, psychosocial, and ethical challenges that need to be addressed to appropriately plan genomic research. Empirical data from a broad spectrum of stakeholders are essential to the development of effective policies and programs. It is therefore critical to understand implications of genomics research for individuals, families, and communities, and the most effective strategies to implement public health policies and regulations informed by research (Green and Guyer 2011). Therefore, further research on informed consent for genomics and non-genomics research in Africa is needed to understand the meaning of autonomy in typically communitarian settings. This study aimed to use a case based approach to examine a specific question in relation to autonomy: who else besides the parents are involved in deciding to enroll a child in sickle cell disease genomics research and what should their contribution be? Perspectives on this question were gathered from research scientists, health professionals, individuals with SCD and their families, traditional leaders, traditional healers, and other community stakeholders (e.g., lawyers, public servants, and educators).

Methodology

This study was part of a larger empirical ethics study aiming to explore the perspectives of a broad range of community stakeholders regarding participation in genomics research on sickle cell disease (SCD) (Treadwell et al. 2017). This was a cross-sectional study that used purposive sampling and qualitative research strategies to develop an in-depth understanding of cultural influences on perspectives on and attitudes towards genomic research and on perceptions about public health interventions for SCD-related complications in Cameroon, Ghana, and Tanzania (Treadwell et al. 2017). For the current manuscript, we drew on in-depth interviews and focus group discussions conducted in this larger project to explore data relating to decision-making for participation in genomics research.

For the current study, we used 64 interviews from focus group and individual discussions conducted in rural and urban areas in Cameroon (n=14), Ghana (n=30) and Tanzania (n=20). Individuals and family members with SCD; healthcare professionals involved in caring for people with SCD; religious leaders; and community leaders participated in the interviews. Focus Group Discussions used were 48; Tanzania (n=14), Cameroon (n=10) and Ghana (n=24). In-Depth Interviews used were 16; Tanzania (n=6), Cameroon (n=4) and Ghana (n=6). FGDs were done mostly with adult patients and families affected with Sickle Cell Disease. IDIs were conducted with key informants (religious leaders, SCD providers). Our goal was to have a diverse sample of participants, to allow us to have broad representation of perspectives on the issue. The international team of investigators together developed instruments for this study including topic guides and vignettes that were used across all the research sites. In Cameroon, the instruments were translated into French, in Ghana into Twi and in Tanzania into Swahili. All translations were back translated to English and reviewed for consistency of the instruments. This was important because all the interviews were analyzed centrally in English language. The codebook was developed in English and therefore all the coding was done in the English translated version of the interviews.

In the interviews, we used a vignette that asked participants about the enrollment process in genomics research. Particularly relevant to the current report is the vignette that explored who should be involved in decisions about research participation. This vignette described a study involving children affected with SCD. We specifically examined whether individuals stated that parents could independently decide to enroll their children, or whether they should or would seek the advice of others:

> Mr. and Mrs. _____ have a baby with sickle cell disease. The doctor has to draw some of the baby's blood to keep track of the baby's health. A researcher came to the parents and asked them if they would be willing to have some of that blood to study. The researcher explained that studying the blood may help us understand why some people with sickle cell disease do well while others have many problems. The researcher explained that the baby's and family's name would not be connected with the blood sample. The researcher also says that if the family really does not want to participate, they can say "no" and their baby will receive the same medical care as always. Please tell me what your reactions would be if the researcher came to you or to your family member with sickle cell disease.

[Probe if it does not come up:]

> Should Mr. and Mrs. _____ make the decision about having their baby's blood used in the research or should they discuss this first with someone else in their family or community [e.g., their own parents, community elders, etc.]

Investigators from all of the study sites analyzed data thematically. Two of the authors (DB and JDV) worked together to progressively develop a hierarchical coding scheme for the entire dataset. Investigators from all the study sites piloted this coding scheme using a detailed codebook describing all the codes and hierarchical relationships between them. Feedback about the applicability of the coding scheme was integrated into a revised coding scheme, which was subsequently applied to the entire dataset. Researchers from each country were responsible for coding the dataset for that country, with support from DB and JDV where they were unsure about certain codes or to establish coding validity. The differences amongst the sites in using the coding scheme were resolved through consensus. Once the entire dataset was coded, DB and JDV extracted all data pertaining to the informed consent process, including specifically information about decision-making for enrollment of children in genomics research. After coding, the analysts develop a framework using thematic content analysis to address a question of whom else would you consult when consented to enroll your child in a genomic research? The framework was developed in 3-specific categories; Tanzania, Ghana and Cameroon. And each country was categorized in Urban and Rural settings. Quotes from all the 64 units were imported in the framework within its specific category.

