

Title: FACTORS AFFECTING WOMEN'S AUTONOMOUS DECISION MAKING IN RESEARCH PARTICIPATION AMONGST YORUBA WOMEN OF WESTERN

NIGERIA.

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- Predictive medicine and genetics
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# ABSTRACT

Research is a global enterprise requiring participation of both genders for generalizable knowledge; advancement of science and evidence based medical treatment. Participation of women in research is necessary to reduce the current bias that most empirical evidence is obtained from studies with men to inform health care and related policy interventions. Various factors are assumed to limit autonomy amongst the Yoruba women of western Nigeria. This paper seeks to explore the experience and understanding of autonomy by the Yoruba women in relation to research participation. Focus is on factors that affect women's autonomous decision making in research participation.

An exploratory qualitative approach comprising four focus group discussions, 40 in-depth interviews and 14 key informant interviews was used. The study permits a significant amount of triangulation, as opinions of husbands and religious leaders are also explored. Interviews and discussions were audiotaped and transcribed verbatim. Content analysis was employed for data analysis.

Findings show that concepts of autonomy varied amongst the Yoruba women. Patriarchy, religion and culture are conceived to have negative impact on the autonomy of women in respect to research participation. Among the important findings are: 1) male dominance is strongly emphasized by religious leaders who should teach equality, 2) while men feel that by making decisions for women, they are protecting them, the women on the other hand see this protection as a way of limiting their autonomy. We recommend further studies to develop culturally appropriate and workable recruitment methods to increase women's participation in research.

Keywords: Nigeria, women's autonomy, patriarchy, culture, religion, research participation INTRODUCTION

Research is a global enterprise requiring participation of women and men for generalizable knowledge; advancement of science and evidence based medical treatment. Participation of women in research is necessary to reduce bias that most empirical evidence is obtained from studies with men in order to inform health care and related policy interventions. Furthermore, generalizable research relies on recruitment of research participants of both genders for procuring balanced and unbiased data. Informed consent is a prerequisite for research participation, made explicit in the declaration of Helsinki.<sup>1</sup> African women are constrained by culture in terms of giving first person voluntary informed consent.<sup>2</sup> Autonomous decision making of women as research participants has been a concern to several feminist researchers.<sup>3</sup> Clinical trial designs that exclude women are not sufficient for the development of treatments because of the differences between men and women with regards to physiological responses.<sup>4</sup> To avoid gender biased results, it is generally necessary to include women in research. Knowledge about factors affecting women's autonomous decision making capacity in relation

<sup>&</sup>lt;sup>1</sup> World Medical Association of Helsinki, 2013. Ethical Principles for Medical Research Involving Human Subject. 64 WMA General Assembly, Fortaleza, Brazil. *Journal of American Medical Association*. 310(20): 2194. Doi:10.1001/jama.2003.281053. 1–5.

<sup>&</sup>lt;sup>2</sup> P.F. Omonjezele. African Women as Clinical Research Subject: Unaddressed Issues in Global Bioethics. *Ethno-Med.*, 2(2) 2008: 121–126; AUTHOR; D.O. Irabor & P. Omonjezele. Local attitudes, moral obligation, customary obedience and other cultural practices: their influence on the process of gaining informed consent for surgery in a tertiary institution in a developing country. *Dev World Bioeth*. 2009. 9(1): 34–42; AUTHOR.

<sup>&</sup>lt;sup>3</sup> Y.R. Smith, A.M. Johnson, L.A. Newman, A Greene, T.R.B. Johnson, J.L. Rogers. Perceptions of Clinical Research Participation Among African American Women. NIH Public Access. *J womens health* (Larchmt). 2007; 16(3): 423–428; B.R Nugent. Beyond Biases and Barriers: Incorporating Women into International Clinical Research. *Journal of Interdisciplinary Feminist Thought* 2012; 6: 14–1.

<sup>&</sup>lt;sup>4</sup> Y.R. Smith, A.M. Johnson, L.A. Newman, A Greene, T.R.B. Johnson, J.L. Rogers. Perceptions of Clinical Research Participation among African American Women. NIH Public Access. *J womens health* (Larchmt) 2007; 16(3): 423–428; A.C. Mastroianni. HIV, Women, and Access to Clinical Trials: Tort Liability and Lessons from DES. *Duke J Gend law Policy* 1998; 5: 167–192; V. Merton. The Exclusion of Pregnant, Pregnable, and Once Pregnant People (aka women) from Biomedical Research. *Am J Law Med* 1993; 19:369.

to research participation is therefore of interest, specifically in cultures where women are faced with societal structures and realities that restrict their autonomy.<sup>5</sup>

Researchers<sup>6</sup> who have studied women's autonomy in developing countries have used indicators such as education attainment, household decision making, and freedom of movement to measure the autonomy of women. Extensive literature exists on the measurement of women's autonomy using indicators mentioned above as well as maternal health care, and reproductive rights.<sup>7</sup> There is however, the need to understand factors that limit the Yoruba women's participation in research as social and cultural factors differ from country to country. Available studies on women's participation in research were conducted amongst African Americans.<sup>8</sup> While these have provided useful insight into women's autonomy and reasons for the low participation of women in research, more studies need to be done on factors that affect Nigerian women's autonomous decision in research participation. A number of studies elsewhere suggest that the diminished autonomy of women is as a result

<sup>&</sup>lt;sup>5</sup> D.K.Thapa, A. Niehof. Women's autonomy and husbands' involvement in maternal health care in Nepal. *Social Science and Medicine* 2013; 93: 1-10; The Sub-Saharan African medical school Study (SAMSS, 2014). www.samss.org. Retrieved11:04:14 @ 11:00am. 9–22.

