# THE EFFECT OF CULTURE ON HIV STATUS DISCLOSURE FOR PREGNANT WOMEN IN TANZANIA: THE CASE OF AMANA HOSPITLA IN ILALA DISTRICT

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A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SOCIAL WORK OF THE OPEN UNIVERSITY OF TANZANIA

# **CERTIFICATION**

The University of Tanzania, a dissertation titled: "An Assessment of Social Cultural Factors Influencing HIV Status Disclosure among Pregnant Women in Tanzania: A Case of Amana Hospital in Ilala District", in partial fulfillment of the requirements for the degree of Master of Social Work (MSW) of the Open University of Tanzania.

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.....

Date

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# **DECLARATION**

I, Angela Pius Matle, do hereby declare that this proposal 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

# **DEDICATION**

This work is dedicated to my family for their kind support and patience while pursuing my studies.

#### **ACKNOWLEDGEMENT**

I would like to thank God for enabling me to complete this study successfully. I also thank my family for their morally and spiritually support during the whole period of my studies and during the research study. Their encouragement, advice and support enabled me to successfully conclude the study.

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#### **ABSTRACT**

This study focused on the assessment on the effect of culture on HIV status disclosure for pregnant women in Tanzania, in this study several factors were put into examination. Factors such as fear of abandonment, stigma, social acceptance, social support, blame and violence were studied intensively. The study was designed to be descriptive in nature and therefore a sample of 100 respondents was approached so as to meet the objectives of the study. The respondent included pregnant women to Amana hospital. The primary data for this study was obtained through questionnaire and observation while secondary data was obtained through documentary review. The quantitative data was analyzed using the statistical package known as SPSS version 22, the percentages, tables and frequencies were produced in order to summarize the results. The finding of the study shows that the identified factors such as fear of abandonment, stigma, social acceptance, social support, blame and violence are still active in influencing people's decision to disclose their HIV status. Further the study outlined some recommendations to deal with the situation such as community based programs i.e. programs need to be community based in an attempt to reduce the stigmatization of individuals with HIV and increase their access to social support systems and health care facilities and voluntary counselling and testing i.e. recommended that there should be multiple counselling sessions after the client has disclosed to provide ongoing support and encouragement.

# TABLE OF CONTENTS

CERT	TIFICATION	ii
COPY	YRIGHT	iii
DECI	LARATION	iv
DEDI	ICATION	V
ACK	NOWLEDGEMENT	vi
ABST	TRACT	vii
LIST	OF TABLE	xi
LIST	OF FIGURES	xii
LIST	OF APPENDICES	xiii
LIST	OF ABBREVIATIONS	xiv
CHA	PTER ONE	1
INTR	CODUCTION	1
1.1	Introduction	1
1.2	Background Information to the Problem	1
1.3	Statement of the Problem	5
1.4	Research Objectives	7
1.4.1	General Objectives	7
1.4.2	Specific Objective	7
1.4.3	Research Questions	7
1.5	Significant of the Study	8
1.6	Study Structure	9
1.7	Key Concepts used in the Study	10
1.7.1	Socio-demographics	10

1.7.2	Disclosure	. 10
1.7.3	Voluntary Counseling and Testing	. 10
1.7.4	Belief	. 12
1.7.5	Cultural Beliefs	. 12
CHA	PTER TWO	. 13
LITE	RATURE REVIEW	. 13
2.1	Introduction	. 13
2.2	Theoretical Framework	. 13
2.2.1	The Theory of Reason Action	. 13
2.2.2	Theory of Planned Behaviour	. 13
2.3	The Ratio of PLWHA and HIV Disclosure Rates	. 14
2.4	Cultural Norms Inhibit Successful PMTCT Implementation and Disclosure	. 17
2.5	Preferred Audience for HIV Disclosure	. 18
2.6	Perceived Consequences of HIV Disclosure	. 19
2.7	Awareness of HIV	. 21
2.8	Cultural Beliefs on HIV Disclosure	. 22
2.9	Conceptual Framework	. 23
CHA	PTER THREE	. 24
RESE	CARCH METHODOLOGY	. 24
3.1	Study Design	. 25
3.2	Study Area	. 26
3.3	Study Population	. 26
3.3.1	Qualitative Study Population	. 26
3.4	Sample Size and Sampling Procedures	. 27

3.5	Data Collection Tools and Procedures	27
3.6	Validity and Reliability of Data	28
3.6.1	Validity of Data	28
3.6.2	Reliability of Data	29
3.7	Data Analysis Methods	29
3.8	Ethical Considerations	30
CHA	PTER FOUR	30
DATA	A PRESENTATION, ANALYSIS AND INTERPRETATION	30
4.1	Introduction	31
CHA	PTER FIVE	40
SUM	MARY, CONCLUSION AND RECOMMENDATIONS	40
5.1	Introduction	40
5.2	Summary	40
5.3	Conclusion	45
5.4	Recommendations	46
5.4.1	Voluntary Counseling and Testing	46
5.4.2	Support Groups	46
5.4.3	Community Based Programs	46
5.4.4	Further Research	47
REFE	ERENCES	47
APPE	ENDICES	54

# LIST OF TABLES

Figure 2.1:	Conceptual Framework	24
Table 4.1:	Respondents Pregnant Woman of Disclosing her HIV Status in the	
	Community	32
Table 4.2:	Culture belief is still an opposing Force to Pregnant Women	
	to Disclosure HIV Status	34
Table 4.3:	Various Motivation to Disclose HIV Status to the Community	35
Table 4.4:	Government to Facilitate Disclosure of HIV Status to the Pregnant	
	Women	37
Table 4.5:	Age of Respondents	38

# LIST OF FIGURES

Figure 2.1: Conceptual Framework	24
Figure 4.1: Various Culture Affect that Still Operates in the Society	33
Figure 4.2: Majority of the Pregnant Women	34
Figure 4.3: Reveal that Majority of the Respondent Amounting to Protecting	
others is a Priority	36
Figure 4.4: The Respondent are in need of free antiretroviral and other Treatment	
Associated with HIV	37
Figure 4.5: Respondents of Age	39

# **APPENDICES**

Appendix	I: Questionnaire	54
Appendix	II: Research Clearance Letter	57
Appendix	III: Letter of Permission to Conduct Research	58
Appendix	IV: Research Permit Letter	59

#### LIST OF ABBREVIATIONS

ANC Antnatal Care

ARVs Antiretrovirals

CDC Centers for Disease Control

FDC Follicular Dendritic Cell

GWH Gender, Woman and Health

HIV/AIDS Human Immune Deficiency Virus/Acquired Immune Deficiency

Syndrome

MoHSW Ministry of Health and Social Work

MTCT Mother-to-Child Transmission

PLWHA People Living with HIV/AIDS

PMTCT Prevention of mother to child transmission

STI Sexually Transmitted Infections

TBA Traditional Birth Attendants

UNAIDS United Nation Acquired Immune Deficiency Syndrome

UNGASS United Nation General Assembly Special Session

URT United Republic of Tanzania

USAID United States Agency for International Development

VCT Voluntary Counseling and Testing

WHO World Health Organization

#### **CHAPTER ONE**

#### INTRODUCTION

#### 1.1 Introduction

This chapter describes issues concerning social cultural factors associated with disclosure of HIV status among pregnant women. The chapter also provides background information on the topic, statement of the problem, objectives of the study, research questions, and significance of the study and anticipated limitation of the study. The chapter also provides ethical consideration that will be used when carrying out the study.

### 1.2 Background Information to the Problem

HIV/AIDS remains a global public health problem worldwide. By the end of 2010, it was estimated that 34 million people in the world would be living with HIV, with 2.7 million being newly infected. Globally, it was estimated that 36/9 million people equivalent to 0/8% were living with HIV by the end of 2014 (UNAIDS, 2015). The number of AIDS related deaths has been noted to decrease worldwide from 2.2 million to 1.8 million from 2005 to 2010 respectively. However, the rate is increasing in Eastern Europe and Central Asia from about 7,800 to 90,000 and it is twice in East Asia from 24,000 to 56,000 (National Guidelines for Comprehensive Care Services, 2013).

However, Sub -Saharan Africa is the most affected region with an estimate of 25/8 million people living with HIV accounting for almost for 70% of new HIV infections. Approximately 2/6 million children under the age of 15 are living with HIV globally, 91% of them come from Sub- Saharan Africa (UNAIDS, 2015). In response to a

reduction of HIV transmission from a mother- to- child, a global plan was launched in 2011 to accelerate the efforts of reduction of the numbers of new HIV infection from a mother- to- child transmission by 90% by 2015 (UNAIDS 2011).

Transmission of HIV from HIV -positive mother to her child is the common way children become infected with HIV over 90%, viral transmission occurs during pregnancy, childbirth or breastfeeding (WHO, 2016). Prevention of mother to child transmission of HIV (PMTCT) interventions can reduce HIV transmission rate to less than 5%, if HIV infected pregnant women and their infants, have access to and participate effectively in the full range of PMTCT services, without any interventions HIV transmission rate is about 15-45%.

