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University of Sussex,
School of Law, Politics and Sociology (Gender Studies).

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This thesis is submitted as part fulfilment of the degree of Doctor of
Philosophy in Gender Studies

**Gambian women, violence and its intersection with HIV/AIDS: Agency
through feminist participatory research**

21st December 2017

DECLARATION

I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree. The data has been obtained from fieldwork using a participatory feminist research approach. I take full responsibility for the production of the thesis which is my own original work.

Signature: Agnes Adama Campbell Nee Kallay.....

ABSTRACT

Research has identified a strong correlation between HIV/AIDS and gender-based violence, yet few studies centre the experiential knowledge of HIV sero-positive women and practitioners. This thesis, based on fieldwork conducted in the Gambia, is grounded in data on HIV positive women's experiences of violence and practices of resistance, revealing context specific complexities and challenges. Data collection methods included diaries, focus groups and in-depth individual interviews with a participant group of sixty sero-positive women in six Gambian HIV Support Societies, and twenty field practitioners working in the areas of violence and HIV/AIDS.

I argue in this thesis that there are intersecting underlying factors (patriarchy, gerontocracy and structural violence) that contribute to women's experiences of violence and abuse that render them vulnerable to HIV. In addition, that alongside the more visible gendered violences which intersect with HIV/AIDS. Accounts of women living with HIV revealed that stigma is discreditable and discredited attributes. It contends that stigma should be seen as an 'everyday' practice of normalised violence, which has very harmful emotional, psychological, economic and physical effects. The research also suggests that violence against women in the context of HIV is not limited solely to male perpetrators. In the Gambia there has been limited success in the translation of women's rights agendas into concrete and effective interventions, partly due to a lack of attention to socio-cultural context and the lived experiences of HIV positive women.

The thesis concludes that culturally specific, integrated health and social justice approaches are necessary, which are grounded in women's everyday practices of agency and resistance, and which in particular address the fear of dethronement (loss of power, privileges and prestige) amongst men and older members of society.

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ACRONYMS AND ABBREVIATIONS

ABC	Abstinence, Be faithful, and use a Condom
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
BCC	Behaviour Change Communication
FGM/C	Female Genital Mutilation/Cutting
FPAR	Feminist Participatory Action Research
FPR	Feminist Participatory Research
GBoS	Gambia Bureau of Statistics
GBV	Gender Based Violence
GBVAW	Gender Based Violence Against Women
HIV	Human Immunodeficiency Virus
HOC	Hands On Care – a clinic for PLHIVs
IEC	Information, Education and Communications
IPV	Intimate Partner Violence
NAS	National AIDS Secretariat
NAGBV	Network Against Gender-Based Violence
NGOs	Non-Governmental Organisations
PLHIV	People Living with HIV
PLWA	People Living with AIDS
STIs	Sexually Transmitted Infections
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
VAW/G	Violence against Women and Girls
WHO	World Health Organisation

DEDICATION

I dedicate this project to all affected women and girls, men, boys and practitioners working with Support Societies in the Gambia who are interested in advancing social justice and the rights of marginalised groups. With commitment and strong conviction both men and women can strive to make a difference and to transform the current status quo of inequality by taking concrete actions in preventing violence against women and girls in society to prevent its harmful effects.

ACKNOWLEDGEMENT

This thesis is the result of collaborative project undertaken with persons living with HIV who tirelessly joined me in this project as co-researchers in focus groups, in-depth individual interviews, and in the use of diaries to generate the data collected during the fieldwork in the Gambia. To all others in the Support Societies, numerous field practitioners, I extend my sincere appreciation, most especially to the strong courageous women at the Mutapola Voices of HIV positive women in the Gambia. I am especially grateful for their insightful contributions and input with the invaluable data collected and final thesis recommendations.

My sincere thanks and appreciation go to my doctoral degree supervisors, Dr Alison Phipps, Professor Jo Moran Ellis both of the School of Law, Politics and Sociology, University of Sussex, and Dr Gillian Bendelow who was my initial supervisor before moving to the University of Brighton, here in the United Kingdom. All of you have carried out your role efficiently, guiding me through the birthing process, and you all served as highly skilled professionals, stern yet gentle midwives, ushering and delivering a live baby at the end. I say a big thank you, and in Wolof, ‘Gerejef’, for your professionalism. It is indeed a privilege to have been supported and encouraged by your supervision.

I would also like to thank the Commonwealth Scholarship funded by the United Kingdom government, for the sponsorship and funding that allowed me to conduct this research in the UK over the past three years. It would not have been possible without their support.

My thanks to go to my son and confidante, Aldel Dele Campbell. To Gareth Finley, and also a dearest sister Mrs. Sue Coxhill, who proofread and gave useful feedback throughout this writing process and provided me with a shoulder to lean on when I felt weak and overwhelmed, with mounds of data to analyse. Thanks to all my family and friends who joined me in deep reflection to make intercessory prayers to the God in whom I strongly believe! God has sustained me and has kept His promise that He would never leave me nor forsake me. As God promised Joshua, I also believe in the word of God that states: “Be strong and be of a good courage, be not afraid, neither be thou dismayed; for the Lord thy God is with thee whithersoever thou goest” (Joshua 1: Verse 9). I remain resolute and most grateful for God’s divine love, grace and mercy.

CHAPTER 1: INTRODUCTION

1.0 Introduction

Anta:

“I married at age 15 when my parents decided that I was ready; I had no choice to refuse ... I was always quarrelling with my husband because I suspected he was having affairs with other women in the village. He was actually cheating on me ... I eventually asked for a divorce. He died shortly after the divorce because he was ill for quite a while. I was later diagnosed with HIV because I was ill too ...”

Adama is a young sero-positive woman, who before HIV diagnosis she fought with her husband because he forced her to have sex. After HIV diagnosis:

Adama:

“When I disclosed my [HIV] positive status to my husband ... every day we had fights, quarrels, and I was beaten.”

She was accused of bringing HIV into the family. She said:

“So ... later I left. It was too much, I was too ill for that, I could not continue living that way”.

Nyima:

“I am an ordinary person with what is rapidly becoming a most ordinary virus. I have stopped feeling sorry for myself and have now learned to live, think and even act positively.

“I have come out of my hideout, and I have found a stage where I can tell the world that I’m not a victim, but rather a manager. A manager of hope! All I require is not even sympathy, but I want you to appreciate me as a person, as a mother, tell me I am still worthwhile. I still matter! I am not a number, a statistic, but an equal partner in this struggle. Agree with me that though this virus has robbed me of health it has not taken away my humanity or dignity ...”

– The above are excerpts from journal entries shared in focus groups by participants in the research conducted in the Gambia, March 2014.

I open this thesis by centring the voices of Gambian women living with HIV/AIDS. These are excerpts from the interactive focus group discussions about journal entries created for the research. They offer glimpses of the experiences of three women in their own words. While they share commonalities of experience, in terms of reaction to abuse, resistance,

and coping strategies for living with HIV, there are also discernible differences in their narratives. Violence Against women (VAW) and HIV/AIDS are two intricately linked health and social development challenges that have profound impacts on the lives and well-being of affected women and dependents, creating high domestic and global expenditures for prevention, care and support programmes. Samaya VanTyler and Laurene Sheilds (2013, p.2) aptly observed that, with the HIV and AIDS epidemic now in its fourth decade, the rampant spread of the disease has robbed countries of the resources and capacity on which both community security and development depend. VanTyler and Sheilds argue that twenty-five years ago HIV/AIDS was generally depicted and analysed as an infectious disease and less understood as a human rights crisis. Within the last decade, they suggest, more attention has been given to the links between HIV/AIDS, human rights and gender issues (VanTyler & Sheilds, 2013, p.2).

Research has identified a strong correlation between HIV/AIDS and gendered violence, yet few studies centre the experiential knowledge of HIV sero-positive women and practitioners, in the Gambian social settings. This thesis, based on fieldwork conducted in the Gambia, is grounded in data on HIV positive women's experiences of violence. Not all PLHIVs in this study cohort experience stigma and enacted discrimination, the majority experienced serious problems consistent with the extant literature, which indicates that HIV/AIDS exacerbates violence in the lives of women and has negative outcomes (Abramsky et al., 2011; Chang et al., 2015; Campbell & Soeken, 1999; Ellsberg, 2008, 2006).

Furthermore, research has revealed that violence has serious health and development consequences for women (Ellsberg, 2006, pp.325-332; Ellsberg et al., 2008; WHO & London School of Hygiene and Tropical Medicine, 2010; WHO & UNAIDS, 2013). The literature on gender-based violence has also shown that, over the past decade, there have been profound policy shifts within the international community aimed at preventing VAW and also increasing recognition of the intersection of Intimate Partner Violence (IPV), and the consequence of physical and mental health challenges as a grave public health and human rights violation (Ellsberg, 2006, pp.325-326).

Findings derived from literature on violence against women suggest that violence is a precursor and consequence of HIV/AIDS, indicating a link between intimate partner

violence and exposure to risks of sexually transmitted infections and HIV from unprotected coercive sex due to gendered power inequality (Jewkes et al., 2010; Jewkes et al., 2006). Additionally, the literature has documented that women's experiences of violence may take the form of physical, economic, sexual, psychological and emotional violence, both before and after HIV diagnosis and demands action for women's safety to prevent VAW (Campbell & Soeken, 1999; Stockman et al., 2013; Swaminathan et al., 2007; Winchester, 2011; Walby et al., 2014). World Health Organization, 2004, 1990; World Health Organisation & UNAIDS, 2013).

The problem of violence and HIV intersection is an under-researched subject in the Gambia. The current research is conducted to unveil the risks Gambian women may experience as a result of VAW. As suggested above, violence has been researched as a precursor and sequel to HIV globally (Jewkes et al., 2010), yet, in the Gambia, few empirical studies have been undertaken to explicitly establish the link in the local context. This is an identified gap as an under-researched subject. Anecdotal reports abound in the Gambia suggesting that many men and some women have not taken the HIV/AIDS test, whilst pregnant women attending antenatal clinics do so as part of their antenatal care services. While women attending Sexually Transmitted Infection (STI) clinics and antenatal care settings are offered counselling and advised to test for HIV, little investigation is explicitly done to examine how stigmatisation may contribute to experiences of abuses in order to utilise the findings to ameliorate any negative consequences. My own research seeks to address this gap. Few studies have documented the effectiveness of HIV/AIDS interventions when testing of pregnant women is crucial in preventing the transmission of HIV (from mother to child), and the potential for HIV positively diagnosed pregnant women to experience HIV stigma related abuses and violations of their rights. HIV stigmatisation could have gendered implications, and the current study is interested in unearthing and rendering visible these issues.

The violence against women literature suggests that violence exists in all parts of the world, across various classes and categories of women, with negative health and well-being outcomes (Ellsberg et al., 2008; Ellsberg & Heise, 2005; Feldman-Jacobs & Clifton, 2014; Folami, 2013; Furr, 2014). Equally significant is the need to recognise the influence of geographic, socio-cultural, economic and political forces actors as significant factors impacting women which may add to the complexities of VAW. Thus, there is a

need to determine how context specific determinants are critical factors to be examined to fully address the elements influencing the nature and characteristics of violence affecting this study cohort as women living with HIV for enhanced preventive, support and care interventions

This study is relevant because, in resource-constrained countries such as the Gambia, the problem of HIV and violence, though recognised as interconnected, is dealt with through two separate parallel programmes; that is to say, the link has not been fully addressed in a synergetic approach through programme interventions in the field. The aim of the current research is to address this gap and to capture Gambian women's lived experiences of violence and the intersection with HIV/AIDS, using feminist participatory research principles that prioritise women's accounts. While a strong correlation between violence and HIV/AIDS has been acknowledged in research for a long time. However, few evidence - based studies have been conducted in the Gambia that focus on the lived experiences of women with HIV, and of the health care practitioners working with them. By adopting a feminist participatory approach to the analysis of extensive qualitative data, my proposed study hopes to create safe interactive platforms that encourage research participants' to share their lived experiences on gender-based violence. Such accounts may unravel the context-specific complexities and challenges that make HIV-positive women vulnerable to violence.

My research topic is on gender and HIV. I draw from Goffman's classical treatise on generalised stigma (1963) to delineate between individuals whose stigmas are unknown and can be concealed (i.e. they possess discreditable/concealable attributes) and others whose stigma is clearly known or visible (i.e. they possess discredited attributes). The study advances Goffman's conceptions of stigma as a 'discreditable and discredited condition' (Goffman, 1963; Chaudoir et al. 2013, pp.75-76) to examine HIV related stigmatisation process and to examine how it affects women living with HIV in a Gambian social context.

Additionally, the proposed research will capture the views of the study cohort to provide insights into broader social factors such as gender inequality, poverty and economic factors, and how they may serve as key underlying structural factors, that impact the relationship between the HIV stigmatised persona and the stigmatiser. Chapter 4, sections

4.1 through to section 4.3 of the thesis provide a detailed explanation of Goffman's (1963) thesis on generalised stigma and its relevance to the accounts of HIV positive women in the Gambia. In the data analysis Chapter 5, the key overarching theme and subthemes using Goffman's thesis of stigma as (discreditable and discredited) attributes to capture the nuanced and contextual forces and issues which may illuminate our understanding of the stigmatisation process and effects of stigma on women living with HIV in the Gambia.

There is a dearth of evidence based literature on this subject in the Gambia. This lack of research may be due to the low prevalence rate of HIV when compared to other countries in Southern Africa where rates are much higher and research funding is available. Notwithstanding this challenge, opportunities abound for future research to be undertaken in the field. As a result of this identified gap, the current proposed research is geared towards the creation of safe platforms to engage women living with HIV to generate data based on their first-hand experiential knowledge of women living with HIV to understand their problem, as I focus on studying HIV and violence intersection. The analysis will examine the existence of intersecting categories and compounding underlying factors that may serve as predictors of HIV disease stigmatisation and abuses of affected women. This thesis will examine the implications of the findings of the study for preventive interventions, treatment, and support services to affected women.

1.1 Research questions

This thesis seeks to answer the three research questions (RQ1 - RQ3) set out below:

- RQ1: Is there a connection between violence and HIV/AIDS in the experiences of Gambian women?
- RQ2: What are the current preventive, support and care interventions that address the challenges HIV positive women face in the Gambia?
- RQ3: How can we enhance practice interventions that support women's agency and meet their needs?

This thesis explores Gambian¹ women's experiences of violence, scrutinising its interconnectedness with HIV/AIDS. Previous feminist research and scholarship has promoted the audibility of the 'voice' of marginalised women by creating safe platforms for hearing and validating their experiences and concerns (Hooks, 2015, p.14). Bell Hooks suggests that in the United States of America, there is a "generation of black women who had been taught to submit, to accept sexual inferiority, and to be silent" (Ibid.). This can also be said of women in the Gambia, as a result I intend to create safe spaces for the research participants to speak out, and if it is possible, to unveil key experiences that provide answers to the above stated research questions.

1.2 The current thesis

This is a feminist participatory project which was designed to uncover the marginalised voices of Gambian women² who are traditionally socialised to remain 'silent' and to internalise pain as a symbol of good 'womanhood'.

In the Gambian social context, silence surrounding gender-based violence is accepted as part of everyday naturalised and normalised violence in the lives of women. This form of enforced silence inadvertently protects perpetrators, exonerating them from blame and justifying their actions as tradition. Women have also learned to 'put others first', before their own lives and well-being. As a result, in this project HIV positive women became co-researchers in defining, naming and explaining their problems based on their own subjective experiential knowledge. It is hoped that this collaboration will open up dialogical spaces for frank and critical reflection on some difficult questions raised during the interactive sessions with the participants. A broad spectrum of field practitioners formed part of this collaborative, investigative process, which in many ways offered a gendered perspective and insights into the problem under investigation.

¹ The term Gambian women does not connote the universality of all Gambian women; nor does it imply that all Gambian women are HIV positive. Women who are HIV positive do have distinguishable differences, based upon their living conditions, and influenced by geographic location (rural versus urban areas), access to or denial of educational opportunities, employable skills, their social class, ethnicity, and other attributes largely affected by their religious and cultural context which influences the socio-cultural norms and practices that impinge upon their lives. Whilst they may share certain commonalities as women living with HIV/AIDS, the PLHIV experiences of single mothers, widows, married, abandoned, and divorced women differ.

² I am aware of, and sensitive to, feminist postcolonial debates and their criticisms that have been ongoing since the early 1980s, surrounding the privileged position of white feminists whose scholarship may assume the universalism of women's oppressions. The call to avoid universalism is noted here, especially that from 'other' women of colour from non-Western and diverse socio-cultural contexts.

The ultimate goals of this research were: to strategically commence from women's position to develop an understanding of their problem; and to share in-depth narratives that allowed persons living with HIV (PLHIVs) to engage in discussions to interrogate the circumstances, prevalence and effects of VAW in their lives. I will also examine the practicalities of implementing interventionist research with participants, employing a feminist participatory stance to generate and analyse the data and seeking ways to engage in future transformative processes (Brydon-Miller & Coghlan, 2014; Loizou, 2013; Seibold, 2000; Seibold et al. 1994; Western, 2013), using a feminist collaborative approach to seek context specific answers aimed at minimising and eventually preventing the negative effects of violence in the lives of women (Bermudez et al., 2010; Chang et al., 2015; Campbell & Soeken, 1999). The next sections (1.3) through (1.5) will examine the rationales and objectives of the thesis and these will be followed by a brief overview of its organisation.

1.3 Research rationales

My rationales for this study are threefold:

- *The intellectual rationale* is to conduct empirical research in order to better understand how HIV/AIDS intersects with violence within the Gambian socio-cultural and political context, examining context specific issues arising from this study.
- *The methodological rationale* is to advance key feminist principles and approaches in conducting research with marginalised women. The participatory action research project will aim to add important theoretical and practical insights to methodological scholarly debates.
- *The policy and practice rationale* is to identify and build upon the Support Societies' capacities in response to PLHIVs' specific needs, as identified in this research, in partnership with other stakeholders in the Gambia.

1.4 Research objectives

- To create a platform where women are supported and encouraged to discuss their lived experiences.

- To utilise the findings of the study to address challenges identified by research participants, to recommend interventions for preventive, care and support services.

1.5 Organisation of the thesis

Following this introductory chapter, *Chapter 2* of the thesis explains the social context of the study, documenting information about the Gambia, with a brief background on the Gambian economy, the social problems related to the subjugated status of Gambian women, gender inequality and violence against women and the challenges women experience.

There are two literature review chapters. The first, *Chapter 3*, presents the conceptual framework informing the research and a literature review on theories of violence, presenting the definitions of power and patriarchy and examining how patriarchy as a system of male dominance legitimises male power and the exercise of control over women. Key family violence and feminist theories, and integrated ecological and intersectionality frameworks on violence will also be reviewed. The chapter also discusses Black and post-colonial feminist scholars' concerns about the need to avoid universalism of women's oppression.

Chapter 4 presents a review of the literature on HIV/AIDS, the foundational conception of stigma, and prevalence rates for HIV in the Gambia. It focuses on the sociological perspectives and relational dynamic of HIV disease stigma and enacted discrimination. The study advances Goffman's conceptions of stigma as a discreditable and discredited condition (Goffman, 1963) and examines how women with HIV, experience and explain these attributes and examines its link to violence.

Chapter 5 deals with the research methodological approach and is divided into two main sections for clarity. The first section, presents an overview of the research methodological approach focusing on feminist participatory and action research approaches, which I consider to be the optimal and most appropriate way to capture data from women experiencing sensitive problems of violence and HIV. The second section explains the detailed methodological approach utilised during the study with discussion of the ethical review concerns involved when researching 'high risk' themes, including the recruitment

process and challenges. The chapter presents the rationale for selecting the multiple inquiry tools of focus groups, journaling and in-depth-individual interviews and management of the multiple inquiry tools during the research process. It explains the data analytical procedure of Thematic Analysis (TA) and outcome of the analysis, with presentation of the final thematic maps and summary of the overarching theme and subthemes.

Chapter 6 and *Chapter 7* are the two research findings chapters, which explain the findings of the thesis in relation to the overarching theme and subthemes identified using thematic analysis process in Chapter 5, describing Goffman's (1963) conceptions of stigma as a 'discreditable and discredited condition'. It also demonstrate how women living with HIV and are discredited, and how they experience underlying gender stigmas interlocking with HIV stigmatisation processes to contribute to a range of abuses, from within the Gambian socio-cultural contexts, using data extracts from accounts of the research participants.

Chapter 8 is the discussion chapter, and it focuses on a number of propositions based on key findings of the research. The findings suggest that Goffman's (1963) thesis on generalised stigma has relevance in explaining the accounts of HIV positive women in the study, as sero - positive women live with discreditable and discredited conditions. The findings also capture nuanced and complex interactions of underlying factors of patriarchy, gerontocracy and structural violence also contribute to women's experiences of everyday normalised abuses. This final chapter also discusses the key contributions of the thesis, it offers recommendations for practical application in securing women's rights, health and social justice, using a holistic and integrated approach and preventive model. Finally, the chapter includes details of the study limitations, recommendation for further research and dissemination of research findings.

Following this, the next Chapter 2 will further explore the Gambian social context, examining its geography, colonial history and legacy, economy and socio-political factors and gender issues that may fuel women's vulnerability to violence and HIV.

CHAPTER 2: THE RESEARCH CONTEXT

2.0 The Gambian social context

The Gambia is a small Western African country in sub-Saharan Africa with a geographic area of 11,000 square kilometres and a diaspora of around 0.5 million (AfDB/World Bank Report, 2012-2015, p.1). The country recorded an increase in population from less than a third of a million in 1963 to 1.4 million people in 2003, and 2.1 million in 2013 according to the Government of the Gambia Population and Housing Census Report (2013). The country has a population density of 176 per square kilometres. Females constitute 50.5% and males 49.5% of the population. Gambia is divided into key administrative regions.