<sup>&</sup>lt;sup>6</sup> M. Rahman, G. Mostofa, A. Hoque. Women's household decision-making autonomy and contraceptive behavior among Bangladesh women. *Sex Reprod Health* 2014; 5: 9–15 S. Becker, F. Fonseca-Becker & C. Schenck-Yglesias. Husbands' and Wives' Report of Women's decision-Making Power in Western Guatemala and their Effects on Preventive Health Behavior. *Social Science & Medicine* 2006; 62: 2313–2326; Jejeebhoy SJ., and Sathar, ZA. Women's Autonomy in India and Pakistan: The Influence of Religion and Region. Population and Development Review 2001; 27: 687–712; Jeffery, R. & Jeffery, P. 1997. Population, Gender and Politics: Demographic Change in Rural North India. Cambridge/New York: Cambridge University Press: 61–89.

<sup>&</sup>lt;sup>7</sup> D.K. Thapa, A. Niehof. Women's Autonomy and Husbands' Involvement in Maternal Health Care in Nepal. *Social science and Medicine* 2013; 93: 1–10; A.A. Riyami, M. Afifi, and R.M. Mabry. Women's Autonomy, Education and Employment in Oman and their Influence on Contraceptive Use. *Reprod Health Matters* 2004; 12: 144–154.

<sup>&</sup>lt;sup>8</sup> B.R. Nugent Beyond Biases and Barriers: Incorporating Women into International Clinic Research. *Journal of Interdisciplinary Feminist Thought: Women, Social Policy and the law* 2012; Vol.6: 1–41; V.A. Diaz, A.G. Mainous, A.A McCall, M.F. Geesey. Factors Affecting Research Participation in African American College Students. *J Fam Med* 2008; 40: 46–51; B.A. Noah. The Inclusion of Pregnant Women in Clinical Research. *Journal of Health Law & Policy* 2014; Vol. 7, 353–389; V. Merton. The Exclusion of Pregnant, Pregnable, and Once Pregnant People (aka women) from Biomedical Research. *Am J Law Med* 1993; 19: 369–451.

of male dominance, culture and religion.<sup>9</sup> The difficulties African women face in obtaining first person voluntary informed consent as a result of payment of "bride price" (which is the money the groom pays to the bride's family during marriage rite) has been highlighted by some researchers.<sup>10</sup> While this has provided some insights, there is need to explore other factors.

According to Chattopadhyay & De Vries,<sup>11</sup> autonomy has been said to be a western concept. If autonomy means for an agent to be able to make decisions and act on those decisions made without external interference,<sup>12</sup> then it cannot be said to be a western concept because all over the world people and states in power have always striven to carry out made decisions without external interference. Autonomy is originally a Greek word meaning self-rule or self-governance.<sup>13</sup> This paper seeks to 1) understand what autonomy means to the Yoruba women. 2) give insight into how patriarchy, religion and culture affect the Yoruba women's autonomous decision in research participation.

Nigeria - a large and diverse nation with different languages and cultures is a particularly interesting context for this type of research.<sup>14</sup> The Yoruba people of western Nigeria are amongst the most educated tribes in Nigeria. Yet they appear to have limited autonomy which

<sup>13</sup> Ibid: 79–81.

<sup>&</sup>lt;sup>9</sup> D.K. Thapa, A. Niehof. Women's autonomy and husbands' involvement in maternal health care in Nepal. *Social Science and Medicine* 2013; 93: 1–10; Jejeebhoy SJ. 1995. Women's Education, Autonomy and Reproductive Behaviour: Experience from Developing Countries. Oxford: Clarendon Press.

<sup>&</sup>lt;sup>10</sup> P.F. Omonjezele. African Women as Clinical Research Subject: Unaddressed Issues in Global Bioethics. *Ethno-Med.*, 2(2) 2008: 121-126; AUTHOR; D.O. Irabor & P. Omonjezele. Local attitudes, moral obligation, customary obedience and other cultural practices: their influence on the process of gaining informed consent for surgery in a tertiary institution in a developing country. *Dev World Bioeth*. 2009. 9(1): 34-42. AUTHOR

<sup>&</sup>lt;sup>11</sup> Chattopadhyay, S. and De Vries, R. Respect for cultural diversity in bioethics is an ethical imperative. *Med Health Care and Philos* 2013. 16:639–645.

<sup>&</sup>lt;sup>12</sup> Beauchamp, TL, and Childress, JF. 2009. *Principles of Biomedical Ethics*. 6<sup>th</sup> edition Oxford University press: New York. 79–81 & 99.

<sup>&</sup>lt;sup>14</sup> Blench, R. 2012. An Atlas of Nigerian Languages. Cambridge CBI 2AL. http://www.rogerblench.info/RBOP.htm. Retrieved 2:11:14 @ 11:00pm.

puts them in an inferior position with their male counterparts in decisions concerning their choice to participate in research and other aspects of their lives similar to women in other developing countries.<sup>15</sup> This makes them dependent on their spouses for their well-being. The study site for this research is Ibadan. The city has been described as gender stratified in the sense that the men make decisions for the women.<sup>16</sup> The Christian and Muslim religions are predominantly practised in Ibadan.