However, factors like fear of disclosure and discrimination and cultural norms and practices related to breastfeeding and childbirth have been identified as important barriers to HIV disclosure during and after delivery among the HIV positive women. Cultural factors have also contributed to HIV women disclosure of their status, For example culturally in Malawi, power is assigned to men as the decision-makers in the household (White et al., 2005). Male dominance through culture "removes choice" from women (Lwanda, 2005).

The majority (70%) of men have ORC Macro, 2004), yet there is also a woman's realm that is maintained and guarded by women; "women accept certain duties as traditional and they will be the first to object if those obligations and duties are interfered with, even if they are servile" (Lwanda, 2005). Power and lack of access to education are

among the highly prevalent socio-cultural factors that potentially affect the health of women (Ian et al, 2003).

Like any other countries, HIV/AIDS in Tanzania has a long history and serious efforts and several interventions have been made to reduce its impact, including the establishment of Voluntary Counseling and Testing services (VCT) whereby in 2009, it was estimated that 44% of PLWHA were on ART (USAID Tanzania, 2010). The HIV/AIDS prevention strategies that include abstinence, being faithful to one uninfected partner, condom use, nutritional education, psychological support and Prevention of Mother to Child Transmission (PMTCT) have been promoted. The PMTCT guidelines in Tanzania endorses the WHO guidelines on infant feeding, however the reality is that pregnant women who test positive face a difficult decision about how to feed their babies which is complicated by poor access to proper feeding counseling support and the influence of family members of culturally and socially accepted feeding methods.

HIV/AIDS disclosure can either be beneficial or harmful depending to the community, or individual partners. It is beneficial in the sense that it encourages people to access HIV prevention and care services and harmful when it brings adverse consequences (UNAIDS Opening up the HIV/AIDS epidemic, 2000). In this case, HIV status disclosure is an important strategy for HIV prevention as it enables HIV positive individuals to access HIV care and treatment programs, creates the awareness of HIV risk to sexual partners and practice safer sex behavior. It also enables couples to make informed reproductive health choices which can reduce unwanted pregnancies hence

reduce the risk of MTCT. In addition, it may enable individuals to receive care and socio-economic support from sexual partners, family and the community.

HIV/AIDS disclosure to sexual partners is a very significant key strategy in HIV prevention as it promotes safer sex practices, prevent new infections to partner, reduce the risk of MTCT, increase social support and reduce depression (Ndayanga 2005; and Vyavaharkar et al 2011). However, in spite the benefits mentioned above, the disclosure rate in some developing countries remains low as it ranges from 16.7% to 86% (Kadowa and Nuwah, 2009; Medley et al, 2004).

However, on the other hand disclosure is harmful when it brings adverse consequences (UNAIDS Opening up the HIV/AIDS epidemic, 2000). Negative consequences as a result of disclosure include the following but not limited to, stigma, discrimination, rejection, divorce, blame, shame, and abandonment, among others, these are major hindrances of disclosure because they reduce the pace of HIV prevention. It has been noted that, disclosure of HIV status to a sexual partner is significant as it plays vital role in overall four key approaches of PMTCT interventions (Medley et al, 2004). First, it helps both partners to start a discussion about HIV/AIDS raising both partners awareness of the risk of infection and may lead to behavior change (Ibid).

In the case of the sero discordant couples, disclosure may prevent the risk of HIV transmission to an uninfected partner. Secondly, disclosure can be a good starting point for HIV- infected women to start a discussion about contraceptives use and reduce the number of unintended pregnancies. Besides, disclosure plays a significant role in women uptake of PMTCT program through their participation in treatment, care and

support program (Medley et al, 2004). The optimal uptake and adherence of PMTCT program is difficult for women whose partners are not aware or supportive of their participation (Nuwah, 2009).

Basically, drawing on these experiences, feelings, thoughts and perceptions with respects to social cultural conditions, provides a more holistic understanding of the phenomena by focusing on social cultural factors that might have been the cause of no-discloser of HIV status among pregnant women, most of previous studies have only focused at caused of HIV and its related social-economic consequences, leaving the of HIV status discloser uncover. From the above background it was seen as a necessity to conduct a study in order to assessment the influence of social cultural factors on HIV status disclosure to pregnant women in Tanzania by using the case of Amana hospital in Ilala district.

#### 1.3 Statement of the Problem

Tanzania government in collaboration with private stakeholders to curb HIV prevalence in the country, the prevalence has only declined slightly from 7% to 5.7% with large variations across regions, varying from 1% to 15%. It is estimated that about 1.4 million people in Tanzania are infected with HIV, with about 90,000 new infections on each year (UNGASS Reporting for 2010; USAID, 2010; URT, 2011).

Similarly, despite of all those efforts most women fear to disclose their status during and after pregnancies, particularly those who are less educated or have low socio-economic status (Makin et al, 2008; Lugalla et al, 2011; Deribe et al 2010). The HIV status disclosure by people living with HIV/AIDS (PLWHA) has negative

consequences including stigma, discrimination, abandonment, rejection, divorce, physical violence, denied socio-economic support and fear of being accused of infidelity (Kadowa and Nuwaha 2009; Wong et al, 2009, Lugalla et al, 2011). Simbayi et al, (2007) asserts that HIV-related stigma and discrimination are cultural factor associated with not disclosing HIV status to sex partners, and non-disclosure is closely associated with HIV transmission risk behaviours.

However, previous studies on HIV status disclosure have provided evidence on low rates of disclosure. There is a big variance of disclosure rates across countries. Studies such as (Wong et al, 2009; Medley et al, 2004) reported that disclosure rates in developing countries after diagnosis ranged from 16.7% to 86%. While the other study (Wong et al, 2009) found out that only 43% of PLWHA from Mityana district in Uganda who was attending posttest care had disclosed their HIV status to partners and other people.

Similarly, in the country, many people who are found to be HIV+ do not disclose their status to their partners and or relatives. Most of the studies on HIV disclosure have focused on the role of social relations in facilitating disclosure to others, acceptability of HIV counseling and testing and participation in MTCT intervention study using antiretroviral, partner's reaction, socio-demographic, behavioural and psychological factors and others focused on stigma and discrimination. However, little is known on the social cultural factors influencing disclosure among PLWHA and disclosure of HIV positive status in Tanzania has been focused on various areas but its association with social cultural factors remains unclear (Wong et al, 2009).

Therefore, a better understanding is needed to know how contextual factors such as cultural beliefs, attitudes and knowledge influence disclosure among PLWHA. Therefore, the problem of this study is to assess effect of culture on HIV status disclosure for pregnant women in Tanzania by using the case of Amana hospital in Ilala district. The study aims at identifying the cultural factors and other determinants factors affecting HIV disclosure among pregnant women living with HIV/AIDS (Wong et al, 2009)

# 1.4 Research Objectives

# 1.4.1 General Objectives

The general objective of this study is to assess effect of culture on HIV status disclosure for pregnant women in Tanzania by using the case of Amana hospital in Ilala District in order to identify social cultural factors which influence HIV status disclosure among pregnant women in Tanzania and their effect to the society.

# 1.4.2 Specific Objective

- (i) To identify cultural beliefs which affect HIV status disclosure for pregnant women.
- (ii) To explain the effect of cultural beliefs on HIV status disclosure for pregnant women.
- (iii) To provide recommendation on how to improve HIV status disclosure for pregnant women.

# 1.4.3 Research Questions

(i) What cultural beliefs affect HIV status disclosure for pregnant women at Amana hospital in Ilala district?

- (ii) What explanations can be said to the effect of cultural beliefs on HIV status disclosure for pregnant women at Amana hospital in Ilala district?
- (iii) What recommendations can be suggested for improvement of HIV status disclosure for pregnant women at Amana hospital in Ilala district?

# 1.5 Significant of the Study

HIV status disclosure of PLWHA to partners and others is of vital significance to HIV prevention. Thus, the issue of HIV status disclosure needs to be addressed to prevent the spread of HIV infection, promote accessibility to care and treatment programs, attain psycho-social support for patients from relatives and friends, reduce stigma, adhere to treatment and promote safer health behavior (Makin et al, 2008; Lugalla et al, 2011; Deribe et al 2010). However, the study focuses on assessing challenges associated with disclosure of HIV+ sero status among pregnant women.

Therefore, the study will be useful in the identification of socio - demographic and socio - cultural factors affecting HIV sero disclosure among pregnant women. Secondly, the study will help health care practitioners to come up with new strategies during the implementation of HIV/AIDS counseling. Consequently, the study findings will help in developing new approaches for increasing awareness and HIV sero status disclosure among pregnant women.

Similarly, the findings of this study will have helped to generate ideas for reducing women's negative perceptions and attitudes towards status disclosure. The recommendations that will be made by this study will play a role towards improving effective use of counseling and provide new HIV counseling techniques, and thereby

contribute towards reaching the millennium development goals by decreasing maternal and child motility and discrimination in the society. Lastly, the study will enrich academicians and add knowledge on the existing literatures and will provide a room for further researches (CDC, 2002; and UNAIDS, 1997).