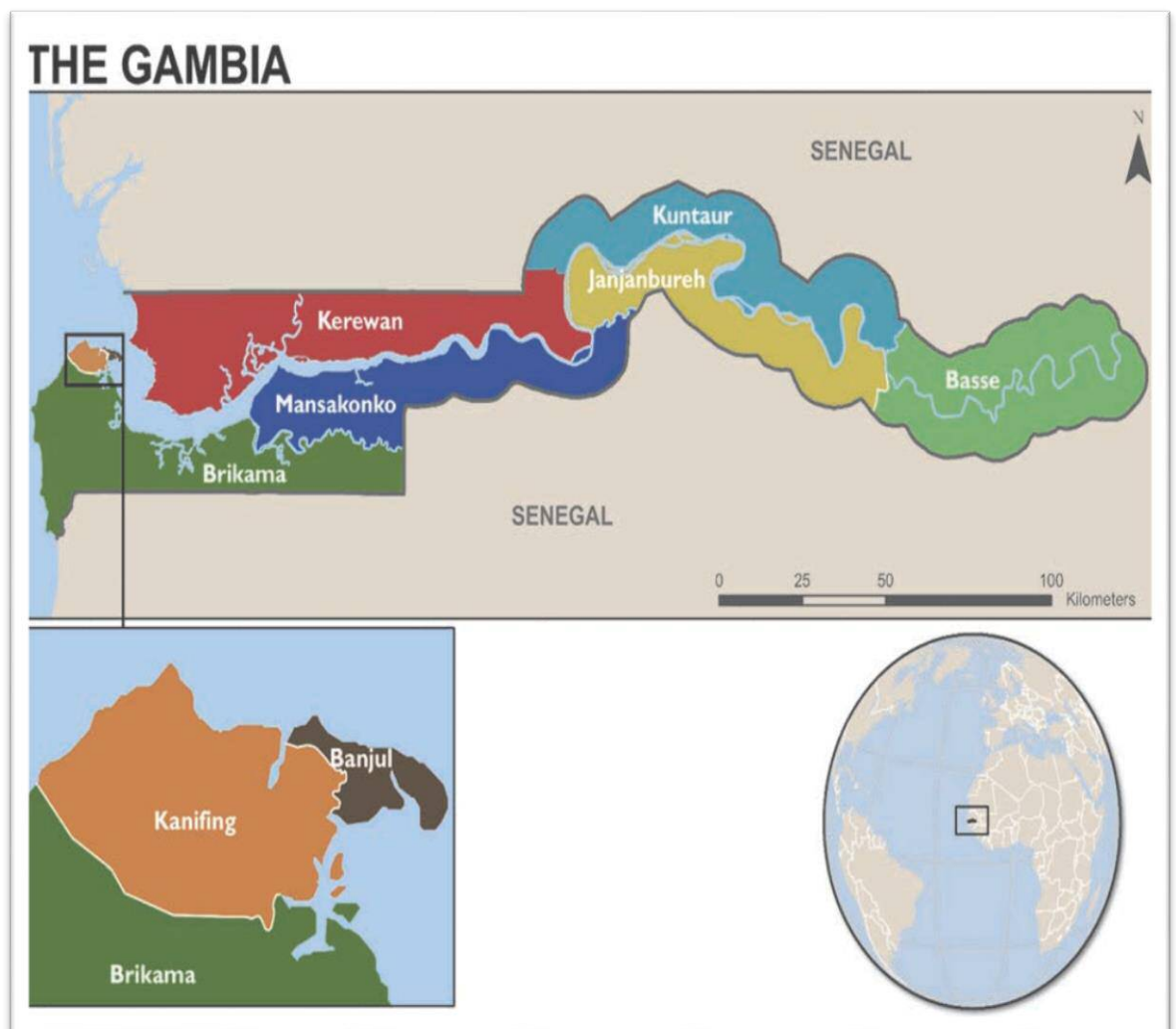


Figure 1: Map of the Gambia

The above figure 1 is the map of the Gambia (see enlarged version in Appendix 1 of this thesis), which is surrounded by Senegal to the North, east and south, and by the Atlantic Ocean to the west. Banjul is the capital city. Gambia was a British colony until it gained

independence in 1965. The main religion is Islam (90%), the remainder of the population (10%) being practising Christians and others. The country's official language is English, although the majority speak local dialects, representing the various tribal groups in the country. Amongst them are the local dialects of Mandinka, Wolof, Krio, Jolla, Sarahule, Manjagoo, and Fulla (28 Too Many, 2015). The Gambia existed as a British province of the Senegambia region from 1763 to 1783 (28 Too Many, 2015, p.16-17; Ajayi, 2003), and the British primarily used it to accommodate and then transport slaves to the West and the Americas.

Over time, Britain's dominance extended and in 1889 an agreement was reached with France to establish the current boundaries. The Gambia then became an official British colony. The port at the mouth of the river Gambia had a fort and was strategic in the Atlantic slave trade (28 Too Many, 2015, p.16). The port grew into the former colonial capital city of Bathurst which was re-named Banjul after independence. In 1954, the legislative council gave the executive a non-colonial majority and the Gambia became a self-governing territory in 1962, and an independent country on 18th February, 1965. Later, in 1970, it became the republic of the Gambia. At independence, his Excellency Dawda Jawara of the People's Progressive Party (PPP) was appointed Prime Minister and then President of the Republic of The Gambia. He held office until 1994 (Ajayi, 2003; 28 Too Many, 2015).

Against this historical backdrop, this question comes to the fore: What was the British legacy for this small colonised nation, dubbed the smiling coast of the Gambia? In response to this question I argue that Gambians were 'given' their independence and freedom to self-govern without having to fight or shed blood, as seen in long, drawn-out liberation struggles against colonialism in eastern and southern African nations which have resisted colonialism and apartheid. A legacy of peace and stability was inherited and maintained in a country that foreign tourists love to visit. For many, the Gambia is indeed the smiling coast, as tourists enjoy the sunshine and tranquil beaches.

However, although there was a peaceful hand over of power, economic and social amenities the colonisers left were little in terms of infrastructural development (28 Too Many, 2015, pp.16-17). Most of the development was around the capital city and urban centre. The rural areas were left with little or nothing in terms of road networks, schools,

hospitals or other basic social developments, despite the number of years of colonial rule. The country continued to be reliant on trade with the West and on foreign aid, in the form of development assistance and loans.

2.1. Tourism and trade relations

In this section, I provide a little more background for readers unfamiliar with the Gambia, exploring further the problems of the country's trade relations and tourism with the West. Tourism is a development area that attracts investment from local entrepreneurs and outside partners. The Gambia's development strategies are Vision 2020 and the Programme for Accelerated Growth and Employment (PAGE, 2012-2015), and both of these national policies clearly spell out the Gambian government's main development agenda (long- and short-term) in terms of tourism, trade and economic growth.

The agricultural sector and tourism industry are pivotal to the country's economic growth and development, and like numerous other colonised nations, Gambia continues its trade relationships with the West and in particular Britain, its former colonial powers. This small Western African nation has an agriculture based economy, and grows sorghum, rice and millet for local consumption, alongside its main crop of groundnuts which are exported to the West. Production of the groundnuts is constrained by environmental factors such as low rainfall and although groundnuts remain the dominant cash crop, but their low and fluctuating international price, high cost of fertilisers and farming inputs presents a challenge for local farmers. This one-crop economy is a legacy of the British colonialism of the 19th Century, and to date it persists despite efforts to diversify the country's economic activities to include fish and fish products, and other fruits and vegetables for export to other international markets (PAGE, 202-2015; Thompson et al., 1995, p.572).

Tourism development in the Gambia commenced in the early 1960s. The Gambia was a popular tourist destination for Swedish and British visitors because of its white sandy beaches and favourable climatic conditions. The 'Smiling Coast' became the winter-sunshine destination for many Europeans, especially tourists from the Netherlands and Germany, in addition to its existing British and Scandinavia visitors. Since 1965, when the Gambia gained independence from Britain, tourists from the West have been attracted to the Smiling Coast for its relative peace and stability. However, recent political unrest

and reports of arrests and detentions by the government of Yahya Jammeh,³ have led to pervasive fear amongst the local population, and the risks of internal conflict resulted to international visitors being evacuated by major tour operators and tourists were returned home on emergency.

Tourism is contributing to seasonal employment amongst local entrepreneurs, hotel staff, taxi drivers and vendors of local handicrafts or Gambian artefacts, and in small restaurants and local accommodation during the peak tourist season of November to March each year. While there are attempts to diversify and include tourism within the rural areas to benefit local communities through eco-tourism, the main challenge remains that the existing inclusive tourist charter flight packages (arranged by European tour operators and offering a low cost, value for money, destination for Europeans) may yield little benefit to Gambians as the country remains a marginal tourist destination when compared to other tourist destinations.

2.2 Poverty and underdevelopment

Gambia suffers from a legacy of colonialism and current international trade skewed in favour of the West.⁴ These systemic forces, economic, and political issues continue to influence the capacity of Third World nations to register meaningful social development gains. This situation impacts on poverty and the development of The Gambia. Poverty and the underdevelopment of the 1970s and early 1980s resulted in a worsening economy which in turn prompted dissatisfaction among civilian groups in the Gambia, and resulted in an attempted coup in 1981. In response, President Jawara sought to reassert democratic practices, and in 1982 the People's Progressive Party won the presidential elections by a majority vote of 72%. Post-1985, the country underwent a series of economic recovery programmes to resuscitate and engineer revival of the economy (Touray, 2000), however

³ On 2nd December 2016, a new coalition government drawn from the opposition was elected, but the Gambia experienced political impasse when Yahya Jammeh, the incumbent, refused to step down. The new coalition government was sworn in in Senegal, a neighbouring country which surrounds the Gambia, and on 21st January 2017 the Economic Community of Western African States (ECOWAS) sent military forces to force Ex-president Jammeh finally stepped-down from office following his defeat in the election and is now in exile. There is renewed hope that the current coalition government will undertake reforms in various areas of development and tourism is one of area for renewed economic growth, if peace is maintained in the Gambia.

⁴ Here I allude to the concerns of post-colonial theorists (Gomba, 2015), who expose the relational dynamics of former colonial masters with their former colonies. In this thesis, I adopt a post-colonial theoretical framework to conduct the situational analysis since the Gambia was a former British colony; hence the rationale of using a feminist post-colonial framework to examine VAW and HIV/AIDS theorisation.

in 1994 there was another military coup, led by former president Yahya A.J.J. Jammeh and the Armed Forces Provisional Ruling Council (AFPRC). The AFPRC later became the Alliance for Patriotic Reorientation and Construction (APRC), after former President Jawara's administration was overthrown.

After the military coup of 1994, the government won four multi-party elections, held in 1996, 2001, 2006 and 2011. In a presidential election in December 2016, however, the incumbent Yahya Jammeh lost to a coalition of eight parties, after twenty-two years of governance. However, after conceding defeat on 2nd December 2016, he reneged and called for fresh presidential elections citing irregularities. He eventually left the country after ECOMOG military intervention and flurry of diplomatic dialogue from West African leaders and he is now in exile in Equatorial Guinea. The parliamentary elections were conducted this year, 2017. The next section briefly reviews the literature on the Gambian economy, poverty and current economic challenges.

2.2.1 The Gambian economy

The Gambian economy is characterised by agriculture, predominantly undertaken by farming families living in the rural and peri-urban areas of the country. As a means of diversifying the economy, the government of the Gambia, in partnership with the private sector, invests heavily in tourism, fisheries, and various other service and trade industries. Although it has a low human development index ranking, which places Gambia 175th out of 187 countries globally, it has made efforts to increase employment opportunities for young people through educational reforms and skills development to boost its economy (AfDB/African Development Bank Group, 2012-2015).

The Gambia is one of the poorest countries in the world and is affected by social and economic development challenges, reported in the Programme for Accelerated Growth and Employment, (herein cited in this thesis) as (PAGE 2012-2015, pp.19-20 citing Integrated Household Survey, 2010). The overall poverty rate in the Gambia decreased from 69% to 58% in 2003 and experienced a downward trend after 2010, with a low point of 36.7% in 2007. The proportion living on less than \$1.25 per day fell by 10% from 2003 according to the Integrated Household Survey (2010), referencing data from Multiple Indicator Cluster Surveys I, II, III, and IV respectively (conducted in 1995, 2000, 2005/2006, 2010). A comparison of the \$1.25 per day indicator for the 2003 and 2010

Integrated Household Surveys showed that poverty reduced significantly from 58.0% in 2003 to 36.7% in 2007 (Ibid.).

Despite significant progress in which Gambia's social and economic development policies have attempted to reduce poverty and promote economic growth (largely driven by economic recovery in the agricultural and tourism sectors), the overall incidence of poverty and inequality persists and notable youth, gender, economic and social disparities continue to exist. For example, according to data presented by the National AIDS Secretariat of the Gambia entitled: *Report on the Gambia Gender Assessment of the National HIV and AIDS and Tuberculosis (TB) Response in the Gambia* (Mwetwa et al. 2016, p.7), over 80% of the population live in rural areas with limited access to, or control over, development resources, although young people increasingly migrate to the urban areas for work and education or migrate abroad.

The report further states that youths and men are affected by national and international migratory patterns, causing women and the aged to remain in the rural areas where they are involved in subsistence farming. Therefore, rural poverty affects more women than men who are either abroad or have migrated in search of more economically viable productive activities in the capital city and greater Banjul regions. According to Population and Housing Census data (2003) the population was estimated at 1.79 million, with annual growth rate of 2.74%. About 60% live in the rural area.

- Women constitute 51 % of total population and fertility rate 5.4 births per woman (the high fertility rate has resulted in a very youthful population structure, with nearly 44% below 15 years and 19% between the ages of 15-24.
- The crude birth rate, in 2003 Population and Housing Census was 46 / per 1,000 people.
- Average life expectancy at birth was 4 years, overall with females 59 and males 55.
- Infant mortality rate of 75 per 1,000 live births, with 60% of deaths attributed to malaria, respiratory infections, diarrhoeal diseases, malnutrition, neonatal sepsis and premature delivery.

- The maternal mortality ratio was 730 per 100,000 live births, due to sepsis, haemorrhage and eclampsia (Please note for all the above data refer to the Republic of the Gambia National Health Policy, 2012-2020, pp.15-16).
- According to data generated from National HIV prevalence, HIV prevalence rates is 1.9 among adults (aged 15-49) and 2.1 % for women and 1.7 % for men in the same age group. HIV prevalence is highest in the age group of (35-39 years) which is 5.9%. it is estimated that 35, 000 people are living with HIV were recorded as 1.6% for HIV 1, with targets to reduce this to 0.5%; and 0.4% for HIV 2, with targets to reduce this to 0.1% by 2015 as reported in the Gambia Demographic and Health Survey report (GDHS, 2013). The differences between HIV 1 and HIV 2 are explained in the footnote below.⁵

Economic data gathered indicates that poor people in the Gambia are living below the threshold of \$1.25 per day. The data also shows that, using the \$1 per person per day threshold, 62.1% of rural dwellers are poor, compared to 21.0% of urban residents. Using the \$1.25 per day threshold, poverty is higher in the rural than in the urban areas of the country. The government is continuing to improve basic access to safe water supplies, nonetheless rural communities are the ones most affected by poor access to infrastructural development programmes. According to reports by (GDHS, 2013) and PAGE (2012-2015, pp.25-26) there are marked differences between the rural and urban areas, in terms of infrastructural development and amenities. The majority of farmers live in rural communities and are poor and continue to engage in subsistence farming, with women constituting the majority of the poor. The rural masses, especially women and young people, continue to struggle to overcome the challenges and negative effects of poverty, exclusion and underdevelopment. For instance, the PAGE report (2012-2015) indicates that the Gambian people's experience of poverty is marked by spatial differences between rural and urban areas. The Government of the Gambia is committed to improving the quality of life of poor people.

⁵ There are two sub-types of HIV virus, HIV1 and HIV 2, the latter being harder to transmit and slower acting. Both originate from the simian (monkey) immunodeficiency virus found in Africa. While HIV 2 derives from West Africa and Sooty Mangabey monkeys, how and when the virus crossed the species barrier continues to be a source of speculation and historical interest. Current thinking is that the epidemic began when chimpanzee and monkey blood entered people's bodies, possibly during the butchering of bush meat in the 1930s (Whiteside, 2008, p.22).

The national strategic interventions in the country focus on poor rural households. Female-headed households are among the poorest groups. Also, the poor and most vulnerable may be found in urban and peri-urban regions of the country (GDHS, 2013; PAGE 2012-2015, pp.25-26). Despite these challenges, the Government's National Poverty Reduction Strategies (NPRS) implementation programmes are generally supported by bi-laterals, multilaterals, international aid agencies, and local non-governmental organisations and community based organisations.⁶



Figure 2: Disparities in quality of housing in rural and urban areas

⁶ These development partners include donor agencies who are collaborating to implement policies and interventions targeting the poor and marginalised namely: The European Union, World Bank, the United Nations systems, International Monetary Fund, and UNAIDS, the Global Fund for HIV/AIDS, programme of support and care, including its preventive work. Other non- governmental organisations include Action Aid International the Gambia, the Catholic Relief Services and the Network for prevention of gender-based violence against women and girls and key players in the field of socio-economic development, gender, micro-finance, agriculture, and health interventions (refer to Mwetwa et al., 2016; GDHS, 2013; PAGE, 2012-2015).

The above figure 2 are images of housing disparities between the rural and urban areas of the country. For example, in the health sector, programmes are offered in support of maternal and child care, nutrition support to prevent malnutrition of under-fives, and of persons living with HIV/AIDS. However, there are still challenges to the country's capacity to make substantial investments in basic social services due to the failing economy and global economic recession. The health indices documented above reveal serious gendered issues affecting women and children in the Gambia. Poverty is closely linked to poor education and health, and it is gendered. For example, the majority of the rural population, and especially women, are either uneducated or under-educated. The data suggests that 58% of people experiencing poverty live in households with little or no education (PAGE 2012, p.25-26).

There are significant health challenges affecting women and children. For instance, the Gambia has achieved almost universal coverage for vaccinations and safe water supply, but children's and women's health, particularly in poor and resource constrained communities, remain a challenge, with mortality rates falling too slowly to meet the 2015 health-related targets (UNICEF (2011, p.2), also refer to Multiple Indicator Cluster Survey (MICS, 2012). Poverty, poor health and inability to access prompt treatment and care intersect and are more pronounced within the lives of the rural poor as reported in Gambia Demographic and Health Survey (GDHS, 2013; PAGE 2012-2015, p.25-26).

2.3 Overlapping gender and structural inequalities

To commence this discussion, I register here that gender and social inequalities in the Gambia, remain very challenging development problems. More than 60% of Gambians live in poverty; women constitute 63% of the poor, and 76% of poor people live in rural areas. Approximately 530,000 children and young people are considered to be poor, and a lack of access to basic social services for a large part of the population increases the depth of poverty, especially in rural areas. The disparities that are evident within and across regions, both in rural and urban settings, have an adverse impact on health, education, and child protection (UNICEF, 2011). In more recent data, approximately three quarters of the rural population are classified as poor (GDHS, 2013). The underlying factors contributing to the country's high poverty rates are a lack of economic diversification, dependence on farming and agricultural activities which are vulnerable to erratic rainfall, volatile food prices, and financial crises. As a result, the majority of poor

people experience the effects of income and food insecurity, overlapping with poor health outcomes such as malaria, malnutrition and most poor people are vulnerable to preventive communicable diseases as a result of health inequalities. The Gambia has now its first Gambia National Social Protection Policy 2015-2025 designed to contribute towards the alleviation of poverty and vulnerability in the Gambia (Gambia Social Protection Policy Report, 2015-2025), as part of the long-term vision of the country's comprehensive social protection system that will target the poor and vulnerable groups and also contribute to broader human development, and greater economic productivity.



Figure 3: Rural men and women struggle to meet their basic needs.

The first image in Figure 3 above shows how women and children walk long distances to collect water. In some local communities, access to potable water remains a challenge. The second image depicts a horse and cart, a common means of transporting goods and people in rural communities. These communities struggle to secure adequate access to their farms and to transport sick people where there is no ambulance service. I problematise the issue of gender division of labour and the burden of care of rural and some urban poor women. Here I find Kabeer's (1999), definition of gender inequality, useful and that it reflects the "ways in which women are different from men, in terms of their biological capacities and in terms of the socially constructed disadvantages women face relative to men" (p.37). Accordingly, Kabeer suggests that gender relationships are framed and influenced by the broader social structures such as gender ideologies, institutionalised norms, values and practices of a given society. These forces determine how masculinity and femininity are defined and who has influence and power to decision making processes, access and control of resources.

Kabeer's (2016) analysis of gender inequality from a feminist neoclassical economic arguments is that individuals make choices and exercise agency within the limits imposed by their personal circumstances. She argues that structural factors imposed by dominant group (for instance) determines the rules, norms, who has access and control of resources, and these identities are defined along lines of gender, class, race, caste, and may pose as constraints (Kabeer, 2016, p.297 citing Folbre, 1994). I consider Kabeer (2016) conception of "gender ascribed constraints" and "intersecting inequalities" as meaningful in analysing a constellation of structural inequalities affecting my study cohort. According to Kabeer (2016) the concept of 'gender ascribed constraints' are rooted in customary norms, beliefs, and values that characterise the 'intrinsically gendered' relationships of family and kinship and spell out dominant models of masculinity and femininity in different societies. It is therefore relevant in understanding how men and women, boys and girls, are assigned to different roles and responsibilities on the basis of socially-constructed aptitudes and dispositions, noting the variations of gender ascribed roles. Hence, Kabeer (2016) argues that the conception of gender inequality is premised upon naturalising a range of differences between women and men and legitimising their differential treatment in the distribution, access and control of resources and how it is important to develop understanding of the ways that gender inequality is normalised, accepted and legitimised by different societies.

Following the above, I interrogate how these concepts of gender inequality and gender ascribed constraints are played out in the Gambian scenario; examining the prevailing gendered norms and practices that perpetuate gender unequal relations between men and women in the Gambia. I am interested in understanding how gender ascribed constraints impact on gender division of labour which persists in the Gambia, although Kabeer (2016, p. 297), suggests that there are variations of gendered division of labour in diverse regions of the world. While I recognise this diversity in gender division of labour in the Gambia, yet, for the majority of rural and poor women, they are overburdened with primary care for the family, the elderly, and the sick.