Results

The following themes emerged from our analysis: 1) Parents should make independent decisions for their child without broader consultation with family members or others 2) Particular cases exists when consultation may be necessary

Parents should make independent decisions for their child without broader consultation with family members or others

We found that the majority of individuals with SCD and their family members as well as healthcare providers that we interviewed believed that parents should make independent decisions for their child without broader consultation with family members or others. For instance

> The one who is supposed to decide is the parent himself. Nobody can come and tell him that he should enroll the child or not when it is you who sees exactly how your child is suffering at home.
>
> (FGD-SCD Provider, Tanzania - Urban)

> The consent regarding the child, it is me, the direct parent since the child is still a minor, he does not know but I do (Probe: what if the child is an adult) he will be the one who will give his consent but with my support because I had to explain to him the benefit of this research.

(FGD-Family member of child with SCD, Cameroon - Urban)

A participant in a focus group in Ghana noted,

> The couple themselves should take the decision SCD-FPT6: Once they took the child to the hospital themselves then they should make that decision without a third party.
>
> (FGD- Individuals with SCD/Family members, Ghana - Rural)

There was a sense that parents could decide independently from their partner also as illustrated by;

> There is no need to consult, the mother alone can decide. Sometimes our husbands do not follow us to the hospital.
>
> (IDI-SCD Provider, Ghana - Rural

Particular Cases exists when consultation may be necessary

With family or community members—Participants also outlined particular cases in which there may be a need for more shared decision-making, for instance when parents were thought to be vulnerable. Our interviewees highlighted several instances where this could be the case, amongst which was lower-than-average educational levels.

> I think it is the parent, the parent himself should make the decision but some parents are like […] if he does not have education then even if there are other elder people in that family like their fathers, grandmothers, the uncles, if they have enough education then they should push them to make decisions but if they have education, if the parent has education and sees that blood needs to be taken from the child for sickle cell disease the parent has to make a proper decision that it is for this disease I have to decide and agree so I think the decision is for the parent.
>
> (IDI-Healthcare Provider, Tanzania - Rural)

A second instance in which shared decision-making may be more appropriate is in cases where parents normally relied on community support for financial or care assistance, for instance, in the case of single parents or where parents relied on community members in the care of an affected child.

> There are some single parents that are suffering all alone with their children… She may decide to rush to the community, those who have been helping her to take care of the child.
>
> (FGD-Healthcare Provider, Cameroon - Rural)

In other cases, a participant thought that it was important to involve family members because SCD has originated within the family

> To me I think family discussion is needed at that point we are thinking may be this child has Sickle cell or not following signs and symptoms. That period could be a better time to involve the family because sickle cell is a disease that can be

> inherited from the family, and so if the results come positive then both families in one way or the other contributed to that child's problem.
>
> (Healthcare Provider, Tanzania - Rural)

On the contrary, in cases where the community does not contribute to the care of an affected child, interviewees did not think there was a strong reason to involve community or family members in decisions about research participation.

> Neighbors or close relatives don't have any voice because when she (the child) is sick, they do not come to intervene.
>
> (SCD Provider, Cameroon - Rural)

Interestingly, interviewees also indicated that whether or not parents consult with others is ultimately the decision of those parents themselves: if they feel they would like to consult then they should, as in the case where the parents are not comfortable with their decision.

> It will depend…if…they are comfortable with what the doctor and the researcher are going to do…they can take an instant decision…,but if they are not comfortable and they feel they need to consult.…Of course,….they have to see relatives and elders in the community so that they can also give them their decision or what they think about the blood sample.
>
> (IDI-Religious Leader, Ghana - Urban)

As such, that interviewees consider that there may be cases in which shared decision-making is more appropriate does not detract from their original stance that parents should make independent decisions for their child. In fact, interviewees affirmed this viewpoint by asserting that it is up to the parents to decide whether or not they seek the involvement of other family or community members about decisions to enroll their child in research.