# **1.6** Study Structure

The study will be comprised of five chapters. The first chapter covered the introduction. The introduction is comprised of background information, statement of the problem, significance of the study, objective of the study and research questions. Chapter two of the study is comprised of literature review. In this chapter, key concept used in the study, theoretical and empirical literatures related by the study are exhaustively covered. Conceptual framework and literature gap are also part of this chapter. Chapter three of the study explains methodology used.

The methodology is comprised of the description of the study area, study design, sampling procedure, and sample size, methods of data collection, data analysis as well as validity and reliability of the study. Chapter four of the study is comprised of results and discussion. In this chapter, the research findings will be put forward and detailed explained and justified. The description of the findings will be related with other related research work to compare if the study will reveal similar or different findings. Chapter five of the study will be about summary of the study, conclusion and recommendations. Also, relevance and contribution of the study to theories and future research area will be explained in chapter five. The chapter will describe general observations of the study based on the findings.

## 1.7 Key Concepts used in the Study

#### 1.7.1 Socio-demographics

Socio-demographics are nothing more than characteristics of a population. Generally, characteristics such as age, gender, ethnicity, education level, income, type of client, years of experience, location, etc. are being considered as socio-demographics and are being asked in all kinds of surveys (https://www.checkmarket.com. Retrieved on 14<sup>th</sup> may, 2017).

#### 1.7.2 Disclosure

Disclosure can be defined as the act of disclosing, uncovering, or revealing; bringing to light; exposure (Webster's dictionary). It can also be said "the release of information about a person or entity" (yourDictionary.com). In the context of HIV/AIDS, disclosure refers to the act of informing any individual or organization (such as a health authority, an employer or a school), of the sero status of an infected person. It can also refer to the fact that such information has been transmitted, by any means, by the person him or herself, or by a third party, with or without consent (UNAIDS, 2000). In this particular research, an individual is said to have disclosed to a sexual partner if he or she has made his partner aware of his HIV status. Sex without disclosure would be any penetrative unprotected sexual intercourse.

#### 1.7.3 Voluntary Counseling and Testing

Voluntary Counseling and Testing (VCT) is an entry point to prevention and treatment services which places a lot of emphasis on HIV status disclosure among HIV-infected clients, particularly to their sexual partners UNAIDS (2001). International organizations like the Centers for Disease Control and the World Health Organization

emphasize the importance of HIV status disclosure (CDC, 2002; and UNAIDS, 1997). Disclosure is a major decision that can have consequences for the person living with HIV and those around him (IPPF, 2002). UNAIDS best practice collection (2000) explains that people everywhere have great difficulty in openly facing issues involving sex, disease and death.

In many countries, the stigma and discrimination surrounding HIV/AIDS prevents many people who are HIV positive to informing their spouses, lovers, family, friends, colleagues and even health care providers about their status. There is every incentive to keep their HIV status secret. In resource-poor countries, particularly, the fear of stigma, lack of treatment options, and the very limited access to voluntary counseling and HIV testing have led only a small number of people voluntarily to test for HIV and disclose their status.

The fact that only a small number of people know they have HIV, and an even smaller number disclose their HIV positive, has added to the difficulty faced by governments and communities in creating greater awareness of the HIV/AIDS epidemic, thereby preventing further HIV infections and accurately monitoring HIV and AIDS on an ongoing basis (CDC, 2002; and UNAIDS, 1997).

Disclosure is a multifaceted issue that may be influenced by an individual's perception of the social, psychological, and material consequences of informing others (Michael Stein MD et al, 1998). The HIV-infected individuals remain sexually active long after they become aware of their infection. Disclosure requires personal responsibility and confidence. Not only past partners, lovers but potential partners need to be informed.

Even though this is a challenge to all relationships, it will remain central to limiting the spread of the acquired immunodeficiency syndrome in the community.

#### **1.7.4** Belief

Belief means information that a person has about an object, an issue or a person. This information can be factual or just an opinion. Furthermore, the information can be positive, negative or may have no evaluative implications for the target of the information (Finn D 2012).

#### 1.7.5 Cultural Beliefs

Cultural beliefs are the ideas and thoughts common to several individuals that govern interaction between these people and between them, their gods, and other groups and differ from knowledge in that they are not empirically discovered or analytically proved. In general cultural beliefs become identical and commonly known through the socialization process by which culture is unified, maintained, and communicated (Greif A. 1994).

#### **CHAPTER TWO**

#### LITERATURE REVIEW

#### 2.1 Introduction

This chapter describes the literature review on the topic researched. The chapter covers theoretical framework, empirical studies. The chapter defines relevant theories followed by the general overview of the challenges associated with disclosure of HIV+ sero status among pregnant women, presents empirical studies relevant to the study as well as the conceptual framework.

#### 2.2 Theoretical Framework

## 2.2.1 The Theory of Reason Action

The theory of reason action proposed by Fishbein and Ajzen (1975; 1980) postulates that behavior is influenced by several factors among them one's belief about the outcome of an action, one's assessment that a particular behavior is desired by significant others and a motivation to comply with views of significant others. According to this theory, individuals would have to believe that avoiding sex or disclose their status would prevent the fulfillment of their sexual desires and or may lead to discrimination, or not allow a chance of having intercourse with their partners, hence through reasoned action consequences such has HIV transmission, unwanted pregnancy and sexually transmitted infections (STI) are likely to happen. Complying with wishes of significant others would mean that individuals meaning HIV positive clients would take action or not take action.

#### 2.2.2 Theory of Planned Behaviour

The theory assumes that individual action is driven by behavioral intentions where behavioral intentions are a function of an individual's attitude toward certain behavior, the subjective norms surrounding the performance of the behavior and the individual's perception of the ease with which that behavior can be performed (Ajzen, 1991). Attitude toward behavior refers to an individual's positive or negative feelings about engaging in behavior. According to the Theory of Planned Behaviour, (Montano and Kasprzyk, 2008). This normative belief which disapprove the disclosure behavior together with motivation to comply to what other group (referent) think it is right damage the behavioral intention of PLWHA to disclose their HIV status. Therefore, individuals are more likely to perform a behavior which will lead to outcomes they value (Mucheto et al, 2009).

This depends on people's beliefs regarding the consequences arising from behavior and an evaluation of the desirability of these consequences. Subjective norm is an individual's perception of whether people important to the individual think the behavior should be performed or not. Similarly, individual affected with HIV+ may have behavioral intentioned to affect or transmit the HIV virus to others yet is fully aware of his/her HIV status (Ajzen, 1991).

# 2.3 The Ratio of PLWHA and HIV Disclosure Rates

It has been reported that, in developed countries, HIV status disclosure rate among antenatal care women ranges from 42%-100% compared to 16.7% - 32% for developing countries (Mucheto et al, 2009). However, previous studies by (Medley et al, 2004; Kairania et al, 2010) have showed that the rates of disclosure in developing countries as ranging from 16.7% to 86%. The disclosure of HIV positive status among HIV discordant couples in Sub-Saharan Africa is extremely low. HIV transmission among discordant couples is quite substantial, as it ranges from 5.0 to 16.7 per 100 people

yearly, which is 5 to 17 times higher than incidence among HIV concordant negative couples. Thus, they considerably contribute to the HIV epidemic (Kairania et al, 2010). For instance, (Perry SW et al, 1994) found that almost one third of HIV positive men and women did not disclose their HIV status to past or present sexual partners.

It has been noted that less than 10% of HIV positive individuals are aware of their partners' status and only about 20% of HIV discordant couples know that they are living in discordant relationship in East Africa (Kairania *et al*, 2010). A study conducted by (Wong et al, 2009) found out that among those who tested positive, 13% of the sampled respondents had never disclosed their HIV test results to anyone. In addition to that, more than one third of all HIV infected adults have never disclosed the information to their sexual partners. A study conducted in Zimbabwe by (Patel et al, 2012) revealed that 97% of the women disclose to at least one person while 78% disclose to their spouse/sexual partners.

In a cross-sectional survey done by Wong et al (2009) in Soweto and the Kwazulu natal, that measured the rate of disclosure of HIV status and factors associated with disclosure, HIV disclosure was reported by 87% of participants and among those who disclosed, 93% disclosed to boyfriends or girlfriends. Following disclosure, 82% requested that their partner be tested and 81% reported that they wanted to limit sex to one partner; 64% stated using condoms than discloser hence sexual their partners were at risk of HIV transmission.

In a meta-analysis study conducted by Medley et al, (2004) which summarized 15 studies on the rate of HIV disclosure among only women in developing countries of which 14 of the studies were conducted in sub-Saharan Africa, the disclosure rate

ranged from 16.7% to 86%. Furthermore, a review done by (WHO/FDC/GWH, 2004)states that studies done on disclosure rates among women only showed that rates of disclosure to sexual partners are higher among women in the developed world (average 71%; range: 42%-100%) compared to women in the developing world (average 52%; range: 16%-86%). The lowest rates found in this review were among pregnant women tested in antenatal care (ANC) settings in sub-Saharan Africa (16.7%-32%). In addition to that, larger proportions of studies from developing countries reported women that did not share their HIV test results with anyone (10%-78%) as compared to women in developed country studies (3%-10%).