### Some philosophical views of autonomy

Immanuel Kant in his famous maxim defines autonomy of the will as 'the property the will has of being a law unto itself independent of every property belonging to the object of volition. <sup>17</sup> For Kant, the real and good is determined not by physical realities or instincts but by moral maxims. Those moral maxims constitute the moral worth of an action whenever the will acts on them. Duty therefore would be to act on those maxims, and to act out of respect for the law. As far as participation in research is concerned and with particular emphasis on women's issues, Kant cautions against actions based on instincts or feelings in lieu of potential benefits. Apart from the fact that the determination of what is right/good in research participation cannot be left to individual ambitions or experience, what is moral is that which is done out of respect for the law. While autonomy stresses self-governance, it is important to equally understand how Kant prioritizes his ethics from the a priori forms. He further explains that the only thing good in itself is the good will, which is the necessity of an action done out of respect for the law. This law is a self-legislated law and not an external imposition. The morality of the act lies in the fact that the individual who has legislated this law for the self

<sup>&</sup>lt;sup>15</sup> D.K Thapa, A. Niehof. Women's autonomy and husbands' involvement in maternal health care in Nepal. Social Science and Medicine 2013; 93: 1–10.

<sup>&</sup>lt;sup>16</sup> Ayeni, B. 1994. *The Ibadan Metropolitan Area of Ibadan: Its Growth and Structure*. In Filani MO, Akinto FO. and Ikporukpo CO (eds) Ibadan Region. Rex Charles Publication, Ibadan: 77.

<sup>&</sup>lt;sup>17</sup> Kant I. 1785. *Groundwork of the Metaphysic of Morals*. 1948. Translated and Analysed by Paton HJ. New York: Harper and RW: 108.

through the act of the will carries out the action not allowing any influence by instincts or the outcome, but only by the law itself. With particular reference to women's autonomy, it would be simplistic to argue that Kant is calling for women to be able to make decisions for research. In light of Kant's understanding of autonomy, Pellegrino and Thomasma argue that patients' autonomy is threatened not by the paternalistic physician but by illness which interferes with the individual's innate capacity for judgment.<sup>18</sup> So women's autonomy in research is ordinarily threatened by culture which is a form of illness that subjects the female gender to male authority in a society.<sup>19</sup> This form of illness interferes with women's self-legislating ability by imposing on them from without. It essentially means not affirming the experiences of women. However, for Kant, those experiences would probably not be what many might expect them to be. They ought to be objective and should not be viewed as gender based. These experiences serve as basis for action and morality. It is on this basis that women's autonomy ought to be considered while underscoring the morality of the individual's action by adhering to the moral maxim that determined such action. In this instance, morality could be described as loyalty.

Personal autonomy has traditionally been defined as the capacity to control oneself, and decisions by controlling one's personal resources and information for personal use.<sup>20</sup> It states that an agent is autonomous if the behaviour of the agent is in line with the agent's motivational state which expresses her real self.<sup>21</sup> It is clear that autonomy is interpreted differently with different philosophical conceptions. Feminist philosophers disagree with Kant on the grounds that if those definitions of autonomy were to be allowed, women will be

<sup>&</sup>lt;sup>18</sup> Pellegrino E.D. and Thomasma D.C. 1988. For the Patient's Own Good. The Restoration of Beneficence in Health Care. New York: Oxford University Press: 103.

<sup>&</sup>lt;sup>19</sup> Glannon W. 2005. *Biomedical Ethics*. New York: Oxford University Press: 29.

 <sup>&</sup>lt;sup>20</sup> T. Dyson, and M. Moore. On Kinship Structure, Female Autonomy, and Demographic Behaviour in India. *Popul Dev Rev.* 1983; 9: 35–60.

disadvantaged because women's autonomy is based on social relationships.<sup>22</sup> Women as members of society are linked with accepted behavioural norms with distinct characteristics. Their autonomy depends largely on the practices and norms of the society to which they belong.<sup>23</sup> A study by Jejeebhoy and Sathar<sup>24</sup> concludes that residing with mothers-in-law affects women's autonomy in a ways which hinder women from making decisions. Looking at the context of medical research, Diaz et al.<sup>25</sup> have attributed a low rate of women's participation in research to gender sensitivity in relation to the health of the foetus during pregnancy. The Council of International Organization of Medical Sciences guidelines 16 and 17 explained clearly that researchers, sponsors of research and ethics committees should not exclude women from research participation and that the potential for becoming pregnant shouldn't be a reason for excluding women from research participation; rather these entities should endeavour to explain in detail the risks and benefits involved to them, their foetus or to the potential foetus.<sup>26</sup>

Feminist theorists<sup>27</sup> have defined autonomy in terms of relational autonomy which involves taken external social conditions into account. They argue that one can only be autonomous if

<sup>&</sup>lt;sup>22</sup> Mackenzi, C. and Stoljar, N. 2000. *Relational Autonomy: Feminist Perspective on Autonomy, Agency and the Social Self.* New York: Oxford University Press; Benson, P. Feminist Second Thought about Free Agency. *Hypatia*, 3. 1990; Vol. 5: 47–64; R.S. Dillion. Towards a Feminist Conception of Self-Respect. *Hypatia* 1992; 7: (1) 52–69; Friedman, M. Autonomy and Social Relationship: Rethinking the Feminist Critique 1997, in *Feminist Rethink the Self*, DT Meyers ed. Boulder, CO: Westview. 40–61.

