AN EXPLORATION OF MOTIVATIONAL FACTORS THAT INFLUENCE RESEARCH PARTICIPANTS' WILLINGNESS TO JOIN IN A MATERNAL REFERRAL SYSTEM TRIAL IN UVINZA DISTRICT, TANZANIA.

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Muhimbili University of Health and Allied Sciences.
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By
Constantine Antepa Mazanda

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Bioethics of the Muhimbili University of Health and Allied Sciences.
October, 2021.

CERTIFICATION

I the undersigned, certify that this dissertation is the work of the candidate which was carried out at Uvinza District in Kigoma, Tanzania under my direct supervision. I certify that I have read and hereby recommends for examination by Muhimbili University of Health and Allied Sciences, a dissertation entitled **"An Exploration Of Motivational Factors That Influence Research Participants' Willingness To Join In A Maternal Referral System Trial Conducted At Uvinza, Tanzania**" in partial fulfillment of the requirement for the degree master of Bioethics of Muhimbili University of Health and Allied sciences.

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Professor Connie M. Ulrich, PhD, MSN, RN, FAAN

(Supervisor)

Date 28/5/2021

…….

Fr. Raymond, ATHANAS, MBE

(Co-supervisor)

Date…….

DECLARATION AND COPYRIGHT

I, **Constantine Antepa Mazanda** declare that this dissertation is my own original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

Signature…… Date……

ACKNOWLEDGEMENTS

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DEDICATION

I dedicate this research first to the Almighty God for giving me the strength in completing my work. Also, I dedicate this Dissertation to my brothers: Yese, Barnet, and younger brothers Yusuph and Frank. I cannot also forget my sister Salama for courageous acts of kindness throughout my research study to ensure all went well.

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LIST OF ABBREVIATIONS

MRST	Maternal Referral System Trial
WLF	World Lung Foundation
CT	Clinical Trial
HIV	Human Immunodeficiency Virus
MUHAS	Muhimbili University of Health and Allied Sciences
FGD	Focus Group Discussion

Informed consent: Informed consent is an ethical requirement of clinical care and clinical research. It is a process where an individual is provided information to make an autonomous decision (i.e., research purpose, voluntariness, benefits and risks, alternatives, procedures and other elements). Informed consent can be obtained from participants orally or in writing (Grady, Bedarida, Sinaii, Gregorio, & Emanuel, 2017).

Motivation: Motivations consists of internal and external incentives that stimulate desire and energy in people to be continually interested and committed to a job or roles or some other purpose(Akintola, 2011)**.**

Inducement An inducement may be a bribe or "something that persuades someone to do something" (Singh et al., 2017).

Benefits and Burdens of Research: Benefit in research is defined as something that is perceived as producing a good or helpful results or thatpromotes well-being:(Fisher et al., 2018). Perceived burden in research are those that are expressed by participants as physical, psychological, economic, familial, and socially challenging due to participation. (Ulrich et al., 2012)

Maternal mortality: Any death of a woman during pregnancy, delivery, or 42 days after pregnancy termination due to pregnancy complications (World Health Organisation, 2015).

ABSTRACT

Background: Participating in research is one way for individuals in low-to-middle income countries to obtain needed treatment. Paying research participants may also encourage participation but there are many ethical concerns related to the use of incentives in global research, particularly within low-to-middle income countries, such as Tanzania. Little research exists to understand the motivations of Tanzanian citizens to participate in research.

Objective: The objective of the study was to explore research participants' motivational factors in their willingness to join the Maternal Referral System Trial (MRST) conducted at Uvinza, Tanzania.

Methodology: The study used a qualitative descriptive design and was conducted at Uvinza district where the 2015 MRST was conducted. Participants for this trial were selected purposively. A total of 21 participants were interviewed upon the point of saturation, including 4 community leaders, 5 health care workers, 5 motorcycle drivers (Bodaboda) and 7 pregnant women who had an emergency condition during the MRST and joined in the maternal trial. Data were collected by the principal researcher together with two trained research assistants. Focus group and semi-structured interview guides were used for data collection. Content inductive analysis approach was used to code data where by sub-themes and themes generated. Data analysis was assisted by NVIVO software version 12.

Results: A total of 21(100%) participants were recruited in the study including 4(19.1%) community leaders, 5(23.8%) health care workers, 5(23.8%) motorcycle drivers (Bodaboda) and 7(33.3%) pregnant women. The study reveals that there are three motivational factors influencing participants to join the MRST in Uvinza, tanzania. The first includes individual related motivational factors like level of education, expertise and information delivery. Second is family related motivational factors including family pressure, burden of family members, and lastly is research related factors including incentives, benefit to participation, and trust.

Conclusion: Conclusively, this study found that people in Uvinza were ready and motivated to participate in a research study, so long as their concerns were recognized by the research study and the researchers.

Budget: This study costed a total budget of Tanzanian shillings 2,400,000/=.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Globally, maternal morbidity and mortality are major problems facing lower-and-middle income countries. The global maternal mortality rate in 2015 was 219 per 100,000 live births. In Sub Sahara Africa, it was 557/100,000, and in Tanzania it was 556/100,000 (WHO, UNICEF, UNFPA, Bank, & United Nations, 2015). In 2015 data, the maternal mortality rate of Uvinza District, Tanzania, was 219/100,000 (Ipsos Kigoma, 2015). In 2015, a maternal referral system trial conducted at Nguruka ward in Uvinza District found that many women in designated World Lung Foundation (WLF) project areas are still unable to reach maternal services or access them after great delay (Ipsos Kigoma, 2015). Sometimes the delay in maternal services may cause severe morbidities such as an obstetric fistula, losing a baby or arriving in such a bad state that the health professionals are unable to save their life (Ipsos-Tanzania, 2015). It is with this intention that WLF undertook a research study on the referral process to evaluate why maternal death are increasing, especially in the rural area of Kigoma Region (Ipsos-Tanzania, 2015; Ipsos Kigoma, 2015). Participating in research studies is one way for individuals who live in low-to-middle income countries to gain access to needed services with the potential for benefit (Newman et al., 2014).

Informed consent is an ethical, regulatory and legal process that respects the right of individuals to determine whether or not they would like to join research studies and whether the research meets their preferences and goals (Kwamboka et al., 2018). Informed consent includes the voluntariness of the individual and disclosure of information, including the purpose of the study, risks and benefits, procedures and alternatives to research participation and capacity of the individual to understand the study details(Kaye, Chongwe, & Sewankambo, 2019).

The information pertaining to the study should be presented by competent researchers and must be freely given by potential participants. These participants should have the opportunity

to ask any questions before they are consented and comprehend the information in the informed consent documents (Williams, 2018). Giving potential research participants time to consider research participation is a measure of respect for persons and can help them formulate any questions pertaining to the planned research study and decide whether research participation is in their best interest (Edwards, 2005).

Paying research participants may encourage research participation but there are many ethical concerns related to the use of incentives in global research particularly within low-to-middle income countries such as Tanzania. Offering financial compensation to healthy participants as well as to those patient participants who are ill to join in research trials may unduly induce them and violate their sense of voluntariness. Any person who volunteers in a research study should provide their informed consent and understand the aspects of the research study, including the use of incentives (Diemert et al., 2017; Williams, 2018).

Therefore, the study aim is to explore the motivational factors of those individuals who were willing to join in a Maternal Referral System Trial (MRST) conducted at Uvinza District, Tanzania.

1.2 Problem statement

Tanzania is considered a low-to-middle income country in sub Sahara Africa. It is among the developing countries that are based on western research guidelines although it has different cultural values and beliefs, levels of education, and income and accessibility of healthcare compared to other developed countries (Nijhawan, 2013). In Tanzania, there is limited literature that specifically focuses on research participants' motivations and willingness to join in research trials based on the contextual area within Tanzania. Research is importatnt to advance science and to understand how to improve care in Tanzania. The dissertation study focused on the Maternal Referral System Trial (MRST) conducted in Tanzania. The MRST found that there were poor referral systems from the village level up to the hospital level in the Kigoma region (Ipsos Kigoma, 2015). To conduct research studies in Tanzania, understanding participants' motivations and willingness to join in research is fundamental to the study's

success and to advance knowledge that helps future patients. Research participants must, however, weigh the risks and benefits of participating for themselves (Uzzaman, et al, 2011). Willingness to join in a research trial may vary depending on individual motivations such as: the purpose of the study, cultural values and beliefs, potential benefits and harms, availability of incentives, and access to treatments that might not otherwise be available in low-to-middle countries, among other concerns. Research participants from low-to-middle income countries might also be particularly vulnerable because of their lack of education (Diemert et al., 2017).

Payments and incentives in research studies may also influence participation, especially in low-to-middle income countries. This can potentially lead to undue influence and affect decision making in inappropriate ways(Gelinas et al., 2018). Therefore, this study intended to explore the motivations influencing individuals' willingness to join in a maternal referral system trial that was conducted at Uvinza, Tanzania.

1.3 Conceptual Framework:

According to several authors (Lanfear, et al., 2011; Bouida et al.,2016; and Ulrich et al., 2012), research participants can be influenced to participate in clinical trials by the following: individual, family-related, and research-related motivational factors. These factors may affect individuals' willingness to join in the research study (Lanfear et al., 2011); (Ulrich et al., 2012) and (Bouida et al., 2016). The conceptual framework below illustrates those factors diagrammatically.