With Healthcare Providers—There were several individuals who thought that healthcare professionals should make decisions about participation because they are knowledgeable about the disease, or at least they should discuss with parents. This seems to be true across stakeholders in the three countries and in both rural and urban settings.

> For whom to decide, I think… the parent cannot decide because the parent just brought the child to the world but the professional, who is a medical professional can decide. Because a medical professional knows the kind of decision to take, if they are taking blood, saliva, hair or whatever thing.
>
> (Administrator, Cameroon - Rural)

> I think it will be advisable if the parents seek advice from a health professional who knows more about the disease since (the parents) may be not much vested in SCD.
>
> (FGD-Individuals with SCD /Family Members, Ghana - Urban)

> First of all they will start by deciding on their own after that if not … satisfied they will seek for advice from others. For example they can go to the doctor for advice

obviously the doctor will be having positive thoughts concerning the research so doctor will tell then to go on.

(FGD-Individuals with SCD /Family Members, Tanzania - Urban)

With Religious Leaders—There was considerable diversity of views about whether religious leaders should play a role in deciding on participation in genomic research. Consulting religious leaders was considered a possibility, especially for some religious denominations, to help them decide whether participation is the right thing to do. These discussions were mainly observed in Ghana, both rural and urban.

Most of the people consider religion to be part (of their decision making) so maybe they will discuss with (their religious leader) or someone that ohh…let say the Jehovah people they do not take blood and other things so they might think it will be best to consult their pastor before they do it.

(FGD-SCD Providers, Ghana - Rural)

Nevertheless, from the same discussion other participants were surprised that people will even think of consulting their pastor for this decision.

Why should No. 3 and No. 1 contact their pastor before allowing the researcher? They are the parents! The pastor, is he GOD? (others laugh) (Another participant responded, it is part of their doctrine so they have to let their pastors know.

(FGD-SCD Providers, Ghana - Rural

With community leaders as a means of showing respect—Few participants described the importance of shared decision-making as a community responsibility or a means of showing respect to elders (in this case, grandparents).

To me, we are in an African society and even if you are age 100, you still respect your parents. That is African culture. The European culture says after you are 21 years old, you are independent they give you what you need. That is why you will see even a man who is 70 will always go back to the village, to meet the father for the directives. So even if you want to do that to somebody, the person will say please let me go and seek advice. And where is he going? Back to the family. Majority of Africans say allow them to go and seek the consent of members of their families.

(IDI-Religious Leader, Cameroon - Urban)

Two participants insisted that SCD screening results and decisions to participate in SCD genomic research should be made by the community:

Because this disease of sickle cell, after results are provided they have to go back to society [to share the results] (*Follow up question; Who are the people you think they need to talk to?)* It is their parents [that they should talk to] from both sides, if it's the father or mother, from both sides.

(IDI-Healthcare Provider, Tanzania - Rural)

> I think it all (boils) down to the status of the couple, if they are independent or let us say the elders of a community, who should they consult. In a typical Ghanaian society what the elders say is final and therefore if they were the elders they would not need to discuss with anyone.
>
> (IDI-Healthcare Provider, Ghana - Rural)

Discussion

In this article, we have provided some empirical evidence from various stakeholders on the decision to enroll children in genomics research in Africa drawing on data collected from rural and urban areas in 3 countries in West, Central and East Africa. Our results indicated that the majority of participants believed that the parents should make independent decisions. We did not identify any real differences in viewpoints between people in rural and urban settings. However, there were groups of people who were considered to likely benefit from consultation across all countries and areas where we conducted our research. These were parents who are less knowledgeable about SCD and genomics research, single parents and for those who seemed ‘not so sure’ of their decisions. In some cases participants mentioned the un-avoidable link between SCD and the family ties to strengthen why family consultation is necessary. The other mode of consultation recommended by the participants was through healthcare providers who were thought to be highly knowledgeable about SCD and genomics research. The participants’ aim with this proposed consultation was to ensure that the parents received comprehensive information in order to reach an informed decision. A third group of stakeholders that may be consulted regarding decisions about participation in research is religious leaders, although only a few of our participants thought that they should be consulted. Based on the results from this study, making individual choices about research participation in African contexts is preferred over communal or shared decision-making. This could indicate that, for selected issues such as informed consent for genomic research, even in the case of deciding about children, the concept of African communitarianism may not be as central to decision-making for research as previously suggested. This matches findings by Ogunrin and others (Ogunrin et al. 2018).