In these rigidly structured family systems the gendered division of labour places an overwhelming burden on women and girls. In a report by Mwetwa et al. (2016, p.7), over 80 percent of Gambians live in rural villages and women are also responsible for water collection, subsistence farming and the production of rice and other vegetables for

household consumption. Traditionally Gambian men are not responsible for household chores and are assigned the role of primary bread-winner and household head. They are involved in cash crops production. As in several other African countries, agriculture is a major component of the Gambian economy, but there are observable gender-based differences which are not properly addressed. Majority of poor people are farmers (men and women), they engage in subsistence farming, and their experiences of poverty are marked by spatial difference, especially between the rural and urban areas (PAGE, 2012-2015). Due to the prevailing gender ideologies of patriarchy and male dominance, many Gambian women remain poor and economically marginalised. Despite the fact that the majority of rural women in the Gambia are farmers, they experience difficulties with ownership and control of land, access to resources, and agricultural extension services which could build their capacities and ensure training and capacity development to increase their yields and agricultural income. Agricultural extension services are often directed at men who are involved in groundnut (cash crop) production for export.

There are several gender empowerment and social development projects aimed at increasing rural women's productivity in agriculture through vegetable gardening, poultry and small ruminants farming, and other micro enterprise projects to improve women's socio-economic status. Yet, there are prevailing traditional gender norms and practices that marginalise them and limit their capacities to engage meaningfully to derive maximum socio-economic benefits from these projects. Hence I rationalise that development interventions need to strategically address their gender specific needs and constraints such as access to land, productive resources, and agricultural extension services, if a gender equality and change in the status quo is desired. Gender inequality, poverty and economic marginalise may expose women to a range of abuses and denial of rights their rights. To advance the discussion, I begin the next section 2.3.1 by asking, how does gender inequality connect with VAW?

2.3.1 Gender inequality and the link with violence

In response to the above question, I draw from feminist scholars' conceptions of violence against women which suggest that gender inequality, reflected in male dominance and control, and the subordination of women, is a contributing factor and the root of all forms of women's vulnerability to violence (Dobash & Dobash, 1979; Kurz, 1993). The term patriarchy is conceptualised in the current thesis as a system of male dominance and

control over women and girls (Dobash & Dobash, 1979), Dobash and Dobash (1979) identified patriarchy as the cause of violence against wives, however, patriarchy has been variously defined and contested. Patriarchy is contested because of false universalism and her conception of a varieties of patriarchy (Hunnicut 2009, p. 558; Moallem, 2006). Hunnicutt suggests that scholars avoid theorising patriarchy as ‘fixed, timeless structures that obscures differences in context and reduce all gender relations into one form’. Hunnicutt (2009) contend that there are degrees and varieties of patriarchy (Ibid.).

Previous studies by feminist scholars maintain that violence against women should centre on gendered social arrangement and power conceptions (Hunnicut 2009; Dobash & Dobash, 1979). For instance, Dobash and Dobash’s (1979) theory on wife abuse suggests that it is an expression of male domination over women. The use of physical violence is a means of control and form of oppression, which exemplifies one of the most brutal and explicit expressions of patriarchal dominance (Lawson, 2012, p.579). Yick suggests that the concept is multifaceted and, as a result, various approaches are needed to understand context specificities of patriarchal influences when theorising violence against women (Yick, 2001, p.558). Another definition by Hunnicutt (2009, p.557) states that patriarchy is a “form of social arrangement that privileges males, whereby men as a group dominate women as a group, both structurally and ideologically – hierarchical arrangements that are manifest in varieties across history and social space.” This analysis of patriarchal relations brings out the macro level dimension of patriarchy (mainly bureaucracies, government, law, markets, religion), linked to the micro level (the family), where men use force and control over women and other family members and this patterned behaviour is apparent in male dominant society.

Today, scholars advance the concept of patriarchy as a useful theoretical building block to explore ways in which gender hierarchies are recognised, where dominance and power arrangement interact to contribute as pathways to violence against women (Hunnicut 2009, p.554), however, the call to avoid universalising the concept of ‘patriarchy’ as fixed and not to conceptualise patriarchy from a “simplistically essentialist and rigid perspective” (Ibid.), rather, to acknowledge that there exists ‘varieties of patriarchy’ reflecting contextual specificities and differences (Hunnicut 2009).

The literature reveals that gender unequally positioned relationships between men and women as the main driver, that accords men as a group power, privilege and higher status compared to women in a given society (WHO, 2013) report on violence against women has evidenced that overlapping inequalities increase vulnerabilities to domestic abuse (WHO, 2013). For example, women's lack of power, poverty and economic dependency on male family members and influential elders (often seen as the main bread-winners), may prevent women from leaving their abusive partners, thus keeping them in unhealthy relationships and resulting in their oppression and vulnerability to violence (WHO, 2013). WHO & UNAIDS (2013, p.3) report also stated that violence against women is a widespread and costly public health challenge, deeply rooted in gender inequality. It is a phenomenon that violates women's human rights and VAW exists in all parts of the world. This report argue that violence against women has serious consequences for women's health and causes fatal and non-fatal injuries, unintended pregnancies, induced abortions, Sexually Transmitted Infections (STIs) including HIV. In addition, VAW causes serious psychological and mental health challenges such as post-traumatic stress disorder (PTSD), depression, anxiety, and suicide among others (WHO & UNAIDS 2013, p. 3).

Research conducted in Southern Africa by Jewkes et al. (2010), unveil the complex interlocking factors influencing the persistence of norms and practices that promote gender-unequal relationships in the family. Jewkes and colleagues (2010) explored the correlation between relationship power inequity and the incidence of violence in the lives of southern African women, and how women are vulnerable to physical, sexual, economic and emotional abuse. They suggested that women's economic dependency on men may expose women to violations of their rights and experiences of a range of abuses. Gender unequal relationships, may therefore serve as drivers of women's experiences of intimate partner violence.

The research contribution by Jewkes et al. (2010) is relevant in analysing the report of a Multiple Indicator Cluster Survey (MICS, 2012) conducted in the Gambia. The study revealed that the general acceptance of unequal power relationships between men and women as natural, may translate into gendered power differential in terms of decision making processes, access and control to resources. Evidence derived from the Multiple Indicator Cluster Survey (MICS, 2012), conducted interviews with women recruited for

the study, and they were asked to respond to a number of questions to assess their attitudes towards wife beating. Overall, about 75% of the sample felt that their husbands had a right to hit or beat them if they neglected their children (52.4%), if they demonstrated autonomy for example go out without informing the husband (53%). Additionally, they believed that their husband had a right to beat them if they refused sex (33.3%), and about 14% thought that beating was justified if a woman had burnt the food whilst preparing it (MICS 2012, p.169).

Another interesting finding was unveiled by this study (MICS, 2012) that links women's level of education and those living in Banjul (the city and urban environs) with intolerance of wife /partner battering. The research found that, the higher a woman's educational attainment, the less likely she was to approve of wife beating. Similarly, wealth or poverty is another dimension that provided insight into the acceptance of VAW. Women from poorer households are more likely to approve of wife battering than women from the richest households (MICS, 2012, p.169).

Poverty and dependence are two interacting forces impacting on economically marginalised women. Gender inequality between men and women is compounded by structural inequality of poverty and gender exclusion of women in the development arena. According to a report by Chant and Touray (2012), women occupy economically marginal, poor, and disadvantaged positions in Gambian society. Rural Gambian women constitute the majority of poor and extremely poor people and are mainly uneducated (young women and girls are denied access to school due to norms and practices of early marriage where girls are removed from school), with limited and restricted opportunities or life skills to facilitate their upward social mobility (GDHS, 2013; *Gambia Gender And Women's Empowerment Policy and Strategic Document* (2010-2020)). Poverty and exclusion negatively influence their quality of life and the health outcomes for women and their children or dependents, as well as their access to good nutrition, adequate housing and finances for education (GDHS, 2013; *Gambia Gender and Women's Empowerment Policy and Strategic Document* (2010-2020)).

Most poor and disadvantaged women are found in low paid jobs as office cleaners, secretaries, and in unpaid domestic work which is often back-breaking. Women's exclusion and marginalised status may contribute to their economic dependence (Chant

& Touray, 2012). While little research is conducted on Gambian women's economic and social inequality, and how it impacts on their health and well-being, a growing body of intersectionality scholarship, specialising in health inequalities (Corbin, 2012; Dworkin et al., 2014; Hankivsky, 2012, pp.1712-1713; Hankivsky, 2011), has evidenced how women in particular may suffer from multiple dimensions and matrix of oppressions. The phenomenon may result in health inequalities and exposure to complex interactions of vulnerabilities and risks. In my view, these studies are useful, because they provide the necessary theoretical lens through which researchers may examine and interrogate compounding underlying structural factors and forces that may overlap to negatively impact on women and their health. By utilising intersectionality analytical tools, it is feasible to examine how factors such as (religion, ethnicity, social and economic factors) may be encroaching on their lives. I again refer to Kabeer's (2016) analysis of gender inequality and concept of "gender ascribed constraints" that stems from patriarchal norms and practices which deny women their rights to power and control of decisions affecting their lives, and prevents their access and control of necessary resources and basic needs.



Figure 4: Women's work/engagement in basic livelihood economic activities.

The two images above are of Gambian women and girls at a Support Society (left) and in a local community (right) engaged in basic, small scale subsistence, marginal economic livelihood activities. In what follows, I will examine how in countries where poverty is endemic (such as the Gambia), poor families, and especially poor women, have little or nothing in the way of assets and income to utilise for basic needs and health care expenditure when faced with a crisis. This further places women at risk to access prompt treatment and care, gender inequality may contribute to denial of women's economic and social rights. There is evidence that connect women's economic dependency to vulnerabilities of everyday violence and its widespread tolerance and acceptance of

domestic violence. Generally, women in the Gambia occupy a lower status, whilst men are given more economically and socially superior positions in the society. Men are generally accorded privilege, power, and control over women and livelihood resources. Thus, transgressing socially sanctioned gendered norms and practices may result in a range of punitive sanctions and abuses to reassert power and control by men and elders.

There is strong evidence that exposure to violence in childhood, either as a witness to violence against one's mother or as a survivor of physical or sexual violence and abuse, may predispose children to repeat the pattern themselves in adolescence or adulthood (Heise, 2011, 1998). For further analysis, I refer to Gupta's (2000, pp.1-6) conception of gender and sexuality, and the effects of gender-based violence is discussed briefly as Gupta examines the connections between gender, unequal power relationships between men and women, and vulnerability to sexually transmitted infections, including HIV in a specific socio-cultural setting. She contends that gender is a culture-specific construct with significant variations in what men and women can or cannot do in any one given socio-cultural context; yet, what is fairly consistent across 'cultures' is that there is always a distinct difference between women's and men's roles, including access to productive resources, authority and decision making (Ibid.). Hence, women are socialised to conform to social and gendered norms and peer pressure, to conform to notions of good womanhood (Gupta, 2000). The data presented above for the Gambia indicates that there is a high level of social acceptance of wife battering, a practice that is justified as a form of discipline for wives who challenge male authority or fail to fulfil their role as wife and mother, with certain socio-cultural contexts.

To further this discussion, I borrow the conception of culture from Tamale (2008, p.48), suggesting that culture is not unchanging and static, but rather, in a constant state of flux. Thus, she argues that the erroneous perception of culture as 'natural and unchanging, exacerbates the problem, because often culture is perceived as static or essentialised, but rather as Tamale (2008) recommends a different approach away from the static notion of 'culture' being viewed as "essentially hostile to women", but instead Tamale (2008) suggests new ways of exploring the emancipatory and transformative potential of culture to accord women their sexual rights and to promote the quality of women's lives in Africa (Tamale 2008, pp. 47-48). I reason in similar line that there is a need to recognise context specificities as we examine this complex problem of violence and HIV intersection, from

a cultural and situated perspective. The need for scholarship to develop analysis that offers nuanced socio-cultural specificities that capture prevailing gender norms, roles and expectations in the Gambia and to explore how they impinge on gendered relationships, is essential in order to offer a vision of hope to transform cultural norms and practices that violates the rights of women and girls.

In the next section I further the conversation on traditional norms and practices such as FGM/C using intersectionality theory. Then I examine how early and forced marriage has been explained in the literature as gender and power inequality and framing the discussion from the perspective of Gambia contextual settings, where elders are respected and they are powerful and influential in lives of women and girls. However I will also examine changes and progress registered to prevent harmful traditional practices, which may render women and girls vulnerable to abuses and other complications such as STIs and HIV/AIDS. I highlight the need to appreciate women's and girls' limited options and choice in securing their personal, social, economic freedoms and rights, in particular when elders imposed norms of marriage and deny them the decision - making power and freedoms about who to marry, when to marry, under what conditions they relate to their partners, and how their sexual reproductive rights are secured (Gupta, 2000).

2.3.2 Intersections of ethnicity, religion and interacting structural factors fuelling harmful traditional practices

The lives of Gambian women are intertwined with complex and compounding categories of vulnerability. Here I scrutinise some of the reasons why certain norms and practices concerning preservation of Gambian girls' virginity, FGM/C and child marriages apply in the Gambian socio-cultural context. I unveil key underlying factors fuelling those traditional practices (ethnicity, religious and educational factors), and women's exposure to them, as explained in the Gambian literature (28 Too Many, 2015, p.44; Gambia National Education for All Review Report, 2014). Data from MICS (2012, p.161) register that early marriage affects women in the Gambia, suggesting that one in five women who are currently married did so before the age of consent (18 years) and the practice is highest amongst Fulla and Sarahule ethnic groups. It is important to note that ethnicity and cultural beliefs may influence the practices of FGM/C and child marriage in the Gambia.

Here I examine the practices of FGM/C (28 Too Many, 2015; Feldman-Jacobs & Clifton, 2014; Afri Consult Group, 2010), and child marriage before the age of eighteen. Early and forced marriage may take place without the consent of the bride and the practice is an example of a harmful traditional practice that constitutes a form of violence against women (Gambia Gender and Women's Empowerment Policy and Strategic Document, 2010-2020; *Women's Act* (2010)). In early marriage, coercive sex may result if the girl refuses, in which case the bridal bedroom becomes a contested site of sexual violence and physiological and emotional trauma; an experience of which numerous young Gambian girls are subjected, as a form of traditional and ethnic norm and practice.

Studies conducted into coercive and forced sex explain the difficulty women have in negotiating consistent condom use to prevent STIs and HIV (Stockman, Lucea & Campbell, 2013, p.832). In the Gambia, similar situations persist because the child brides are too young and uninformed; they may lack the power and influential voice to make informed choices in sexual and reproductive health matters. Thus, some women remain silent and accept the various practices involved with a forced sexual debut and early marriage. Some speak of the pain and trauma following these encounters, however they consider their suffering to be a normal part of womanhood. In the MICS (2012) and 28 Too Many (2015) report, ethnic minority groups such as the Krio and Aku demonstrate intolerance to gender-based violence in general. Only 27.7% of Aku people state that it is justifiable for a husband to beat his wife, compared with other ethnic groups such as the Bambara; 84.9% of Bambara headed households regarded wife beating as justifiable. Almost 75% of the Mandinka tribal group indicated that wife-beating was acceptable.

In most patriarchal and rigidly traditional families, women are accorded low status and voice. Some women may not be consulted in polygamous marriages, and in the Gambia there are high rates of polygamous marriage within certain ethnic groups. For example, about 38.8% of women aged 15-49 in a Mandinka-headed household were reportedly in polygamous marriages, and 44.9% of Mandinka women were in a marriage with someone ten or more years older than themselves. The data captures the rate of marriage for Mandinka girls under 15 years old as 7.7%, and the adjusted net attendance rate in primary education for Mandinka girls as low in comparison to other ethnic groups living in the Gambia, at 66.3% (28 Too Many, 2015, p.24 citing MICS, 2010). The MICS (2010) report also indicates that the Krio/Aku ethnic group report the highest rates for girls'

enrolment in primary education at 98.4% and low rates of early marriage with 1.2% of girls under 15 married. These findings were corroborated by 28 Too Many (2015, p.19). Another issue with reveal overlapping factors such as ethnicity or tribe influences these traditional practices. The links between practices of FGM/C, early marriage and denial of rights to education are clearly visible in the Gambia in the extant literature. The *Gambia Gender and women's empowerment policy and strategic document (2010-2020)* highlights the importance of analysing overlapping and interacting structural factors such as ethnicity, regional differences in women's vulnerability with regard to VAW:

“There are ethnic and regional disparities in the acceptance of wife beating. Educated women and wealthy women are least likely to approve of the practice. A major cause of women's poverty is embodied in unequal power relations between women and men. Poor women are more vulnerable to all forms of violence because they typically live in uncertain and dangerous environments. Too often violence is not acknowledged. This is because many communities overlook the occurrence of violence, as it is regarded as a normal phenomenon especially in human relationships” (*Gender and women's empowerment policy and strategic document 2010-2020*, p.20).

This report further suggests that violence against women and girls is normalised and the prevalence and magnitude of gender-based violence in the Gambia is yet to be determined because of the deeply embedded culture of silence on domestic violence. Lack of systematic processes to record and report incidents of VAW, and exemption from punishment are critical factors that sustain the prevalence of abuse of women (*Gender and women's empowerment policy and strategic document, 2010-2020*, p.20). Sexual harassment and rape, for example, are often under-reported and unchallenged, as the report states:

“Rape is not discussed and often goes unpunished. It is mostly committed by family members or persons known to the victim/survivor. The prevalence and magnitude of GBV in The Gambia is yet to be determined. The culture of silence makes it extremely difficult to get the required data though there are studies that indicate that the practice is prevalent. It is condoned and not reported thus resulting in impunity. It is a cause for concern and requires in-depth and proper record keeping” (*Gender and women's empowerment policy and strategic document, 2010-2020*, p.20).

Ethnicity is important in determining women's vulnerability to FGM/C and virginity sealing. There are several ethnic groups in the Gambia, some of the main ones being the Mandinka, Wolof, Sarahule, Jola, Fulla, Serere and Krio. Three predominant ethnic

groups, the Mandinka, Fula, and Jolla, have the highest recorded incidence. Of these, the Mandinka account for 36% of the population (28 Too Many 2015 citing the Gambia Census Report, 2003). The juxtaposition of the underlying influence of religion and ethnic explanations in perpetuating FGM, early or child marriage are practices are revealed in the 28 Too Many report, in which the Bambara ethnic group for example adhere to Islam and observe traditional rituals. The report indicated that the structure of Bambara households is patriarchal and patrilineal, and that they have a similar hierarchical system to the Mandinka. Hence, the reported prevalence rate of FGM is 96.7% of women aged 15 to 49 being affected (28 Too Many, 2015 citing Gambia Census Report, 2003).

An intersectionality analysis offers a window through which we can glimpse key underlying factors affecting Gambian women, which will enable readers to develop insights and understanding of the root factors of everyday normalised VAW in the practice of FGM/C. While ethnicity is an underlying factor, the quotation below demonstrates the intersection of other compounding factors such as religious belief concerning the practices of FGM/C. There are variances in explanations that justify and sustain the practices of FGM/C, for instance, ethnicity, culture or tradition, and religion being the most common factors and also patriarchy which is aimed at controlling the bodies and sexuality of women and girls. The quotation below explores how the religion of Islam is used to justify FGM/C, suggesting that:

“[Gambia is ...] an Islamic-majority population, and where religion is thought to be a significant reason for practising FGM, understanding the connection between religion and FGM in The Gambia is crucial. FGM predates the major religions and is not exclusive to one faith. FGM has been justified under Islam, yet many Gambian Muslims do not practise FGM and many agree it is not in the Qur’an” (28 Too Many, 2015, p.44).

Furthermore, I examine how the literature on gender inequality indicates that there are forces that shape persistent gender inequalities and these factors do not operate independently from within different social context. Religious, ethnicity, socio-cultural factors such as peer pressure and coercion from men and influential elders in the family (both male and female elders) and are critical issues to investigate for the continuation of traditional practices that render women exposed to everyday normalised gender-based abuses. I argue that traditional practices such as FGM/C constitutes the denial of a woman’s rights to her bodily integrity. FGM/C for example is also an act of violence

against women and the practice of virginity sealing is useful to understand how women's bodies are subjected to harm by influential elders and parents to ensure that young maidens are married off as virgins. Virginity brings pride and honour to the girls' family. There are reports of interacting factors that justify the practice of FGM/C, forced and early marriage (28 Too many 2015, p.19 citing MICS, 2010) shows that a combination of interacting factors largely influence the practice of FGM/C, forced and early marriage.

The next section further explores how this problem is explained under the practice of virginity sealing in the Gambia.

2.3.3. The practice of virginity sealing (locally known as 'fata')

Some ethnic groups, like the Mandinka, Jahankas and Fulla may also practice 'sealing' to ensure their daughter's virginity is intact at marriage, with 5.9% of women and 4.8% of daughters reporting being sewn closed. For example, the narratives of women in the current research suggest that most Mandinka girls go through an initiation ritual called 'Nyaka' between the ages of 4 and 10 and the ceremony is closely linked with the practice of female genital cutting. Anecdotal reports collected in the current study from focus group women and girls who underwent FGM reveal that their understanding of the ceremony is an initiation rite. According to 28 Too Many, FGM/C rituals initiate uncircumcised 'solima' (uninitiated) girls by telling them important secrets – they prepare them for marriage and motherhood.

Marriage is very important in the Gambia and unmarried women and girls are negatively labelled and devalued. Women who are 'uncut' in certain ethnic groups experience shame and feel ostracised, and are undervalued as full grown matured women. Attending the 'circumcision' (initiation rites of passage) are critical ceremonies to the FGM/C practicing communities. During several weeks of seclusion, girls learn the values of respect, obedience, endurance and privacy/discretion, and other practical skills such as songs, dances, proverbs and secrets of good womanhood (28 Too Many 2015, pp.19-21 citing MICS, 2010). After the initiation ceremony, they graduate as fully-grown women. Many claim that they experience negative outcomes from FGM/C, but most remain silent. It is deemed a secret and a taboo subject, and many initiates are indoctrinated to avoid discussing FGM/C in the Gambia with non-initiated women or uncut women who are labelled as 'solima' and stigmatised.