<sup>&</sup>lt;sup>23</sup> Kishor, S. Autonomy and Egyptian Women: Findings from 1988 Egypt demographic and Health Survey. Occasional Papers No. 2. Calverton, Maryland: Macro International Inc 1995; i–xiii.

 <sup>&</sup>lt;sup>24</sup> S.J Jejeebhoy & Z.A. Sathar. Women's Autonomy in India and Pakistan: The Influence of Religion and Region. *Popul Dev Rev* 2001; 27:
 687–712.

<sup>&</sup>lt;sup>25</sup> V.A Diaz, A.G. Mainous, A.A. McCall, M.E. Geesey. Factors Affecting Research Participation in African American College Students. *J Fam Med*; 2008; 40: 46–51.

<sup>&</sup>lt;sup>26</sup> Council for International Organization of Medical Science (CIOMS). 2002. International Guideline for Medical Research Involving Human Subjects. http://www.cioms.ch/frame. Accessed 4/8/09. 50–52.

 <sup>&</sup>lt;sup>27</sup> Mackenzi, C and Stoljar, N. 2000. *Relational Autonomy: Feminist Perspective on Autonomy, Agency and the Social Self.* New York:
 Oxford University Press; Oshana, M. 2006. *Personal Autonomy in Society.* Hampshire, UK: Ashgate.

one lives in a social context that grants one the right to make autonomous decisions. However, what is paramount in all these definitions is the ability for one to make decisions for oneself and act on those decisions.

According to Author<sup>28</sup> autonomy is central to western perspective of decision making where the individual is said to be autonomous and independent. The individual solely makes the decision whether or not to participate in research having considered the benefits and risks involved. Researchers are now considering the applicability of this principle of autonomy in Africa because of the emergence of the field of bioethics and the increasing number of health studies being conducted in Africa.<sup>29</sup> The worldview of Africa demands an ethics that supports order, cohesion and communal responsibility by way of customs and traditions.<sup>30</sup> Scholars<sup>31</sup> have examined how cultural considerations might strengthen autonomy. Individual autonomy is often compromised in Africa because the basis of existence in most African societies is communalism.<sup>32</sup> Individual autonomy in the African type of autonomy could be referred to as "social autonomy" which invariably is synonymous to relational autonomy. This concept of "social autonomy" is a collective responsibility which is a shared responsibility among members of a community. In Africa, individuals make decisions by taking into consideration the implications of their decisions on their community, family and themselves.<sup>34</sup> For this

<sup>34</sup> Ibid; AUTHOR.

<sup>&</sup>lt;sup>28</sup> AUTHOR.

<sup>&</sup>lt;sup>29</sup> Tangwa GB, Bioethics: an African perspective. *Bioethics* 2004, 10,1:183–200.

<sup>&</sup>lt;sup>30</sup> A.S. Daar, H. Thorsteinsdottir, D.K. Martins, A.C. Smith, S. Nast & P.A. Singer. Top ten biotechnologies for improving health in developing countries. *Nature Genetics* 2002; 32: 229–232.

<sup>&</sup>lt;sup>31</sup> Zion D, Community without communitarianism: HIV/AIDS research, prevention and treatment in Australia and the developing world, <u>Monash Bioeth Rev.</u> 2005; 24(2): 20–31; AUTHOR; P.F. Omonjezele. African Women as Clinical Research Subject: Unaddressed Issues in Global Bioethics. *Studies on Ethno-Med.*, 2(2) 2008: 121–126; AUTHOR.

<sup>&</sup>lt;sup>32</sup> AUTHOR.

<sup>&</sup>lt;sup>33</sup> Tangwa GB, Bioethics: an African perspective. *Bioethics* 2004b, 10,1:183–200, PubMed; AUTHOR.

reason, respect for individual is synonymous with respect for others and this is a collective responsibility. This type of social autonomy has implications for women in decision making.

# METHODOLOGY

Ethics approval was obtained from the UI/UCH Ethics Committee, Ibadan, Nigeria.

# Setting

This study was carried out at the University College Hospital (UCH), Ibadan. UCH is one of the premier teaching hospitals in Nigeria, established in 1945.<sup>35</sup> Ibadan is the capital of Oyo State and the third largest metropolitan area in the south-west of Nigeria. It has a population of about two million people.<sup>36</sup>

#### Study design

An exploratory qualitative research method was employed for this study. In-Depth Interviews (IDIs), key Informants Interviews (KIIs), and Focus Group Discussions (FGDs) were used for data collection. Data analysis was narrative and descriptive.

# Study participants

Participants and their spouses were purposively recruited from a malaria study of the General Out-patients and Pediatrics Department (GOPD) of the UCH. A number of religious leaders were also interviewed. Permission was sought from both the members of the malaria research team and the Principal Investigator (PI).

Women who enrolled their children/wards for the study were asked if they were willing to participate in the study on women's autonomy. Recruitment for this study took place

<sup>&</sup>lt;sup>35</sup> The Sub-saharan African medical school Study (SAMSS, 2014). www.samss.org. Retrieved11:04:14 @ 11:00am. 9–22.

<sup>&</sup>lt;sup>36</sup> Ayeni, B. 1994. *The Ibadan Metropolitan Area of Ibadan: Its Growth and Structure*. In Filani MO, Akinto FO, and Ikporukpo CO (eds) Ibadan Region. Rex Charles Publication, Ibadan. 77.

independently of whether they agreed to enroll their children into the malaria project. Eligible participants were either introduced to the study by the PI or a member of the malaria research team.