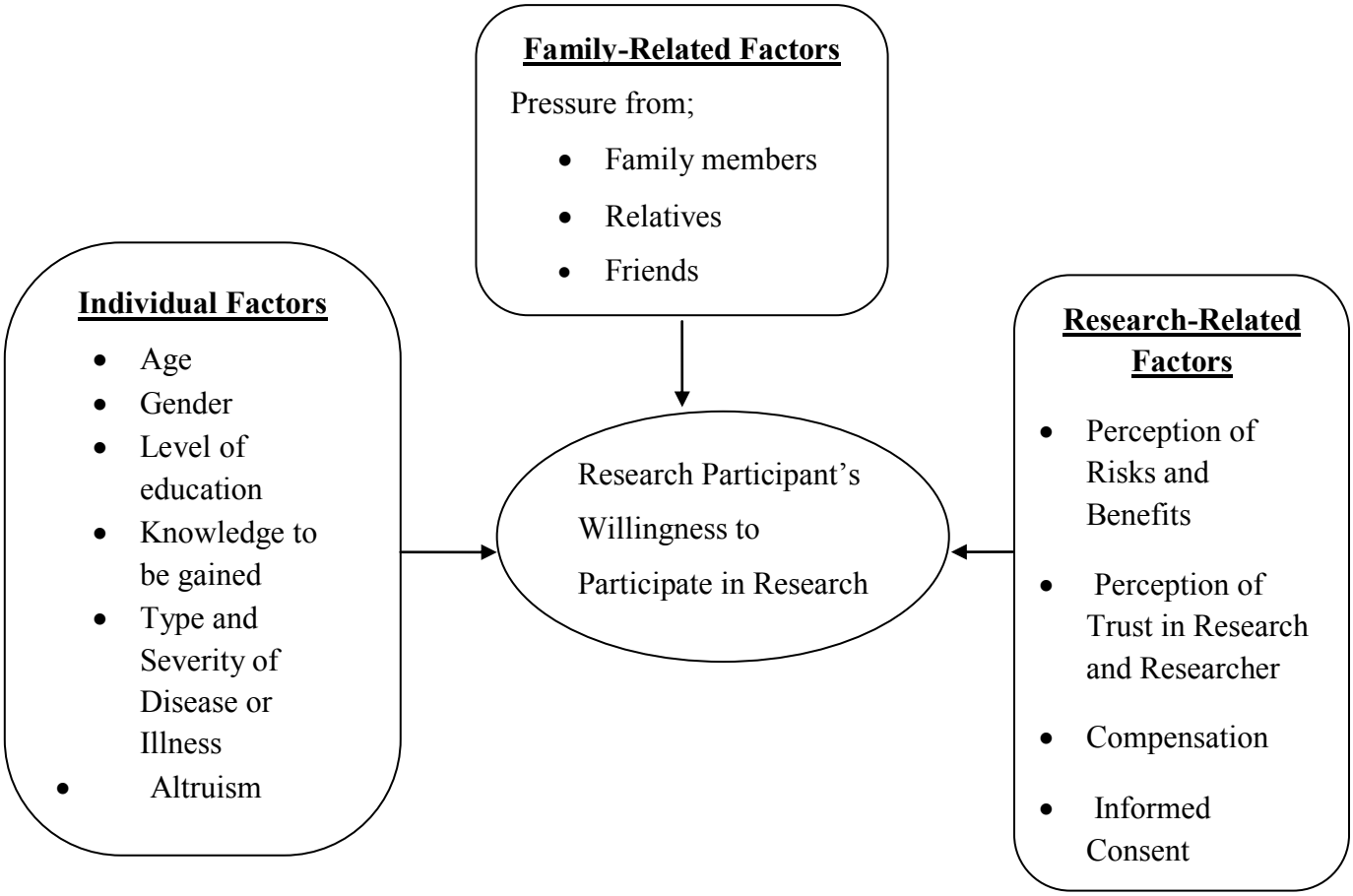

Figure 1: Conceptual framework work showing the motivational factors influencing research participants' willingness to join in a trial as adopted from Bruce and colleagues (Bruce et al., 2016)

1.4 Rationale of the study

Findings of the study will assist researchers to better understand the motivations of research participants and the motivational factors that influence their willingness to join in certain types of research studies. Information from those who actually participated in a research study that took place in Uvinza district, Tanzania will help to improve the research process and to understand what factors were important in their participation and what needs strengthened. Motivations are an important mechanism that can influence recruitment and retention of participants in research trials if based on ethical research principles and guidelines.

1.5 Main Research Question

1. What factors motivated research participants' willingness to join in a MRST conducted at Uvinza District in Tanzania?

1.5.1 Specific research questions

1. What are the individual motivational factors that might influence research participants' willingness to join in a MRST at Uvinza District in Tanzania?
2. How do family-related motivational factors influence research participants to join in a MRST at Uvinza District in Tanzania?
3. What are the research-related motivational factors that influence research participants' willingness to join in a MRST at Uvinza District in Tanzania?

1.6 Broad objective

1. To explore the motivational factors influencing research participants' willingness to join in a MRST conducted at Uvinza District in Tanzania.

1.6.1 Specific objectives

1. To explore individual motivational factors influencing research participants' willingness to join in a MRST at Uvinza District in Tanzania
2. To examine family-related motivational factors influencing research participants' willingness to join in a MRST at Uvinza District in Tanzania.
3. To assess research-related motivational factors influencing research participants' willingness to join in a MRST at Uvinza District in Tanzania.

CHAPTER TWO

2.0 Literature Review

The chapter will explore in-depth the motivational factors influencing research participants' willingness to join in a heath research study and the research environment in low-income countries that relate to the current situation in Tanzania. In addition, the chapter will explore the contributing factors that address the ethical challenges in Tanzania.

2.1 Individual motivational factors influencing research participants' willingness to join in a health research study

Several individual motivating factors that might influence research participation includes: age, gender, level of education, knowledge to be gained, type and severity of disease or illness and altruism. Research participants can be influenced to join in clinical trials due to one or several motivations (Mbunda,et al, 2014).

Willingness to join in a health research study is guided by the ethical principle of respect for persons (Limkakeng et al., 2013). For an individual to join in any study, informed consent is necessary but not sufficient. Although not focused specifically on research, Sanavi, et al, (2012) found that education level, gender and age were correlated with adolescents' attitude and willingness for organ donation.These individual variables might also be important for individuals' willingness to participate in research.

Smit and colleagues (2006) conducted a study in South Africa on willingness to join an HIV Vaccine Trial and found that participants' willingness was linked with age, gender, and increasing knowledge of participants. The findings recommended that because willingness to join an HIV Vaccine Trial is relatively low, educational campaigns are important to encourage individuals' willingness to join in a health-related study (Smit et al., 2006).

A study conducted by Nyasani and his colleagues (2018) revealed that the majority of participants (94%) of those enrolled in the study expressed willingness to join in a future HIV vaccine trial. However, only 40% had a positive attitude to join an HIV vaccine trial due to

motivational factors of altruism and 25% indicated a desire to learn the body's response to the vaccine. And of the 86 study participants who were previously screened and expressed willingness to join, only 30% came for information related to the trial. These numbers were not enough to advance the study and the researchers used other methods to meet the deficit(Nyasani et al., 2018).

Vallely et al. (2010) conducted a trial in Mwanza on HIV prevention by using MDP301 vaginal microbicide. In this study, individual participants were influenced by their socio-cultural perspective and research team trust. These authors used a multi-method, continuous informed consent process to support comprehension and retention of participants.

Women were more likely to volunteer in a phase I/II HIV vaccine trial in Dar Es Salaam, Tanzania due to altruism compared to men (Tarimo et al., 2016). Trust in explanations by researchers about the HIV/AIDS vaccine studies motivated more men than women to volunteer due to the study details provided by the researchers. Research participants who were educated up to secondary school were also motivated to participate, in part, because of the explanation of study details. In a similar way, research participants in Tarimo and colleagues' study were also influenced to participate in the vaccine trial so they would get knowledge for educating others, and because of severity of the diseases within their families, and to receive protections against HIV infections. This study also indicated that more research is needed on motivations of research participants, especially in HIV vaccine trials among Tanzanians (Tarimo et al., 2016).

2.1.1 Knowledge gap pertaining to individual motivational-related factors

It has been shown that there are various factors that influence individuals to participate in clinical or vaccine trials including age, gender, level of education, knowledge to be gained, type and severity of disease or illness and altruism(Limkakeng et al.,) As such this study aimed to specifically explore individual motivational factors influencing research participants' willingness to join in a MRST at Uvinza District in Tanzania.

2.2 Family-related motivational factors influencing research participants' willingness to join in a health research study

Pressures from family members, relatives, and friends can influence an individual to join in a trial (Chu, Kim, Jeong, & Park, 2015). More data is needed, however, to understand these pressures.

