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Experience of Community Leader's Involvement in The Participants' Informed Consent Process: A Case of Malaria Clinical Trials Conducted in Tanzania

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Abstract

Background

International ethical guidelines for biomedical research involving human subjects recognize the need for study permission from community leaders before conducting research in low-resource countries or approaching individuals for consent. The guideline assert that community permission does not replace the requirement for individual informed consent. However, there is limited understanding of community leaders' roles in this process. This study aimed to explore experience of community leaders' involvement in the participants' informed consent process in Tanzania.

Methods

This exploratory case study was conducted in three purposively selected villages in Tanga region. In-depth interviews were conducted with community leaders using a semi-structured interview guide and all interviews were audio-recorded using a digital recorder. Data were organized using NVivo software, and thematic analysis was applied.

Results

The study identified key themes related to ethical considerations for involving local community leaders during the consent process. First, unclear ethical roles exist between community leaders, participants, and researchers. Second, power of authority from community leaders influences participants' perceptions of voluntary consent, confidentiality, risks and benefits, thus many participants felt compelled to engage in research due to ties with their leaders' trust. Third, how the information was shared within the community raised concerns about ethical guidelines and proper information.

Conclusion and Recommendation

Findings suggest that important information about the study should be clear from the beginning to the end, this creates trust, freedom of decision, confidentiality, voluntariness and clear information on risk and benefits of the study. Clear demarcation of responsibilities between community leaders and researcher should be observed, to wave away leaders' differential potential power of authority towards community members.

Keywords: *Community leaders, Roles, Informed consent, Power of authority.*

Introduction

The Nuffield Council on Bioethics (NCOB) 2002 report stresses the importance of community involvement when researching developing countries. Paragraph 6:19 of the NCOB 2002 report states that “In some societies , it would be considered ethically inappropriate for researchers to ask individuals to participate in research without consulting the community or permission from community leaders (1). For example, in 2002 CIOMS, International Ethical Guidelines for Biomedical Research involving Human Subjects includes a requirement to respect customs such as "obtaining permission from a community leader, a council of elders, or another designated authority"(2).

These important ethical considerations such as the need for community respect and permission serve as an added dimension to individual informed consent guidelines, becoming one of the key requirements for conducting ethical research involving communities. However, information on community engagement is a core element of any research effort involving communities (3). Respect of communities is an intrinsic ethical reason for the need to respect communities in community permission to individual informed consent process. Guidelines act as a requirement for ethical research involving communities (4,5) It implies the provision of comprehensive information to potential study participants on the focus of the study, potential risks and benefits of participating in the research, and the securing of voluntary participation in the study without coercion or duress and the avoidance of any type of coercion in the processes of recruiting study participants. It is ethical, that voluntary expression of consent by a competent participant and adequate information disclosure about the research are critical and essential elements of the informed consent process (4,6).

Moreover, community participation is a fundamental aspect of individual decisions, such as the decision to participate in medical research. There are thus intrinsic ethical reasons, such as the need to respect communities, for adding community permission to individual informed consent guidelines as a requirement for ethical research involving communities(7).

However, experience of community leaders in the participants’ informed consent process facing issues of poor comprehensive information deliverance, power of authority, confidentiality, selection of eligible participants for study, voluntariness and trust that constrain individual autonomy in providing true consent to research participation (1).

Methods

Study design

An exploratory case study design was employed to investigate the phenomenon of community leaders' involvement in obtaining consent from potential trial participants within their real-life

context. The qualitative approach was used to gain contextual and in-depth understanding of the community leaders' roles in the informed consent process. The thematic analysis guided the analysis of data (8).

Participants and data collection

Study participants were community leaders VEOs who are village leaders; were selected and recruited using a purpose sampling method, involved because were conversant, experienced and directly involved in community activities. They were recruited for the study because they had been involved in the malaria clinical trials for more than 3 years.

Face-to-face in-depth interviews were conducted with respondents using a semi-structured interview guide with open-ended questions. Questions were pilot tested before starting the study. The researchers introduced themselves clearly before every study informant, explained to them about the study title, objectives, rationale as well as confidentiality. Written consent was obtained from the study informants, and then open-ended questions were asked to each informant exploring the experience of community leaders' involvement in obtaining participants' informed consent (See supplementary material). Interviews were done at participants' place of choice in the ward/street council office. A ward/street office was a quiet and conducive place to enhance privacy, confidentiality, and quality of recording. All interviews were done in Kiswahili, a language that is spoken by the majority of people in that area. With the permission of informants, interviews were recorded using an audio digital recorder. Furthermore, a note-taking was done while the interview was going on to summarize the key points of the interview and to follow up on the merging themes during data collection.