In cases where participants emphasized the importance of consultation and shared decision-making, then the focus seemed to be more on empowering parents to make an informed decision. Our participants did not mention more traditional reasons given for shared decision-making in the African research context, including for instance because this would demonstrate ‘respect to elders’ or follow more traditional hierarchical decision-making processes. These results were similar to other studies assessing the role of local leaders and chiefs when seeking for permission to consent (Marshall et al. 2006). It is also important to distinguish the extent of consultation that may unduly influence participation in research, with empowering individuals with adequate information to make an informed choice. Consultation with family members aiming to provide additional protection may be considered appropriate as indicated by the International Ethical Guidelines for Health Related Research Involving Humans guideline number 15, on research involving vulnerable persons and groups (Council for International Organizations of Medical Science (CIOMS) 2016). This is very much similar to the recommendations provided by Tekola et al, in their

study with podoconiosis patients. Community sensitization was considered important before seeking individual consent (Tekola et al. 2009).

In very few cases the Ubuntu concept as suggested by Chuwa (Chuwa 2012) did come up strongly, suggesting that communitarianism is still important in some contexts. When the view was put forward, it was by community elders and religious leaders, who themselves are the keepers of cultural norms and values.

Study Limitation

General limitations of the project as a whole have been discussed in a dedicated paper on the study methodology (Treadwell et al. 2017). Specific to the present article, language could be a limitation, as translation in English was needed for some interviews from French in Cameroon, Twi in Ghana, and Swahili in Tanzania. Research team members were not always facile in the dialects of people in the rural areas and found that some scientific concepts were difficult to translate and we cannot know for certain that concepts that were discussed actually had equivalents in all languages that were represented. We recognize that there might be some influence on responses based on how the data was collected (focus group versus individual interview), however, in reviewing the transcripts, we found that both individuals interviewed in groups and individually were quite forthcoming about their perspectives. It is also important to acknowledge that in this article we aimed to test the concept of communitarianism and individualism in African context using a case that involved child participation in research. The findings might not be the same if a different case scenario had been used, for example, decision about genetic screening prior to marriage. It is also worth to note that the issues of assent were not discussed in this paper, although the vignette was involving a child. Our future direction for research is to explore assent and how it is being practiced in African's settings.

Despite these possible limitation the current study will contribute to address the views/ perspectives of Africans regarding genomic and ELSI issues. The values and practices of health professionals and community members must be considered, to ensure culturally appropriate strategies to fully realize the potential of genomic research.

Conclusion:

We started this paper with a discussion about the importance of shared-decision making for consent to research participation. Whilst some authors have argued that such decision-making is more reflective of a more traditional communitarian African worldview, one critique of such a perspective is that it is lacking an empirical grounding. Our evidence contributes to these critiques in that we found very limited support for shared decision-making as the primary process for decision-making about research participation. Whilst consultation may be important to support decision-making – important particularly when the parents are more vulnerable – there was no suggestion in our data that shared decision-making would be more important or valuable a means of seeking consent to research participation in the African research context. Our results will help to guide recommendations for community and individual participation in genomic research in Africa and can guide optimal design and implementation of genomics research and implementation strategies.

Acknowledgements

We thank parents and patients who have participated in this research and the following organizations for their help and support with data collection: Faculty of Medicine and Biomedical Sciences, University of Yaoundé 1, and the Globule Rouge Association in Yaoundé; Faculty of Health Sciences University of Cape Town, Sickle Cell Foundation in Ghana, Muhimbili University of Health and Allied Sciences and Sickle Cell Foundation of Tanzania. The development of the project coding scheme and the data analysis workshop for this paper were supported by funding from the National Research Foundation of South Africa under Fund Number 103750 (PI: De Vries, J).

Funding

Research reported in this publication was supported by the National Human Genome Research Institute of the National Institutes of Health under Award Number U01HG007459. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health

List of abbreviations

SCD	Sickle Cell Disease

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