2.3.4 Perpetrators and instigators of VAW

From the above, it is becoming clear that violence against women in the Gambia is not only committed by intimate partners or men. There are multiple perpetrators and instigators of abuse and everyday normalised violence. The perpetrators and instigators of everyday normalised abuses assume these roles as a powerful and influential elders (both sexes). Patriarchy and gerontocracy are two interacting underlying factors closely linked to the practices of male dominance and rule of elders prevailing over family decisions and control and administration of family social structures. Young women who live in extended and intergenerational households may experience challenges because there are key influential family heads or elders (including husbands, uncles, mothers-in-laws, grandmothers and influential aunties), who may insist on observing the ascribed gendered roles in the family and norms. Some of these may also be linked to abuses and violations of women's rights.

Families that adhere to rigid traditional, ethnic and cultural norms and practices are governed by elders, who take firm and final decisions with regard to the marriage of a young bride, allowing or denying the education of young women and girls. Elders play very influential roles in the Gambia, and are generally responsible for economic, social, reproductive rights and fertility decision-making concerns at the household level.

In summary the above chapter has evidence how the literature reveal that women in the Gambia, like other women in Sub Saharan Africa, have experienced a range of everyday normalised abuses. Some of them are coerced and cajoled to conform and to acquiesce to norms such as the traditional practices of FGM/C, virginity sealing, and unprotected and forced marriages, supported by religious, ethnic and cultural justifications. Here I refer to data cited in Too Many (2015, p.24), which reported that nationally, ethnicity and religious explanations matter to the prevalence of FGM/C. Peer pressure is another issue that may limit abused women's agency to report or resist violence. Many women in my own study cohort associate compliance to these norms and practice notions of being 'good' and chaste wives and mothers.

Similar findings by Yick (2001) contend that this situation presents as dilemmas for women who bear all the responsibility for the pursuit of harmony in the home, with most young women and girls, forced to respect their elders and most acquiesce to ascribed

norms for the sake of their marriage and the family interests. Without essentialising the lives of Gambian women, there are high rates of perceived acceptability of gender-based violence in form of wife beating. Tolerance of domestic abuses against women and girls in the Gambia, is influenced by contributing influence of ethnicity, religious, and rural location all play a significant part in fuelling VAW. In the Gambia, the issue of respect for family elders and men, and conformity to social, ethnic, and religious moral norms, demands that women behave as ‘good’ married women, mothers and wives. While the problems discussed in the sections concerning everyday normalised abuses and violations of women’s rights are common, nevertheless, there are significant observable changes taking place in the Gambia, and I will explore the interventions currently addressing prevention of gender-based violence against women in the country below.

2.3.5 Interventions to prevent VAW in the Gambia

The problems of everyday normalised abuses and violations of women’s rights are common, and has negative outcomes in the health and well-being of affected women. However, there are discernable efforts to transform gender unequal relationships, and there are observable changes taking place in the Gambia, including better access to preventive information on VAW and the strengthening of the Gambia’s policies concerning women’s advancement in various spheres of life (The Women’s Act, 2010; *Gambia Gender and women’s empowerment policy and strategic document, 2010-2020*). Some of the key interventions and mechanisms adopted by the government and key partners aimed to address abuses affecting women were the creation of the Sexual Offences Bill (2013) and the Domestic Violence Bill (2013).⁷ The Women’s Act (2010) is another “progressive document and the first of its kind across Africa, representing a positive and sincere commitment at the institutional level to women’s rights” (Women’s Bureau/UNDP, 2014 cited by 28 Too Many, 2015, p.33).

The Government of The Gambia (GOTG) is a signatory to international conventions and protocols for gender empowerment, and the country’s national policy and strategies for mainstreaming gender issues in all development initiatives have also been reflected in its Health and HIV/AIDS preventive policies. Additionally, Chapter IV of the Constitution of the Republic of the Gambia guarantees that “every woman has rights and shall enjoy

⁷ See Faal, A. F. & Njie, B. (2013). Gambia passes Domestic Violence Bill. Observer online.

the protection set out in the Act”, “[...] and also every woman is entitled to respect for the dignity of her person, and accordingly, no woman shall be subjected to torture, or inhumane or degrading treatment or punishment; or held in slavery or servitude; and required to perform forced or compulsory labour” (Women’s Act, 2010, pp.4-7).

Following the landmark 1995 United Nations Conference on Women, the Fourth International Women’s Conference held in Beijing, and subsequent processes, The Government of The Gambia became a signatory to several international instruments that guarantee the rights of women and offer them protection against violence and gender-based discrimination. For example, the Women’s Act (2010, p.7) of the Gambia, has been designed, extensively deliberated upon, and finally enacted in parliament to address the shortcomings of the Constitution regarding gender discrimination and to promote gender mainstream interventions. The Women’s Act (2010) reviewed the definition of gender ‘mainstreaming’ as pivotal to the development of our understanding of the concept.



Figure 5: Poster urging men to make a difference in preventing VAW

The government of the Gambia and its partners (non-governmental agencies, civic society organisations and local community based groups) have made significant strides in influencing and designing policies, national laws, and undertaking programmes to mainstream gender in various development initiatives.

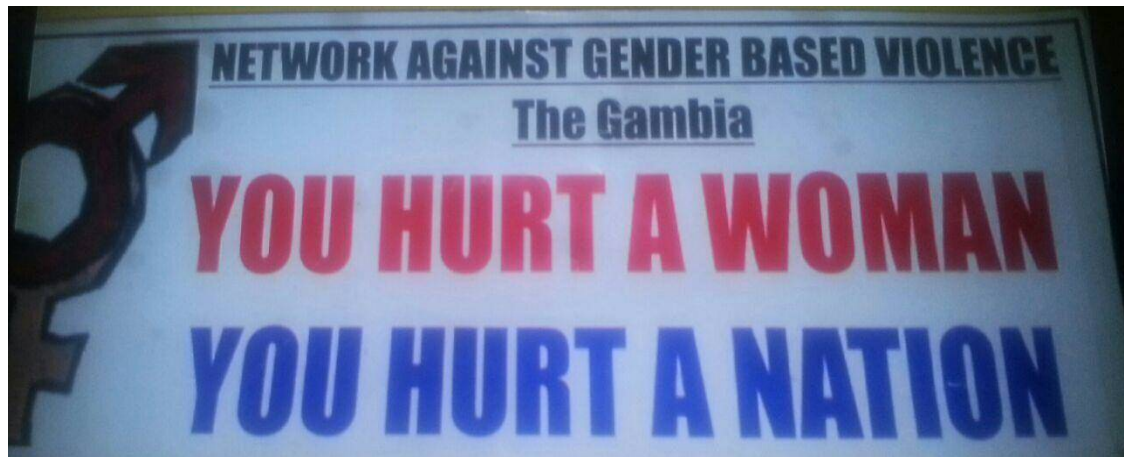


Figure 6: Poster to prevent gender-based violence, to prevent hurting women.

The above figures 5 and 6 are behaviour communication and change posters (the first) urging men to make a difference and (second poster) is on violence and to avoid hurting women, prepared by the Network Against Gender-Based Violence The Gambia. These are key messages in preventing gender-based violence. Gender inequality and persistence of VAW continue to affect women disproportionately. There are several factors that contribute to the problem of inequality and violence against women.

Programmes are implemented to through gender mainstreaming interventions, but notwithstanding these initiatives, the rhetoric on gender mainstreaming remains unclear in terms of specific strategies and outcomes to gauge transformation in the lives of women. Also, the concept of ‘gender mainstreaming’ means different things to different people. Despite these developments, the lack of clarity and defined processes at various levels to mainstream gender in the development agenda has been problematised. For example, the Gambia Women’s Act (2010, p.7) states: “mainstreaming includes all efforts being undertaken or to be undertaken as will secure a parity of opportunities, rights and privileges between men and women”. This is a good beginning yet this inclusive dimension is often ruled out due to problems surrounding conflation of terms. Often there is a lack of clarity when conceptualising terms such as ‘gender’ and ‘gender mainstreaming’ and this exposes these concepts to a diversity of interpretation. There are public awareness campaigns in decentralised regions of the country, aimed at educating the Gambian public on legislative processes and laws against harmful norms, and on the traditional practices of FGM/C, and unprotected and forced marriage. Yet despite the

available legislation, people still justify these practices and there is a risk that they will be carried out in secret to avoid legal and punitive action.

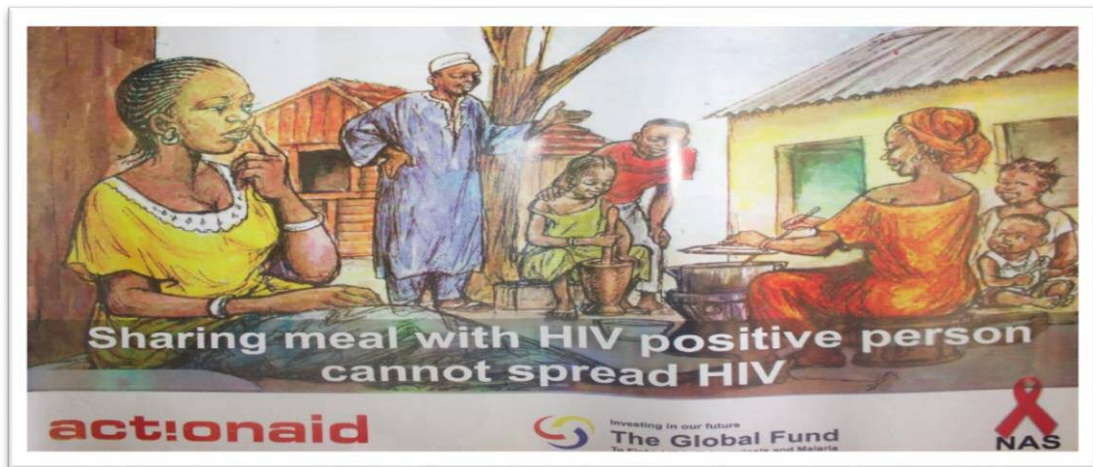


Figure 7: Behaviour Change Communication to create public awareness on stigma

The above figure 7, is a behaviour change communication poster advocating for persons living with HIV/AIDS to share in the family meals by Action Aid International the Gambia and the Global Fund. There is evidence in literature establishing the link between VAW, stigma and discrimination of persons living with HIV/AIDS, based upon these research globally and in sub-Saharan Africa (Dunkle et al., 2010; Dunkle et al., 2004; Kilpatrick, 2004, pp.1209-1231), it is vital that similar studies be undertaken in the Gambia to find out the connection between VAW and HIV as an under-researched topic.

There are programme interventions that challenge gender inequality and structural violence as a link to HIV/AIDS preventive work, but it is limited. The contribution of Network Against Gender-Based Violence of the Gambia, a consortium of government officials from government departments of health, social welfare, the judiciary, and police working in a consortium with local and national non-governmental organisation is registered here as a useful mechanism to address the health and justice for women who experience denial of their economic, social, sexual, and reproductive rights are denied. However, lack of coordination, competition for merge funding and access to resources to create wider coverage in decentralised regions of the country are hampering their progress (Personal communication concerning a scoping study and desk review of key players and interventions preventing VAW, by the Programme Coordinator of the Network Against

Gender-Based Violence, March 2014) during an in-depth individual interview conducted during the data generation phase of the current study.

There is evidence on the ground of widespread public education and training on preventive approaches by non-governmental organisations, civil society and community based organisations. It was a significant achievement when, in November 2015, the former President of the Republic of the Gambia (Yahya Jammeh) made a declaration banning FGM/C, partly due to continued advocacy and FGM/C activism and advocacy work to end FGM/C. The focus is predominantly on advocacy interventions, suggesting strong efforts cumulating to the banning of FGM/C, amongst other harmful traditional practices affecting women. I consider this as a significant part of the ground-breaking work on prevention of violence against women. As a result of the on-going advocacy work in the Gambia on prevention of FGM/C, a major achievement is the banning of FGM/C by the government after several years of advocacy and grassroots activism. Progress is being registered despite the numerous challenges of securing funding, limited capacity to enhance coverage) for enhanced care and support to survivors of VAW, countrywide.



Figure 8: Poster depicting young women activism against gender-based violence.

The figure 8 above is an example of some of the public awareness and advocacy messages developed in the Gambia to prevent gender-based violence sponsored by Action Aid the Gambia and the Network Against Gender-Based Violence.

Advocacy work on to prevent VAW in terms of harmful traditional practices are being made visible, researched and publicly debated in the Gambia, as in numerous other countries globally, and that this movement is gaining momentum, especially with regard to harmful traditional practices affecting women negatively. For example, The Network against gender-based violence, the Gambia Committee on Traditional Practices Affecting the Health of Women and Children (GAMCOTRAP), Action Aid International the Gambia and several other key organisations working to prevent and end VAW (GAMCOTRAP Report, 2011, 2012; *Gambia Gender and Women's Empowerment Policy and Strategic Document*, 2010).

There has been collaboration between government and various non-governmental organisations, and civil society organisations who are strategically forging partnership to implement interventions, ensuring that legislation and enforcement of women's rights instruments go hand in hand with community mobilisation and sensitisation (UNICEF Gambia Project report, 2015; (GAMCOTRAP Report, 2011, 2012; *Gambia Gender and Women's Empowerment Policy and Strategic Document*, 2010). I register here that national gender advocates working in human rights, gender and health promotion projects are playing an active and supportive role and are engaged in national programming, debating, designing and implementing interventions to prevent VAW in the Gambia. There are several organisations in the Gambia developing behaviour change communication messages and undertaking projects to prevent VAW. These organisations have been proactive and are in the forefront of FGM/C and other grassroots preventive interventions. Their contribution to gender activism, influencing and lobbying for the banning of FGM among harmful traditional practices affecting women, is evidence of the difficult work they have been engaged in in the Gambia. For instance, an international anti-FGM/C organisation, 28 Too Many (2015), compiled a country profile as a useful resource for data and contextual analysis of FGM in the Gambia. This report states:

“Globally, the reasons for FGM are highly varied between ethnic groups and communities; it is a deeply embedded social practice associated with adulthood, marriageability, purity and sexual control” (2015, p.5).

At global and African regional levels, countries in sub-Saharan Africa, including the Gambia, subscribe to the advancement of women's rights as human rights and the

mainstreaming of gender in all development initiatives. There are known harmful effects of normalised violence and abuses on the mental health, sexual and physical and its immense economic and social cost, as reported by (Heise et al., 1994) also refer to data generated by Morgan (2015) in their article *Violence against women: The hidden health burden*. The work of Morgan (2015) and the World Report on FGM and Donors Working Group on FGM/C (2010), amongst other African and national initiatives, the data documents prevalence of FGM/C as critical to in preventing harmful traditional practices. Work on prevention of harmful traditional practices has been on-going for decades, and such data adds to visible empirical evidence to monitor change. Apart from numerical data, rendering visible male power and rule of elders as influential power brokers in preventing early child marriages and FGM/C are critical, through participatory research. For instance, it is insightful to learn from Chant and Touray who contend that “the Gambia’s social system could best be described as patriarchal and gerontocratic” (Chant & Touray, 2012, p.3 citing Touray, 2006), own scholarly work contribute to a body of research suggesting that gender and age are two hierarchies that intersect with Islam and perpetuate male supremacy and domination in the Gambia (Ibid.), thus interventions must be participatory and inclusive processes to hear voices of the affected women who are experiencing the problem of violence, at all levels of society, including local community stakeholders, health workers, influential men and women, boys and girls.

2.4 Conclusion

The background information has documented economic factors, poverty and how gender-based abuses occurs in the Gambia. We have seen how practice of FGM/C, early marriage and coercive sex pose as a major burden to women and girls. Whilst much has been written about the structural drivers that fuel women’s exposure to HIV and AIDS elsewhere (Dunkle et al., 2004; Winchester, 2011) in studies undertaken to examine intimate partner violence and HIV link most programming in the Gambia fails to work towards establishing the clear policy and interventions needed to address the intersections of VAW and HIV/AIDS. The contextual analysis of the Gambia has revealed that gender and structural inequalities intersects, contributing to a range of abuses and violations of women’s rights. It would be interesting to observe how in my own study cohort these factors and forces are explained in the constructed accounts of the research participants.

To date, empirical research on VAW and HIV link in the Gambia remains an under-researched area. Evidence-based research is useful in providing usable data to develop recommendations for policy and practice interventions that address the intersection of VAW and HIV. It is acknowledged by Ellsberg and Heise (2005) that: “Violence against women is the most pervasive yet under-recognized human rights violation in the world ... it is a profound health problem that saps women’s energy, compromises their physical and mental health, and erodes their self-esteem” (Ellsberg & Heise, 2005, p.9). As a result, their recommendation that men’s violence towards women can and needs to be prevented, because of the negative health and social cost (Ellsberg & Heise, 2005, p.10) and also the violation of women’s rights. Therefore it is necessary to conduct research to explore and unearth the causative factors that fuel VAW as a context specific issue, from the perspectives of affected women, my proposed research intends to engage women to hear their narratives.

The problem of culture, religious and ethnic beliefs surrounding norms of ‘good womanhood’ has been highlighted in the review and fully discussed in the aforementioned sections of the introductory chapter and the problem is difficult to change, yet there are visible transformative processes taking place gradually, as more people become aware and are engaging with changes in gender ideologies, behaviour and practices of the younger generation who are educated and urban-based. I argue that the need for culturally sensitive approaches are necessary to avoid backlash and resistance to change when dealing with elders in the family and local community. Thus, when interpreting and developing nuanced socio-cultural specificities that capture prevailing gender norms, roles and expectations in the Gambia and exploring how they impinge on gendered relationships of power and dominion. This means researching to understand how underlying structural issues affects women and expose them to vulnerability of abuses and HIV. This is the gap the current research seeks to address through participatory approaches.

The next chapter is the first of two literature review chapters. It explains the key theoretical framework guiding this research, including the debates and perspectives by both feminist and family violence theorists. It also reviews ecological and integrated perspectives on violence, as well the post-colonial criticisms against universalising patriarchy and women’s oppression.

CHAPTER 3: CONCEPTUALISING VIOLENCE AGAINST WOMEN (VAW): THE LITERATURE REVIEW

3.0 Introduction

The link between gender-based violence against women (GBVAW) and HIV is not new, and neither are its consequences for women's physical, psychological, emotional, sexual and reproductive health. While there is growing recognition that it is a worldwide social and public health problem stemming from underlying interlocking factors and causes, it however, the intersection remains an unexamined and unchallenged phenomenon in the Gambia. The chapter will examine gender-based violence, HIV/AIDS and structural inequalities, exploring the interactions for policies and interventions to prevent HIV, address poverty, gender and social inequalities.

3.1 The literature review strategy adopted for Chapters 3 and 4

Initially, a general search of the databases was carried out to examine the historical perspectives on past and current debates, and main themes concerning gender-based violence against women, and link with HIV, including perpetrators of VAW. I carried out a search of the literature from a number of disciplinary backgrounds using books and other documents on international women's studies, sociology, psychology, nursing and community health.

The journal articles I selected were sourced from abstracts available from several databases. These were peer-reviewed journal articles identified by the University of Sussex library search engine, namely the Allied Social Science Index Abstract (ASSIA) which is an Indexing and Abstracting tool covering themes on health, social services, and sociology. Also, I used the International Bibliography of Social Sciences (IBSS) with keyword searches targeting the following key substantive themes: gender-related norms and explored notions of hegemonic masculinity and female subordination; harmful traditional practices affecting women and girls; gender based-violence and HIV intersections; and health outcomes of violence against women. Other journals were accessed from Science Direct, and the Web of Science core collection. In addition, I registered with on line journals, and received current peer-reviewed articles on: violence against women, with reference to feminists; theories of family violence, factors influencing violence against women drawn from literature of international women's

studies; and from the Journal of Gender and Society. Searches of Biomed, Wiley Inter Science, PubMed/Bio Med Central, and Medline, and from the Journal of the International AIDS Society, for the themes family and domestic violence and risks, intersectional theories on violence, and preventive interventions for violence, were regularly reviewed and updated.

The majority of research focuses on Intimate Partner Violence (IPV), and especially sexual violence and HIV intersections. I searched for general information and definitions of the conception of violence, the causative factors and effects of violence against women, including HIV and stigma theories. These provided useful insights into a general understanding of recurrent themes of gender-based violence, gender-inequality and its link with intimate partner violence, conceptions of patriarchy and male dominance, culture, health, sexuality, intimate partner violence and HIV vulnerability.

Since my research documents the experiences of Gambians in an African social context, where it was difficult to obtain adequate material, I examined literature from other African countries, predominantly South Africa, Uganda, Kenya, Nigeria, and Ghana. Only a limited number of research studies on gender-based violence and HIV intersections had been carried out in the Gambia. This review of African research, in many respects, offered useful sub-Saharan perspectives that offer a contextual understanding and insights that enriched my work. Apart from the above, I included grey literature from the Gambia to capture statistics on HIV prevalence rates, and data from national health and gender policies, as well as health reviews, nongovernmental strategic documents, and information on current interventions in gender-based violence and HIV prevention, care and support.

When selecting peer-reviewed articles, only those whose abstracts were available from two or more selected databases, which were published in full text online journals, were included in the literature review. Of special interest were online journals dealing with: feminist and family violence theories, feminist post-colonial and intersectional theoretical debates, and critiques of mainstream Western feminist social research. Key search words included ‘culture and domestic violence’, and ‘harmful traditional practices’, to provide contextual understanding of the social norms, practices and behaviours fuelling violence against women and girls.

Having read widely around the debates and themes concerning the intersection between gender inequality, normalisation and acceptance of gender-based violence and HIV, I then narrowed my search to include in the review only those items that met pre-defined inclusion and exclusion criteria. Inclusion and exclusion criteria, was strategic, since the aim of the current study was to develop an in-depth understanding of HIV positive women's experiences, and connections between violence and HIV/AIDS, although I did not review the literature on gender violence against men, I do recognise that gender-based violence includes both male and female perpetrators, as well as violence in lesbian relationships. The review included articles that specifically mentioned gender-based violence, violence against women, and intimate partner violence. I was interested in searching for general background literature with information concerning gendered relationships and inequalities, including issues on structural and wider social forces and factors that serve as drivers to women and girls' experiences of abuse, and most particularly, women living with HIV/AIDS. I did not specify an age limit.