Data collection was done from early June 2020 to early July 2020 in Korogwe District in three villages: Bagamoyo, Kitifu, Mgombezi. The interviews (lasted approximately 30 to 45 minutes each) were recorded digitally and notes were taken during the interviews. All nonverbal responses were noted and taken into account, including emerging key themes and issues.

Data analysis

The data was analysed using a thematic data analysis approach. The audio recordings were transcribed verbatim, and the Swahili transcripts were then translated into English by the principal investigator. Subsequently, the researchers cross-checked the original Swahili and English transcripts with the original audio files. Then key themes and sub-themes were developed systematically based on an in-depth reading and re-reading of the transcripts, with the aid of NVivo version 12 software.

Results

Demographic characteristics of participants

A total of 12 participants were reached after saturation point: males were 7 (58.3%) and females were 5 (41.7%). Consideration was given to the age groups of community leaders; One study participant (8.3%) aged below 40 years, four aged 40-49 (33%), 2 aged 50-59(16.7%), three aged 60-69 (25.0%) and two aged 70-79 (16.7%) (see Table 1).

Table 1: Demographic Characteristics of the Community Leaders Interviewed at Selected village a in Korogwe District, Tanga

Characteristics	Number (n) = 12	Total (n)%
Sex		
Male	7	58.3%
Female	5	41.7%
Age		
30-39	1	8.3%
40-79	11	91.7%
Marital Status		
Married	11	91.7%
Single	0	0
Divorced	0	0
Widow	1	8.3%
Academic Qualification		
Primary	11	91.7%
Secondary	1	8.3%
Villages		
Mgombezi	4	33.3%
Bagamoyo	4	33.3%
Kitifu	4	33.3%
Experience working with Malaria Project		
3 – 5 yrs	2	16.7%
6 – 8 yrs	4	33.3%
9 – 10 yrs	6	51.0%

All the community VEOs interviewed for this study said that involvement in the process of obtaining participants informed about malaria clinical trial participants presented real experience in their daily work during the period of clinical trial. The experience and perceived roles of respondents are summarized in Table 2, showing key themes, subthemes and detailed coding.

Table 2: Overview of themes, sub-themes and codes

Themes	Sub theme	Coding
Actual roles of community leaders	Obtaining permissions for the study from the community	• Responsibility • Permission to receive the project • Information about project
	Protection and care of vulnerable study participants	• Special group protection • Honesty towards community leaders
	Facilitate recruitment of trial participants	• Mobilization of clinical trial potential • Identification of participants
Community leader's power of authority over participant informed consent process	Power of authority over participant voluntariness	• Power of authority • Strong faith towards leader
	Confidentiality	• Home to home visiting • Direct involvement in informed consent process
	Freedom to consent	• Free will • Justice • Strengthen the research capacity
	Building community trust	• Sincerity • Assurance • Information • Feel of secure
Challenges related to shared Information from community leaders	Use of ethical guideline Shared information	• Information • Sharing instruction • Ethical guide • Training

Actual roles of community leaders

The study found several actual roles of community leaders; community leaders participate in obtaining participant informed consent in the research process, this advanced from the community level to individual participants. These actual roles include; obtaining permissions

for the study community, selecting eligible participants in malaria clinical trial, Respecting and caring for vulnerable study participants

Obtaining permission for the study from the community

The study revealed that before the beginning of the Malaria project, community leaders were informed about the Malaria clinical trial by the town council authority, and they were told to accept the project that was about to take place. This unduly influenced community leaders to agree to the malaria project to take place in their communities:

One of the participants responded that:

> *"Initially, the government received the project, and then a meeting was done with communities. It was the fixed time at which we met with the researcher for discussion and more clarification on the project. We acknowledged the project, and then we were imparted with brief tutoring about the project by a researcher. The main goal for such a briefing is for us to acquire knowledge which in turn makes it easier to explain the project to the community when meeting them" (CL 1)*

The study also revealed that, obtaining permissions for the study from the community was a crucial thing that was done by the community leaders as reported by the following participant:

> *"…after I received the letter of request for permission to enter the village, we alerted our people to keep their environment clean and roofing, 'kupiga bati'. Afterwards, we sat down together and gave them information about the new coming malaria project for them to volunteer to participate in (CL 3)*

Respect and care of vulnerable study participants

Consideration was given in respect and care of vulnerable study participants from community leaders. Special groups reflected in this study include orphans, refugees, children and pregnant women. Participant said that:

> *"Special groups are really respected and taken care of … orphans, refugees, children and pregnant women… mmmh this group requires very good attention due to their situation since it is easy for them to be cheated or deceived." (CL 7)*

Community leader's involvement in recruitment of potential participants'

Findings of this study show that community leaders visited community members' home to look for potential clinical trial participants before researchers. They discuss with them specific

information about the research projects and when they agree to participate, they list their names. One participant said that:

> *"I select potential participants… then me and the project officer usually go to their houses where they live." (CL5)*

Another participant stated:

> "*In this research project I am the main mobiliser /facilitator because, as you know, a newcomer will not be able to look for them. After selecting the eligible participants, we and project officers usually go to their houses where they live after meeting." (CL 10)*

Ethical issues in community leaders' power of authority over participant informed consent

The principle of research ethics is a fundamental requirement that participation in a study is voluntary, community trust, freedom to consent, confidentiality, risk and benefit and free of coercion and undue influence.

Participant voluntariness in obtaining informed consent

The study portrays that voluntary participation in clinical trials is paramount. However, this study shows that community leaders compromised the voluntariness of individuals to participate in the clinical trial. It is an undeniable fact that the differential power of the authority of the community leaders influenced individual's faith to participate in the study and opposes also the voluntariness of individuals to participate in a clinical trial in the informed consent process.

Participant said that:

> *"Faith of power from me as their leader motivated and convinced them to volunteer for the study" (CL 4)*

Study participant revealed that participation in a study is voluntary-that is free of coercion and undue influence as reported by the following respondent

> *"Yah, I have deprived them voluntary, they have decided to join the project, because they depend on the village government power, I am a village government leader." (CL 3)*

Assuring of benefits and mitigation of risk

The study reveals that for individuals to participate in the clinical trial risks, benefits from the study are crucial. Some community leaders revealed that be assured of benefit and risks for study, help decision to participate in a clinical trial.

The participant said that:

"The information on the project given to them is that the malaria project has saved us a lot from the malaria disease children and grandchildren who were sick, taken by car to hospital and treated." (CL 8)

Another participant:

"I have testimony from my own family. My niece was on a malaria project and got a complication of a head filled with water (hydrocephalus), then the project assisted her with all the medical cost and transportation to and from Kilimanjaro Christian Medical Centre (KCMC) hospital." (CL 11)

Confidentiality

The study finds that there was limited confidentiality about participating in the trials. It shows that researchers took individuals' consent in the presence of the community leaders. Community leaders were part and parcel of the informed consent process. This compromised confidentiality as they knew whatever the researchers discussed with individuals in the process of obtaining consents. Participants said that:

"I go to a person's home direct, together with an Investigator, to ask a person some sensitive question we need in order to participate in the study as she is eligible directly to consent" (CL 2)

"…. Yes, of course, I must be there …no confidentiality. When they see community leaders, they get inspired and have a strong faith that our leader is around and helping to direct us on how to give consent." (CL3)

Freedom to consent

Clearly, Free Consent means the absence of any kind of coercion, undue influence, fraud, misrepresentation or mistake. This study revealed that there was a limitation of free consent from participants due to undue influence from community leaders. They responded that:

"Because participating in the research project is of your own will (consent), people are given freedom to join the project willingly, if not, you will not get any penalty." (CL 3)

However, other community leaders showed concern about individuals' participation in the trial and the response said that:

"Yah is right that I make sure the participant doesn't join the study by force because that happens openly at the meeting and directly agree that we would like to participate." (CL 1)

Another responded:

> *"True…I deprived them of justice, of their own free will, yes after permitting the project before them." (CL 9)*

Building community trust

Community leaders revealed that their involvement in the study was very important as it generated a trust for community members to participate in the trial. Community leaders were trusted as they are close to their people. Their involvement gave the assurance to the people that the trial is for the wellbeing of their community. Through their involvement, community members participated without hesitation. One of them said

> *"I make them trust the project by giving them information "The importance of involving the village leaders in this project is very crucial, because we are the ones who are close with the community members …" (CL 09)*

Challenges to shared information seeking community consent

The study reveals that, there were some challenges in shared information to participate in the trial the key information that has to be provided with the researchers was being provided by the community leaders. Actually, it is the duty of the researchers to give explicit information from research ethical guidelines about the procedures of the research on trial including the informed consent and proper information to the participants of malaria clinical trial.