In regard to Tanzania, studies have revealed that 55% of infected married men disclose their HIV status to their wives and 34% of married women disclose their status to their husbands (Lugalla et al, 2011). For example, a study conducted in Dar es Salaam revealed that only16.7% of HIV infected women disclose their HIV status to their sexual partners and only 22.2% of women disclose their HIV status to significant others (Kilewo, et al, 2001).

Furthermore, another study conducted in Dar es Salaam by Antelman, et al, (2001) revealed that the prevalence of disclosure being 22% within two months to 40% after nearly four years. Ndayanga, A.(2005), conducted a study in Tanzania, reported that 64.5% of HIV sero-positive pregnant women receiving PMTCT services are reported to have disclosed their HIV status. Antelman et al, (2001) found that disclosure to sexual partner among women attending an antenatal clinic increased from 22% within two months of diagnosis to 41% after nearly four years.

## 2.4 Cultural Norms Inhibit Successful PMTCT Implementation and Disclosure

Cultural norms that inhibit successful PMTCT implementation include prolonged (Kapoor, 2012) breastfeeding and delivery in traditional birth settings. Abrupt weaning or formula feeding is a frequent component of PMTCT programmes to reduce the transmission to the child after birth. However, a women who is not breastfeeding her child in sub-Saharan Africa may inadvertently disclose her HIV status.

In sub-Saharan Africa, only 46% of women give birth in a health facility with a nurse-midwife or doctor, while the (Kapoor, 2012). Remaining give birth at home with traditional birth attendants (TBA) (22%), relatives (26%), or no attendant at all (6%) (Farquhar, 2004) Acceptance of HIV test and enrolment in the PMTCT programme were lower in married or cohabitating women than single women, in women belonging to the minorities/marginalized segments, and in lower educational status. At times the only variable significantly associated with failure to return for post-test counseling can turn out to be a positive HIV test result.

These indicates that the fear of being identified as HIV positive in the family, fear of being recognized by service providers and lack of awareness are still strong limiting factors. The major concern of women in VCT is for the reaction of their male partners to the possibility of a positive HIV test and low trust in the confidentiality of HIV testing. Particularly the role of husbands in the success of PMTCT programmes is pointed out to be critical, since partner participation in VCT and couple counseling increase uptake of nevirapine and formula feeding by many folds. According to (Bajunirwe, 2005) Male involvement affects many aspects of a mother's ability to travel, get tested, and attend an antenatal clinic. (MoHSW, 2008) adds that, related to

inadequate community and male partner engagement, a mother's ability to disclose her HIV status and participate in a PMTCT programmes is greatly limited Researchers in Uganda and other settings identify the strongest predictor of a women's acceptance to test was approval of her husband. While others report: When male partners are included in counseling and testing, there is increased uptake of all PMTCT interventions; women are more likely to undergo testing, return for results, take antiretroviral drugs, avoid breastfeeding, and use condoms. But cultural beliefs about male participation in pregnancy, along with daytime clinic hours and women-only clientele of the clinics make many men uncomfortable and discourage their attendance.

#### 2.5 Preferred Audience for HIV Disclosure

The process of disclosing HIV status differs from one person to another, depending on one' attitude and perception. It involves decisions about timing, to whom, how and under what circumstance (Makin et al, 2008). Some people disclose their status soon after receiving HIV test results, others take some time to disclose the information after a which may even take a months, while some take longer to disclose almost a years as while some may decide not to disclose anything to anyone, fearing the consequences if their status became widely known.

However, most PLWHA most especial pregnant women tend to disclose their status to people whom they are closely related, and who they truly trust, mostly family members such as spouses, parents, siblings, children, aunts and uncles. Similarly, some PLWHA disclose their status to friends, neighbors, and even members of the public (Lugalla et al, 2011) PLWHA tend to share their status with family members due to the social ties they have and the psychosocial support they expect from them. However, this might

always not be the case, as most of these people do not trust their family members as they do trust their friends. Previous study by (Bouillon et al, 2007) reports that friends appear to be closer confidents than immediate family members among gay men. He further explains that relatives may be chosen over spouses.

In country like China, a health care provider has the choice to disclose HIV status of the HIV infected person to the person himself/herself or to family members taking into consideration the circumstances surrounding the infected person. For example, the study conducted by (Li et al, 32008) concludes and recommends that health care providers should honestly inform the patient or his/her family member(s) about the condition of the disease. In this study, 49% of health care providers who responded were of opinion that family members (mainly spouses and children) should be the first to be informed on a patient's HIV status by the provider.

### 2.6 Perceived Consequences of HIV Disclosure

PLWHA who are on ART are more likely to disclose their status compared to those who are not on ART (Kadowa and Nuwaha 2009). This is due to the fact that before starting ART, they receive ART adherence counseling in which among other things, they emphasize on disclosure so that they can be assisted especially by being reminded to take their medication (ARVs) or to be helped to pick the medications from the center once the patients cannot do by themselves for a strong reason. However, in most studies from both developing and developed country settings, HIV status disclosure to sexual partners was associated with positive outcomes including increased social support, acceptance, kindness, decreased anxiety and depression, and strengthening of relationships (WHO, 2004). While fear of negative outcomes was a major reported

barrier to HIV status disclosure, most individuals who choose to disclose reported experiencing positive social outcomes as a result of their disclosure including support and understanding from partners.

Counseling encourages the HIV infected persons to disclose their HIV positive status to others. A study by (Antelman et al, 2001) reports that counseling has influence on disclosure. Counseling can be done during pre-test and post-test counseling sessions or during the routinely clinic visit for care and treatment programmes (Kadowa and Nuwaha 2009). The study reports that clients who received ongoing counseling at every clinic visit are more likely to disclose, this is due to the fact that clients are coupled with benefits of disclosure. Negative outcomes included blame, abandonment, anger, violence, stigma, and depression and were less commonly reported among those who disclose than positive outcomes.

However, it is important to note that those who choose not to disclose may well be those who are most likely to experience negative outcomes due to the disclosure. In studies that looked at violence as an outcome of HIV status disclosure for women who chose to disclose, violent outcomes were reported more often by women in sub-Saharan Africa (3.5% to 14.6%), than by women in USA studies (0.4%-4%). The highest rates of disclosure-related violence were reported among women in ANC. HIV-infected women in sero-discordant couples were the most likely to experience violence as a result of disclosure. However, majority of HIV infected persons afraid of disclosing their HIV status to others for many reasons. Fear of stigma and discrimination remains the main reason for non-disclosure among PLWHA. Most HIV infected individuals are scared widespread information of their HIV status, which might lead to stigma and

discrimination (Lugalla et al, 2011), this study reveals that 5 out of 11 respondents did not disclose their HIV status to anyone, fearing of discrimination.

Another study reveals (Vyavaharkar et al, 2011) that HIV positive status disclosure may expose a woman to stigmatization, discrimination and rejection from relatives, friends and health care providers which may cause social withdrawal, psychological stress and depression. However, HIV status disclosure may reduce depression due to the fact that a woman may no longer has to keep her status secret and hence minimize psychological stress.

The World Bank (2007), disclosure of information about HIV is not only needed for the partner and significant others alone but may also be required for public health surveillance, for the provision of appropriate medical care, and for certain non-health purposes such as law enforcement or insurance. A study undertaken in Uganda and Tanzania (Lugalla et al, 2011), show that HIV status disclosure has risk of being accused of infidelity especially for women.

# 2.7 Awareness of HIV

In Tanzania, HIV knowledge is rather high, with 87% to 90% possessing some knowledge on HIV (Tanzania Demographic and Health Survey, 2010). Many people know about HIV transmission and prevention, but the problem is that they don't act upon what they know; this makes HIV prevalence still remains high in some regions. A USAIDS report shows that 98% of all Tanzanian aged between 15 and 49 years have heard about AIDS but don't have thoroughly understanding of the disease (USAID, 2010). The knowledge is significantly higher in urban rather than rural settings.

However, the knowledge on the importance of HIV disclosure is unknown. Counsellors at VCT centres do put more emphasis on the confidentiality of the test results but they rarely mention the advantage of disclosure to significant others (Lugalla et al, 2011).

#### 2.8 Cultural Beliefs on HIV Disclosure

Cultural beliefs of different societies shack different lights on the right way of truthful disclosure. The study on traditional Navajo beliefs (Braddock, 2008) reveals that some people in some culture holds the belief that mere hearing about possible risks of treatment amounted to inviting the mishaps. Such beliefs make people withhold truthful information about their HIV sero status for fear of inviting harmful effect. While in some of the societies associate specific signs with HIV/AIDS disease, thus if HIV infected persons do not manifest any signs generally associated with HIV/AIDS such as weight loss, the community does not believe that they have infected even when they disclose their status (Mbonu, 2009).