Participants were given informed consent document to take home for a week for comprehension. After a week, those who indicated willingness to participate in the study gave written consent. Some requested to be interviewed right away while some others gave date, time and place for the interview. Religious leaders were approached at their various places of worship. The malaria project just provided access to the cohort of women purposively identified for this study. The total number of participants recruited for IDI and KII was 54. The final categories of participants recruited were; 20 married women, 20 single women, five members of the malaria research team and five spouses of the married women recruited. Additionally, four religious leaders were interviewed. Participants who are not from the Yoruba ethnic group, elderly women above 60 years and young women below 20 years were excluded. Reasons for exclusion criteria were that in Yoruba culture, women above 60 years of age exercise autonomous decision making capacity as matriarchs of the family. At this age they tend to reinforce male dominating principles. On the other hand, women below 20 years of age are still under the authority of their parents and by culture they are expected to obey their parents. The recruited spouses belonged to a random subsample of the women from the malaria research group who were invited to participate in this study.

#### Qualitative data collection

For the purposes of this study, women between the ages of 20 to 40 are referred to as young women while women between the ages of 41 to 60 are referred to as adult women. The purpose of the KIIs with the spouses was to get their opinions on how they viewed women's autonomous decision making in research participation. Regarding the research team, the idea was to understand the initial consent procedure for the malaria research and then compare it

with that of this study, while for the religious leaders the aim was to get their opinion on the religious stand on women's autonomous decision making in research participation. Each interview lasted for about one hour.

Four FGDs comprising four different groups of women were conducted separately. Each FGD consisted of four to six women and lasted for about 45 minutes to one hour. Each session of IDI, KII and FGD addressed the women's perception and understanding of autonomy, as well as the impact of patriarchy, religion, and culture on women's autonomous decision in research participation. For the IDIs and FGDs, interview guides were developed on the definition of autonomy and factors affecting women's autonomous decision in relation to research participation. Key informants' views on women's autonomy, and reasons for accompanying wives to hospital were asked. Prior to the interviews and FGD, participants' background information such as age, educational qualification, number of years married, religious background and family setting were recorded. The interviews were semi-structured; questions were flexible to allow for the spontaneous emerging responses of participants. Majority of the interviews were done within the hospital environment of the UCH. Interviews were conducted by the PI and a research assistant speaking English and Yoruba language. The PI and the research assistant were both present during all interview sessions in order to take notes and record body language, sudden comments and special expressions. Data collection was from August to October, 2010. All interviews and FGDs were audiotaped with prior consent from participants and transcribed. Extensive notes were also taken, for accuracy checks of the transcriptions.

# Data analysis

At the completion of the interviews and FGDs, the PI and research assistant transcribed all interviews and listened to the audiotapes several times in order to familiarize themselves with the expressions and words used by all the participants. Emerging concepts from each

transcript were always compared against new data before being included in the described content. The recorded interviews were transcribed verbatim in English and Yoruba. Both the English and Yoruba translations were then double checked by a bilingual researcher to check the accuracy of the translations<sup>37</sup>.

## RESULTS

In the following, we refer to participants from individual interviews by using pseudonyms and to participants from FGDs by providing a short description of the research participant's marital status.

Understanding of autonomy

From the definitions of autonomy described above, some participants appear to have fair knowledge of the term autonomy:

Women's autonomy means that a woman should have the right to do as she pleases. (Matilda, an adult single woman during IDI)

Similarly, another woman during one of the FGDs said:

Women's autonomy means ability to make decisions without anybody interfering. Although, there are a lot of things one has to consider. (Adult married woman)

Bose, another lady during IDI defined autonomy as women liberation. According to her, it has to do with women being equal to men, and that is not acceptable and should not be encouraged as it is not part of the Yoruba culture.

The FGDs and IDIs reflect predominantly a relational concept of autonomy, based on the significance of relationships for the autonomy of women. Some women said that although they understand that autonomy is about making personal choices and decisions, it is not easy

<sup>&</sup>lt;sup>37</sup> Diekelman, N. Allen, D. and Tanner, C. 1998. *The NLn Creteria for Appraisal of Baccalaureate Programs: A Critical Hermeneutic Analysis.* New York: Natl League for Nursing Press.

for them to live according to this concept as there are underlining factors that hinder women's autonomy. When asked what these factors were, husbands, families, children and the community were mentioned. The women said that it is expected that the husband should know what happens in the house and decision to participate in research by the woman should be brought to his notice. Women who have been married for a longer period of years appeared to exert their individual autonomy because with advance in age the man becomes less authoritative and relaxes his patriarchal rules.

Interviews and FGD revealed that educated women and women with regular income who contribute to the family finance are described as having more autonomy than uneducated women and women who depend solely on their husbands for financial support. Thus, education was by the interviewees perceived as necessary to enhance women's autonomy. Although educated women and women with regular income who contribute to the family finance were described as having more autonomy than uneducated women who depend solely on their husbands for financial support, their autonomy was still described as limited due to culture and religion. Bola, an adult married woman during IDI responded thus:

I am a professor and a head of department in this hospital, yet I am not expected to make decisions on my own without consulting my husband because culture demands that as the head of the family, he must be aware of what I do and traditionally, once a woman is married, she is seen as the "property" of the man.