Use of ethical guide in clinical trial

The study shows that, community leaders admitted that there was no any procedure followed to abide by the guidelines that guided them to help people participate. Information was given by researchers, and participants were just given a piece of paper to read themselves. Participant said that:

> *"I have no any guideline, document or procedure to follow, I was just briefing them as a leader, and they agreed, with those researchers therefore we were making conversation with individual participant when got knowledge agree and registered in researchers' papers" (CL 5)*

Lack of proper information to the participants of malaria clinical trial

Community leaders revealed that such information is very important for them to let their people be assured for study and decide to participate in clinical trial. But there were challenges on lack of proper information on clinical trial procedures, study found that community leaders

were not having a correct information about the reason of the study, with the researcher they were trying mobilizing participant about their intention of obtaining informed consent. One participant noted that:

> *"We and the researchers were on the same thing, mobilizing the public, by telling them the intention of this project yah… that is the guide" (CL 7)*

Discussion

In Africa, research naive communities can significantly contribute to research processes if they are adequately engaged through organised meeting between researcher, community members and community leaders (9). In developing countries, community leaders are the ones who provide permission to the researchers, "gate keepers of the project", also they are part and parcel of the informed consent process information that is against ethical guidelines in individual informed consent before passed through the written informed consent (10,11) consent process may be influenced or supported by the community engagement activities as there are important interdependencies between the two (12).

Community trust is of great significance for individuals to accept and consent to be recruited as participants in a research study. The study found that there was some kind of relationship between researchers, community leaders and participants before starting the clinical trial.

Community leader's involvement in the study was very important as it generated a trust for community members to participate in the trial. Community leaders were trusted as they are close to their people, this gave assurance to the people and Wellbeing of their community. Lack of trust from participants could increase the risk of biases in research (e.g. social desirability) (13).

Furthermore, there is greater understanding that community engagement through community leaders has essential value that is, it is important to engage communities because it is the right thing to do. In clinical research, the involvement of the community has largely been confined as instrumental, e.g. in order to meet recruitment and retention targets, to strengthen consent processes, address issues as they emerge etc. As collaborative international research increases, involvement of diverse range of community representatives and participants also is important for broad buy-in of the studies and to ensure that stakeholder interests feed into the conduct of the studies wherever possible (14).

Researchers, reported that community structures were most helpful during recruitment phase of the studies, as they helped in solving small conflicts among the community regarding a research project, Furthermore, it is clear that; trust, sense of being respected to community members assured safety of participation (15).

Findings of this study show that community leaders visited community members' home to look for potential clinical trial participants before researchers. Belmont Report sets three basic ethical principles, which provide logical enclosure for understanding of the ethical issues arising from research involving human participants: respect for people, beneficence, and justice (16,17). Moreover, other studies show that the selection of study participants and identification of eligible study participants is the responsibility of researchers (10,18). Informed consent process implies the provision of comprehensive information to potential study participants on the focus of the study, potential risks and benefits of participating in the research, and the securing of voluntary participation in the study without coercion or duress. International regulations and guidelines for human subjects in research stress the fundamental ethical principle of seeking voluntary informed consent to participation, and the avoidance of any type of coercion in the processes of recruiting study participants (2).

The study found that community leaders were concerned with the care and wellbeing of the vulnerable population, CIOMS and Article 9 of the Declaration of Helsinki provide conditions for vulnerable subjects who need special protection (19). Community leaders influence community members to participate voluntarily in a trial as they have good relation and a positive attitude towards them in their cultural setting (5). The potential power of authorities to obtain participants' informed consent influences the informed consent process and distorting voluntariness (20–22), intensified in low-income settings by greater inequities in resources, power, and information among stakeholders in research (17).