Additionally, in terms of language and research location, I initially considered qualitative and quantitative research abstracts on the themes of violence and HIV, predominantly written in English. At first I focused my search on sociological journals, from the USA and other European countries, on feminist and family violence, and as the broad themes (mentioned earlier) emerged, I examined the global health literature from the African continent. Most of the available literature from the Gambia is on FGM/C and other harmful practices, with limited scoping studies on GBVAW.

These search criteria were used to find peer-reviewed articles from African socio-cultural contexts with perspectives on gender; articles that deepened my knowledge of gender inequality and the links with violence and HIV vulnerability, prevention of harmful traditional practices affecting women, HIV/AIDS, and stigma and discrimination.

Following this description of the search strategy adopted for the current literature review, I commence by stating that there is evidence that gender-based violence against women affects approximately one third of women globally (World Health Organisation, 2013, p.1) from diverse class, racial and ethnic backgrounds, with harmful and negative outcomes, including physical injuries, emotional trauma, vulnerability to STIs and HIV. According to WHO & UNAIDS (2013, p.3) report also stated that violence against

women is a widespread and costly public health challenge, deeply rooted in gender inequality. It is a phenomenon that violates women's human rights and VAW exists in all parts of the world.

Violence against women is a complex and multi-dimensional phenomenon, and over the years, there have been a number of theoretical approaches that have attempted to explain this complexity (Fulu & Miedema, 2015, p.1431). Violence against women is conceptualised in the current review, drawing from global perspectives as explained by feminist, family violence, intersectional and ecological theoretical frameworks as advanced by Heise (2011, 1989). Following this brief introduction to the literature search strategy and the concept on feminism, for clarity and to avoid conflation and ambiguity, I now define the key terms utilised in this research.

The current research is explained and located within feminist epistemological and key methodological tenets. It is also guided by critical feminist participatory scholarship (Maguire, 1996, 1987), generally influenced by the writings of feminist women of colour and by postcolonial scholarship Crenshaw, 1991, 1989; Hill-Collins, 1990,1991; Hooks, 2015, 2000, 1990; Mohanty, 2003, 1986; Tamale, 2008). These scholarly writings would be explored in this chapter to understand their contribution in the literature. My own preferred theoretical framework is based on feminist intersectionality and post-colonialism, as well as ecological theories on violence against women (Heise, 20011, 1989). Below I examine how the term feminism is understood and utilised in this thesis.

3.2 Feminism

First, I acknowledge here that there are varieties or 'plurality of feminisms' (Renzetti 1997, p. 133 citing Delmar, 1986, p.9). However, Renzetti contends that there are several principles that distinguishes feminist from positivists methodologies (Ibid.). In this thesis I define feminism as a philosophical stance that is opposed to patriarchy and hegemonic male power which are utilised to control women and to create situations of oppression and injustice (Dunkle et al., 2010; Harding, 1987; Maguire, 1987). Feminist inquirers raise fundamental challenges to the way social science analyses women, men, and social life, and focus their research on the study of women who are victimised by patriarchy and male dominance. Mainstream feminist researchers are concerned about power differentials between men and women in society and denial of rights and choice. Feminist

social inquiry focuses on gender and women, is dedicated to uncovering and understanding what causes and sustains women's oppression, in all its forms in society, and is committed to working individually and collectively to end that oppression within a multicultural framework (Harding, 1987, pp.1-5; Harding & Norberg, 2005, pp.2010-2011).

Feminism has its critiques. I am conscious of the debates that rage in the West in terms of 'universal' notions of women's oppression and the need to interrogate our assumptions and avoid universalism and essentialising women's experiences (Mohanty, 2003, 1986; McEwan, 2001, p.98). McEwan (2001, p.98) suggests that "the relationship between (White) western and 'other' feminisms has often been adversarial, partly because of the failure of Western scholars to examine and recognise that, as Western elites, they stand in a power relationship with Black women which is traced to the legacy of imperialism and colonialism. Postcolonial feminist scholars consider the writings of Western feminists to be problematic when applied to Black women because of universal notions of gender and women's oppression (McEwan, 2001, p.98 citing Hooks, 1984; Mohanty, 1988).

First I define the terms of power and patriarchy, offering explanations of how men's power is used as a force and control mechanism over women, the family and other patriarchal institutions in society (Hunnicutt, 2009, p.557; Kelly, 1988; Millet, 1969). Then, I discuss research and evidence on VAW conceptions, referencing works on family violence and feminist perspectives, intersectionality and post-colonial theories, as well as ecological viewpoints. Below, I present the definitions of power and why it is critical in the analysis of violence.

3.2.1 Definition and conceptions of power and patriarchy

'Power' is critical in the analysis of violence against women and girls, and from within intimate relationships is explained at various levels; at the state level, it includes a range of possible forms of control over individuals and groups, and has the potential to invade privacy and to utilise legitimate force at interpersonal levels. Kelly's (1988) feminist conception sees power not as property, but rather in relation to the structures and interactions between men and women in all areas of social life. She argued that women, unlike other oppressed groups, are expected to live in intimate contact with those who

have power and control over them, not only respecting but also loving them, and this makes women's subordination both pervasive and insidious (Kelly, 1988). An analysis of 'power' is deemed necessary to examine how it is obtained and reinforced by men's occupation of other social roles – roles which are given to men through specific forms of authority in public and private spheres, creating a high status for them and relegating women to the lower ranks of society. For example, power has been used to explain the particular dynamics involved in wife battering, marital rape, and forms of sexual harassment at work where subordinate female staff may be intimidated and coerced by a male boss (Hunnicutt, 2009; Kelly, 1988; Campbell & Soeken, 1999; Millet, 1969).

3.2.2 Millet's (1969) conception of patriarchy

Here I briefly introduce how the term patriarchy has been conceptualised as a system legitimising the use of male power and control, to sanction violence against women. Let us take, for example, Millet's (1969) essay, *'Sexual Politics'* in which Millet conceptualises the term patriarchy as a social and political system in which men control, and have power over, women, emphasising women's subordination and male dominance, suggesting that in most societies, across different cultures and socio-economic systems, the systematic oppression of women by men occurs as a result of patriarchy. The concept of patriarchy is a contested one. Kelly (1988, p.21) argues that feminists consider it impossible to understand, let alone theorise, women's oppression without the concept of patriarchy, referring to Sylvia Walby's (1987) argument that criticisms of particular formulations, or specific uses, of the concept of patriarchy do not invalidate the concept itself. Kelly, reacting to Walby's (1987) viewpoint on criticism levied on patriarchy as a form of systematic oppression writes: "These critics move from pointing out very real and important deficiencies in accounts of patriarchy to the false conclusion that all accounts of patriarchy must necessarily suffer from the same problems. Rather than abandon the concept which names the systematic oppression of women by men, feminist theorists should build on previous insights in order to develop more complex accounts of patriarchy" (Kelly, 1988, p.21).

Following on from this brief overview and definition of terms, as a way of organising the presentation of this section, I first present the literature on family violence theories (Lawson, 2012), and then explore how proponents discuss feminist theories and the ecological perspective (Heise, 1989, 2011). I aim not to discount any theoretical

perspective which might explain the underlying cause and factors contributing to violence against women. My main objectives in selecting these themes for the current study are twofold. First, to present background information that will historically trace the contending theories from family violence and feminist debates. Second, to examine alternative ways of conceptualising the problem of violence against women, drawing from writings of intersectional theorists (Crenshaw, 1989, 1991; Hills-Collins, 1991; Anthias, 2012) and post-colonial scholars (Tamale 2008, p.52; Mohanty, 1988) in order to move the debate from a single factor theoretical explanation.

3.3 Family violence theories

This section reviews family violence theory and interrogates how theorists contribute to the past debates to illuminate our understanding of the determinants of violence within the family. This theoretical perspective moves beyond feminist explanation of gender (to be examined fully in the section on feminist theories on violence against women) to examine other causative factors contributing to domestic violence. I explore how proponents of family violence theory and research (Gelles & Maynard, 1987, p.270) noted that the initial concern of those who studied family violence was to answer the three questions below:

1. How extensive is violence in the family?
2. What factors are related to family violence (e.g., which families are at the greatest risk of being abusive)?
3. What causes violence in the home?

Family violence researchers' answers to the above stated questions suggest that they have consistently found these interrelated or multi-dimensional factors, largely influenced by:

- The cycle caused by intergenerational transmission of violence;
- Low socioeconomic status;
- Social and structural stress;
- Social isolation and other personality problems and psychopathology.

Family violence model does not theorise from an individual or psychopathological model, instead family violence is explained from a multi-dimensional model which examines the individual, the family system, and society (Gelles, 1985). The theoretical approaches to family violence all tend to recognise the multidimensional nature of violence in the family

and tend to locate the roots of family violence in the structure of the family and/or society, or at the interface between the two (Straus, 1973; Gelles & Maynard, 1987). Straus developed a theory of the social processes which contribute to the use of violence and the maintenance of physical force as an “enduring element in the interaction of family members” (1973, p.106, see Kurz, 1989).

Further, I draw from explanations of the causes of family violence, referencing contribution of (Straus & Gelles, 1990; Straus & Gelles, 1987). The ‘family violence’ approach pioneered by Straus (1973) models offer a general systems method of analysing violence as a framework that “provided a mechanistic/cybernetic view wherein family violence was explained as a product of a system caught in a positive feedback loop” (Wright, 2002, p.4). For further illustrative purpose, Wright (2002) examines Giles-Sims’ (1983) work built on Straus’ model in which women who escaped violent relationships were interviewed, and the following stages have been identified as part of the cycle of violence: (a) the establishment of a family system; (b) the first incident of violence; (c) stabilisation of the violence; (d) the choice point; (e) leaving the system, and (resolution to more of the same and finally, the cycle of violence continues (Wright 2002, p.4). Generally, the central argument of family violence scholars Murray Straus (1973) and suggests that there are various types of violence occurring within the family, one of which is violence against women.

Gelles and Maynard (1987, pp.270-271) argue that empirical research on child abuse, wife beating and domestic violence has conclusively evidenced that the causes of domestic violence “are multi-dimensional and not related to any one causative factor” contributing to domestic violence. The core assumption of conflict theory is that humans are engaged in a constant struggle for status and are continually working to maximise their advantage. If individuals are pursuing self-interest, then people will necessarily be engaged in struggles over power (Hunnicutt, 2009, p.558 citing Collins, 1975).

Beyond exploring the origin and causes of family violence, the hidden cost of violence was researched and documented by Murray Straus and Richard Gelles in their article entitled: ‘*The cost of family violence*’ (1987) argue that it is important to know the economic cost of non-lethal family violence which typically precedes lethal violence (p. 638), because of the medical and non-medical costs to family and societal resources. They

contend that the true cost of family violence, must account for treating the mental and psychological effects of violence as experienced by survivors as well as the treatment and counselling of perpetrators. In addition, women who experience wife beatings endure untold human suffering and detrimental effects. For instance, survey findings suggest that wife beating has registered serious adverse effects on the mental and physical health of women who experience severe forms of assault. In the survey conducted by Straus and Gelles (1987) work unveil compounded negative effects of spousal abuse in particular wife beating, which involves physical assault such as: kicking, biting, punching, choking, beating and use of weapons.

The findings of the survey by Straus and Gelles (1987) revealed that most of these incidents involved minor assault, such as slapping and throwing of objects at the spouse, has negative effects stated below. Drawing from the definition of Straus and Gelles (1987, p.638) wife beating is defined here as an act or more violent acts that pose a serious risk of injury to the assaulted individual including kicking, biting, punching, choking, beating and use of weapons, with adverse effects (Straus & Gelles 1987, p.638), such as physical, emotional and psychological distress which included the following:

- Headaches or pains in the head: 30.9% had experienced severe violence in the last year; 26.2% had experienced minor violence in the last year, and 14.6% had no experience of violence in the last year;
- Cold sweats: 6.2% had experienced severe violence in the last year; 2.7% had experienced minor violence in the last year, and 3.5% had no experience of violence;
- Felt nervous or stressed: 45.9% had experienced severe violence in the last year; 28.4% had experienced minor violence in the last year, and 18.9% had no experience of violence.

Other symptoms documented by the survey included feelings of sadness and/or depression. Affected women reported emotional feelings and difficulties that they “could not overcome” like feeling bad or worthless and some of them reported that they felt completely “hopeless and suicidal” (Straus & Gelles, 1987, pp.368-369). In view of these adverse effects, there is a need to not only count the human cost, but also to recognise the human suffering, and work towards prevention to enhance human and family life (Straus & Gelles, 1987).

Following the above, I now examine the literature to scrutinise how the feminist model focus on power and the feminist insight into the complex problem of domestic violence is explained from the perspective of power and dominance. For feminists gender inequality is very useful in explaining violence against women and it is argued using a patriarchal ideological framework of conceptualising the problem of gender-based violence. I shall examine the contribution of feminists in the violence against women literature drawing from feminist conception of violence against women, variables around gender, gender inequality, societal attitudes, norms and practice towards violence and the family is explored. Below we examine how patriarchy is analysed from a socio-structural model by feminist theorists and criticism levied against ‘patriarchy and ‘hegemonic masculinity’ as universal constructs (Moller, 2007; Moallem, 2006; Mohanty, 2003, 1986).

3.3.1 Feminist theories on violence against women

Although feminist theories take a number of different forms (Renzetti 1997, pp.132,-133) there is a common acknowledgment among all that: (a) although women and men live intimately, gender is a principal division among members in society; (b) theory should uncover the social sources of gender oppression and inequality; and (c) the patriarchal structures of societies are one of the sources of such oppression and that violence against women is one type of oppression that requires its own theoretical explanation. Hunnicutt (2009, pp.554-555) contends that theories focusing on ‘gender’, by radical feminists, have contributed the greatest share of work related to the conceptualisation of violence against women by promoting the concept of ‘patriarchy’ to explain male violence against women. The use of power as a form of dominance and control is a useful theoretical contribution by feminist theory to the study of violence against women. Their foundational conceptions of power will serve as a useful framework to anchor my research and to explore how conceptions of power of men and others is explained to control women within traditional and patriarchal families in the Gambia. While research on violence against women continues to amass at impressive rates, Hunnicutt (2009, p.555) contends that theory development remains slow, even stagnated. Against this background information, I will first examine how patriarchal power is applied as a ‘force’ for instance,

rape/sexual coercive relationships between men and women, specifically in heterosexual relationships.⁸

In her essay, *Sexual Politics*, Kate Millet (1969) argues that “coitus can scarcely be said to take place in a vacuum”; although, in itself, it appears to be a biological and physical activity, it is set so deeply within the larger context of human affairs that it serves as a charged microcosm of the variety of attitudes and values to which culture subscribes. Among other things, Millet contends, it may serve as a model of sexual politics on an individual or personal plane. In her essay, she stated that in introducing the term “sexual politics”, one must first answer the inevitable question, “Can the relationship between the sexes be viewed in a political light at all?” Her reply to this question was that the answer depends on how one defines politics. Her essay draws on political theory to advance the conception of power relations and the privileged position of men over women. Millet (1969) explains that overt use of force is a form of “coercive power” utilised by the dominant group (men) over a subordinate group. Her work, largely derived from Max Weber’s concept of *herrschaft*, is an exposé of patriarchy as a system of dominance that goes largely unexamined, often unacknowledged (yet institutionalised nonetheless) in our social order, something akin to a birth right privilege whereby males rule females in a given patriarchal system.

Furthermore, Millet (1969) posits this form of dominance is the most ingenious form of “interior colonisation”, one that tends to create segregation, and even more rigorous than class stratification, more uniform and certainly more enduring. She suggests that, however muted its present appearance may be, the use of sexual coercion or abuse is a violation of women’s rights and violence is a form of abusive male power, dominance and control over women and girls, stemming from the deeply embedded and pervasive ideology of patriarchy. I argue that here the problem of violence against women is anchored in the socio-cultural and social conditions rather than an individual attribute (Millet, 1996; Hunnicutt, 2009) and the need to explore this problem is prioritised in the current research, to tease out context specificities and use the findings to inform policy and preventive interventions as stipulated in the research objectives.

⁸ Non-heterosexual relationships also utilise violence as a form of coercive power. Refer to the work of Claire Renzetti (1992) on battered women in lesbian relationships in her book entitled, *Violent Betrayal: Partner Abuse in Lesbian Relationships* (1992). Newbury Park, CA: Sage.

3.3.2 The conception of the ‘continuum of violence’

Kelly utilised the concept of the ‘continuum’, citing two of its meanings, as given in the Oxford English Dictionary: first, a continuum is a basic common character that underlines many different events; and second, a continuum is “a continuous series of elements or events that pass into one another and which cannot be readily distinguished”, suggesting that the basic common characteristic underlying the many different forms of violence is the abuse, intimidation, coercion, intrusion, threat and force men use to control women (Kelly, 1988, p.76).

Feminist scholars argue that men utilise tactics and a range coercive tactics while acknowledging that there are no clearly defined and discrete analytic categories into which men’s behaviour can be placed. Kelly argues that her usage of the word continuum “should not be taken to imply that there is a linear straight line connecting many different events or experiences ... nor should it be interpreted as a statement about the relative seriousness of different forms of sexual violence” (Kelly, 1988, p.76). She differentiates between the findings in Leidig’s (1981) work, entitled *Violence against women; a feminist psychological analysis*, and her own conception of the term continuum of violence, suggesting that they differ, arguing that Leidig’s (1981) placement of domestic violence and incest at the extreme end of the continuum, risks according more weight to these forms of violence against women, suggesting that they have greater negative effects than those at the other end of the scale (Kelly, 1988, p.76, citing Leidig, 1981). However, she does not share this perspective of ranking seriousness of typologies of abuses against women. She accords them equal weight, considering the serious nature and negative effect of physical, emotional, and economic violence, and proposes that “all forms of sexual violence are serious and that it is inappropriate to create a hierarchy of abuse” within a feminist analysis.

Kelly recognises that whilst certain groups of men have far more power than others by virtue of class, and for some, race privileges, men always have more power than females (1988, pp.26-27). Power in feminist conceptions is revealed as complex dynamic forces and power structures that define women and men’s everyday encounters and relationships. In studying violence, it is vital to recognise how power, gender based violence, and HIV intersect. Let us take for example the Gambian social context. The concept of the continuum of violence provides the current study with a useful analytical

guide that describes the extent and range of sexual violence women may experience at the hands of men. This framework analyses how ‘typical’ and aberrant male behaviours are linked within a continuum and manifested in the lives of women who are victimised by their power. Kelly offers an analysis of the “basic characteristics of violence” which she explains as follows:

“[the] basic character underlying the many different forms of violence is the abuse, intimidation, coercion, intrusion, threat and force men use to control women” (Kelly, 1988, p.76).

It should be clear by now that Kelly’s (1988, p.76) use of a continuum of violence will enable us to:

“document and name the range of abuse, intimidation coercion, intrusion, threat, and force whilst acknowledging that there are no defined and discrete analytical categories into which men’s behaviour can be placed” (Kelly, 1988, p.76-77).

While I recognise that the value of Kelly’s (1988, pp.74-82) continuum and its application to the Gambian context are valuable in terms of illuminating the conception that men’s use of violence is a form of control over women, especially with regard to sexual violence against women at different trajectories in their lives, yet it has its limitations. This argument is based on understandings derived from our own unique socio-cultural realities, especially our family and social context. Gambian families and their social context differ in many respects from what Kelly describes because in the Gambia, we predominantly live within extended family settings (not nuclear families, although urbanisation is changing the trend) and in intergenerational households. Thus, in a social context such as the Gambia, the interdependent nature of the family relationships may trigger different power dynamics and the influence of extended family members on women’s rights may be different. As mentioned earlier, critiques of mainstream feminism have contributed in the deconstruction of patriarchal power and advanced equality for women. However, Irene Smith (2014, p. 58) noted that theory of patriarchy is useful, but it risks re-creating imperialist discourse. She writes:

“Feminism, as an idea and a movement, has deconstructed patriarchal power relations and promoted equality for women. However, despite the excellent work done by many feminists, feminism has also been used to veil the re-creation of

harmful discourses, including colonial ones. The potential for feminism to function in this regard is particularly acute when Western feminist attempt to propel the movement across national and cultural borders in a global movement known as transnational feminism. Africa has been the prime target for this particular kind of activism, as Western feminists have reached out in solidarity to other women in what is widely regarded as the most underdeveloped part of the world.”

Thus, Smith (2014) argues that while the intentions of global feminist interventions are undoubtedly philanthropic, the power differential inherent in this form of relationship between the hegemonic West and the historically subordinated African continent requires careful and critical scholarship and action to avoid replicating harmful power hierarchies (Smith 2014, p. 58).

Feminist perspective have contributed have examined how gender inequality contributes to power struggles from the point of view of the individual as well as of larger society (Hunnicutt, 2009), and the recognition of diverse ways that patriarchy and other structural factors may contribute to the problem of violence is useful to examine further. Thus, I have come to the point where I argue that both feminist and family violence theories offer a window through which to view and conceptualise violence against women, but as Keating (2015, p. 108) suggests that there is a need to move the debate on VAW away from the static polarised positions held by feminist and family violence theorists. Keating (2015) advocates responsive ways to prevent the “high rates of either violence against women or intimate partner violence. I agree with scholarly views that the problem of social science research as “polarised into Family Violence and Feminist perspectives, are mired in the debate over gender symmetry and its implications” (Keating, 2015, p.108) is a problem. Keating (2015) recommends the following: 1.) integrating the two perspectives; 2.) incorporating the work on family violence strengths, youth resilience and developmental assets; 3.) strengthening interdisciplinary connections; and 4.) integrating research, teaching, and activism for long-term and primary prevention work (Ibid.).

I will explore the usefulness of the recommendations to the Gambian contextual realities, because I realise that to influence policy and practice and create transformational process using research findings, there is a need to develop holistic understanding the sociological, and contextual realities of VAW is very important if realistic and sustained policy and

practice interventions are to be developed to address context specific problems. Therefore, it is imperative that our research address the situatedness (Haraway, 1988) of the problem of violence against women must reflect the context, particularly examining the root causes and underlying elements, which I intend to do in my own research. to capture the unique and complex features of their experiences of research participants, yet avoiding universal and Western-centric approaches.