Participants' willingness to join in a dengue trial conducted in Acch-Province Indonesia, showed that participants' willingness was very low among community members in Acch-Province. The factors concerning very low participation were knowledge and attitude regarding dengue fever. The study concluded that to increase participation rates, efforts to improve the knowledge and attitude of family members regarding dengue fever and dengue-related research was needed before such studies launched (Harapan et al., 2016)

Efforts to increase participation in health research should focus on ensuring access to health research for all groups (Smit et al., 2006). But, there are also efforts from the experience of individual participants. A qualitative study conducted by Ulrich and colleagues developed a model of the benefits and burdens of research participation in cancer clinical trials based on their qualitative data. The study showed that cancer participants noted some of the following burdens to research participation: fear of side effects, worry, loss of job support, fear of the unknown, and financial concerns (Ulrich et al., 2012).

2.2.1 Knowledge gap pertaining to family-related motivational factors

A variaty of studies have indicated that pressure from family, fear of side effects, worry, loss of job supports, financial concerns, attitude and fear of the unknown are the factors that influence participants' willingness to participate in clinical studies (Chu, Kim, Jeong, & Park, 2015; Ulrich et al., 2012). Hence this study aimed to examine family-related motivational factors influencing research participants' willingness to join in a MRST at Uvinza District in Tanzania.

2.3 Research-related motivational factors influencing research participants' willingness to join in a health research study

Resaearch-related motivational factors may include the following: perception on the risks and benefits of the research, trust in the research and researcher, compensation, being cared for, and informed consent. Financial compensations can also be very enticing, especially in low-to-middle income countries. In her study, Bruce and colleagues reported that young black men participated in an injury research study because it was low risk and that the researcher was caring toward the participants, among other reasons.(Bruce et al., 2016).

Potential benefits to participants and their communities is one reason that individuals may wish to join a trial. Benefits such as access to needed medications that participants otherwise might not be able to afford, early detection and monitoring of the disease, potential for remission or cure, and the ability to take control of their lives through actively participating in the trial were identified as important to participants (Ulrich et al., 2012).

A study conducted in Taiwan about motivations influencing participants' willingness to join in medical research showed that the majority of research participants participated in medical research because they were trusting of the researchers. These participants were willing to join because they agreed that the researchers would never ask them to join medical research studies that might harm them. Also, study participants thought that joining in a medical research study would be compensated(Liu & Li, 2018).

In a South Korean study, Chu, Kim, Jeong and Park (2015) reported that benefits of clinical trials (CT) included free health check-ups, medical screenings, free treatments, and altruism; these were all identified as significant predictors of willingness to join a CT. An awareness of the potential benefits of CT was also associated with a general willingness to join in a CT (Chu et al., 2015). Another study that was conducted in Mumbai India about the benefits of willingness to join in an HIV Vaccine Trial, reported that free medical treatments, life

insurance, financial incentives, and free medical care had significant importance on willingness to join in the HIV Vaccine Trial (Newman et al., 2014).

2.3.1 Knowledge gap pertaining to research-related factors

However, more work is needed to understand how participants actually weigh the risks and benefits in a balanced way, so participants can make an autonomous decision. Indeed questions remain. For example, what benefits do Tanzanian participants find important in their willingness to participate in MRST? Also, what do they perceive as burdensome in the MRST study and are they able to weigh the benefits and burdens of participating, especially in Tanzania? In the MRST study, participants received financial incentives for transport and other types of incentives were given (e.g.,refreshments). These motivations may have had an impact on research participation, but it remains unclear. Therefore this study aimed to better understand what research-related factors motivated Tanzanian citizens to participate in the MRST conducted at Uvinza district, Tanzania.

CHAPTER THREE

3.0 STUDY METHODOLOGY

3.1 Study design.

The study design used was a qualitative exploratory descriptive approach. This approach is important to use when exploring phenomenon, such as the motivation and willingness of participants to join in research studies (Ipsos Kigoma, 2015). Qualitative descriptive is used when little is known about a research phenomenon and it allows for both inductive and deductive codes to be generated from the data in the course of the study. Like other qualitative research approaches, qualitative descriptive studies generally are characterized by simultaneous data collection and analysis. The presentation of data from a qualitative descriptive study involves a descriptive summary of the informational contents of the data that is structured in a reasonable manner (Cataldo et al., 2011).

3.2 Study area.

The study was conducted at Uvinza district, Kigoma region. Uvinza district is among the districts within the Kigoma region. It is a highly populated district in the Kigoma region with a population of 486,418. Also, Uvinza district is amomg the districts in Tanzania contributing to a high number of maternal deaths. Nguruka ward in Uvinza district is one of the districts having participants who joined in a Maternal Referral System Trial (MRST) (Ipsos-Tanzania, 2015; Ipsos Kigoma, 2015).

3.3 Study population.

The study included the following populations: 1) Community leaders who joined MRST in Uvinza district in 2015. These individuals have the experience to share their thoughts on community involvement pertaining to the trial details; 2) Motorcycle drivers (Bodaboda) who participated in MRST; 3) Health care workers such as nurses and physicians who joined MRST in 2015; and 4) Pregnant women who had an emergency condition during the MRST and joined in the maternal trial.

3.4 Study duration

The study was conducted over one year following proposal development, ethical review, testing data collection tools, fieldwork and data collection, and analysis and dissemination of the findings.

3.5 Sample size

A tentative number of participants for qualitative research is between 20 to 30 participants, but it depends on saturation. For qualitative data, saturation is recognized when details received from potential participants is not adding any new information to the study questions(Sherwood & D. Atmurr, 2005). The sample size for this study was 21 reached after saturation point, this sample size included 4 community leaders, 5 motorcycle drivers (Bodaboda) who participanted in the MRST to joined a focus group discussion [FGD], 5 health care workers and 7 pregnant women who had an emergency condition during the MRST.

3.6 Inclusion and Exclusion Criteria:

3.6.1 Inclusion criteria:

All participants who participated in the MRST conducted at Uvinza District from May to October 2015 were eligible to participate in the study after consenting voluntarily.

3.6.2 Exclusion criteria:

All those who were not available during the study.

3.7 Sampling procedure.

Purposive sampling were used in this study. This is a technique widely used in qualitative research for the identification and selection of information rich cases for the most effective use of limited resources. It involves identifying and selecting individuals or groups of people that are especially knowledgeable about or experienced with a phenomenon of interest (Gentles et al., 2015). In this study, participants were selected purposively according to their experience and who were involved in the MRST.

3.8 Data collection and Management

Informed consents were obtained from all participants prior to data collection. A focus group discussion [FGD] guide was used for community leaders and motorcycle drivers (bodaboda). Two FGDs of 5 community leaders and 4 motorcycle drivers were conducted. FGDs were employed in this study as they are useful to provide insights into how people think and provide a deeper understanding of the phenomena being studied (Nagle, Barry Williams N, 2011). Semi-structured interview guides were used for health workers and pregnant women who had an emergency condition during the MRST to collect data on their views on research participation (Doody et al., 2013). The semi-structured interview guide were adapted from Ulrich et al, on the benefits and burdens of research participation in cancer clinical trials (Ulrich et al., 2012). Data in this study were collected through note taking and recording participant's responses to the questions, however this activity was preceded by an explanation of study objectives to the interviewees. A total of 21 interviews were conducted, however the final decision to proceed or not to proceed was determined after reaching the saturation point. Each interview lasted for 30 to 45 minutes depending on the amount of information the participants possessed and discussed with the Principal Investigator (PI).

3.9 Data analysis and interpretation

Content analysis was used in this study for the qualitative data whereby coding categories were derived directly from the text data; it was assisted by NVIVO Software. A deductive approach was used where direct, verbatim quotes from the transcripts were used to explain the trends based on the objectives and research questions (Ditai et al., 2018). Moreover, all recorded interviews were transcribed verbatim. The transcribed text was translated from Swahili language to English and read several times to gain familiarity with the data. After reading all transcripts, demarcated segments of texts were created to represent the main issues that emerged during data collection. Each segment was labelled with a "code"-such as 'willingness', voluntary', motivations' in line with the research questions and objectives. After completion of coding, we created a summary of the common/recurring codes, taking into account the similarities and differences in related codes across the entire transcripts, distinct

original sources/contexts, or comparing the relationship between one or more codes. Coded transcripts were arranged according to themes such as motivations, willingness, benefits and burdens to answer the study objectives(Seeley, J., Kielmann, K., Cataldo, 2011).

Minor differences on renaming of the codes were discussed with research assistants and the research team for consensus. Observational notes summarized to complement with the information which were obtained through the interview and FGD. Direct quotations from participants used and presented to ensure that the participants' concerns are reflected in the final report.

Table 1: Example of steps used for data analysis

s/n	**Objectives**	**Inductive analysis**	**Sub-themes**	**Themes**
1	Objective1:To explore individual motivational factors influencing research participants' willingness to join in a MRST at Uvinza District in Tanzania	⟹	1. Benefits for participating voluntarily 2. Expertise 3. Information delivery 4. Personal decision 5. Level of education	Individual Motivational-Related Factors

3.10 Recruitment and training of the research assistants

Two research assistants were recruited before data collection. Selection of research assistants was based on previous experiences in research and work in the communities of interest. All research assistants were trained on how to collect data based on the general overview of the study, interviewing skills and procedures and finally, adaptation with the study instruments. The training also emphasized on how to obtain consent and adhering to all principles in the ethical conduct of research.