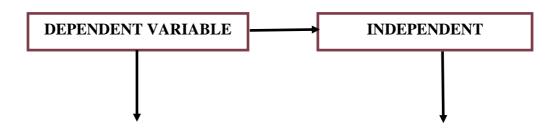
Moreover, some societies associate HIV/AIDS with witchcraft, a tendency which affects the disclosure. This makes a person with HIV positive hide the status as the results the person misses the health care services resulting to his/her death. For example the study conducted in Zimbabwe reveals that traditional healers told people that HIV was not a virus, but a misfortune caused by unhappy spirits (Duffy, 2005). Therefore, the diagnosis of unhappy ancestors or bewitching leads to non-disclosure of the true health status of a person. Religious belief also has a vital role to play in HIV status disclosure. It shapes individual outlooks on living with HIV and also used as a coping strategy among PLWHA by providing a sense of peace and hope through prayers and faith in God (Mbonu et al, 2009). A study conducted among HIV positive pregnant

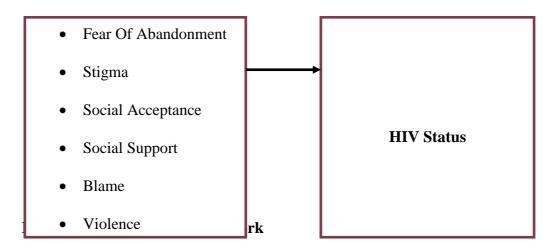
women in Kinshasa by Maman et al, (2009) found out that faith in God and/or religious leaders does influence women's disclosure and coping strategy.

A previous study (Lugalla et al, 2011) reveals that there are some cultural rules that discourage the disclosure of mischief conduct. Similarly, the study conducted in Tanzania by Zou et al, (2009) reports that respondent's intentions of disclosing their status to the religious community if they become HIV infected is primarily associated with non-religious factors. This concurs with the findings of another study (Klopper, 2011) which reports that there was no relationship between HIV status disclosure and religion.

#### 2.9 Conceptual Framework

This study is guided by the theoretical framework, which is depicted by key themes presented and discussed. The major themes around the concept of cultural belief which form the dependent variable and the disclosure of HIV status which is the Independent variable have been indicated in diagram below. Issues such as fear of abandonment, stigmatization, social acceptance, blame and violence have been shown in the diagram and somewhere in this study the said themes have been discussed in detail. Boxes and arrows have been to show the pattern of relationship that exist in major themes and their relevance to the study.





Source: Own Developed from Literature review, by a researcher, 2017

# CHAPTER THREE RESEARCH METHODOLOGY

#### 3.1 Study Design

According to Chamwali (2006) research design is the arrangement of conditions for collection and analysis of data in a manner that aims to combine relevance to the researcher purpose with economy in a procedure. Research designs include the survey, experimental and case study design. In this study, it is considered to be important to adopt a case study design by the researcher. Case study is the research design that entails the detailed and intensive analysis of a single case (Bryman, 2004).

It is a way of organizing social data for the purpose of viewing social reality and it also examines the social unit as a whole (Best and Kahn, 1999). Cozby (1977) argues that case studies are valuable in informing us of conditions that are rare or unusual and thus not easily studied in any other way. This design were chosen because of its flexibility in terms of data collection, data analysis as well as its depth and breadth of studied variables. Case study design is a qualitative analysis, which involves careful and complete observation of a social unit, a person, a family, an institution, a cultural group or even the entire community.

It is a method of study in depth rather than breadth (Kothari, 2004). According to Young (2000) case study is a comprehensive study of a social unit comprising of a person, a group, a social institution, a district or a community. It is essentially an intensive investigation of a particular unit under consideration. However, in this study, the researcher uses Case study because—it enables the researcher to have an in-depth understanding of the study. The design is selected for this study as it intends to establish the prevalence of HIV/AIDS and related factors of disclosure. A case study design is

most appropriate where a detailed analysis of a single unit of study is desired as it provides focused and detailed insight to phenomenon that may otherwise be unclear.

#### 3.2 Study Area

This study was conducted in Ilala district at Amana hospital t, one of the Five districts of the Dar es salaam Districts. Other districts are Kinondoni, Temeke, Ubungo, Kigamboni and Ilala districts Dar es Salaam is surrounded by Ilala and Kinondoni districts to the South East, Rufiji District to the South, Morogoro District to the West and Kibaha District to the North. The district has four divisions, 14 wards and 77 villages. It covers a 4,464 km area, being 13.3% of the total area of Coast Region. The 2002 national census estimated the population of the district to number 95, 323, a figure that was expected to rise to 101, 638. The district has 19 health facilities, one hospital, three health centers and 15 dispensaries. The district was selected as the area of the study just because HIV is among the top ten diseases causing high rate of morbidity, and it is characterized with cultural practices by the Zaramo tribe and other people of low profile. Ilala is the highest among other districts with high prevalence rate of HIV/AIDS in Dar es Salaam Region.

#### 3.3 Study Population

#### 3.3.1 Qualitative Study Population

The study population involved HIV patients attending CTC at Amana hospital in Ilala District who are aged 18 years and above to observe research ethics and regulations. Recent data indicated that, the district has14800 enrolled PLWHA attending clinics under Amana hospital supervision in Ilala district. Participants of in-depth interviews were those who will fulfill the above criteria, and who are on ART for long period of

time (more than one year) and those who are on ART for a short period of time (three to six months). 4 health care providers were involved in in-depth interviews so as to allow the researcher to get additional information from the health care provider's perspectives on the factors affecting PLWHA in disclosing their status to others.

#### 3.4 Sample Size and Sampling Procedures

Sampling technique is a definite plan for obtaining sample from a given population. According to Kothari (2004) sampling technique is a procedure that the researcher would adopt to select items for the sample. Sampling technique lay down the number of items to be included in the sample. Baker (1999) notes in her book "Doing Social Research" that there are two major goals that sampling can achieve. Therefore, random sampling was used in this study to avoid bias and to allow equal chance of respondents to have a probable chance of participation.

On the other hand, the study uses Purposive sampling to obtain key informants. Mason (2008) argued that purposive sampling is a set of procedures where the researcher manipulates the analysis, approach and sampling activity interactively during the research process to a much greater extent than in statistical sampling. However, in this study 100 respondents were involved; this is set as a tentative sample since the researcher is not sure of the number of respondents who are available during data collection day.

#### 3.5 Data Collection Tools and Procedures

This study uses different methods and this was done intentionally because no single method is adequate in itself in collecting valid and reliable data on a particular problem. Similarly, Bogdan and Biklen (2002) observed that exclusive reliance on one method

might bias or distort the researcher's picture of a particular reality. The study collected it's by using structured two methods of data collections these are: questionnaire and indepth interview guide. The questionnaire was used to collect information regarding HIV/AIDS discloser among pregnant women with a focus but not limited socio-cultural, socio-demographic factors and preference of HIV/AIDS. A questionnaire is essentially a structured technique for collecting primary data. It is generally a series of written questions for which the respondents have to provide the answers (Gay, 2001).

Similarly, in-depth interview guide was used to collect information on the supply and service delivery. The English version questionnaire was translated to Swahili language to help the respondents understand what is written and be able to respond on it because we understand that our respondents are from Kiswahili language community.

#### 3.6 Validity and Reliability of Data

#### 3.6.1 Validity of Data

Validity is the instrument capable of measuring what is supposed to measure accurately, effectively and efficiently (Omari, 2011). To improve the validity the researcher will pre-test the questionnaire over a number of people before officially distributing to the participants, this will be achieved through setting standards on constructing questionnaires and interview questions which related to the researcher's objectives and questions. In this study, interview and questionnaires were generated in conjunctions with the researcher this is to ensure that the interview guides and questionnaires focus on the topic under investigation and the purpose of the study is clearly explained to the respondents and issues of concerned are resolved satisfactorily. The procedures of the interview and questionnaire were explained to the respondents. Lastly, respondents

were assured of anonymity and confidentiality. This encouraged frankness during the interview.

#### 3.6.2 Reliability of Data

Babbie (2005) describes reliability that, as a condition in which the same results were achieved whenever the same technique is repeated to do the same study. In this study, the result was achieved by the following means. The anonymity and confidentiality of the respondents was ensured so that they were able to provide information for use strictly for the purpose of the study. A rapport with the respondents was successfully being established during the preliminary fieldwork study.

#### 3.7 Data Analysis Methods

There are various methods of data analysis that can be used by researchers when they are conducting the research. However, the nature of study and type of data collected are the major aspects to consider during the time of data analysis (Kothari, 2004). Qualitative techniques begin by identifying themes in the data and relationships between the themes. The study employed qualitative technique to analyze data in the form of logical statements and arguments. Content analysis was done on the collected data. This is because qualitative research helps people to see the world view of studies concerned. The study uses quantitative to analyze data mathematically, whereby calculations of numbers, percentages, tables and charts were used to summarize the amount of data obtained from the field.

#### 3.8 Ethical Considerations

The Informed Consent forms (ICF) were distributed to all study participants for being signed and to justify of their willingness to participate in the study. They were signed by the research assistant (or PI) prior to commencement of the interview. To avoid confusion and duplication of responses interviews were conducted in the separate room with assurance of confidentiality. Afterwards the completed questionnaires were collected and kept in the proper place, for the sake of confidentiality. Data collector was trained on how they should collect the quality data and quality control were observed by the researcher. Respondent's information's that was confidentially kept and protected by the researcher. Sullivan (2001) argues that social researchers are bound to ethical considerations in their studies.