3.4 Avoiding universalism and Western-centrism

This section examines Black feminist and postcolonial critiques of the accounts by mainstream feminists and their theories on violence against women. Black feminists like Crenshaw (1991) and Hills-Collins (1991) were critical of the erroneous assumptions that all women's experiences were similar to those of women who lived in dominant White middle class heterosexual, patriarchal, nuclear families, resulting in a backlash from Black feminists, post colonialists and non-heterosexuals. This led to a flurry of criticism levied at White feminists for their assumptions about gender and patriarchal universalism, and the essentialism of women's oppressions (Anthias, 2012, pp.3-4; Davis, 2008; Hills-Collins, 1991). This brings us to the work of proponents of intersectionality theory who challenge the primacy of gender as the *only* explanatory model to conceptualise women's oppression. The main concerns and contentions with dominant White middle-class feminism(s) largely hinge upon notions of the universalism of women's oppressions. Although social divisions such as gender, ethnicity and class have been understood through the lens of intersectionality for at least two decades, and have had a profound effect on feminist theories in particular. This approach has only recently acquired a more central place in academic and political life (Anthias, 2012, pp.3-4). Hence theories of intersectionality have traditionally examined the interactions of gender, race, and class (Crenshaw, 1991; Reimer-Kirkham & Sharma, 2011, p.113).

3.4.1 Exploring key intersectionality theoretical arguments

Mainstream feminism argues that men's power and privileged position in society often result in oppression, and the phenomenon of gender-based VAW is part of this oppression. While there are truths surrounding such claims, they fail to capture 'other' narratives and counter-narrative claims, which point to inherent flaws of Western ethnocentric superiority of mainstream feminism in universalising women's sources of oppression and failure to capture intersections of factors and forces affecting women of

various categories and identities in society (Crenshaw, 1991, 1989; Collins, 1990; Hooks, 1990). This has led, since the 1980s, to highly contested and continuing difficult debates in the academia, with insistence that there is a need for recognition of race, ethnicity, gender and various other overlapping and interacting factors which can be traced to underlying structural oppressions, injustice and inequalities. Using an intersectionality framework of analysis allows an examination of several overlapping categories such as gender, race, and class (Sokoloff & Dupont, 2005, p.39) and in my own research I will further explore how various other structural factors such as religion, poverty, and women's lack of education, interlock to create complex of intersecting issues with potential to negatively influence the lives of the research participants.

Here I draw from a study conducted by Corbin (2012), entitled *Intersections of context and HIV/AIDS in Sub-Saharan Africa: What can we learn from feminist theory?* It offers valuable lessons and evidence supporting the usefulness of intersectionality analysis and of addressing intersections in this current thesis. For instance, in her essay, Corbin (2012) illustrates how adopting an integrated multidimensional approach in research offers valuable information that analyses the complex structures and intersections of factors linked to gender disparity and gender inequality that affect women in health research. This is made possible by asking questions and digging deep to unravel and develop knowledge and insights into the layers and complex mesh of inequalities affecting women. Corbin explores how micro-sociological and macro-sociological layers may intersect and interact with categories of gender, race, social practices, institutional arrangements, cultural ideologies, and various other categories of difference in individual lives, as well as investigating the outcomes of these interactions in terms of power (Corbin, 2012, p.8-9) and the overlapping inequalities that contribute to women's experiences of violence and violations of their rights.

Advocates of intersectionality perspectives, Kimberlé Crenshaw (1989), and Patricia Hill-Collins (1990, 1989) amongst others, serve as African American pioneers, advocating the inclusion and recognition of gender, race and class and other dimensions of inequality, particularly referencing the need for researchers to take account of historic and geographic contexts, where complex analysis of matrixes of oppressions and women's vulnerabilities could be examined and understood to offer solutions to the challenges for resolution of the identified problems, causative factors . While Crenshaw

has been credited with coining the concept of ‘intersectionality’ (Anthias, 2012) as an analytical approach focusing on the overlapping of categories of oppressions (Crenshaw, 1991, 1989; see Hooks, 2015, 2000, 1990), she was in fact one of the many feminist scholars like Hill-Collins whose contribution in the literature on violence explore how men and women may straddle multiple locations in the landscape of dominion and power dynamics. An intersectionality analysis may reveal how women can be both survivors of violence and villains (similarly men can also be villains and /or survivors of abuse of their own power), because any individual, male or female, straddles multiple positions in a landscape of domination, in any given social context. As Hill -Collins (1991) argue “an individual may be an oppressor, a member of an oppressed group, or simultaneously oppressor and oppressed” (p.225).

For the proponents of intersectionality, the central theoretical principles suggest that emphasis on gender as the sole explanation or root cause of violence against women has limitations. Intersectionality theories have shown that ‘gender’ is not the only defining category; human experiences cannot be accurately understood by prioritising any one single factor or constellation of factors. Thus, the central issues of race/ethnicity, class, sexuality and ability are constructed as fluid and flexible, and the social locations of the participants being studied are “inseparable and shaped by interlocking and mutually constituted social processes and structures that are influenced by both time and place” (Hankivsky, 2012, p.1713).

Scholars writing on intersectionality approaches argue that they: “provide an important corrective to essentialising identity constructs that harmonise social categories. Although social divisions such as gender, ethnicity and class have been understood through the lens of intersectionality for at least two decades, and have had a profound effect on feminist theories in particular, this approach has only recently acquired a more central place in academic and political life” (Anthias, 2012, pp.3-4). In a similar vein, Hankivsky (2012) also traced the historical background to intersectionality to the work of African American feminist scholars such as (Crenshaw, 1989; Collins, 1990; Hooks. 1990). These scholars submit that intersectionality “moves beyond single or typically favoured categories of analysis (sex, gender, race and class) to consider simultaneous interactions between different aspects of social identity ... as well as the impact of systems and processes of

oppressions and domination” (Hankivsky, 2012, pp.1713 citing Hankivsky & Cormier, 2009, p.3).

Intersectionality theorist arguments demanded the centrality of the voices of Black women in the mainstream feminist agenda (Crenshaw, 1991). This means that feminist research and scholarship promotes marginalised women’s concerns and advances their full participation in social research by creating safe platforms for hearing and validating their voices as marginalised groups. These scholars do not privilege gender but are concerned with examining multiple interlocking factors which fuel women’s oppressions (race, gender, ethnicity, class) and other structural forces interacting to ‘cause’ women’s oppression and VAW. Their contribution serves as a useful guide to applying an intersectionality theoretical framework in health research, which I intend to explore further as I undertake my own project. As Corbin suggests, intersectional analysis interrogates and examines a “broad framework of macro and micro relations, institutions and processes that are involved in the social construction of inequality” (Corbin, 2012, p.8). In my view, therefore, it is possible to interrogate, and to scrutinise complex overlapping structural factors and forces such as patriarchy, interacting simultaneously with structural violence, and gender inequalities in my own study. It should be possible to examine multiple interconnected socio-cultural factors, religion and ethnicity contributing to women’s oppression and consequently vulnerability to VAW and HIV in my own current research with women living with HIV.

3.4.2 Post-colonial critiques

The next section, briefly outlines key post-colonial critiques. I adopted post-colonial theories because they are relevant to my study, Gambia being a former British colony. There have been numerous critiques of mainstream feminist universalism (Tamale 2008, p.52; Mohanty, 1988) and my own work, with poor and marginalised persons in collaborative research encounters, is informed by the criticisms of post-colonial scholars concerning the manner in which ‘others’ from non-Western countries – especially the Third world – have been represented in scholarly discourse. I am a Gambian indigenous researcher, and I recognise that it is important to represent women in a non-essentialised and non-derogatory manner, and also to avoid paternalistic tendencies towards them. This criticism informs my study because the Gambia has retained a relationship as a commonwealth country until recently when it ended this relationship and withdrew from

the Commonwealth nations. In the past, as a former colony, we received external support and funding from donor nations in form of technical and development assistance (given to resource constrained countries) from Britain and other European nations (see Rodney, 1973) for an insightful . In what follows, I examine a dimension of dependence on external assistance for implementation of HIV prevention, support, and care programmes.

The first reference is to Sylvia Tamale's (2008) work which documents the colonial powers' exclusive approach to developing human rights, which she considers to be a form of imposition of Western value systems with nuanced underpinnings of imperialism. Her work clearly presents the debates surrounding the creation of the Universal Declaration of Human Rights (UDHR, 1948) which guarantees the rights of everyone to freely participate in the cultural life of the community. These are her criticisms of the UDHR (1948):

- “[It is] rooted in Western liberal philosophy (Tamale, 2008, p.50 citing Mutua, 2001; Cobbah, 1987) and echoes male values” (Tamale, 2008 citing Cook, 1994b; Charlesworth, 1994); and it is
- “[B]uilt on heterosexual perspectives of the human being” (Ibid. citing Otto, 1999).

The dominance of the West, in advancing a Universal Declaration of Human Rights is a major issue. According to critiques, the ‘universal’ aspect of the UDHR was problematised because it was drafted, debated and adopted in the aftermath of World War II and, as Tamale (2008, p.50) noted, the process was not inclusive: “only a handful of women and sub-Saharan African” representatives were present at the UN General Assembly when it was drafted and adopted. Furthermore, the broad character of the rights espoused in the human rights framework generally reflects Western normative values, aspirations and interests and it was developed from within a specific stage of historical evolution. Hence, it is clear that the ‘human rights’ discourse emanates from a specific historical context, with claims of common values and ‘universalism’ of rights; however, the scholars noted that it has a strong colonial and hegemonic disposition, as Tamale writes:

“... [D]iscourse is not value-free, but is greatly underpinned by a hegemonic philosophy and assumptions that reflect the interests and values of the actors that

drafted the UDHR. In other words, such discourse is woven around an ethnocentric paradigm that reinforces the position of those with economic, political and social power (who are mainly western, white, middle class, male, heterosexual" (2008, p.51).

What is the relevance of the above to this thesis? The central issue for postcolonial arguments is that, yes, gender is important and while women are subject to male dominance and power but that this is shaped by colonial histories and neo-colonial structures, so cannot be seen as solely about gender. Further, Tamale (2008, p.52) suggested that post-colonial critiques like those of Mohanty (1988) and Anzaldua (1983) effectively demonstrated how Third World women were represented as "helpless" "as objects devoid of agency" because of their culture. They described this as "myopic" and suggested that such analysis creates a restrictive framework from within which African women may limit their creative power and agency to challenge their domination (Tamale, 2008, p.52 citing Mohanty, 1988; Anzaldua, 1983).

Tamale's (2008) central argument is that mainstream feminists often present the two concepts of 'culture' and 'rights' as distinct, invariably opposed and antagonistic (Tamale, 2008, p.52). She contends that the concepts 'culture' and 'rights', presented by theorists of African women's rights, where culture is viewed as being essentially hostile to women, and this narrow interpretation risk collapsing 'custom' or 'tradition' 'tradition' (Tamale, 2008, pp.47-48) is limiting the possibility for agency and transformation using the positive dimensions of African culture of shared 'community' values and respect for the individual 'personhood'. The tendency to describe non-Western cultural practices as barbaric and harmful, by mainstream feminist and / or women's rights advocates who use the benchmark of their Western standards to judge non-Western cultural practices is to be avoided. This issue remains a major point to be overcome if we hope for meaningful change to end VAW and to avoid the erroneous assumptions of universal oppression of the women living in diverse cultural contexts. The assumptions which represent 'others' (non-Westerners) as 'passive' survivors of abuses whose bodies are assaulted both within the family, in the community and by state institutions and men as 'aggressors' and/or perpetrators, is limiting.

In conclusion, Tamale (2008, p.64) suggests that the recognition of culture in African socio-cultural milieu is strategically important, arguing that African scholars and social

science researchers need to proceed with caution and to explore creative and authentic ways to expand our understanding of culture, eschewing the narrow and rigid perspective of cultural explanations and its link to women's human rights. Rather, Tamale (2008, p.64) contends that culture needs to be approached in a "dynamic and unritualised" fashion, by examining the linkages between its positive aspects and its emancipatory potential for women to spur agency and resistance. She argues further that after all, the evolution of culture is shaped by agency, suggesting that "activism implied agency and legal feminist agency will come from a conscious understanding of the social, economic and cultural lives of the African women we are trying to reach out to" (Ibid.).

This is a significant cautionary note to researchers to avoid presenting non-Western cultures as "essentially hostile to women" because of narrow interpretation of culture that collapse culture with customs or tradition are seen as natural and unchangeable (Tamale 2008, p. 47). Further, the writings of others, like Uma Narayan (1988) is cited by (McEwan 2001, p.99) as a useful reference to examine the ways in which both Western and Third World scholars have misrepresented Third World culture and feminist agendas. She argues that there are political forces that have spawned, shaped and perpetuated these misrepresentations since the colonial period, and examined the underlying problems which notions of culture pose with respect to differences and cross cultural understanding. She issued a further cautionary note that, in trying to account for differences among women, seemingly universal essentialist generalisations about 'all women' are inadequately replaced by culture-specific essentialist generalisations that depend on totalising categories such as 'Western culture', 'non-Western cultures', 'Western women', 'Third World women', and concept of dislocating cultures as advanced by (Narayan, 1997). McEwan (2001, p.99 citing Narayan, 1998, pp.87-880), whereby feminist writings about women in the South, may risk falling into the trap of 'cultural essentialism' by using Western standards as yardstick.

The contribution of another scholar, Obari Gomba (2015), is also referenced here. His scholarly work explores how colonialism and post-colonialism are two separate periods – if anything can indeed be described as post-colonialism. Gomba (2015, pp. 77-78) raised a pertinent question about post-colonialism: Why should postcolonial theory be an anathema when it sheds light on the experiences of postcolonial societies? The strength of post-colonial theory is that it comes from the root of the postcolonial societies; it is

particularly provoked by the histories and cultural products of those societies. It is important to note here that the term ‘post-colonialism’ is a “difficult and contested term, not least because it is far from clear that colonialism has been relegated to the past” (McEwan, 2001, p.93, citing Ashcroft et al., 1995, p.2). Similar observations were made by Soyinka whose response to a question about ‘post-colonialism’ was a dismissive: “Africa is not postcolonial yet. Africa is not yet free of imperial influence” (Obari, 2015, p.138 citing Soyinka, 2010).

The culture of formerly colonised nations and their experiences (both past and present) have been depicted often in derogatory terms (see also Tamale, 2008). Again I make reference here of Tamale (2008) who proposed a creative solution in which to avoid being caught in cultural relativist versus universalism debate and she argued against “commonly held belief that holds culture and rights in binary opposition”; as it limits our strategic interventions for transforming society, within a restrictive framework, which risk re-creating and perpetuating women’s subjugation. As Tamale argues, in the growing era of fundamentalism in which certain hetro-patriarchal interest groups may choose to usurps the dominant narrative by choosing “selective version of culture to keep women in subordinate positions”, it is vital therefore that the research we undertake unravel and foreground alternative versions of interrogating culture and to explore the positive, egalitarian aspect of African culture, to use these alternative often known and less visible aspects of our culture to promote change and improve women’s rights. In my view, if this advice is to be utilised, it would require critical analysis and examination of nuanced and intricate aspects of the Gambian culture where this study is situated, drawing out the negative as well as positive cultural and gendered norms and practices , examining the influences that sustains VAW, while at the same time promoting the positive elements of our culture to advance women’s rights and to support agency and resistance as central mechanisms in prevention of violence against women and girls.

I did not come the above conclusion without reasoned justification. Rather, I have been a gender advocate and now a practitioner scholar, for many years, I worked within non-governmental organisations (NGOs) and I have been concerned about issues of sustainability and self-reliance, especially our reliance on outside funding for key development programmes. First, Gambia’s colonial history and continued relationship with the West for funding of its social development projects (for HIV prevention and care

work through global funds) raises questions about sustainability, particularly with the scaling down of funding in the future. Donor funding may have conditions attached, funds may be made available for direct care, rather than for training and capacity development to engage in advocacy and prevention gender based violence as it links with HIV/AIDS, which takes time to transform. Most funding available may be operating within limited timeframe (of three to five years), however, transforming behaviour, challenging deeply rooted gender norms and practices that support and normalise VAW, may require long term planning and implementation to register significant change.

Furthermore, I contend that as researchers and scholars, we need to avoid stereotypes and adopt humane, respectful and non-derogatory representation of research participants in our scholarly discourse. We can work with people by developing openness and sensitivity to a variety of socio - cultural, ethnic, political and religious influences – influences that may have an impact upon the lives of research participants. Thus, in conducting the current study I argue for the need to develop clarity in understanding how various factors may interlock and expose them to violence and risks of STIs and HIV.

Second, the current study aims to unveil and develop an understanding of women's experience of VAW and how it connects with HIV/AIDS. There is a need to undertake research (both qualitative and quantitative) to examine intersections of poverty, political, cultural and social rights and to unearth the link with VAW. I also hope to examine how gender inequality may co-exist with other forces, such as structural violence, to deepen women's marginalisation and add to denial of basic needs, which in turn may render them vulnerable to oppressive situations and violence, as a result of their HIV positive status.

Additionally, intersectionality theory is also useful for examining how globalisation and the effect of neo-colonial links can serve as useful forces or barriers when addressing national challenges of women's abuse through international agendas (Moallem, 2006). As a former British colony, the Gambia has gained independence, however, we remain interconnected in terms of trade and our receipt of support from external donors, whose development agendas may be seen as a continuation of neo-colonial and imperialistic agendas. The former President Yahya Jammeh withdrawal of the Gambia from the Commonwealth Nations is explained as in relationship with Britain as a former imperialistic power and reducing its influence and control over the nation. But the reality

is that while, the Gambia is no longer part of the Commonwealth, we still maintain links (directly and indirectly) with neoliberal institutions such as the International Monetary Fund, World Bank, and Bretton Woods Institutions. What this implies is that, as a nation, we remain connected to our colonial past and present postcolonial reality. The links between these periods are still evident and they throw light on each other, as aptly described by Obari Gomba (2015), who contends that there is no nation that has once been colonised that has escaped that history, suggesting that the weight of its colonial past may either drag it down or stroke its aggression against its past and present. Thus, I concur with Obari Gomba's (2015) argument that the pains of colonialism still persist in the after-effects of colonialism is being registered in the writings on postcolonial literature (Gomba, 2015; Rodney, 1973), recognising that no colonial power has escaped its past, rather they all find it difficult to break the habit of plunder, and this practice is still noticeable in the various guises of neo-colonial projects.

In the light of the above, while there is a need to recognise the roots of our past histories, and also to acknowledge that our post-colonial experiences may differ significantly (Gomba, 2015) across diverse geographic and historical settings, yet I argue that across various regions (nationally and international) there are spaces for reciprocal, dignified and synergetic work to enhance collaboration between the West and former colonised nations to transform dominance and unequal power and relationships (economic, political, and cultural) hegemony. This is especially useful amongst 'sisters' working across national and international boundaries to promote democratic and egalitarian relationships, as they engage in advocacy campaigns to promote gender and social justice work. Possibilities exists out there to undertake collaborative and transnationally, engage in advocacy to claim women's rights across borders, yet without imposition of imperialist and paternalistic values and dictatorship, to avoid backlash. I therefore suggest that we become aware of the caution expressed by post-colonial critiques (Mohanty, 2003; Narayan, 1997) and also draw from the work of intersectionality theorists whose contribution I find invaluable in articulating voices of marginalised people, drawing them from the margins into the centre-stage (Crenshaw, 1991; 1989; Corbin, 2012; Hooks, 2000) and I believe that through an intersectional lens, it is possible to unveil the complex matrix of oppressions and underlying interlocking factors of affected women. It is hoped, therefore, that researchers and scholars from various backgrounds, undertaking cross-cultural feminist work will become more "attentive to the micro-politics of context,

subjectivity, and struggle, as well as to the macro-politics of global economic and political systems and processes” (Mohanty, 2003, p.501).

I have presented an overview of key works by Black and post-colonial scholars and their concerns about promoting an anti-imperialist outlook on mainstream feminist scholarship. These were attempts to reorient mainstream Western feminisms, ensuring that Western feminist theory was no longer perceived as exclusive and dominant but as part of a plurality of feminism(s), each with a specific history and set of political objectives, as well as sharing some common ground. With evidence to suggest that with the emergence of various strands and typologies of feminism(s), and the realisation that different gender relationships exist beyond heteronormative ones, critical questions have been raised concerning feminist philosophies and concerns about women’s oppressions.

These are unsettling questions for all researchers, not only for Anglo and North American investigators who are foreign and researching in the Third World nations. Even as insiders working in our own familiar local contexts, we still wrestle with the inherent challenges as feminist researchers and scholars looking inwards and engaging in reflexive processes (however, difficult it may seem). When we conduct research, we face challenges of documenting our results from a multicultural perspective, and avoiding universalising research findings (Harding, 2005, 1998, 1993; Wolf, 1996, p.6).

Whilst I find the theoretical explanations of VAW useful, but I do acknowledge the limitation of mainstream feminist explanations of VAW, and the concerns raised by critiques. The potential for practical application in my study will be explored further, as I am concerned, from my past work experience, about gender advocacy and would like to examine the extent to which an uncritical adoption of a top-down Western-led transnational development agenda may influence transformational processes that limit the effectiveness of preventive processes to end VAW. The uncritical adoption of donor driven projects may not be contextually suited to our own development agenda. The need to avoid universal notion of women’s oppression is relevant and there is a need for contextual and cultural sensitivity to avoid using approaches and interventions that fail to acknowledge intricate interlocking forces affecting women who experience abuses. In the paragraphs that follow an ecological analytical framework will be examined and this is particularly valuable in the current research for explaining the influences of various axes

of power and interacting variables (historical, socio-cultural, political, structural, and economic), and other critical underlying factors in the analyses of women's oppressions and exposure to violence.