3.11 Pre-testing of research instrument

Pre-testing was not conducted because the research instruments were based on published questionnaires used for clinical studies. The FDG and semi-structured interview guide are adapted from Ulrich et al, on the benefits and burdens of research participation in cancer clinical trial and have been used successfully with patients enrolled in clinical trials.

2.12 Rigor of the Data/Trustworthiness

To ensure the trustworthiness of data, the four approaches proposed by Lincoln and Guba (2008) include: credibility, transferability, dependability, and conformability were taken into consideration (Ulrich et al., 2012).

Credibility is defined as the confidence that can be placed in the truth of the research findings (Pembe A, 2010). By selecting suitable participants, introducing them to the aim of the study and asking participants' permission to participate supports credibility of the findings. Also, the interviews were recorded, and notes taken to ensure that the information provided was not missed and reflected the participants' thoughts and concerns. The PI also held debriefing sessions with the research assistants and study team to review the data.

Transferability refers to the degree to which the results of qualitative research can be transferred to other contexts with other participants; it is the interpretive equivalent of generalizability (Lester, 2000). In ensuring transferability the researcher provided a 'thick description' of the study setting and the way purposeful sampling was done as well as when saturation of the data occurred.

Dependability refers to the "stability of findings over time"; getting the same findings if the research is repeated in the same context with the same subjects (Pembe , 2010). To ensure this, the research design was viewed as a prototype model, what was planned is what was executed. A detailed record of the data collection process was implemented. Conformability establishes that the data and interpretations of the findings are not fabrications of the researcher's

imagination, but are clearly derived from the data (Shenton, 2004; Ulrich et al., 2012). These were achieved by use of direct quotes to ensure that findings are abstracted from experiences and the ideas of the participants are not the characteristics and preferences of the researcher.

2.13 Limitations & mitigations of the study

This study explored motivations influencing research participants' willlingness to join in a Maternal Referral System Trial (MRST) conducted at Uvinza District**.** However, because the study relied on self-reported information, there is always the potential for recall bias due to over or under reporting. And, participants may be selective in what they choose to express. The interview provided a more detailed explanation about the situation in order to mitigate this limitation. Participants were told that they did not have to answer any question(s) that they choose not to answer and that all information remained confidential.

2.14 Ethical consideration

Ethical clearance to conduct this study was obtained from the Directorate of Research and Publication of the Muhimbili University of Health and Allied Sciences. The approval to conduct the study was obtained from Uvinza District Council, Health Department. Detailed information about the study were explained to the health care workers at Nguruka health centre as well as to community leaders, motorcycle drivers and pregnant women who had an emergency condition during the Maternal Referral System Trial (MRST), and the informed written consent were given to them before participating in the study. Every participant were well informed on full description of the study, its objectives, procedure, benefits, confidentiality, and contact details in case of any enquiries. The research participants were asked to sign the consent form to show their voluntary consent.

Through informed consent forms, all participants were briefed about the right to agree or disagree to join in the the study. Research participants were informed that the information they provide will be strictly treated confidentially and that information which will be collected from study participants will be used only for this study's purposes. Initials were used in the in-depth interview guide for maintaining privacy and confidentiality.

CHAPTER FOUR

4.0 FINDINGS

4.1 Description of study participants

This study included the following participants' four community leaders and five motorcycle drivers (Bodaboda) who participanted in the MRST who joined a focus group discussion [FGD]. Five health care workers and seven preganant women who had an emergency condition during the MRST were asked to participate in a semi-structured interview as well.

4.2 Presentation of findings

Deductive themes were derived from the conceptual model and analysis and include: Individual-motivational, family and research-related factors. First, there are five sub-themes under the major theme of individual-motivational factors: (1) Benefits for participating voluntarily, (2) Expertise of research team, (3) Information delivery, (4) Personal decision, and (5) Level of education. The second theme, family-related factors have four sub-themes: (1) Burdens for family members to volunteer, (2) Decision making influence from the family, (3) Pressure from the family, (4) Hindrances to participation (Time, family beliefs, fear and understanding of information), and (5) Other influences to participate (i.e., Incentives). Finally, research related a factor also has five sub-themes: (1) Benefits to participate in MRST (such as decrease of maternal death), (2) Understanding or awareness of safe birth, (3) Offering of incentives, (4) Good information, and (5) Importance of informed consent. In a diagrammatical way these themes and sub-themes can be shown as follows.

S/N	THEMES	SUB-THEMES
01	Individual Motivational-Related Factors	1) Benefits for participating voluntarily 2) Expertise 3) Information delivery 4) Personal decision 5) Level of education
02	Family-Related Factors	1) Burdens for family members to volunteer 2) Decision making influence from family 3) Pressure from the family 4) The hindrance to participation ➢ Time ➢ Family beliefs ➢ Fear ➢ Understanding of information
03	Research-Related Factors	1) Benefits to participate in MRST ➢ Decrease of maternal death ➢ understanding or awareness of safe birth 2) Offering of Incentives 3) Good information 4) Importance of informed consent document 5) Trust and informed consent

4.3. Qualitative Themes

4.3.1. Individual Motivational-Related Factors

The study revealed various individual motivational factors that influenced research participant's willingness to participate in MRST. These included the benefit for participating voluntarily, expertise of the research team, information delivery, personal decision, and participants' level of education. One participant was inspired to join the study because of the nature of the study and that the research was about mothers in the fight against maternal and child mortality. This was expressed in the following words:

> "*One of the things that inspired me to join the study is when I was told that the research is about mothers in the fight against maternal and child mortality, therefore I found this to be important*." 002

Moreover, the study revealed that the following factors motivated people to join MRST voluntarily.

4.3.1.1 Benefit for participation voluntarily

The study revealed that there are several benefits that motivated people to participate in MRST as one of the participants said that the biggest benefits is awareness, that through research they knew that some of the information they were not aware of before joining MRST as noted below:

> "*The biggest benefit is gaining awareness, and people being relieved of fear have become the source of their participation in the study*".008.

Another participant pointed out having the right information removes fear, hence participating in research removes fear and this enables the person to share research without worries, he said:

> "*Well, the benefits are huge, I think once you get right understanding it removes the fear and this helps to share the research without any worries. The key is to eliminate fear*".001.

This study revealed that the foreseen benefits motivated people to participate in MRST as one of the participants said that participating in the study helped to learn about the responsibility of protecting pregnant mother and unborn children. This was expressed in the following words:

> *"I think if an individual participates in a study will get a lot of learning benefits including knowing the responsibility of protecting the pregnant mother and protecting the unborn children and this will help to improve the health of the mothers***.**" 002.

Capacity building was also a factor that motivated people to join MRST and helping research participants understand what research is as stated below:

> "*If a person is willing to participate in research, he will be able to get many benefits, including training on research. But it will also help him to understand what research means*"**.**002.

Also, the study revealed that people volunteered to participate in research to reduce maternal death, this was pointed out by one of the participants who said that:

> **"***They volunteered to help out because they saw mothers losing their lives because of maternal deaths…the benefits of volunteering benefit those who participate because it is especially helpful to mothers*".004.

4.3.1.2 Expertise

Expertise also emerged as one of the motivational factors that was important to willingness to participate in research, especially if quality education was provided by the village leaders.

> "*One of the things that can lead people to participate in research is the quality education provided by the village leaders, I believe through the village leader people will understand and participate well in the research*"**.**007.

The study also revealed that people participate in research to solve problems facing the community. This was noted by the participant below:

"*After the experts point out the challenges in their community will be motivated to participate due to the problems, they have in the community and needs to be helped so in any case they must participate in the studies*."0012.

4.3.1.3 Information delivery

Information delivery from experts was another important subtheme that motivated participants. Participants wanted to understand the purpose of the research with clear information that they could trust. The quotes below express these points:

"*The person himself decides after understand the purpose of the research".0010.*

"*... Information and answers provided by the experts are the key factors that made people participate*".008.

"*…True answers from experts; here good answers or good information such as its benefits people to participate voluntarily this will help them to understand how to deal with maternal child and maternal death".001.*

Another participant added that people were motivated to participate in MRST because the information which was given was true, hence this gave a sense of confidence that the study which is planned is safe, as stated by one participant who said."

"...People came forward because of the information being given that it was true".009.

Another added

"*I think people came out in large numbers after the researcher gave some good ideas. In front of the study participants*"

The chairman also cemented the above clarification by adding:

"*…The information the researchers provided actually built my confidence and belief that the study did not have any bad implications*". Chairman.

Another added

> *"I think the main thing is the education provided by the researchers, I believe that for those people who do not want to participate is not that they do not want to at all but it is because of not having have …003."*

4.3.1.4 Level of education

The study also revealed that education is much needed to support research participation and that concerns surrounding ignorance was perceived as the cause of maternal death by giving birth at home. Two participants' quotes are below:

> "*An individual can be interested in participating in any research based on and has understood how the benefits and consequences of research are, we come back to the point that education on the benefits of participation is much needed among participants".003.*

> "*I know it's because mothers were ignorant that's why they give birth at home, they have problems and that's why sometimes mothers die at home during childbirth.*" 004.