Interviews and FGDs with young married women show that it is difficult for them to exercise their autonomy as they are constantly in fear of being divorced or ending up in polygyny marriage if found to be 'disobedient' or not acting according to the wishes of their husbands, mother-in-laws or husband's family members. To avoid this, they let the husband have the final say. Thus a young married woman during FGD said:

Hmmm! It is not easy to exert one's autonomy as the woman is expected to obey her husband and his family, especially the mother-in-law. Anything contrary to this means trouble which can lead to divorce.

KIIs with the five researchers of the malaria research group revealed that in some cases during the informed consent procedure, women insisted that the researchers speak with their husbands because the husbands alone can give consent. Other husbands insisted on sitting with their wives during the process of informed consent. Husbands were of the opinion that since they are responsible for the well-being of their wives, they should know what the wife is getting into as they would be held responsible for any unfortunate incidence that happens to their wives. The informed consent process of the malaria study was different from this study as none of the men was present during the process. But, the women said they had to discuss it with their husbands at home. They also said that enrolling in this study would not have been possible without the permission of their husbands.

Impact of factors on women's autonomy in relation to research participation

#### Patriarchy

Interviews and FGDs revealed that patriarchy defined as male dominance negatively affects the autonomy of women in research participation. Women said that husbands or family heads have to give consent to a woman's decision to participate in research. Adult women said they have to inform their husbands of their decisions to participate in research out of respect. Younger women said they discuss their decisions with their husbands or fathers as the case may be:

If I have to participate in research, I have to tell my father because he is responsible for me; he has to know where I am and what is going on with me. (Jane a young single lady during According to the women, if a woman decides to participate in research without the consent of her husband or family head, when anything goes wrong she will be held responsible for her action and may not get help from anyone as she would be deemed to have taken laws into her hands. The right the husband has over his wife was linked to the payment of bride price by the groom's family during marriage:

Payment of bride price has given men the authority to infringe on women's autonomy. Our culture does not expect women to make independent decisions. The husband should approve or disapprove of decision to participate in research made by the wife. (Aminu, a married man during kII)

Babajide gave a response similar to that of Aminu during KII.

Women should not be allowed to be autonomous because it will disorganize the society. Consent to participate in research should be given by the man. Men are family heads and decision to engage in research should be approved by them.

Some men agree that a woman should be autonomous in her decision to participate in research but should inform the head of the house.

A young woman during one of the FGDs explained that during the process of preparing a woman for marriage, she is told never to disobey, or challenge her husband, mother-in-law and his family members. It was also added that the bride is warned by her family that once married, she is no longer welcomed into her father's house because marriage is for life, and the success of any marriage rest on the woman.

Some other women were of the opinion that autonomous decision by women will lead to chaos in the family setting. According to them, being an autonomous woman would pose serious problems between the husband and his family. Single ladies were of similar opinion that exercising one's autonomy would put them at logger heads with their fathers and family head as they would be seen as being disobedient and stubborn. This they said could jeopardize their education and cause either delayed marriage or no marriage for them.

# Religion

Interviews with the religious leaders showed that religion was conceived to have negative impact on women's autonomy in research participation. The Christian and Muslim leaders interviewed said women's autonomy was against the teachings of the Holy Bible and Quran because women were expected to submit to their husbands in all things. According to Ben, a Christian religious leader during KII:

The Bible commands that women should submit to their husbands and husbands being the head of the family should be respected, The Bible also teaches that women should not speak in public without the permission of their husbands. So if a woman wants to participate in research, she has to seek the consent of her husband.

Mustapha, a Muslim leader during KII responds was similar to that of Ben:

Women are not to be seen or heard in public places without their husbands or permission from their husbands and so participation in research translates to being seen outside. Therefore, the husband's consent is needed.

Most women agreed that religion affected women's autonomy negatively:

Religious teachings do not help matters; instead they perpetually preach doctrines that erode women's autonomy. Women are constantly taught to submit to men. So as not to disobey God's command, I must seek the consent of my husband to participate in research. (Safia, a young single woman during IDI)

It is perceived that fear rather than obedience is the reason women follow these religious teachings. Interestingly, from the interviews both religions hold the same views regarding the

position of men and women. Respecting and reverencing the man as the head of the house is observed by both religions as interpreted by the religious leaders interviewed.

#### Culture

Findings from the study reveal that culture plays a major role in limiting the autonomy of women in research participation. According to the women interviewed culture emphasized that women should respect, and submit to their husbands as well as family heads in all things just as we saw in the aspect of religion. It was gathered from the women that this cultural practise is handed down from generations to generations and so change will be slow:

Tradition is very strong. Change will be slow as people are socialized according to a way of life and once they grow with it, it is difficult to change. Culture demands that we seek consent from our husbands or family head before participating in research. (Adult single woman during FGD)

It was also revealed that by culture, mother-in-laws and husband's family members interfere in couples' decisions and how they live. This is worsened if couples live in the husband's family house. Bimbo, a young married woman during IDI said:

Elderly women in the husband's family and mother-in-laws enforce male dominance on younger women in order to ensure that they obey their husbands. If I participate in research without seeking consent from my husband, then I am asking for trouble.