Gender-based violence has its roots in gender inequality and ecological theorists Heise (2011; 1998) have indicated that male dominance and control is the foundation for any realistic theory of violence, however using this as a single model for analysis of the problem is inadequate. I have thus examined other perspectives derived from family violence theories, beyond using gender as the main cause of violence against women. These include, economic as well as structural, political issues interlinked with gender-based violence (Heise, 2011, 1998; Ellsberg & Heise, 2005; UNAIDS, 2013; VanTyler & Sheilds, 2013; World Health Organisation, 2013; Keating, 2015). It explores how these scholars theorise partner violence against women, and draws out multiple causative factors as no single factor explanation gives conclusive analysis to comprehensively conceptualise the problem of violence (Heise, 2011, p.6; Jewkes, 2012), because there is room for generation of new insights and from diverse socio-cultural background to add to the current debates. Heise contends that there are different constellations of factors and pathways that may converge to cause partner abuse in different circumstances and contexts (Heise, 2011, p.6). Therefore her ecological model offers a useful diagram for examining how those constellations best theorise underlying risk factors of partner violence against women, in low and middle income countries.

Violence is a consequence of gender power inequalities, at both a societal and relationship levels, and also serves to reproduce power inequities. Qualitative research has demonstrated the links between HIV/AIDS, gender inequity and gender-based violence in the patriarchal nature of society that advance ideals of masculinity based on dominance and control of women and girls (Jewkes et al. 2010, pp. 41-42). Some of the factors such as patriarchal ideologies, gender inequality, rigid and deeply rooted norms and practices that promote male dominance and subordination of women are strong predictors of the phenomenon of violence against women and girls. For example, Lori Heise (2011) writes that there is strong evidence that norms related to male authority and rigid control, the normalisation and acceptance of wife beating and female obedience affect the overall level of abuses experienced by women in different settings.

Another example of the ‘causes’ and contributing factors that fuel the vulnerability and exposure of violence against women is related to situations in which men internalise and enforce through friendship networks and other social institutions, social norms that normalise, accept and justify the use of aggression and abuses as a form of control and dominance. The role of peer influence and how the normalisation and tolerance of norms of violence increases the likelihood that individual men will engage in the use of violence against women, is problematised. Thus, she proposes a theory capable of accounting for the reasons why individual men become violent and why women as a class are so often their target (Heise, 1998, p.263).

I will examine Ellsberg and Heise (2005) contribution in explaining VAW. First it is registered here that both men and women experience a range of gender-based abuses, however, research has registered that there are key differences as Ellsberg and Heise (2005, p.9) registers in the following quotes that suggests:

“[Men] are more likely to be killed or injured in wars or youth and gang related violence than women, and are more likely to be killed or assaulted by a stranger, and men are also more likely to be the perpetrators of violence regardless of the sex of the victim [survivor].

Women, on the other hand, are more likely to be physically assaulted or murdered by someone they know, often a family member, or an intimate partner”.

While Ellsberg and Heise (2005, p.10) clearly differentiate the forms of violence to which men are exposed in contrast to violence committed against women, women experience a continuum of abuses. I draw from Kelly’s (1988, pp.26-27) conception of the continuum of violence as a useful framework because in part theoretical contribution advances the debate in gender-based violence highlighting an unexplored dimension that unveil men’s use of power to demonstrate control and dominate women in society. She argues that:

“Power is reinforced by men’s occupation of other social roles which are accorded specific forms of authority, for example husband, boss, [and] father. This combination of levels of gender power has been used to explain the particular power dynamics involved in battering, sexual harassment at work and incest” (1988, pp.26-27).

The next section explores the ecological perspective advanced by Heise (1998), as another useful theoretical framework that offers researchers of violence against women a tool to conduct analysis of a complex array of interconnected factors across (individual, relationship, community and macro-social) levels of analysis which provides useful lens to examine the underlying factors contributing to violence against women and girls.

3.5 Ecological and intersectionality perspectives

The published work of Heise (1998) provides a theoretical model of analysis that seeks to deepen our understanding of the aetiology of violence against women, capturing it as a complex multidimensional phenomenon. The integrated ecological model suggests that adopting a single factor explanation of violence is inadequate and limiting, and proposes an alternative perspective: a “theory must be able to account for both why individual men become violent and why women as a class are so often their target” (Heise, 1998, p.263). Her proposed model examines a complex array of interconnected factors that influence the manifestation of intimate partner violence (2011, 1998).

Heise (1998) model is developed from Belsky’s (1980) interrelated multidimensional ecological approach – a nested systems theory derived from her conception of violence as a complex and multifaceted phenomenon, largely influenced by individual factors, family, community and societal (socio-cultural) factors. Heise own theory suggested that at the individual level (i.e. the innermost circle, the micro-system represents the personal history and factors of each individual, that determines his or her behaviour and relationships. For instance, being male, witnessing marital violence and conflict as a child, paternal absenteeism, rejection by one’s father, being abused as a child, and alcohol misuse, may all be linked to male violence against women.

The next circle reflects the micro-system, which represents the immediate context in which abuse takes place at the family level, and how that influences intimate and acquaintance relationships. For example, Heise (1998) explores how violence may stem from marital conflicts, spurred by male dominance and control of wealth and decision making processes by men in the family. This situation is further complicated by the compounded interlocking presence of other factors such as poverty and unemployment, and these structural elements may constitute as the contributing factors to violence in the family. Further, at the community level (i.e. the third level, the ecosystem, which

encompasses the institutions and social structures, both formal and non-formal, embedded in the micro-systemic level. This includes the workplace, neighbourhood, social networks and peer influences. Here at this level, violence may occur in situations where women and the family are isolated, and men may become influenced by delinquent peers and conform to hegemonic tendencies and norms under the influence of those peers. Also, low socio-economic status may complicate or aggravate the situation.

The macro-system represents the final level as Heise (1998) suggests it represents the societal level, reflecting the general systemic level or worldviews that influences attitudes, practices and norms perpetuating VAW. VAW can be traced to several interlocking underlying structural factors and forces that interact and prevail as normalised elements of a given society. These may include the acceptance and tolerance of hegemonic norms, traditions, and laws which grant men power and control over females. The normalisation of violence as an accepted means of resolving domestic conflicts (Heise 1998, pp.263-265) is a challenge has been problematised by other scholars. Here I refer to similar theory on violence against women as advanced by Connell's (2005) whose notion of 'hegemonic masculinity' as a form of masculinity that exercise male dominance, power and control and the use of aggression, is similar to Heise (1998, 2011) own conception of the causes of VAW at this systemic level. For instance, Connell (2005) writes about male gendered norms (dominance and control) fuelling violence against women and girls.

According to Connell and Messerschmidt (2005) own conception of hegemonic masculinities reflect their understanding of "masculinities are not simply different but also subject to change" (Connell & Messerschmidt 2005, p.835) and these pair of scholars recognise multiple masculinities and "diversity in masculinities" which I concur with, because there is evidence from the literature (Lapsansky & Chatterjee 2013, p. 41) that contributed to our understanding of "masculinity as fluid social construct (as opposed to an unchangeable natural construct)" which in many ways presents the opportunity to create and implement programme policies and interventions to prompt critical reflective engagements that spur resistance and non-conformity to th notion of dominant hegemonic masculinity (Lapsansky & Chatterjee 2013, p. 41). A growing recognition and call to avoid universalising and essentialising a single or dominant form of 'masculinity', but rather to develop an understanding of "diversities of masculinity" (Connell &

Messerschmidt, 2005). There is need to explore creative ways to support women's agency and resistance within a given socio-cultural milieu, recognising the dynamic potential for change. A useful reference is Tamale (2008, p.64) contribution in the debate in which she calls for the needs to conduct analysis reflecting cultural specificities. In so doing, it is possible for culture to be viewed from a "dynamic and unritualised" perspective, thus examining the linkages between its positive aspects and its emancipatory potential for advancement of women's rights.

The global discourse, and activism towards freeing women from violence have been problematised the issues of violence against women by men (Fulu et al., 2015, p.1440), yet in the Gambia, despite national and international agencies' interventions, there are limitations in registering the effectiveness of these interventions that seek to influence the women's rights agenda of mainstreaming women in development processes. These are key areas that remain under-researched, despite years of programmes that claim to address gender-based abuses across themes such as child marriage, FGM/C, women's socio-economic rights. Interesting though, one key success is the ban on FGM demonstrating the positive influence of gender and human rights activism in the Gambia, in the pursuit of national and international advocacy interventions aimed at preventing against harmful traditional practices. While I argue that the banning the practice of child marriage and FGM/C in the Gambia is a good start, however, it is not, on its own, an adequate means of preventing and eventually ending the practice of FGM/C. More needs to be done to provide the resources and political commitment to fund programming at various levels, and also to conduct evidence – based research to generate baseline data on prevalence of the problem and to evaluate programme interventions in order to track changes over a period of time, as well as identifying the negative factors and barriers to change. Additionally, research is useful in drawing out positive factors that prevent harmful traditional practices and VAW, exploring the connection of violence with intersections to HIV/AIDS. This remains a gap and needs to be addressed. My own research will contribute to providing data and to propose relevant recommendations based on the findings of my research which explores the link between violence and HIV in the experiences of women living with HIV in the Gambia.

I envisage a process in which I would be utilising a multi-dimensional approach to carry out research and conduct analysis examining overlapping and interacting factors

contributing to violence against women for appropriate policy and practice interventions. While I agree that male dominance is a foundation for any realistic theory of violence I also realise that ‘a single factor explanation’ is inadequate and unrealistic (Heise, 2011, 1998) given the diversity of factors and pathways to gender-based violence against women. Hence, I recommend that research using an ecological and intersectional frameworks (Crenshaw, 1991 Crenshaw, 1989; Hill-Collins, 1991) may offer researchers useful insights into the multifaceted phenomenon of violence, teasing out in our analysis more complex interplay of forces (personal factors, the role of immediate and extended family, the peer influences) affecting women’s lives.

3.6 My preferred theoretical conception of VAW

My own theoretical approach introduces what I have coined as an amalgamation of feminist theories of male violence against women in which male power is utilised to control and rule over women and other family members. My stance is based on the recognition that conceptions of ‘gender’ cannot be privileged as the only variable or underlying causative factor contributing to women’s experiences of VAW. I contend that there may be other useful explanations, for which I have provided an overview in the preceding sections. As a result, it is critical to theorise on VAW by seeking to conduct in depth analysis of the problem to unearth and create better contextually grounded explanations to VAW. In conducting the current study, I prioritise developing understanding based on contextual analysis and situatedness of the problem as defined and explained by the research participants’ own worldview and situatedness of lived experiences (Haraway 1988). Epistemologically, feminists scholarship recognise multiple ways of knowing and when analysis of the problem of violence against women is explained through the lens of social constructionism and intersectional perspectives I argue that through an intersectionality analysis framework of analysis it is possible to capture and to unveil the complex and nuanced matrix of oppressions and interlocking factors of gender, structural violence and poverty which researchers, policy makers and field practitioners must strive to unravel to explore to register change in the prevention of violence against women. Understanding the situatedness and contextual realities informing violence matters, because knowledge is always local, situational and provisional (Braun and Clarke, 2006) and consequently, no single explanation is adequate in theorising the cause of VAW. This is critical because it provides relevant data to anchor the work of advocates and their engagement with gender and political activism on

domestic violence and abuses, and may be useful in many ways to transforming policies and interventions for enhanced services and interventions as previous studies have revealed (Parker & Hefner 2015).

As researchers we must strive to avoid universalising the problem of women's oppression and be keen to interrogate other dynamic factors and forces that best explain the problem under investigation. I argue that, apart from gender, there are equally useful explanations as advanced by family violence, ecological and intersectionality theories which we need to consider as researchers to tease out the root causes and also to avoid oversimplified analysis of very complex problem of violence against women and girls. Thus, in my own research I will be looking at a combination of concepts drawn from explanations of feminist and family violence. I will be examining how intersectional and ecological/integrated theoretical perspectives may assist me to disentangle the influential factors linked to the problem of violence and how it is explained by my research participants.

For example, while feminist arguments are recognised as useful, in directing our attention to role of male dominance and control, and use of male hegemonic power (Connell & Messerschmidt, 2005; Jewkes et al, 2015; Kelly, 1988; Millet, 1969) as a form of controlling force, in explaining the pathways of intimate partner violence, it may be useful, but it is limiting. Thus, I argue in line with Jewkes (2015) who recommend that researchers examine and recognise that masculinity (in its diverse forms) and also the recognition that gender-related social norms and practices are implicated in violence against women, however, it is equally important to examine broader structural issues, systemic forces or structures that could be part of the problem and to explore how understanding these issues may contribute to transformative potentials to challenge and eventually improved unequal gender relationships as critical elements in preventing VAW (Jewkes et al. 2015, p.1580). It is envisioned that both men and women can collaborate to prevent and to reduce the incidents of VAW. In this regard, Jewkes et al. (2015) contribution is advanced here as realistic opportunities and strategic programme direction in which men can benefit personally from promoting equitable relations with women.

3.7 Conclusion

In conclusion, I found the literature concerning feminist and family violence theories on violence useful for deepening my understanding of the causes and pathways to VAW. It is insightful to learn about theories of power dominion and control by men over women for instance, in Millets' notion of Sexual Politics (1963), the use of economic and resource control as mechanisms of power to subjugate women (Jewkes et al. 2015, p.1580). It is useful to understand how gender, power conceptions, is influenced by historical realities of colonialism and neo-colonial processes affect the lives of women and men, globally. By examining both VAW literature, it is possible to tease out the multiple sources and causes of VAW. Equally important to understand are the structural forces (gender inequality, patriarchal and gerontocratic powers, as well as various economic, political, social factors the which overlaps and interact contributing to women's vulnerability, and exposure to other intersections (such as poverty and structural violence and exclusion) and how it intersects with women's experiences of violence against women with HIV/AIDS. It is possible to utilise intersectional and ecological analytical models to unveil interacting factors and forces affecting women in this proposed study as advanced by scholars (Parker & Hefner, 2015; Heise, 1998).

In my current research I hope to examine and capture the dynamics of power relationships and privileged positions between the sexes to identify the underlying factors which cause men to use violence against women. Also, postcolonial critiques suggest, there is a need to move from Western-centric essentialised processes and to avoid representing non-Western, African women in extremely restrictive frameworks. There are risks and limitations in essentialising their cultures and representing them in a colonised and devalued fashion (Narayan, 1997). The tendency to depict non-Western cultures as essentially hostile to women is based on a narrow interpretation of culture that collapses culture with custom or tradition and assumes culture to be natural and unchanging (Mohanty, 1986, 2003; Narayan, 1997; Tamale, 2008, p.46-47). I also agree with Narayan and Harding's (2000) call to explore a multicultural dimension in our research methodological approach as this may yield better insights into understanding the diversity of women's experiences and contextual realities, or situatedness (Haraway, 1988). I therefore choose intersectional and ecological perspectives to examine the potential occurrences of multiple socially constructed categories of ethnicity, religion, gender and class (amongst other variables), largely influenced by macro-systemic factors. I am

interested in unearthing how all of these structural categories interact and overlap to expose women to vulnerabilities of violence, exposing the manner in which these factors may contribute to women's oppressive conditions from an ecological and intersectional theoretical framework (Parker & Hefner, 2015; Heise, 1998). The literature review has evidenced that there are different contextual realities and no single factor can adequately explain the phenomenon of violence in the lives of women and girls. Consequently, it is possible to examine and undertake research to tease out culturally specific issues and also to identify key challenges. In doing this, it is possible to scrutinise ways in which in diverse socio-cultural settings, there is a possibility for agency of women and men in seeking creative culturally responsive ways to engage to in resistance or subversive interventions to transform unequal relationships and to prevent the denial of women's sexual, social and economic rights, which is a precursor to VAW.

My rationale for such a stance is based on the fact that, if long-term change is desired, there is a need to examine the threat of resistance and to fully understand potential forces that may prevent transformative processes from taking place. It is critical to develop a deeper understanding of influential 'powers' whose interest is to maintain the status quo (Yick, 2001, p.550) and to avoid playing into their hands (Tamale, 2008). I contend that while the feminist conceptualisation of violence against women and family violence theories are useful, they have limitations. What is less explored is how to move the debates from a polarised position to proactively engage in analysis that tease out complex intersections of arenas of power and to examine broader influences of structural factors that negatively limit and affect women's ability to secure and exercise their own rights and freedoms.

Finally, the problem of intimate partner violence is captured by feminist academics which in many ways draws attention to the fact that the existence of power within intimate partner relationships (Dunkle et al., 2010) is a real problem as the feminist statement shows "the personal is political" (Kelly 1988, p. 26; Oloka-Onyango & Tamale, 1995). Issues affecting women at the micro-level in the family needs to be addressed as a public and political concerns in order to transform negative norms and practices that normalise and accept VAW ((Human Rights Watch, 2002; 2000) and to spur agency by questioning idealised conception of hegemonic masculinity, seeking to render visible alternative notions of masculinities that respects women and their rights and freedoms alongside

dominant masculinities (Lapsansky & Chatterjee 2013, pp.41-42) and these alternative masculinities should be supported to model new behaviours to contribute to VAW preventive endeavours (Ibid.) by changing norms and hegemonic practices.

To continue this discussion, the next chapter presents a literature review on the subject of HIV/AIDS, including its definition and prevalence rates. It also introduces the conceptions of stigma, HIV disease stigmatisation processes, and discrimination, examining their links to VAW.

CHAPTER 4: LITERATURE REVIEW OF HIV/AIDS AND STIGMA

4.0 Introduction

“The fear of stigma leads to silence, and when it comes to fighting AIDS, silence is death. It suppresses public discussion about AIDS, and deters people from finding out whether they are infected” – Statement by Kofi Annan, former Secretary General of the United Nations, on World AIDS Day (Annan, 2002).

What has really changed since the former UN Secretary General made this remark fifteen years ago? Since the mid-1980s, decades before Annan’s comment, concerns had been voiced about the effect that stigma and fear of stigma may have. They are a deterrent force and limit actions taken to test and to disclose, whilst silence affects the lives of people living with HIV/AIDS. Yet the perennial challenge of stigmatisation, and its link to social inequalities which create a framework within which the HIV/AIDS stigmatisation process and discrimination are permitted to take place (Deacon et al., 2005, p.50) have still not been fully understood and conceptualised. It is my view that Kofi Annan’s observation is still relevant because HIV/AIDS-related stigma and discrimination continue to present major barriers to the prevention of new infections. This thesis emphasises the need to understand the social context of stigmatisation and discrimination, in order to explore its complex effects without restricting our views to those that support the status quo of social inequalities and the power differential between the stigmatised and the perpetrators.

4.1 Overview and definition of HIV/AIDS

This literature review chapter deals with HIV/AIDS and stigma. First, it presents a definition of HIV/AIDS, together with statistical data on prevalence rates, then offers a brief overview of general definitions and conceptualisations of stigma, including a review of the classic works of Goffman (1963).

‘HIV’ is an acronym for Human Immunodeficiency Virus (HIV), a virus that compromises the immune system, and ‘AIDS’ is an acronym for ‘acquired immune deficiency syndrome’, which is a syndrome of diseases of the immune system that is characterised by increased susceptibility to opportunistic infections (Coordinating Centre

for Infectious Diseases, 2012).⁹ Sub-Saharan Africa has the largest number of people living with HIV. UNAIDS (2012) data indicates that, by 2012, between 34 and 35 million people globally, and an estimated 0.8% of adults between the ages of 15 and 49 globally, were sero-positive.

Globally, the number of people newly infected continues to fall as records show that adults and children acquiring HIV infection in 2011 numbered between 2.5 and 2.8 million, almost 20% lower than in 2001 (UNAIDS Global Report, 2012, p.8). There are regional differences in HIV infection rates. For example, in sub-Saharan Africa, nearly 1 in 20 adults (4.9%) are affected and account for 69% of the number of people living with HIV throughout the world (UNAIDS, 2012, p.8). Indeed, according to the UNAIDS Global Report on HIV/AIDS (2012), in sub-Saharan Africa the regional prevalence rates of HIV infection are nearly 25 times higher than in Asia, where it is estimated that 5 million have HIV. After Africa, the regions most affected are the Caribbean, Eastern Europe, and Central Asia where about 1.0% of adults were living with HIV in 2011. It is important to note that, according to UNAIDS (2012), new infections have declined in sub-Saharan Africa by 25% and the Caribbean by 42% since 2001, and to date this trend is continuing.

The decline is attributed to global commitment to finance and support resource constrained countries, marshalling resources from international organisations and governments including the United States of America, European Union, UNAIDS, The World Health Organisations, UNICEF and several other funding agencies, all aimed at combating HIV and other communicable diseases. Other contributors to the fight against HIV/AIDS are the Bill and Melinda Gates Foundation, global funds for the prevention of HIV/AIDS, malaria and tuberculosis, the Gambian government's own health budget for HIV prevention, and numerous other funding and donor agencies. Alongside these, there has been vigorous HIV prevention work and steps have been taken to reduce the transmission of mother-to-child transmission and increase the resources for treatment of PLHIVs with antiretroviral drugs and to promote the use of condoms (National Health

⁹ See Centre for Disease Control (CDC) website for updates. Available at <http://www.cdc.gov/hiv/basics/index.html>

Policy & Strategic Document, 2012-2020; National AIDS Secretarial Final Evaluation Report, 2010; UNAIDS Global Report, 2012, 2015).

The literature on HIV and AIDS shows that sub-Saharan Africa is the region of the world most heavily affected by HIV with 33 million people living with HIV/AIDS, and with three quarters (75%) of the world's AIDS deaths (Njororai, Bates & Njororai, 2010). It also indicates that HIV/AIDS has reduced life expectancy by more than 20 years, slowed economic growth, and deepened household poverty. There is a need to look at how heterosexual intercourse has become the primary route of contracted HIV infection within Sub-Saharan Africa. The Gambia is in the Western African country where the prevalence rates are lower compared to Southern African region. In the next section, we shall examine the available data and prevalence rate of HIV in the Gambia.