4.3.1.5 Personal decision

The study revealed that people participated in MRST because of personal convictions, or because of perceived problems in their society; therefore, their intention to participate was to eliminate those prevailing complications in their society as the following participant said:

> **"…** *People understood that there were maternal problems in society so people fully agreed to participate so that they could eliminate the maternal problem that leads to maternal mortality***".**005.

Also like the theme of education, understanding was an accelerating factor that motivates people to participate in research, after understanding the benefits, risk and other issues pertaining to the planned study as noted by the participants below:

> "…*Only a person who gets an understanding of the study decides to participate, and if you do not have the understanding you cannot participate*".008.

> *"...Here I think a person decides for himself especially when he gets a good understanding and decides for himself".001.*

4.4 Family-Related Factors

The study revealed that there are various family related factors that motivated people to join the MRST in Uvinza. This ranged from burdens on family members for the participant to volunteer, Decision making influence from the family, pressure from the family and the hindrance to participation.

4.4.1 Burdens on family members for individual to volunteer

Burdens on the family also emerged as one of the factors that motivated participants not to participate in MRST. Here, the burdens of the family hindered participation because of having other activities needed of the families or doing business to sustain the family. There was a sense that the time to spend in the study was an act of wasting time. This was evidenced by one participant who commented as follows

> *"I think when you go out to stud y it is a time when you had to do your personal activities for example looking after a family or doing business, so it was like wasting time. I think that's the problem that happened to my family".0012.*

Moreover, family members can disappoint a person not to participate in research because of not having proper knowledge or adequate knowledge about the planned study; this was aired by one participant who commented as follows.

"In fact, sometime family can disappoint due to poor knowledge about a research" 001.

Another participant cemented the above views by saying:

"I have volunteered to really participate in the study and my family is not bothered at all due to their lack of understanding about the study".003.

One of the participants from the Focus Group Discussion said that relatives cannot have objections to participate in the study because he participated under his own free will. This participant said:

"I think my relatives can't have any problems, because I participated in my own free will so I believe my family can't have any problems" FGD2 participant

Another said that family members were happy for him to participate in MRST because the study added knowledge to the family members and through the study, they knew things that they were not aware about. As noted by this participant:

"*There were no side effects except they were very happy because were able to find out things they were not aware of".004.*

4.4.2 Decision making influence from the family

Some of the participants of the MRST said that the family's decisions for them to participate in the MRST was important while others said that their families have no influence for them to participate in the study. These statements are noted below:

"In fact, involving the family in participating in the study I think is right because maybe I'm married, and I have a husband therefore I can't decide to be involved in the study without informing him".007.

"Yes, there was an influence because when I came back, I told them what I was going to do in the study. When I told them they really understood a lot of the things I saw there in the studies regarding maternal referrals". 0012.

"I think the issue of sharing research does not require much influence from the family" 002.

"Absolutely not, not even the statement I did not tell my wife, except that my first son was the one I told, and I told him because he was the one who was there at home and his mother was not".001.

Moreover, another participant added that their family was happy for him to participate in the study because after returning home, he shared the information to family members. This made the family know more about some of the issues related to maternal referrals. This participant said:

"My family was happy because there were some things they did not understand before. But when I returned, I informed them, and they understood the benefits of giving birth in a hospital, so they were very happy".004.

Another participant added that there was no influence from the family since because these studies are voluntary so a person can decide to participate or not to participate, the participant said as follows:

"No, they did not have any influence because these studies are voluntary, so I have the power to decide whether to participate or not" 006.

4.4.3 Hindrances to participation

The study revealed that there are several obstacles or hindrances to research participation. The participants pointed out a number of factors that hinder them from participating in research as explained below:

4.4.3.1 Family beliefs

Family beliefs was one among other factors which hinder participants to engage in research as one of the participants said that misconceptions about research prevents people to enroll in the study.

> *"One of them is the misconception about research, in the community there are those who prevent research processes from taking place due to the poor education available in the community".003.*

The participants added that to change people's mind so as to see the importance of research, education has to be provided in the community; the participant expressed this in the following way

> *"But education can help change people's minds and realize the importance of research. Through education we get liberated out of these bad beliefs and myths about research. Because most of us in the community have been holding on to these beliefs despite of not having evidence and knowing if they are relevant … we tend to take them as real ones at the end of the day hindering these studies."003*

Another participant added:

> "*One of the things that can keep us from participating is bad belief, for example, the phenomenon that occurs with cervical immunizations, our little ones are very confused and sometimes it is challenging*".007.

4.4.3.2 Time

Time is also one of the factors that can hinder research participation. This is because people fail to recognize the time that is needed for participating in research as one of the participants said:

"*The problems are really not so much; the problem I have seen is time. Because some failed to balance time for engaging in research and to do other activities. So, the problem was time*".005.

Other participants from the focus group discussion added that an allowance must be provided so as to compensate the time taken to participate in research. This participant also raised the issue of weather, especially conducting studies in the rainy season as this prevents people from participating in research and campaign periods:

"What causes it is time, because a person wastes time and does not get anything, so it is better to have an allowance. Which prevents one from participating in the seminar is that researchers are coming in during the rainy season something that prevents people from attending the seminar." FGD1 participant

"*What hinders Tanzanians from participating in research is time, for example during a campaign period it is difficult for a person to venture into research and when there is a campaign period, sometimes the allowance becomes less now one can stop his activities and then go to research*." FGD2 participant.

4.4.3.3 Fear

Fear emerged as one of the factors that hindered research participation as one of the participant's said:

"*Fear and heresy is a very bad thing that contributes to many participants having a very negative attitude due to the fact that groups disagree with the study, now they are spreading propaganda and find the study lacking or having few participants***." 002**

4.4.3.4 Understanding of information

Not having what was perceived to be the "right" information also emerged as an important hindrance. One of the participants noted:

> **"…***One of them is the misconception about research, in the community there are those who prevent research processes from taking place due to the poor education available in the community***".**003**.**

Another participant added that for people to get involved in research is to be given enough information from research experts. The information given will wash out bad information they have in their minds, and this is evidenced by the participant who said:

> "*The only thing that can get people involved is information from research experts, the only thing that can stop them is the bad information that can make people who want to participate not participate for example people feel they will probably be given drugs like worms or have their blood drawn".0010.*

Moreover, the study revealed that language hinders people to participate in research because of not understanding what the research is about as was reported by one of the participants who said:

> *"But there are also things that can keep people from participating including Language" 001*

4.4.3.5 Influential Reasons to Participate in Research

The study revealed that there are incentives that influence people to participate in research as explained below.

Some participants in this study have acknowledged the influence of incentives for people willingness to participate in research. Concerning the incentives they articulated that:

> "*The participants are happy because sometimes they are given an allowance to get food, so if they continue to get food, they wish they could come back another day to study*".004.

> **"***What causes it is time, because a person wastes time and does not get anything so it is better to have an allowance…….if there is a small amount of money people can come forward quickly knowing there is a budget***"** FGD1 participant.

Moreover, another participant added that information also motivates people to participate in research because this makes them know the importance of research, that is planned to be conducted. As this participant said:

> **"***The first thing that makes people participate in the study, is the information in the village meeting so becomes easier for us to volunteer***"** 001.

4.5. Research-Related Factors

Research related factors in this study revealed the following

4.5.1 Benefits of research participation:

4.5.1.1 Decrease of maternal death

The study revealed that before MRST maternal death was high as compared before MRST this is because mothers did not know the benefits of attending a hospital to give birth. Before MRST, mothers were giving birth at home:

> "*My first benefit was to know why mothers were losing their lives, especially during childbirth, so this has helped to motivate mothers to go to hospital this helped to solve that what which was happening in the beginning*".004.

Another participant from the focus group discussion added that

> "*I saw the benefits, because many pregnant women lost their lives, but after the research maternal mortality decreased*." FGD participant

Participation of mothers in MRST also made the work of nurses in the health facility center easy because mothers knew the importance of reproductive health, one of the nurse's evidenced this by saying:

> "*I really got the benefit especially when I was in the health center as a nurse, I was really relieved of my responsibilities, the work was very difficult and later when the mothers participated in the research training the work was really easy because the parents were coming on time and the work became much easier. This is the biggest benefit I have seen in this study*".005.

Another participant added

> "*With this referral system, it has helped many mothers find information and make decisions, and this has really helped to reduce maternal mortality".006.*

Moreover, another participant added that currently she knows that a safer place to give birth is in the hospital, because mortality rate was high when mothers were giving birth at home. She said:

> "*As I said earlier, I have benefited a lot because now I see mothers giving birth at home is not good, a safe place to give birth is in a hospital and doing so will help reduce the number of maternal deaths due to childbirth*.".007.