Obedience was mentioned as a critical issue that will enhance smooth relationship between wives and in-laws. This was emphasized by some single women as indicated:

Good relationship between mother-in-laws and daughter-in-law is very important. The mother-in-law can determine whether the wife remains married to her son or not. So husband's consent for the wife to participate in research is necessary. (Mary, a young single woman during IDI)

Yet others saw autonomous decision making by a woman as a taboo. Something that if practised would be of great spiritual consequences to the woman and eventually to the society as response below indicate. There are cultural beliefs of having to suffer severe consequences if husbands or family heads are disobeyed and so these beliefs keep the women in perpetual fear. Magdalene, a young married woman during IDI was particularly against women's autonomy:

Autonomy is a taboo. It is wrong to even think of any form of decision without the husband. Women should not be allowed to make decisions without consulting their husbands or family heads and should not be encouraged so as not to disorganize the society to which women belong.

Abosede, sees the study as women liberation movement:

Culture teaches that women should be submissive and obedient to their husbands. Anything contrary to that is unacceptable to the people. Autonomy is simply women's liberation. (A young married woman during IDI)

Few women said that it is important to allow the woman exert her autonomy if she wishes to participate in research because she has the right to her life but added that with a society like ours, this will take the education of more women and awareness creation to help break the hold these factors have on women's autonomy. They also said that allowing women exercise their autonomy would help societal development especially in the issue of government policy.

# STUDY LIMITATIONS

The first perceived limitation is that the study population was recruited from a malaria research study. Although it was explained to participants during the process of informed consent that their participation in this study would not influence care for their children, we cannot fully exclude that participants may have thought that if they agreed to participate in this study, there may be special attention on their children by the malaria research group. It is

possible that they saw enrolling in this separate study an added advantage to better care for their children since the malaria research team introduced them to this study; this could be called a variation of "indirect" therapeutic misconception. However, given that the participant information was transparent and that researchers insisted that no benefits of this kind were given for participating in this study, we think that this type of bias will be overall small. Second, lack of adequate and appropriate words for some technical terms may have influenced responses of some participants, although efforts were made to explain in simple terms the meanings of technical terms in Yoruba language. Third, we may have, to some extent not captured the opinion of some, in particular more shy or anxious women during the FGDs as some did not speak, some others just nodded to affirm what other women said. This behaviour may be due to fear of being reported since almost everyone in the research group knew each other. However, we do have reasons to believe that this type of bias remained limited, as participants were asked to keep the content of the FGD confidential and the number of silent women was small.

#### DISCUSSION

This research has helped to provide insight into factors that limit Yoruba women's autonomous participation in research. This study is unique in its design and permits a significant amount of triangulation, as opinions of husbands and religious leaders are also explored. Amongst its most important findings is that, interestingly, male dominance is strongly emphasized by the religious leaders who are silent on the equality of all human beings before God and the respect for one another. Another interesting finding is that while men feel that by making decisions for women, an act they see as beneficence, they are protecting them, the women on the other hand see this protection as a way of limiting their autonomy.

Confronted with the theoretical definitions of some scholars on the concept of autonomy<sup>38</sup> as ability to make personal and rational decisions and choices concerning oneself without external interference, women interviewed and included in the FGDs were perceived to have a basic knowledge of autonomy, although their definitions varied. They defined autonomy as being able to make decisions that concern oneself without external interference but added that several factors have to be considered for this to be achieved. In the Yoruba culture, a woman does not own herself, whether single or married. A single woman is identified by who her father is. While a married woman is identified by whom her husband is. Thus you hear things like "omo lagbaja" (the daughter of so and so) or "iyawo lagbaja" (the wife of so and so). This means that autonomy of a woman is understood in terms of relation to the family, environment and society she finds herself. This supports feminists' concept of autonomy in terms of relationship.<sup>39</sup> Interestingly, this relational determination of autonomy was put forward not only by the women themselves but also by the male interviewees. The Western view of autonomy is to a great extent shaped by libertarian views such as those expressed by John Stuart Mill "on Liberty": that everyone should be allowed to live his or her own life as long as he/she does not harm others. For Kant, autonomy means that the individual makes decisions on things that concern self. In other words, it is self-governance. Furthermore, in that process of decision making, one makes use of the freewill which according to Kant is to act from duty. In research involving Yoruba women, in an atmosphere where women hardly enjoy any freedom, Kant's approach could best be interpreted to mean communal autonomy or an altruistic act on the part of the women individually. In that way, it is the woman who is making decisions herself. That act of decision making is central to the concept of autonomy. By contrast, interviewees in this study insisted on the idea of responsibility for others, which

<sup>&</sup>lt;sup>38</sup> Dyson T, and Moore M. On Kinship Structure, Female Autonomy, and Demographic Behaviour in India. *Popul Dev Rev.* 1983; 9(1): 35–
60. Beauchamp, TL, and Childress, JF. 2009. *Principles of Biomedical Ethics*. 6th edition. New York: Oxford University Press: 79–81 & 99.

<sup>&</sup>lt;sup>39</sup> Dillion, RS. Towards a Feminist Conception of Self-Respect. *Hypatia* 1992; 7: 52–69; Mackenzi, C. and Stoljar, N. 2000. *Relational Autonomy: Feminist Perspective on Autonomy, Agency and the Social Self.* New York: Oxford University Press. 165–168.

is also a way of caring for each other. It is however problematic within this "caring" view, that the care concept is asymmetrical. Women care for their husbands by obeying and men care for their wives by making decisions for them.