The researcher observed the rights of all respondents including the information given by respondent, which will be kept confidential to avoid harming the respondent. The study followed and considered all research directives such as seeking permission from the required offices and officers. Also, all respondents were respected and the information provided by respondents was kept confidentially. Human research ethics rest on three basic principles that fully considered the foundation of all regulations or guidelines governing research ethics.

#### **CHAPTER FOUR**

DATA PRESENTATION, ANALYSIS AND INTERPRETATION

#### 4.1 Introduction

This chapter focuses on the data presentation and discussion of the results based purposely on research objectives laid down by this study. The general study objectives of this study was to assess the effect of culture on HIV status disclosure for pregnant women in Tanzania: the case of Amana Hospital in Ilala. Major themes included identification of cultural beliefs which affect HIV status disclosure for pregnant women, to explain the effect of cultural beliefs on HIV status disclosure for pregnant women and lastly to provide recommendation on how to improve HIV status disclosure for pregnant women. A sample of 100 participants were interviewed at the same time observation was done. However, the study participants included the pregnant women who were later on served with self-administered questionnaire.

The following are the questions asked based on objectives and other question was not among of objectives but was very crucial in order to recommend effectively in our study. In order to address issues related on effect of culture on HIV status disclosure for pregnant women in Tanzania, the concept of Identifying cultural effects to a pregnant woman of disclosing her HIV status in the community in which she lives was raised in the study. The question asked was: *Identify cultural effects to a pregnant woman of disclosing her HIV status in the community in which she lives*.

The results are presented in Table 4.1. The results show that, the majority of the respondents (about 34 percent) said that the stigmatization is still a cultural effects to a pregnant woman of disclosing her HIV status in the community in which she lives. Followed by 25 percent of the respondents which said that lack of acceptance also is one of cultural effects to a pregnant woman of disclosing her HIV status in the

community in which she lives. Minority about 5 percent said that violence also still a cultural effects to a pregnant woman of disclosing her HIV status in the community in which she lives, 10 percent they said about Discrimination, other 10 percent they said about Fear of abandonment, 6 percent they said about Poor social support and other 10 percent they said about blame. For more details let we see the Table 4.1.

Table 4.1: Respondents Pregnant Woman of Disclosing her HIV Status in the Community

	Frequency	Percent	Valid Percent	Cumulative Percent
Fear of abandonment	10	10.0	10.0	10.0
Stigmatization	34	34.0	34.0	44.0
Discrimination	10	10.0	10.0	54.0
Lack of acceptance	25	25.0	25.0	79.0
Blame	10	10.0	10.0	89.0
Violence	5	5.0	5.0	94.0
Poor social support	6	6.0	6.0	100.0
Total	100	100.0	100.0	

Source: Research Data (2017)

The data is well illustrated on the Figure 4.1, this helps to precisely present the findings, its interpretation and explanation. However, presenting the results in two different formats reinforces our clearer understanding of the problem under discussion as we can see in Figure 4.1.

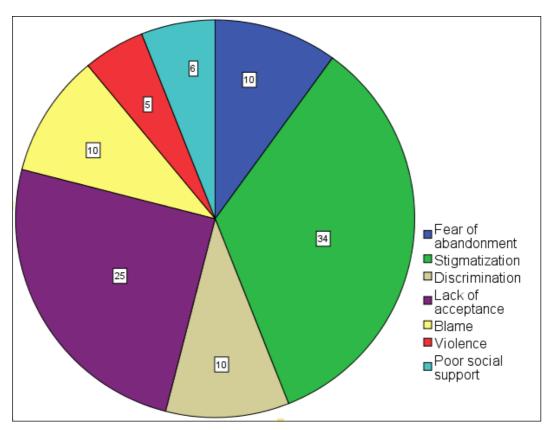


Figure 4.1: Various Culture Affect that Still Operates in the Society

Source: Research Data (2017)

The Figure 4.1shows that in a society there are various culture affect that still operate. The most important thing is to know that stigmatization is still a big factor by 34 percent followed by domestic violence by 25 percent. The stigmatization occurs because a sizable portion of a society is not educated on how to avoid stigmatization and domestic violence can be said to be a result of male dominated society. Therefore upon discovery that a woman Is HIV Positive then violence would result because a male is dominant in a household.

A question asked again was: Do you think cultural belief is still an opposing force to pregnant women to disclosure HIV status? Was asked to the respondents and the results

revealed that 34 percent of the respondents said No while 66 of the respondents said Yes. The results are presented in Table in the 4.2.

Table 4.2: Culture Belief is Still an Opposing Force to Pregnant Women to Disclosure HIV Status

	Frequency	Percent	Valid Percent	<b>Cumulative Percent</b>
Yes	34	34.0	34.0	34.0
No	66	66.0	66.0	100.0
Total	100	100.0	100.0	

Source: Research Data (2017)

The data is well illustrated on the Figure 4.2, this helps to precisely present the findings, its interpretation and explanation. However, presenting the results in two different formats reinforces our clearer understanding of the problem under discussion as shown in the Figure 4.2.

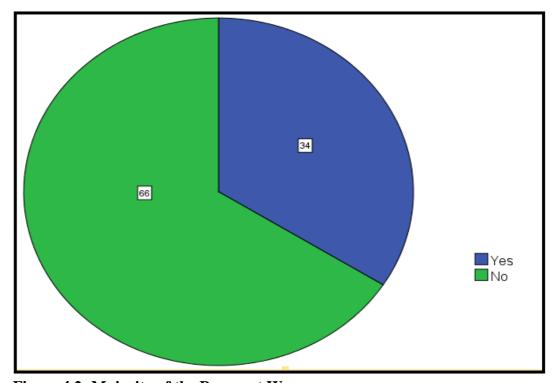


Figure 4.2: Majority of the Pregnant Women

Source: Research Data (2017)

The Figure 4.2 shows that the majority of the pregnant women about 66 percent still hold belief that cultural barriers are in operation in the communities they bare living while the minority about 34 percent feel that cultural belief are not a hindering factor to disclosure of HIV status. From the findings it shows that cultural beliefs still pose a problem to the society to expose their health society and society has to fight theses cultural beliefs.

## Other question was: Why do you think pregnant women disclose their HIV status to the community in which they live?

There are various motivation to disclose HIV status, the Table 4.3 shows that, those who mentioned to receive support were 54.0 percent, change in behavior were 26.0 percent to protect others from HIV infection were 14.0 and to promote HIV prevention were 6.0 as shown in the Table 4.3.

Table 4.3 Various Motivation to Disclose HIV Status to the Community

	Frequency	Percent	Valid Percent	Cumulative Percent
To receive support	54	54.0	54.0	54.0
Change in behavior	26	26.0	26.0	80.0
To protect others from HIV infection	14	14.0	14.0	94.0
To promote HIV prevention	6	6.0	6.0	100.0
Total	100	100.0	100.0	

Source: Research Data (2017)

The results in the Table 4.3 have also been presented in the Figure 4.3 for clarification.

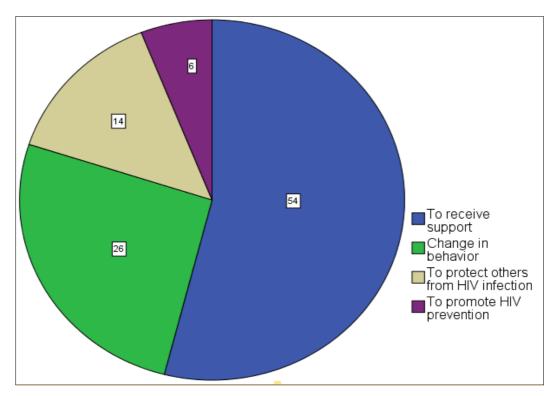


Figure 4.3: Reveal that Majority of the Respondent Amounting to Protecting others is a Priority

Source: Research Data (2017)

The Figure 4.3 reveal that majority of the respondent amounting to 54 percent said it was to receive social support while the minority about 6 percent mentioned about protecting others. The message here is that AIDS is still a big problem for people of poor background and still very few people would see protecting others is a priority. Therefore economic empowerment can be used as motivation to encourage people to expose their HIV status.

## Another question was: What recommendations do you give specifically to the government to facilitate disclosure of HIV status to the pregnant women?

The researcher wanted to make the recommendation on the study and it happened that a form of question was asked to the respondents to dig deeper for the appropriate answer' what recommendations do you give specifically to the government to facilitate disclosure of HIV status to the pregnant women? The results came as follows those participants who mentioned that the government has to provide free antiretroviral were 72.0 percent, HIV Aids testing campaign were 4 percent, those who mentioned education were 16 percent for social support were 8 parent, more details available in the Table 4.4.