4.5.1.2 Understanding or awareness of safe birth

The study discovered that because of reproductive health awareness people understand or are aware about safe births, a birth which does not cause maternal death. One of the participants added that by being a mother through MRST they got early education on reproductive health. And, it helped them to avoid death of their children by stopping giving birth at home:

> **"***One of the main benefits for us women are getting early education on reproductive health, but also another benefit through MRST helps us to avoid the deaths of our children by giving up the habit of giving birth at home***".003.**

4.5.2 Good information for the community.

To motivate people to participate in research, this study revealed that there is a need for sharing information with the community; this was evidenced by one participant who said:

> *"I think information is the most important thing in connecting people or participants in research. Having good information through the cooperation of leaders and citizens can help participants to get information in advance and decide whether to participate or not".007.*

Another participant added

> "*As I think, good information from researchers, for example those previous researchers were telling us the risks and benefits, we really understood very well that there are maximum benefits more than risks*".001.
>
> *"I think the good information provided by the researcher would be an important factor in persuading people to join the study" FGD2 Participant.*

Moreover, another participant added that the information was given by the researchers on the benefits of participating in MRST, this gave her the courage to participate in the study, she said:

> "*In fact, in terms of information, I did not have any problems as I read the consent forms and understood them, but more information on the benefits of participation made me decide to participate without being forced*".003.

4.5.3 Importance of informed consent

Informed consent was one of the research related factors that motivated people to participate in research. This form explained in detail the purpose of the study and clearly showed the benefits and the risks. After reading the consent forms participants trusted the study and decided to participate. Several participant comments are below:

"*The information really encouraged me to join the system, it didn't give me any objection and it was part of my job I was doing at the time, so there was no problem"*.005.

"In fact, my faith does not preclude me from participating in the research, the researchers 'comments and explanations were sufficient and made me to participate in the study".001.

He also added:

"The biggest thing I enjoyed in the study was getting information on time and I decided to make decisions based on what I understood from the research".001.

Another participant spoke to the importance of information from medical professionals as noted below:

"*I think the information of health professionals is what I think needs to be provided so that the community can believe through these medical professionals*".0011.

4.5.4 Offering of incentives

Allowance was one of the benefits perceived as important for participating in research as noted below:

"*I think another benefit will be that he will be able to get an allowance because we are used to see a lot of researchers when they come here at least there are allowances they give us as part of the motivation***".**002.

Another participant added

"*I think when a person stops his activities and comes to research then we should respect his thoughts and respect the time he volunteered until he came to the study at least by giving him a small allowance as part of bus fare, because he stopped his activities and decided to participate in the study*".003.

Moreover, another participant added that when people are given food this becomes a catalyst for them to come back.

> "*The participants are happy because sometimes they are given an allowance to get food, so if they continue to get food, they wish could come back another day to participate in the study"*.004.

The participant said that allowance must be given depending on the length of the interview and the time taken.

> "*The amount that can be as an incentive is from 10,000 or 50,000 but depends on the duration of the interview, for example a person may come in the evening is different from a person who will be participating from morning till evening so allowances must be considered***".** FGD1 participant.

A focus group participant indicated:

> "*I think the allowance rate should be commensurate with the time that researchers spend meeting participants, i.e., the allowance should be given according to the time."* FGD1 participant

Despite mentioning allowance as the motivating factor for participating in research, one of the participants cautioned that this allowance should not be high as people might give more attention to money rather than research.

"10,000? ... No that's not a salary if you do that people will run for money and not research, I think a small amount is enough for at least to buy soap. Another incentive that would be good, for example, if a person was given a t-shirt, would be better because people would be able to get a message or researchers would be providing this wrap would help people understand and get education through t-shirts or wraps apart from allowances that can be provided by researchers.".FGD1 Participant.

Another participant added that many people participated in the study because they were given allowances and water.

> *"Many people took part in this study because they were given allowances and water. FGD2 Participant*

CHAPTER FIVE

5.0 DISCUSSION

This study found significant factors that were important to study participants' willingness to join in a martenal referral system trial (MRST) in Uvinza. The factors found through this qualitative analysis brought new insights to understanding research participation in Tanzania. Therefore this chapter discusses the findings including individual, family, and research-related motivational factors. They are detailed as follows.

5.1 Individual Motivational Related Factors

Various individual motivating factors that might influence research participation include age, gender, education level, knowledge to be gained, type and severity of illness and altruism (Mbunda et al., 2014). However, this thesis found different factors affecting participants' willingness to participate in health related research. This study found that some people participate because of the benefits participants expect to receive such as: to gain awareness and the responsibilities of protecting pregnant mothers, Also expertise was perceived as an important factor whereby some individuals participated because they believed in experts and their knowledge. These aspects are reflected in the principle of respect to persons as found in the study by Limkakeng et al., (2013) and a key bioethical principle.

This thesis study also differs slightly with the study by Smit and colleagues (2006) who after conducting a quantitative study on HIV in South Africa, found age, gender and increasing knowledge of participants was a significant influence for people to join in their study. This study did not find age or gender to be factors that motivated individuals to join the MRST, however, the MRST study was specifically focused on pregnant women. On the other hand, this thesis study found that the way information delivery is presented by researchers may trigger one's willingness to join the study. Therefore age did not matter to a great extent for people to participate in the current study but might be significant in a larger quantitative study.

One's personal decision making to participate in the MRST found in this study is similar to a study conducted by Nyasani and his colleagues (2018) who found that participants had the desire to participate in the study altruistically. This brings the concern that even in Tanzania some people are ready to join the study voluntarily or altruistically insofar as they are not intervened by a third party. Personal decision making has been emphasized as a measure of respect for persons in many ethical codes and guidelines regarding the conduct of reserch, including the Belmont report.

This thesis study also found that educational level of participants triggers their participation in research studies because they feel comfortable in knowing what research means to them. Therefore, because there are concerns about literacy levels in Tanzania in certain areas, researchers who plan to conduct research in low resourced areas should work with local researchersto prepare training guidelines for potential research participantsto. A similar recommendation was suggested by Smit et al (2006) on a study focused on willingness to participate in an HIV vaccine trial.

5.2 Family-Related Factors

The study found that family-related factors in the MRST played an important role in participants' decision making in their willingness to participate. This included burdens for family members if the individual decided to volunteer, and other concerns.

The findings on family issues is similar to other research where there are concerns that particpating will take time away from one's life and work. Moreover this study found that family members can discourage a person to participate in research because of not having adequate knowledge about the planned research, this accelarates the targeted population not to volunteer in order to participate in research this is in .line with the study done by (Harapan et al., 2016) which indicated low knowledge regarding dengue fever as the factor for poor participation in research.

Decision making influences and pressures from the family was also identified by some participants as an issues of concern. Here, the family had the power to make decisions on behalf of the person who was considering participating in the MRST. This does not support the principle of respect for persons which ephasizes that we should treat a person as an autonomous being Chu et al (2015). Also found that family members can have an influence on individuals joining in a trial.

Hindrances to participation was also found in this thesis study. This included time and balancing research participation with other activities to sustain life goals (e.g., working at one's job) and family beliefs. Some participants indicated their families had misconceptions about research because of poor knowledge about the planned research.

Fear also created negative attitudes toward research and this affected the study's research participation. In her study on the benefits and burdens of research participation in cancer clinical trials, Ulrich and colleagues' (Ulrich et al., 2012) participants had fears of the unknown about their cancer diagnosis but were still willing to participate in the research trial.

5.3 Research Related Factors

Benefits to participate in MRST was an importantresearch- related factor. Indivisuals who participated int eh MRST reported that they are ready to participate if they have understood the benefits of the study. The benefits they wanted focused ondecreasing maternal deaths and to be aware of safe births. In fact, this is similar to the findings by Bruce et al. (2016) who reported that young Black men participated in clinical research for human connection, self-improvement and low risk, among other reasons.

Some other studies like that of Chu, Kim, Jeong and Park (Chu et al., 2015) reported that benefits to participate in a clinical trial were free checkups, and free treatment and medical screening. However, these benefits are not the same as was found by participants in the MRST.

The offering of incentives is another factor that motivate individuals to participate in MRST at Uvinza. They reported that they were willing to participate if they were compensated for their time.

Incentives may attract more people to join a study in Tanzania because participants appreciate being compensated for the time spent in the research trial. But, it is not clear how much or what type of incentive is important for Tanzanians without creating undue influence. The study conducted in Mumbai India about the benefits of willingness to join in an HIV trial (Newman et al., 2014) indicated that financial incentives and free medical care had significant importance on willingness to joining in the vaccine trial.

Last, participants must feel that they have received sufficient informaiton to make a decision about their participation. This includes understanding that they are participating in reesarch, the risks and benefits, alternatives, procedures, ability to withdraw without penalty, and other aspects of the research. The importance of informed consent has been addressed in various ethical codes, laws and regulations about involving human subjects in clinical research (United States Department of Health & Human Serviices, 1979),(Katz, 1996)

Respondents also reported that trust of the researchers was significant to them. Some respondents reported that they joined the study because they had trust in researchers. This is similar other research that reported that participants joined the study because of their trust in researchers(Liu & Li, 2018). Therefore, it reminds researchers to develop the good habit and to work adhering to professionality so that to keep trust so as to be able to motivate individuals to join the study when needed.

CHAPTER SIX

6.1 Conclusion

People participate in research for a variety of reasons. This is also true for Tanzanian citizens. This thesis study found that people in Uvinza were ready to participate in a research study so long as their concerns had been recognized by the research study and the researchers conducting the trial. Most found the benefits to outweigh the burdens. Future research should focus on the role of incentives in research participation as MRST participants felt they were necessary to assist in research participation. More work is needed on the amount and type of incentive that would be most helpful to respect the time that participants give to advancing.