Findings also show that with regard to women's autonomy, individual autonomy, respect for personhood, first person informed consent and confidentiality are concepts that contradict with the cultural context if research participants are women. This supports the finding that first person informed consent for women's participation in research is eroded in an African setting. <sup>40</sup> The culture promotes an asymmetrical idea that men are 'keepers' for other family members. Consequently, it means that for a woman to participate in research, actual consent has to come from the man. Results from the study suggest that Yoruba women are treated like beings that have lost the ability to make informed decisions and not capable of giving first person consent and this puts them in a vulnerable position.

This study raises the question as to how Western concepts of research ethics can be transferred to patriarchic African contexts. Critics of this context come not only from outside, but also from inside African societies.<sup>41</sup> In particular, the way the issue of bride price is perceived and interpreted by culture is a source of concern. In most African traditions, once the bride price is paid, it strips the woman of all her rights.<sup>42</sup> In the India and Pakistan culture where dowry is paid,<sup>43</sup> this payment does not strip the man of his rights. Therefore, the

<sup>&</sup>lt;sup>40</sup> AUTHOR.

<sup>&</sup>lt;sup>41</sup> P.F. Omonzejele. African Women as Clinical Research Subjects: Unaddressed Issues in Global Bioethics. *Ethno-Med.* 2008; 2: 121–26;
D.O. Irabor, & P. Omonzejele. Local attitudes, moral obligation, customary obedience and other cultural practices: their influence on the process of gaining informed consent for surgery in a tertiary institution in a developing country. *Dev World Bioeth.* 2009; 9: 34–42.

<sup>&</sup>lt;sup>42</sup> P.F. Omonzejele, PF. African Women as Clinical Research Subjects: Unaddressed Issues in Global Bioethics. *Ethno-Med.* 2008; 2: 121–126.

 <sup>&</sup>lt;sup>43</sup> Jeffery, R. & Jeffery, P. 1997. Population, Gender and Politics: Demographic Change in Rural North India. Cambridge/New York:
 Cambridge University Press: 61–89; Jejeebhoy SJ. 1995. Women's Education, Autonomy and Reproductive Behaviour. Experience from Developing Countries. Oxford: Clarendon Press Publication.

diminished autonomy of the African woman goes beyond the issue of bride price. The culture of making women subordinate to men is also enforced by women as reported by participants.

Some women interviewed expressed how they were not allowed to make decisions on their own simply because they feel there is a social obligation for them not only to be submissive but most importantly to keep the peace of the home. This study also showed that age, education and the possibility to contribute financially to the family purse are means to increasing women's autonomy. This supports findings of some researchers that financially empowered women have more autonomy.<sup>44</sup>

The Christian and Muslim religion tend to be linked in general to more conservative opinions as responded by interviewees, but religion does not need to have that effect, as both religions strongly insist on God valuing all human beings, not only men, and there are some subforms of protestants that very strongly favour women's rights. Therefore religious leader could induce change if they distinguish more clearly local cultural determination from religious norms and take seriously their duties to teach respect for all human beings based on nondiscriminative "love of God."

## CONCLUSION

The information gathered in this study is an important and unique platform to understanding how the Yoruba women of western Nigeria define autonomy. Without a thorough understanding of their perception of autonomy in a specific context as research participation, we run the risk of homogenising and universalizing women and individual autonomy which will weaken the concept of autonomy in a communitarian cultural setting. . If autonomy

<sup>&</sup>lt;sup>44</sup> A.A. Riyami, M. Afifi, & R.M. Mabry. Women's Aautonomy, Education and Employment in Oman and Their Influence on Contraceptive Use. *Reprod Health Matters* 2004; 12: 144–154; Jejeebhoy SJ. 1995. Women's Education, Autonomy and Reproductive Behaviour. *Experience from Developing Countries*. Oxford: Clarendon Press Publication; M. Rahman, G. Mostofa, A. Hoque. Women's household decision-making autonomy and contraceptive behavior among Bangladeshi women. *Sex Reprod Healthc* 2014; 5: 9–15; Z.A. Sarthar, & K. Mason. How female education affects reproductive behaviour in urban Pakistan. *Asia and Pacific population Forum* 1993; 6: 93–103.

requires some form of coercion as is seen in the influence of these factors as responded by the women interviewed, then it is no longer autonomy but heteronomy.

This study provides some explanation as to why the Yoruba tribe despite being the most educated in Nigeria have women who have limited autonomy. Increasing women marriage age, implementation of the existing government's policy on compulsory girl child education and empowering women through income generation will positively impact on their autonomy. Raising female children from early age as equal to the male children will also impact positively on women's autonomy.

There is a need for further studies to develop culturally appropriate and workable recruitment methods for research participation and a system that would encourage autonomous decisions of women who wish to participate in research. Such strategies may need to address factors such as patriarchy, culture, religious doctrines; increase in female researchers, confidentiality and respect for privacy. Strategies have been successfully developed for other specific contexts and countries, and these may serve as a useful model.<sup>45</sup>

Increasing participation of women in research requires improved understanding of the factors affecting the decision of women's autonomy to participate in research. Factors that undermine the autonomous decision making ability of a woman ultimately reduces her ability to contribute her intellectual potentials to personal and societal development.

<sup>&</sup>lt;sup>45</sup> M. Hudson, et al. *Guidelines for Māori Research Ethics: a Framework for Researchers and Ethics Committee Members: Health Research Council of New Zealand* 2010; Australian National Health and Medical Research Council. *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*. Australia 2003; *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, Ottawa Canada, December 2010. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada.

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