Confidentiality was shown to be limited in this study. The taking of consent needs to remain confidentiality between the researcher and the participant, but in this study community leaders together with researchers obtain informed consent from potential participant. The relationship between researcher and participants become very difficult especially in the process of obtaining informed consent, since the ethical duty of confidentiality refers to the obligation of an individual or organization to safeguard entrusted information, the ethical duty of confidentiality includes obligations to protect information from unauthorized access, use, disclosure, modification, loss or theft (13) . Fulfilling the ethical duty of confidentiality is essential to the trust relationship between researcher and participant, and to the integrity of the research project. Researchers shall also inform participants and seek their consent if their personal information may be shared with mandated government departments or agencies (such as local public health authorities) (13).

Researchers shall avoid being put in a position of becoming informants for authorities or leaders of organizations. Researchers shall maintain their promise of confidentiality to participants within the extent permitted by ethical principles and/or law (23). Poor

confidentiality done by a researcher not only develop harm to participants but also impacts the overall critical appraisal of the research outcomes. Therefore, considerate and applying confidentiality in research is key for steady research (24). Community leaders around the world are openly challenging researchers and cautioning communities about these types of research practices, as well as those based on exploitation, racism, and power.

Obtaining collective consent can take many forms, depending on the community's identified protocols. As noted, some communities have established research ethics boards that possess the authority to approve, guide, and oversee research, which often requires obtaining support and consent from the appropriate overseeing body, (25) ethical principles require confidentiality to be adhered to in any clinical research, this should go abreast to community based studies that, ethical protocols and standards should not be collective (13). Breaches of confidentiality could harm participants, hinder the trust relationship between participants and researchers, and even hurt the reputation of a group or community. Without the assurance of confidentiality, they might refuse to share data or hide data that are important to answer research questions, especially when the study focuses on sensitive issues (e.g. hidden behaviours, controversial views, perverse effects). In the context of global health research, respecting confidentiality is crucial because some participants already feel apprehensive towards researchers, who tend to be outsiders in relation to the local context.

In Cameroon, a study shows that the majority of potential participants lack the ability to read written information sheets of consent forms, and those that read has some problems with interpreting the information contained in the document (26). It is important that key messages from the informed consent form are expressed mutually by the researchers and community leaders, though other studies showed that community leaders acts as an intermediary –neutral educator, or ombudsperson to help the potential participant understand what the study helps, so that they can make an informed choice regarding research participation (27).

Studies done in India revealed that shared information is a challenge for research participants as 14 (24.6%) said that they did not know what to ask (12). However, in Kenya, community understanding of research has been described as a form of assistance in ensuring good health (28). The application of a community engagement framework which is grounded in the relationships between the researcher and the community relationship can help participants understand the research information provided by researchers as they have already created a mutual relationship (3,4,29).

Limitations of the study

This study was based on a single Centre – Korogwe district dealing with a malaria clinical trial. However, community leaders (VEOs) in most Korogwe wards in Tanga are likely to be confronted with similar issues involved in the informed consent process.

Conclusion and recommendation

The experience's explained by community leaders imply that, there is the need for researchers, community leaders, and study participants to have all important information about the study from the beginning to the end of clinical trial, this creates trust, freedom of decision, confidentiality and voluntariness. There should be a clear demarcation of responsibilities between Community leaders and researchers, due to community leader's differential potential power of authority towards community members. Ethical principles should be observed while community leaders obtaining permission of the project from the government and when convey information to community as an intrinsic ethical reason of respecting communities.

Ethical considerations and clearance

Ethical clearance was obtained from the Senate Research and Publication Committee of Muhimbili University of Health and Allied Sciences (MUHAS). In Korogwe; permission to conduct the study was requested from all appropriate authorities starting from Korogwe Regional and Administrative Secretary (RAS), District Executive Directors (DED) and ward executive officers, where the study was conducted. Consent forms in Swahili were provided to all community leaders for signing prior to data collection. Participants who gave their consent were able to withdraw from the study at any time during the interview. To secure confidentiality, each transcript of the interviews was given an ID number without mentioning the respondents' names.

Declarations

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Authors' contributions

SM designed the study, developed interview guide, collected data, undertook the data transcriptions in Swahili and in English then performed data analysis and wrote the first draft of this manuscript. LM & GP participated in study design, supervised data collection and analysis. OV, LM & GP participated in the preparation of the manuscript. All authors read and approved this manuscript.

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