6.2 Recommendation

1. Study recommend that more research is needed to better understand how to improve the informed consent process to make sure that individuals and communities have sufficient information where a study is being planned.

2. Study recommend the researchers offer a small incentive to potential participants in order to compensate them for the expenses that are incurred by the participants.This is a measure of respect for their time and their contributions to the research.

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APPENDICES

APPENDIX 1: INTERVIEW GUIDE QUESTIONS FOR SEMI-STRUCTURED INTERVIEWS (English version)

Date of an interview……time……..

(A) Personal particulars:

1. Form number…….
2. Registration Number…….
3. Age……
4. Sex: a)Male……..b)Female…….
5. Place of residence……
6. Marital status:
    a) Marriage
    b) Single
    c) Divorced
    d) Widowed
7. Occupational:
    a) Employed
    b) Self-employed
    c) Housemother/Father
8. Education level:
    a) Higher
    b) Secondary
    c) Primary
9. Religious:
    a) Christian
    b) Islamic
    c) Others……

Have you ever participated in a research study in Tanzania?

Yes

No

If yes, what type of study did you participate in?

……

Probe: Did you attend any training sessions before joining in the MRST? How many times have you participated in research? Can you share with me what was involved?

……

1. What do you think are motivational factors that influence research participants' willingness to join in a MRST?

   Probe: Why do you think individuals volunteered to participate in a MRST?

   What do you think are the benefits for the individual to volunteer in the MRST?

2. How do you think families might have influenced research participants to join in a MRST at Uvinza District in Tanzania?

   Probe: What do you think helps/hinders research participation by Tanzanian citizens? What are the burdens for your family members or friends to volunteer in a MRST?

3. What do you think was important from the research that might have influenced research participants' willingness to join in a MRST?

   Probe: Can you tell us the benefits which you earned due to your participation to a MRST? How did Trust in reseach and researchers and informed consent affect your decision to volunteer in a MRST? Can you tell me what you think about offering incentives to participate in research? What type and amount of incentives do you think would be appropriete?Cash? How much would be appropriate for this type of study? Other type of incentive, such as travel reimbursement? Or other? How important was the informed consent document to your decision to participate? Was their anything that you didn't understand?

APPENDIX 2: INTERVIEW GUIDE QUESTIONS FOR SEMI-STRUCTURED INTERVIEWS (Swahili version)

Fomu hojaji.

Tarehe ya mahojiano……Muda……..

(A) Taarifa Binafsi:

1. Fomu namba……..……
2. Namba ya usajili…….……..
3. Umri…….…….
4. Jinsia: a) Mwanaume……b) Mwanamke ……
5. Mahali unakoishi……...
6. Hali ya ndoa:
    a) Umeolewa
    b) Haujaolewa
    c) Umeachika
    d) Mjane
7. Kazi yako:
    a) Umeajiriwa
    b) Umejiajiri
    c) Mama wa nyumbani/baba
8. Kiwango chako cha Elimu
    a) Elimu ya juu
    b) Elimu ya sekondari
    c) Elimu ya msingi
9. Dini:
    a) Mkristo
    b) Muislamu
    c) Dini nyingine (Taja)……

(B) Mahojiano

Tafadhali niambie kipindi cha nyuma ulishawahi ukashiriki kwenye tafiti yoyote hapa Tanzania?

Ndiyo

Hapana

Kama ni Ndiyo, ni utafiti upi ulishiriki?.....

Je unakumbuka ulishiriki mafunzo yoyote kabla haujashiriki kwenye utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua? Ulisha shiriki mara ngapi kwenye tafiti kama hizi? Unaweza kunishirikisha ni kwa jinsi ngani wewe ulishirikishwa?

1. Unadhani Ni kwa sababu zipi/gani watu walijitolea kushiriki kwenye utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua?

   Probe:unafikiri ni kwa nini watu walijitolea kushiriki kwenye utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua? Nini unadhani ni faida kwa mtu aliyejitolea kushiriki kwenye utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua?

2. Kutokana na ushiriki wako unafikiri watu wa familia yako walikuwa na ushawishi wa wewe kujitolea kushiriki kwenye utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua?

   Probe: unaweza kunielezea unafikiri ni kipi kinaweza kuzuia au kusaidia watu walijitolea kushiriki kwenye utafiti? Ni matatizo gani yaliwapata watu wa familia yako au rafiki zako walijitolea kushiriki kwenye utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua?

3. Naomba unielezee unafikiri kipi ni muhimu kutokana na utafiti kinaweza kikawashawi watu kujiunga na utafiti?

   Probe: Hivi unaweza ukatuambia faida uliyoipata kutokana na ushiriki wako katika utafiti huu wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua? Ni kwa namna gani imani yako kwenye utafiti na kwa watafiti na maelezo ya kina ya utafiti yalivyo athiri maamuzi yako ya kujiunga kwenye utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua?. Hivi unaweza ukaniambia unafikiri nini kuhusiana na utoaji wa motisha kwa wanaoshiriki katika utafiti? Unafikiri ni aina gani na kiwango gani cha motisha/pesa kinafaa kutolewa kwa washiriki wa utafiti?. Je ni kiasi gani cha pesa kingefaa kwa aina hii ya utafiti? Je unafikiri motisha nyingine ni zipi ukiachilia posho ya usafiri Ni kwa namna gani maelezo ya kina ya utafiti yalikua muhimu kwako katika kuamua kujiaunga na utafiti? Je kuna kitu kingine chochote ambacho hukukielewa?

APPENDIX 3: GUIDE QUESTIONS OF FOCUS GROUP DISCUSSION FOR COMMUNITY LEADERS (FGD) (English version)

Date of an interview……time……..

(A) Personal particulars:

1. Form number…….
2. Registration Number…….
3. Age……
4. Sex: a)Male……..b)Female…….
5. Place of residence……
6. Marital status:
    a) Marriage
    b) Single
    c) Divorced
    d) Widowed
7. Occupational:
    a) Employed
    b) Self-employed
    c) Housemother/Father
8. Education level:
    a) Higher
    b) Secondary
    c) Primary
9. Religious:
    a) Christian
    b) Islamic
    c) Others……

I would like to ask you several questions about research participation and welcome your thoughts. You are under no obligation to answer any question that you choose not to answer

1. First, can you tell me what/why you think people willingly volunteered for MRST?

   Probe: What was your role as a community leader? What factors do you think were important? Individual motivational factors? family-related factors? research-related factors? Why do you think influenced individuals volunteered to participate in a MRST? What are the benefits for the individual to volunteer in the MRST?

2. How do you think families might have influenced research participants to join in a MRST at Uvinza District in Tanzania?

   Probe: What do you think helps/hinders research participation by Tanzanian citizens? What do you think are the burdens for your family members or friends to volunteer in a MRST?

3. What do you think was important about the reseach that might have influenced research participants' willingness to join in a MRST?

   Probe: Can you tell us the benefits which you earned due to your participation to a MRST? How the Trust in reseach and researchers and informed consent influenced you to volunteer in a MRST? Can you tell me what you think about offering incentives to participate in research? What type and amount of incentives do you think would be appropriete? Do you think cash or some other type of reimbursement would be appropriate?

Thank you very much for you cooperation

APPENDIX 4: GUIDE QUESTIONS OF FOCUS GROUP DISCUSSION (FGD) (Swahili version)

Fomu hojaji.

Tarehe ya mahojiano……Muda……..

(A) Taarifa Binafsi:

1. Fomu namba…….……
2. Namba ya usajili…….……..
3. Umri…….…….
4. Jinsia: a) Mwanaume……b) Mwanamke ……
5. Mahali unakoishi……...
6. Hali ya ndoa:
    a) Umeolewa
    b) Haujaolewa
    c) Umeachika
    d) Mjane
7. Kazi yako:
    a) Umeajiriwa
    b) Umejiajiri
    c) Mama wa nyumbani/baba
8. Kiwango chako cha Elimu
    a) Elimu ya juu
    b) Elimu ya sekondari
    c) Elimu ya msingi
9. Dini:
    a) Mkristo
    b) Muislamu
    c) Dini nyingine (Taja)……

(B) Mahojiano

Nipenda nikuulize baadhi ya maswali kuhusiana na ushiriki wako kwenye utafiti uliofanyika juu ya mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifungua, nakaribisha fikra zako. Unaweza kujibu au kutokujibu swali lolote utakalotaka kuto-kulijibu kuwa huru kujibu.

1. Je unaweza ukaniambia ni kwa nini watu walijitolea kujiunga na utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua?

   Probe: Nini ilikua wajibu wako kama kiongozi wa kijamii?.Unafikiri sababu zipi zilikua muhimu? Binafsi?Za kifamilia? Za kiutafiti? Hivi unafikiri kitu gani kiliwashawishi mtu mmojammoja kujiunga na utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua? Nini faida ya mtu kujiunga na utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua?