Table 4.4: Government to Facilitate Disclosure of HIV Status to the Pregnant Women

	Frequency	Percent	Valid Percent	Cumulative
			Percent	Percent
Free antiretroviral and other				
treatment associated with	72	72.0	72.0	72.0
HIV				
Aids testing campaign	4	4.0	4.0	76.0
Education	16	16.0	16.0	92.0
Social support	8	8.0	8.0	100.0
Total	100	100.0	100.0	

The results in the Table 4.4have also been presented in the Figure 4.4 for clarification

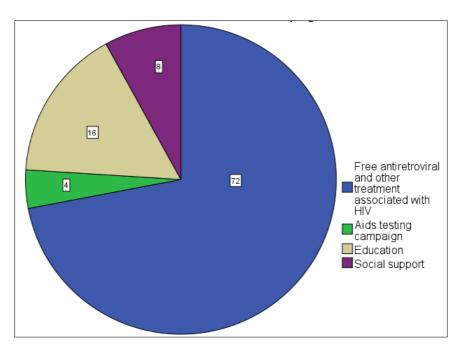


Figure 4.4: The Respondent are in need of free antiretroviral and other Treatment Associated with HIV

Source: Research Data (2017)

From the Figure 4.4 it appears that the majority about 72 percent of the respondent are in need of free antiretroviral and other treatment associated with HIV meaning that these people are poor followed by education about 16 percent, 4 percent said about AIDS testing campaign while other respondent about 8 percent mention about social support. Therefore the government has to insist on the free medication and education to people.

#### The other question was: Please Identify your Age

Age of the respondent, the researcher had the keen interest to know the age of therespondent because he wanted to know if the views would vary according to the age. The finding revealed that, respondent with the age 18-25 made up 10 percent, while those with age category 26-35 made up 44 percent and 36-45 made up 32 percent, while that of 46-55 made up 12 percent and last respondent with age above 55 years of age made up 2 percent, more information available In the Table 4.5.

**Table 4.5 Age of Respondents** 

	Frequency	Percent	Valid Percent	<b>Cumulative Percent</b>
18-25	10	10.0	10.0	10.0
26-35	44	44.0	44.0	54.0
36-45	32	32.0	32.0	86.0
46-55	12	12.0	12.0	98.0
55+	2	2.0	2.0	100.0
Total	100	100.0	100.0	

The results in the Table 4.5 have also been presented in the Figure 4.5 for clarification

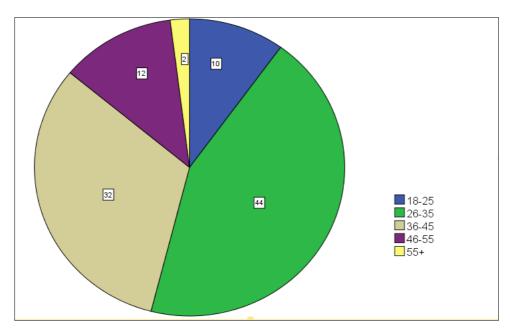


Figure 4.5: Respondents of Age

Source: Research Data (2017)

The Figure 4.5 revealed that majority of the respondent aged between 26-35 years of age and that of age category 55+ years of age made the least of the participants. This is because most of the expecting mothers are young females and due to social causes such as unemployment enter into sexual relationship at early years.

#### **CHAPTER FIVE**

#### SUMMARY, CONCLUSION AND RECOMMENDATIONS

#### 5.1 Introduction

This chapter presents summary, conclusion and recommendations of this study for that meant to assess the effect of culture on HIV status disclosure for pregnant women in Tanzania: the case of Amana Hospital in Ilala with objective to identify cultural beliefs which affect HIV status disclosure for pregnant women, to explain the effect of cultural beliefs on HIV status disclosure for pregnant women and to provide recommendation on how to improve HIV status disclosure for pregnant women. The researcher believes that recommendations put across will be potential and applicable by different stakeholders in health sectors for the aim of improving the AIDS disclosure among pregnant women in Tanzania.

#### 5.2 Summary

This study focused on the effect of culture on the AIDS disclosure among pregnant women in Tanzania: the case of Amana Hospital. Similar to other studies conducted in Africa, nearly all participants had disclosed to someone; however, rates of disclosure varied widely depending on the social target group, as many had disclosed to a family member or friend, but far less respondents had disclosed to spouses and members of the community.

For the most part, there were no marked age differences with regard to disclosure to specific targets, except for the observation that among the few who reported disclosure to children, all were older women, and among those who reported disclosure to work

colleagues most were men. Older women may be more likely to disclose to children because they are more likely to have children who are old enough to disclose to and who could understand its meaning and circumstances.

The study identified a wide range of reasons for disclosure, but for the most part these reasons could be classified into four primary themes: to receive support (financial, material, moral and emotional, treatment), relationship ties, to explain change in behavior and to promote HIV prevention or protect others from HIV. These reasons are consistent with previous research on motivations for disclosure (Chandra et al, 2014).

Reasons for disclosure differed depending on the social group of the disclosure recipient. Disclosure that was motivated by the desire to gain support was mostly associated with disclosure to family members. This association highlights the role of the family in Africa in offering support and providing a safety net for people, especially considering the limited proliferation of formal social security mechanisms in Uganda and most other parts of Africa.

Promotion of HIV prevention or protecting the person from HIV was mostly associated with disclosing to spouse or partner and friends. Disclosure by males (especially) to their female spouses, was often driven by the desire to protect the spouse from HIV infection (if she was not yet infected), so that she would be there to look after the children in case the male discloser died. For female disclosers, where disclosure was associated with HIV prevention, it was so that the spouse could consider using condoms. Disclosing to friends with regard to HIV prevention was simply associated

with protecting them from infection, often prompted by viewing the friend's sexual conduct as risky, and involved encouragement to get tested for HIV.

Disclosure of HIV status to explain obvious changes was more commonly reported as a reason for disclosure to family and friends, than to spouse or partner, while strength of relationship ties featured more with disclosure to family and friends. The association between strength of relationship ties and disclosure to family and friends highlights the length of time the HIV client may have related with the family and friends, enabling the family and friends to note and ask about changes in appearance and behavior, which may be unlikely with newer relationships such as sexual or romantic partners. These reasons and their association to specific targets highlights the importance of closeness and social distance to the disclosure target as a key factor in the decision-making process to disclose one's HIV status.

The most common barriers reasons for nondisclosure were fear of abandonment, which was mostly associated with disclosure to spouse/partner and friends; and inaccessibility to the disclosure target and not wanting to worry or upset the disclosure target, both of which were mostly associated with disclosure to family members. As with the reasons for disclosure, the reasons for nondisclosure are also motivated by closeness to the target, mostly based on fear of upsetting the target or being abandoned. Although this was expressed by all categories of respondents and for each disclosure target group, it was especially prominent with young females, in relation to their sexual partners, who in many instances had sexual partners other than our respondents. Also in many instances, these relationships had not lasted long as in the case of the older women. This finding concurs with previous research which highlight fears of verbal and physical

abuse, fear of rejection and other forms of negative responses from the disclosure target as deterrents of disclosure.

Disclosure of a positive HIV diagnosis to a pregnant woman is an important aspect of coping with the disease and understanding the circumstances surrounding it. It is also plays an essential part in changing behaviour, to both prevent HIV and alleviate its impact (Norman et al., 2007; Varga et al., 2005; Sowell et al., 2003). Disclosure can also empower the pregnant women, especially women, to make better reproductive choices as well as garner psychosocial support. Women who have disclosed to their partners may be more likely to participate in antiretroviral treatment (Deribe et al., 2009).

Positive consequences of disclosure of a positive HIV diagnosis to a sexual partner may include a strengthening of the relationship and mobilizing the couple to deal with the disease in a unified manner, thus adopting safer sex practices (Parsons et al., 2004). The individual is then able to avoid the anxieties of having to hide their positive HIV status, thus lowering their stress and lowering risk behaviours (Elford et al., 2008; Bouillon, Lert, Sitta, Schmaus, Spire & Dray –Spira, 2007; Lam, Naar -King & Wright, 2007; Almeleh, 2006).

It is important to recognize the role that culture plays in disclosure. Those who feel ashamed of their positive HIV status are less likely to disclose their HIV status (Parsons et al., 2004). Stigma and a lack of acceptance following a HIV positive diagnosis have been recognized as barriers to disclosure, health care and social support (Ncama, 2007). Fear of being a burden to family members, fear of being identified and labeled as HIV

positive and stigma surrounding a positive HIV diagnosis may be some of the factors that come into play in keeping a positive diagnosis a secret (Deribe et al., 2009). This is also in keeping with the findings of various studies that disclosure of HIV to others may elicit negative responses such as blame, rejection or violence. (Elford et al., 2008; Bouillon et al., 2007; Skogmar et al., 2006).

Non-disclosure of a positive HIV diagnosis can frequently be attributed to a fear of negative consequences that may include rejection, blame, abandonment, isolation; verbal and physical abuse and withdrawal of financial support (Kalichman et al. 2007; Sowell et al., 2003). It is against this backdrop that the disclosure process is about much more than having to adjust to an HIV positive diagnosis.

It would seem from the above discussion that dealing with the implications of disclosing a positive HIV status is influenced by the negotiation of fears around anticipated reactions, whether they are positive or negative, following disclosure. However, whom the afflicted person decides to disclose to in accessing much needed support is also important.