2. Hivi unafikiri ni kwa namna gani familia ziliweza kushawishi watu kujiunga na utafiti?

   Probe: Unafikiri kitu gani kinafanya au kinazuia ushiriki wa watanzania kwenye tafiti? Unafikiri ni matatizo gani familia au marafiki wanaweza kupata kwa kushiriki kwao kwenye utafiti?

3. Unafikiri kitu gani kilikua muhimu kuhusiana na utafiti kingeweza kushawishi watu kujiunga na utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua?

   Probe: Hivi unaweza ukatuambia ni faida gani umezipata kwa kushiriki kwako kwenye utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua? Ni kwa namna gani imani yako kwenye utafiti na kwa watafiti na maelezo ya kina ya utafiti yalivyo athiri maamuzi yako ya kujiunga kwenye utafiti wa mfumo wa rufaa kwa akina mama wajawazito wakati wa kujifumgua?. Unafikiri ni aina gani na kiwango gani cha motisha/pesa kinafaa kutolewa kwa washiriki wa utafiti?. Je ni kiasi gani cha pesa kingefaa kwa aina hii ya utafiti? Je unafikiri motisha

nyingine ni zipi ukiachilia posho ya usafiri?. Ni kwa namna gani maelezo ya kina ya utafiti yalikua muhimu kwako katika kuamua kujiaunga na utafiti?

Asante sana kwa ushirikiano wako.

APPENDIX 5: INFORMED CONSENT (English version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
DIRECTORATE OF RESEARCH AND PUBLICATIONS

ID. No

Introduction

Greetings! My name is Constantine Antepa Mazanda a student of Master of Public Health at Muhimbili University. This research is part of my studies with the main objective "To explore motivations influencing research participants' willingness to join in a maternal referral system trial conducted at Uvinza-Tanzania.

Purpose of the study:

The purpose of this study is to explore the motivations influencing research participants' willingness to join in a maternal referral system trial conducted at Uvinza-Tanzania. Researchers and study participants will be interviewed in this study. In view of the fact that you are one of the participants of this study, I will ask you some questions regarding the willingness, benefits and burdens towards volunteering in a maternal referral system trial conducted at Uvinza-Tanzania. This will take approximately 45 minutes of your time.

Type of participation involved

If you agree to join in this research, an interview session will take about 30 to 45 minutes.
If you agree to join in this study, you will be required to sign this consent form and answer the questions that you will be asked by me.

Participant Selection

You are invited to join in the study because we feel that as a respondent in this study you can have a vaued contribution on the issue of the motivations that influencing research participants' willingness to join in a maternal referral system trial conducted at Uvinza

Benefits

From this study, you will not get direct benefits but the information provided by you will help to produce information in the literature on the sensitivity towards the motivations influencing research participants' willingness to join in a maternal referral system trial among study participants and researcher globally. The information you share will help in making suggestions and come up with fair deliberations on the issue of using motivations according to the cultural setting of the Nation where research takes place. But also information will be a useful source of information to clinical researchers, study participants and program planners in the streamlining the guidelines for clinical trials.

Risks

This study involves no invasive procedures so we expect that no harm will be done to any participant.

Confidentiality

I wish to assure you that, this information will be treated in confidentiality between you and the researcher. All the information collected in the questionnaire forms will be entered in the computer with only the study identification number.

Voluntary participation

Taking part in this study is totally voluntary, that is, you can decide to join or not. You can stop participating in this study at any time, even if you have already given your consent. Refusal to join or withdrawal from the study will not involve penalty or loss of any benefits to which you are otherwise entitled.

Who to contact if you have any question about this study

In case of any questions about this study please don't hesitate to contact Principle Investigator, Constantine Mazanda, of Muhimbili University of Health and Allied Sciences (MUHAS), P.O. Box 65001, Dar es Salaam (Tel. No 0717773511). And any questions about right to conduct this study, you may call Chairman of University Research and Publication Committee,

Dr Bruno Sunguya P.O. Box 65001 Dar es Salaam, Telephone +255 22 2150302-6 and **Fr. Raymond Muhotya**, who is the supervisor of this study through Telephone No.0762021208

Do you agree? Yes…….. No……

I ……..… Have read the contents of this consent form and my questions have been adequately answered. I therefore agree to join in this study.

Signature of the participant ……Date ……

Signature of the interviewer …….. Date ……

APPENDIX 6: CONSENT FORM (Swahili Version)

CHUO CHA SAYANSI ZA TIBA MUHIMBILI

KURUGENZI YA UTAFITI NA MACHAPISHO

FOMU YA RIDHAA

Namba ya utambulisho……..

Utambulisho

Salamu! Jina langu ni Constantine Antepa Mazanda , Mwanafunzi wa shahada ya uzamili katika fani ya afya ya jamii katika chuo kikuu cha sayansi cha afya na tiba Muhimbili. Ninafanya utafiti huu kama sehemu ya masomo yangu, ambao lengo kuu ni kufanya utafiti wa "Kuchunguza maoni ya washiriki wa utafiti katika kujiunga na utafiti kibinafsi kwa ridhaa yake au bila kutumia vishawishi katika maamuzi ya kujiunga katika utafiti uliofanyika juu ya mfumo wa rufaa kwa mama mjamzito katika tarafa ya Nguruka wilaya ya Uvinza, Tanzania

Kusudi la utafiti:

Dhumuni makuu ya utafiti huu ni Kuchunguza maoni ya washiriki wa utafiti katika kujiunga na utafiti kibinafsi kwa ridhaa yake au bila kutumia vishawishi katika maamuzi ya kujiunga katika utafiti uliofanyika juu ya mfumo wa rufaa kwa mama mjamzito katika tarafa ya Nguruka Wilaya ya Uvinza, Tanzania

Aina ya mshiriki

Washiriki wa utafiti uliofanyika juu ya mfumo wa rufaa kwa mama mjamzito watahojiwa katika utafiti huu. Kwa kuwa wewe ni mmoja wa washiriki wa utafiti huo, nitakuuliza maswali kadhaa kuhusu maoni binafsi jinsi kujiunga na utafiti kwa ridhaa yake au kwa kutumia vishawishi katika maamuzi ya kujiunga katika utafiti uliofanyika juu ya mfumo wa rufaa kwa mama mjamzito katika tarafa ya Nguruka, Tanzania.

Hii itachukua takriban dakika 30 had 45 za muda wako.

Ushiriki

Kama utakubali kushiriki katika utafiti huu, itabidi usaini fomu hii ya makubaliano pia ujibu maswali utakayoulizwa na mtafiti.

Faida

Kutokana na utafiti huu, hautapata faida za moja kwa moja, lakini taarifa utakayoitoa wewe itasaidia kutengeneza maoni na taarifa sahihi juu ya namna bora kwa washiriki wa utafiti katika kujiunga na utafiti kibinafsi kwa ridhaa yake bila kutumia vishawishi katika maamuzi ya kujiunga katika tafiti.

Madhumuni ya utafiti huu ni kuongeza uhamasishaji kwa watunga sera juu ya mshiriki wa utafiti kuridhia yeye mweyewe bila ya vishawishi vya aina yoyote katika kujiunga katika tafiti. Taarifa hiyo pia itakuwa chanzo muhimu cha habari kwa watafiti wa kliniki, washiriki wa masomo na wapangaji wa programu katika kuhakikisha kuwa mshiriki/ washiriki wanahiari wao wenyewe katika kushiriki kwenye tafiti.

Madhara

Utafiti huu hauhusishi vitendo vyovyote vya kudhuru mwili wako, kwa hiyo hatutegemei mshiriki yoyote kupata madhara.

Usiri

Taarifa zote zitakazokusanywa zitashughulikiwa kwa usiri mkubwa kati yako na mtafiti. Taarifa hizi zitaingizwa kwenye mfumo wa komputa kwa herufi sio kwa majina yenu.

Haki ya kujitoa au Vinginevyo

Kushiriki kwako katika utafiti huu ni kwa hiyari, Unaweza kujitoa katika utafiti huu muda wowote ukiamua kufanya hivyo hata kama ulikubali kujiunga hapo mwanzo. Kuacha kushiriki au Kujitoa katika utafiti hakutakuwa na adhabu yoyote wala hutapoteza haki zako za zozote zile.

Mawasiliano

Tafadhali, kama utakuwa na maswali yoyote kuhusu utafiti huu wasiliana na mtafiti mkuu: Constantine Antepa Mazanda wa S.L.P. 65001, Chuo Kikuu cha Tiba na Sayansi za Afya Muhimbili Dar es Salaam, au Mwenyekiti wa Kamati ya Tafiti na Uchapishaji **Dr Bruno Sunguya**, S.L.P 65001, Dar es Salaam Tel No: 022-2150302-6. Au Msimamizi wa Utafiti huu **Padri Raymond Muhotya** kwa simu namba 0762021208.

Sahihi;

Je unakubali kushiriki katika utafiti huu? Ndiyo…….. Hapana……

Mimi…..... nimesoma /nimeelezwa yaliyomo yote katika fomu hii na maswali yangu yote yamejibiwa. Nakubali kushiriki katika utafiti huu

Sahihi ya mshiriki …….Tarehe……

Sahihi ya mtafiti msaidizi …….Tarehe ……