Many communities also stigmatize people who are infected with HIV/AIDS. Discrimination is common and includes being unwilling to share eating utensils with someone who is suspected of being infected with HIV/AIDS, name -calling and malicious gossip (Almeleh, 2006). In some communities extreme weight loss is associated with AIDS illness. People believe they are able to identify an HIV infected individual by observing his or her weight (Nicole et al., 1993 cited in Almeleh, 2006). Having to avoid stigmatizing attitudes from the community, while at the same time

accessing treatment, care and support is a tricky path to negotiate for people living with HIV/AIDS.

#### 5.3 Conclusion

Disclosure of HIV status among pregnant women is a complex and multi-dimensional process that transcends the individual's personal circumstances and moves into his or her social sphere. It involves motivation of whether or not to disclose, whom to disclose to, as well as the consequences of making the disclosure. It would seem from this discussion that the process of disclosing a positive HIV diagnosis is unique to each pregnant woman and is informed to a large extent by his or her social context.

Disclosure of a positive HIV diagnosis is determined by pregnant woman personal beliefs, social and family environment and the prevailing community discourse around HIV/AIDS. The disclosure process is also influenced by the negotiation of fears around stigmatization from not only the immediate family, partner or husband, but also the community at large.

The literature review sought to present some insight into the HIV and AIDS pandemic, with special focus on the vulnerability of women to HIV infection, as well as on the psychosocial effects of disclosure. The disclosure process involves more than the act of telling others about the positive HI diagnosis, so as to access or garner support from significant others. It involves a process of adjusting to one's positive HIV diagnosis (which can take years), negotiating one's fears in anticipation of either positive or negative consequences of disclosure as well as the motivation to disclose.

#### 5.4 Recommendations

#### **5.4.1** Voluntary Counseling and Testing

The results in this study, which were reiterated in the open-ended questions, revealed that though the participant benefited from the initial counseling session, there were certainly ongoing unresolved issues such as continued unawareness of the partner's status, underlying anger and resentment. It is recommended that there should be multiple counseling sessions after the client has disclosed to provide ongoing support and encouragement.

#### **5.4.2** Support Groups

The findings from the open-ended questions also emphasized the importance of assuring that individuals have access to support groups as these were enormously advocated by the participants of this study. Support groups seem to provide the much needed support and coping skills needed to accept their HIV positive status and live normal lives. These support groups also encourage and advise pregnant women on aspects such as disclosure as well as information about the medication.

#### **5.4.3** Community Based Programs

Programs need to be community based in an attempt to reduce the stigmatization of individuals with HIV and increase their access to social support systems and health care facilities. These include programs that are based on information about the disease, coping skills and support groups. Programs aimed at empowerment of pregnant women to change social norms and access some form of income and financial security, which would allow increased independence and reduce the fear of abandonment when disclosing should be introduced.

#### **5.4.4** Further Research

More research is needed to determine the effectiveness of couple counseling, which may reduce blame and rejection of the person who is tested first and accused of being the primary source of the infection. More females are tested for HIV first, often at antenatal clinics, which place them at an increased risk of discrimination and rejection.

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#### **APPENDIX**

# THE EFFECT OF CULTURE ON HIV STATUS DISCLOSURE FOR PREGNANT WOMEN IN TANZANIA: THE CASE OF AMANA HOSPITLA IN ILALA DISTRICT

Inter	viewer reads: Thank you for a	greeing to meet with me today and participate
in thi	s research.	
Parti	cipant ID NO	
Inter	viewer ID NO	
Inter	view Start Time:	
Inter	view End Time:	
Date	of interview/	/
Qn1.	Please identify your age	
(i)	18-25	
(ii)	26-35	
(iii)	36-45	
(iv)	46-55	
(v)	55+	
Qn2.	Do you think cultural belief is disclosure HIV status?	is still an opposing force to pregnant women to
(1	i) Yes	
(1	ii) No	

Qn3. Identify cultural effects to a pregnant woman of disclosing her HIV status in the

community in which she lives.

Fear o	f abandonment	
(i)	Stigmatization	
(ii)	Discrimination	
(iii)	Lack of acceptance	
(iv)	Blame	
(v)	Violence	
(vi)	Poor social support	
Qn4. V	Why do you think pregnant women disclos	se their HIV status to the community in
which	they live? Tick the right answer	
(i)	To receive support	
(ii)	Change in behavior	
(iii)	To protect others from HIV infection	
(iv)	To promote HIV prevention	
Qn5. V	What recommendations do you give spec	ifically to the government to facilitate
disclos	sure of HIV status to the pregnant women	?
•••••		
Qn6. V	What is your marital status?	
	(a)Married	

(b)Not married	
(c)Widow	
(d)Divorced	
Qn7. What is your occupation?	
(a)Employed	
(b)Not employed	
(c)Self employed	
(d)Farmer and agribusiness woman	
Qn8. What is your education level?	
(a)Primary school leaver	
(b)Secondary school leaver	
(c)Vocational education	
(d)College level	
(e) University level	

Thank you very much for taking your time answering this questionnaire

Appendix II: Research Clearance Letter

#### THE OPEN UNIVERSITY OF TANZANIA

DIRECTORATE OF RESEARCH, PUBLICATIONS, AND POSTGRADUATE STUDIES

P.O. Box 23409 Fax: 255-22-2668759Dar es Selaam, Tanzania, http://www.out.ac.tz



Tel: 255-22-2666752/2668445 ext.2101 Fax: 255-22-2668759, E-mail: drpo@out.ac.tz

29/08/2017,

To The District Commissioner

Ilala District.

#### RE: RESEARCH CLEARANCE

The Open University of Tanzania was established by an act of Parliament no. 17 of 1992. The act became operational on the 1\* March 1993 by public notes No. 55 in the official Gazotta. Act number 7 of 1992 has now been replaced by the Open University of Tanzania charter which is in line the university act of 2005. The charter became operational on 1\* January 2007. One of the mission objectives of the university is to generate and apply knowledge through research. For this reason staff and students undertake research activities from time to time.

To facilitate the research function, the vice chancellor of the Open University of Tanzania was empowered to issue a research clearance to both staff and students of the university on behalf of the government of Tanzania and the Tanzania Commission of Science and Technology.

The purpose of this letter is to introduce to you Ms. Angela Pius Matle; PG201610207, who is a Master student at the Open University of Tanzania. By this letter, Ms. Angela P Matle has been granted clearance to conduct research in the country. The title of her research is "An Assessment of Social Cultural influencing HIV Status Disclosure among Pregnant Women; The Case of Ilala District.", The research will be conducted in Ilala District. The period which this permission has been granted is from 23/08/2017 to 30/10/2017.

In case you need any further information, please contact:

The Deputy Vice Chancellor (Academic); The Open University of Tanzania; P.O. Box 23409; Dar es Salaam. Tel: 022-2-2968820

We thank you in advance for your cooperation and facilitation of this research activity. Yours sincerely,

Prof Hossea Rwegoshora

For: VICE CHANCELLOR

OPEN UNIVERSITY OF TANZANIA

### ILALA MUNICIPAL COUNCIL

ALL COMMUNICATIONS TO BE ADDRESSED TO THE MUNICIPAL DIRECTOR

P.O. BOX PHONE NO:

20950 2128800

2128805

FAX NO.

2121486

REF.IMC/DR.6/Vol.VI/287



MUNICIPAL OFFICE.

1 MISSION STREET,

P.O.BOX 20950,

11883, DAR- ES- SALAAM

21st Sept 2017

Medical Officer in-charge Amana Referral Regional Hospital ILALA MUNICIPAL COUNCIL.

## RE: PERMISSION TO CONDUCT RESEARCH

Kindly refer to the heading above

This is to introduce Angola Pius Matle a student at The Open University of Tanzania pursuing master of social work.

She requested permission to conduct research titled "Assessment of social cultural factors influencing HIV status disclosure among pregnant women in Tanzania".

Permission has been granted to her to conduct such study within Ilala Municipal with an agreement of bringing feedback to MMOH office.

! kindly request your assistance.

Dr.Mwanahamisi Hassan

For: MMO

MMOH-ILALA MUNICIPAL COUNCIL

Copy: Researcher

FOR MUNICIPAL MEDICAL OFFICER OF HEALTH

Appendix IV: Research Permit Letter

## The United Republic of Tanzania PRIME MINISTER'S OFFICE REGIONAL ADMINISTRATION AND LOCAL GOVERNMENT

DAR ES SALAAM REGION Phone Number:

Phone Number: 2860081/2863716 in reply please quote:

Reg. No. FA.282/293/01S/7

DAR ES SALAAM



REGIONAL COMMISSIONER'S OFFICE, RASHID KAWAWA ROAD, P.O. Box, 5429,

12880DAR ES SALAAM

District Administrative Secretary,

1 - A L A

C. O. Box

RE: RESEARCH PERVICE

	ANGELA PIUS MATLE	
OPEN UNIVERS  AN ASSESS  DUCLOSURE  OR JUALA	TY OF TANZANIA have been permited to AN ASSESSMENT OF SOCIAL  CULTURAL INFLUANCING HIV STAR	32
Kindly request your good	l assistance to enable their research.	

For: Regional Administrative Secretary
DAR ES SALAAM

Copy:

Municipal Director,

DAR ES SALAAM.

Principal/Vice Chancellor, OPEN UNIERSITY OF TANZAMA