4.2 HIV/AIDS in the Gambia

The Gambia is a country with low HIV prevalence where, as in most African countries, the main mode of transmission is through heterosexual contact (National Health Policy, 2012-2020). The Demographic Health Survey (2013) indicates that the prevalence rate for women of reproductive age (15-49) is 2.1% compared to men (aged 15-49) which is at 1.7%. It is, however, difficult for this study to determine vulnerabilities to HIV for women by age and location, partly due to limited access to data on prevalence and new infections using gender disaggregated information. HIV infections in the country with HIV 1 being the predominant virus driving the epidemic.¹⁰ Since 1986, over 16,800 people in the Gambia have been infected with HIV 1 and about 500 people die annually from AIDS. In 2013, HIV data records showed that prevalence rates amongst adults (aged 15-49) for HIV 1 were 1.6% and for HIV 2 were 0.4%, with targets to reduce these to 0.5% and 0.1% respectively by 2015 (UNAIDS, 2013) and from data cited in National Health Policy paper (2012-2020) which is currently being implemented.

4.2.1 Why study HIV and VAW in a low-prevalence country?

The conspicuous gap in research undertaken in the Gambia, when compared to other sub-Saharan African countries, highlights the urgency and the need to conduct large-scale quantitative and qualitative research to examine socio-cultural, economic and political

¹⁰ As already mentioned in Chapter 1, there are two sub-types of HIV virus, HIV 1 and HIV 2.

dimensions that expose women who have HIV to violence. The rationale for this study is threefold. First, my interest in developing understanding about the phenomenon of VAW and HIV, and the need to implement holistic preventive framework centering the views and concerns of affected women, field practitioners and policymakers in order to understand the main drivers of HIV and to examine whether VAW forms part of the analytical and preventive puzzle. Second, by actively engaging women in sharing their first-hand experiential knowledge through feminist participatory research, the findings will contribute to a deepening of our understanding of the complexities fuelling the two phenomena of violence and HIV in the Gambian context. Third, I hope that culturally appropriate preventive and support mechanisms will emanate from the findings of this study and that recommendations will be made for enhanced programming with regard to gender, and addressing structural issues as part of the on-going HIV/AIDS preventive, support and care services, informed by local and contextual realities.

The effect of gender inequality and economic marginalisation of women, and its impact on the lives of women living with HIV/AIDS, has been studied. Research on the intersections of gender, and economic marginalisation document several challenges for women who are affected and living with HIV/AIDS (WHO, 2017; UNAIDS Global HIV Statistics, Fact Sheet, 2016; UNAIDS Global Report, 2013, UNAIDS Global Report, 2012; Kako et al., 2012; Logie et al., 2011). For example, the National AIDS Secretariat (NAS) and Global Fund Final Evaluation Report (2010) conducted an evaluation of their projects and centred PLHIVs (women's experiences), I joined a team of consultants to conduct some of the qualitative interviews, documenting the economic hardship experienced by the women. The final evaluation report, produced by NAS, has revealed key findings that economic marginalisation, lack of income and dependency contributing to women's exposure and vulnerability of women to a range of enacted discrimination and HIV stigma related violence and rights violations.

While the findings suggest that gender-based violence affects women living with HIV, and that some of the challenges can be traced to gender inequality (in terms of access and control of resources such as land, credit and economic livelihood options), HIV preventive and support projects in the Gambia and several countries where there are limited resources experience challenges of implementing programmes to address the twin problems (UNAIDS, 2012). Globally, there is commitment and the political will to

channel resources to programming, however, UNAIDS (2012) reveals that there is still a 30% shortfall between the available resources and what is actually needed annually for prevention, care and support services. It therefore appeals to all partners to respond in unity to address the identified gaps and to meet the commitments for adequate resources at globally (UNAIDS Report, 2012, p.5). To date, research has evidenced the need for gender analysis in HIV/AIDS programming and to address the need for funding for the remaining challenges (UNAIDS, 2013), also the need to develop clear strategic approach to generate funding and to strategically mainstream health, gender and social justice programmes and interventions for HIV preventive, support and care programming .

In what follows, I examine the current HIV situation in the Gambia, together with gender disaggregated data on prevalence rates wherever feasible, given that this is an under-researched area. I also present literature on the HIV prevention, support and care interventions currently being undertaken in the Gambia, and will identify any gaps in the literature.

4.2.2 Gender disaggregated data on HIV

Globally, there are approximately 380,000 (estimated 340,000-440,000) new cases of HIV infection among adolescent girls and young women every year (UNAIDS Gap Report, 2013). According to the WHO (2017, p.1) report, there were an estimated 17.8 million women aged 15 and older living with HIV in 2015. Almost 15% of all women living with HIV were aged between 15 and 24 years. The report estimates that adolescent girls and young women were particularly affected in 2015 and they constituted 60% of young people living with HIV. The report also indicates that in many countries women living with HIV do not have equitable access to good quality health care and also face multiple and intersecting forms of stigma and discrimination. Furthermore, women living with HIV are disproportionately vulnerable to violence, including violations of their sexual and reproductive rights (WHO, 2017, p.1).

Of the women living with HIV, 80% lived in sub-Saharan Africa. Within this region, women acquire HIV infection 5-7 years earlier than men. In the Gambia, as in the rest of Africa, there are two transmission mechanisms that account for most new HIV infections: heterosexual contact, accounting for nearly 80% of all new infections; and parent-to-child transmission (PTCT), which is estimated to account for between 10-15 percent of new

infections. HIV data is routinely collected from pregnant women through the sentinel sites and antenatal clinics for records. There are records of higher percentage of females (54%) than men (46%) living with AIDS. The report suggests that several factors contribute to this problem, including women's exposure to a combination of physical and sexual violence which may be direct pathways to risks of sexually transmitted infections, unwanted pregnancies, and HIV/AIDS.

4.2.3 Interventions for HIV/AIDS prevention, support and care

The key interventions for HIV management in the Gambia include prevention, support, and care services and are summarised as follows. Since the discovery of the first case of HIV in May 1986 in the Gambia (National Aids Secretariat Report, 2010; National Health Policy, 2012-2020), the Government of the Gambia have collaborated with non-governmental organisations, supported by international aid agencies such as the United Nations AIDS programme, and has forged partnership interventions with various other civil society and community-based organisations whose main goals are aimed at preventing and controlling the spread of the virus. Support Societies in the Gambia are central to the inclusive process of addressing the needs of persons living with HIV/AIDS. (Harris & Touray, 2004).

As part of the collaboration effort in HIV/AIDS programming, a multi-sectoral approach was adopted and the National AIDS Control Programme, the National AIDS Council, and collaborating partners developed preventive, care, and support programming at local and national levels. The funding was created for intervention programmes that offer comprehensive services for HIV testing, treatment and care. Additionally, key stakeholders also funded projects for the creation of public awareness programmes which focus on addressing preventive measures targeting heterosexual relationships, because they account for nearly 80% of all new infections (UNICEF Report, 2015). The prevention of parent -mother-to-child (PMTCT) prevention of the virus, especially during antenatal care and post natal services is prioritised to reduce transmission rates. Also interventions include support to HIV Support Societies and other umbrella organisations of women living with HIV in the country such as the Mutapola Voices of women living with HIV, who supported me to conduct this research. The current HIV programme interventions undertaken by government health care services and collaborating partners (NGOs, civil society and grassroots organisations) are aimed at providing resources to

promote public education and for behaviour change communication messages to encourage HIV testing so people can find out their own HIV status. With an HIV-positive status, affected and infected individuals are helped to access universal treatment, support and care. The provision of antiretroviral drugs are free and food rations and basic assistance for school fees to families with orphans and vulnerable children are key support given to PLHIVs in the Gambia.

Public awareness campaigns and HIV preventive work are widely used in schools in the Gambia to prevent the spread of HIV/AIDS. These activities are supported by condom distribution and interventions that encourage condom uptake by sexually active individuals. Additionally, these individuals are targeted to encourage behaviour change and support of the 'Abstinence, Be faithful and use a Condom' (ABC) and Know Your Status strategies, which are central to HIV/AIDS prevention. The national HIV preventive programmes gauge the level of public awareness about HIV prevention (through its knowledge and assessment of safe practices and condom use) as critical measurements of the success of their public education interventions.

4.3 General conceptions of stigma

“Does the stigmatised individual assume his differentness is known about already or is evident on the spot, or does he assume it is neither known about by those present nor immediately perceived by them? In the first case one deals with the plight of the discredited, in the second with that of the discreditable. This is an important difference” (Goffman, 1963, p.4).

The above quotation is taken from Erving Goffman's (1963) classic work on stigma and management of a spoilt identity. His work delineates the difference between individuals with discreditable 'concealed stigma' and individuals who possess discredited attributes, their spoilt identity (1963, p.4).

In general parlance, the concept of stigma has been used to explain the various ways in which negative stereotypical attributes are assigned to the stigmatised persona. This review first explains how stigma has been explained by Goffman (1963), as a discrediting and discredited attribute, and this is followed by conceptions of 'disease stigma' and

stigma ideologies and how that affects the social encounter between the stigmatised and stigmatiser. Goffman's explanation of stigma (i.e. having a condition that is discreditable, it is concealed and unknown stigma) or discredited (i.e. the stigma is attributed to the possessor of a spoiled identity). Thus being diagnosed with HIV may result in the acquisition of a new HIV positive persona which can be concealed or revealed.

Goffman's work is explored here as a model which may help my analysis of the experiences of Gambian women living with HIV. It may provide a framework to anchor my research as accounts of women may reveal those live with discreditable and how they struggle to conceal their sero-positive status. On the other hand their condition may progress to become visible or non-concealable. Goffman's contribution on generalised stigma paradigm is helpful because it offers a theoretical conception that explains how persons with discreditable attributes may adopt strategies to manage or conceal their identity and to pass as 'normal' and the challenges they face. Also it sheds light on persons living with tainted attributes (Goffman, 1963; also refer to Chaudoir et al., 2013, p.75), particularly as their HIV status manifests stage with signs of physical deterioration, diarrheal disease, wasting and general malaise. Individuals possessing these visible signs and symptoms may evoke stigmatisation and enacted discrimination.

The literature on stigma conceptualisation and its definition is largely derived from sociological and social psychology analytical frameworks and research. Early works on stigma preceded and led to the notable work of Goffman (1963, pp.9-174), who explained how, in early Christian times, the word 'stigmata' was a metaphor for the bodily signs of holy grace, taking the form of eruptive blossoms on the skin. Stigma also refers to bodily signs of physical disorder, and in recent times, it has come to connote disgrace in itself more than bodily evidence (Goffman, 1963, p.11).

Stigmatisation is also a process of establishing categories of persons in routine social intercourse, as it allows us to anticipate others with special attention or thoughts and also enables us to differentiate between us and them. Stigma may refer to attributes and traits, virtual or actual, which are assigned to the stigmatised persona (Goffman, 1963, p.12). As previously mentioned, according to Goffman (1963), the term stigma can refer to a

deeply discreditable or discrediting condition. Further, he proposes three distinct types of stigmata, as mentioned below:

- “*Stigmas referring to abominations of the body* – various deformities”;
- “*Blemishes of individual character*: for instance, weakness, a domineering personality, possession of unnatural passion, treachery, rigid beliefs, dishonesty, having a known record of mental health disorders, having been imprisoned, addicted, homosexual, unemployed, suicidal, and even radically political”; and
- “*Tribal stigma* – associated with race, nationality, religion, family lineage and kinship or tribal lineage” (Goffman, 1963, p.14).

Goffman’s work applies to generalised stigma and brings out dimensions of concealable and non-concealed attributes, which in many ways may create differing experiences for the individuals with those discreditable and discredited attributes (Goffman, 1963, p.4). The literature on HIV/AIDS, the foundational conception of stigma, and prevalence rates for HIV in the Gambia. It focuses on the sociological perspectives and relational dynamic of HIV disease stigma and enacted discrimination.

Goffman’s original idea regarding the impact of concealability has been further explored through the writings of Chaudoir et al. (2013, pp.75-76), in an essay entitled: “*Discredited*” versus “*Discreditable*”: *Understanding how shared and unique stigma mechanisms affect psychological and physical health disparities*, which offers a useful model to help conceptions of stigma, particularly for people possessing spoiled identities, and to understand how stigma management strategies are employed. I argue that the framework devised by Chaudoir et al. (2013) articulates how stigma can ‘get under the skin’, meaning it can lead to the concealment of a discreditable attribute by the possessor of a tainted persona, and that this may lead to psychological and physical health disparities (Chaudoir et al., 2013).

Drawing from the work of Chaudoir et al. (2013), I explore how persons living with discreditable conditions like HIV can adopt concealment strategies. They suggest that the ability to ‘cover-up’ one’s HIV status is dependent on the following: 1) the extent of the disease progression (there are various stages of the disease, from ‘diagnosis’ to

‘manifest’); and 2) the social context where stigmatisation processes may occur (Chaudoir et al., 2013).

On the one hand, if a person is living with a discreditable attribute this means that their stigma is unknown and there is a degree of concealability. What this means is that there is a degree to which the disease is not visible or known and it can be concealed. The capacity to manage a degree of concealability also moderates the effects of stigma. On the other hand, for the person possessing a discredited condition or living a spoilt identity, life may be different as the disease is not concealable. Thus, as Goffman advances, the experiences of stigma depend on the degree of concealability of the stigmatised attribute, creating divergent outcomes for individuals living with discreditable or discredited attributes (Chaudoir et al., 2013, pp.66-67). For example, individuals living with visual conspicuousness of the stigmatised attribute, they rationalise that it may pose difficulty to hide. From this explanation, I argue that their contribution in the stigma literature builds on Goffman’s thesis of individuals possessing discredited conditions and how they manage their spoilt identities, which they describe as stigma “gets under the skin” (p.67) applies to general forms of stigma. This is useful, however what is less explained is what actually happens in a cross-cultural and diverse social contexts, with differing stigma ideologies and how will gender influence the stigmatisation of women who are living with HIV? These are the gaps I am interested in identifying and seeking answers in my own research.

4.3.1 Conceptualising HIV disease stigma

Two definitions of ‘disease stigma’ have been proposed by Deacon et al. (2005) who contend that, historically, stigma has been a feature of many diseases, especially those that are sexually transmitted or terminal (Deacon et al., 2005, p.1). Deacon and colleagues argued that, in the early years of the HIV/AIDS pandemic, the scientific and policy literature focused mainly on identifying the disease agents and modes of transmission, and seeking cures or vaccines (Ibid.). Now that HIV-specific interventions are available and HIV/AIDS affects a growing proportion of the world population, problems that create social barriers to implementing prevention and treatment strategies have come into sharper focus (Ibid.).

These scholars (2005) explained how definitions are important because they structure how we think about a phenomenon; they are critical tools in our theoretical toolbox (2005, p.15). They defined disease stigma as a concept that “has come to mean almost anything people do or say that stands in the way of rational responses to public health campaigns on HIV/AIDS, or that restricts the access of people living with HIV/AIDS to employment, treatment and care, testing and a reasonable quality of life” (2005, pp.ix-3). Following this clarification, they proceeded to define ‘disease stigma’ (which could be HIV/AIDS-related stigma) in terms of ideology:

“Disease stigma can be defined as an ideology that claims that people with specific diseases are different from ‘normal’ in a [given] society, more than simply through their infection with a disease agent. This ideology links the presence of a biological disease agent (or any physical signs of a disease) to negatively-defined behaviours or groups in society. Stigma is thus negative social baggage associated with a disease” (2005, p.19).

But what is different between Goffman (193) and Deacon’s explanation and what can we learn from their contribution? I rationalise that whilst Goffman offers a generalised explanation of stigma, Deacon et al. (2005) discuss stigma linked to specific diseases (in the case of this thesis, HIV/AIDS) which are deemed as communicable and may evoke fear and social distancing. Deacon et al. (2005) offered another definition, clearly identifying stigmatisation as a process and here the issue of risk and blaming to justify actions against persons living with the communicable disease is theorised:

“Disease stigmatisation can be defined as a social process by which people use shared representations to distance themselves and their in-group from risks of contracting a disease by (a) constructing it as preventable or controllable; (b) identifying ‘immoral’ behaviours causing the disease; (c) associating these behaviours with ‘carriers’ of the disease in other groups; and (d) thus blaming certain people for their own infection and justifying punitive actions against them” (Deacon et al., 2005, p.23).

The ‘disease stigma’ analytical framework proposed by Deacon et al. (2005) is very useful, and differs from Goffman’s theory on general stigma because it renders a more

specific understanding of stigma as an ideology associated with notions of risks related to disease stigma. This definition specifically conceptualises stigma linked to diseases whereas Goffman's own definition is generalised stigma. Deacon's own definition is useful and can be applied to examine the Gambian social context and influence of stigma ideologies and how stigma affects stigmatised individuals living with HIV. This is important given that stigma ideologies influence people's perception of risks associated with HIV within a relational encounter, yet what is less explained by the model of disease stigma are the various forms of stigmatising experience that the cohort of the current study described which I define as mundane or violent in nature. Drawing from Goffman's own work, as mentioned earlier, experiences of stigma depend to a large extent on the manner in which persons living with discreditable and discredited stigma manage their identity, through information control mechanisms (in the case of women living with concealable attributes of HIV) however, for women with manifest and visible stigmas it is more difficult to hide their visible discredited attributes, especially when they are too ill and manifest AIDS symptoms (data generated from my own study, 2014 field report).

4.3.1.1 Self-stigma: internalised stigma

Not all of the study participants in the current research experienced enacted discrimination. Some of them constructed narratives of 'internalised stigma', commonly labelled as 'self-stigma', upon positive HIV diagnosis. In accordance with the work of Pryor and Reeder (2011) and Chaudoir et al. (2013, p.76), the term 'self-stigma' is used in the current study to broadly describe how individuals respond to possessing a stigma. They explain the ways that people manage anticipated stigma from others using self-stigmatisation processes.¹¹ For instance, avoidance and isolation of the 'self' from social encounters may be the result of self-stigmatisation utilised as a strategy by individuals who possess both discredited and discreditable attributes. Upon positive diagnosis, an awareness of the HIV stigma ideologies and messages surrounding HIV and its negative connotations may trigger self-stigmatisation (or internalised stigma). A person's

¹¹ Self-stigma is a common phrase or term amongst PLHIVs in the Gambia, perhaps due to their involvement with previous stigma index studies. Many claim that they experience self-stigma, and that fear is a sub-theme that characterises their feelings. PLHIVs live in fear of what others may think about them, fear of being devalued and shamed, or finger-pointing, locally known in the Gambia as 'Chodiro'. The notion of Chodiro, as a loaded and complex concept, has been examined in detail in the findings section, as avoidance of Chodiro would mean adoption of restrictive/controlled strategies to avoid social encounters and risks of being a target of stigmatising experiences.

knowledge and fear of being known to have HIV can be termed, at this stage, as their knowledge and fear of a discreditable and concealable attribute.

I draw from Gilbert (2010, p.140 citing Scambler, 1989, 2004) own explanation suggesting that there is a distinction between ‘felt’ and ‘enacted’ stigma explaining that felt stigma is internalised, a fear of being stigmatised and discriminated against, while the latter relates to the actual case or incidence of being discriminated against by others. In Scambler’s study (1989) of people with epilepsy, fear of stigma was seen as the most disruptive issue in their lives. Gilbert (2010, p.140), reporting on this study, explains how felt stigma is internalised and includes manifested feelings of guilt, experiences of shame and blame, and disruptive, inhibiting, disabling fear of being discriminated against (Ibid.). Consequently, the conception of disease stigma helps us to understand how discriminatory acts can be both mundane and at the same time manifested as an extreme form of ‘stigma as violence’ exacerbating and increasing vulnerability through use of covert and hidden acts of violence often missed out by the various ways that disease stigma has been conceptualised.

Chaudoir et al. (2013) suggest that an individual’s response to possessing a stigma is informed by anticipated, enacted, and internalised responses, indicating that it is necessary to understand the whole range of stigmas, from the individual perception of internalised stigma to its broader social context (Chaudoir et al., 2013, p.76 citing Earnshaw & Chaudoir, 2009). These scholars define ‘anticipated stigma’ as the degree to which individuals expect to be the target of enacted discriminatory norms and practices or how they anticipate social rejection because of their discreditable attribute. They suggest that *enacted stigma* refers to the degree to which individuals actually experience discrimination, whilst *internalised stigma* refers to the degree to which individuals with stigmas feel shame and self-loathing. The literature has shown (Taylor, 2001, p.792) that stigma is socially constructed, and I argue that individuals who possess discredited conditions, for example manifest symptoms of HIV/AIDS, wasting, coughing, prolong illness, possess attributes which mark them out as ‘different’ from individuals deemed as ‘normal’ in Goffman’s (1963) theory. In my view the need to shift from fixed notions of negative traits and attributes (discreditable and discredited attributes), to bring out more nuanced explanations that discriminating actions labelled as stigma are in fact extreme forms of abuse in the context of HIV/AIDS.

4.3.2 Stigmatisation processes: Contexts, power and intersecting forces

Many scholars and researchers, including Campbell and Deacon (2006), Goudge et al. (2009), and Parker and Aggleton (2003), indicate clearly in their work that power, social, political, economic, gender, race, sexuality related, and other intersectional variables are all capable of having an impact upon stigmatisation processes. At the centre of the analysis lie the issues of power and privilege, and in certain cases people who contract stigmatised diseases are blamed (Deacon et al., 2005, p.7).

Link and Phelan (2001, p.363) traced the historical background of stigma to Goffman's 1963 book, hailing it as the inspiration for profuse research. Their own contribution to the conception of 'stigma' describes it as an "enormous array of circumstances ... [I]nvestigators provide no explicit definition and seem to refer to something like the dictionary definition ('mark of disgrace') or to some related aspect like stereotyping or rejection" (2001, p.364). Link and Phelan's own definition offered that 'stigma' is a harmful societal phenomenon (enabled by underlying social, political and economic powers) that begins when a difference is labelled, then – as stigma – becomes linked to negative stereotypes, it leads to separation of 'us' from 'them', and finally to status loss and discrimination for those possessing carrying the stigmatising traits (Link & Phelan, 2001).

Alonzo and Reynolds' (1995, p.304) work on conceptions of stigma, as it relates to the use of 'power' over others to label them as 'deviant', is explored here to show how the 'powerful' reaffirm their normality by labelling others. Stigmatisation processes are concerned with social relations and the use of power to accuse or confer blame on 'others'. In the case of disease stigmatisation these 'others' may be, for example, people suffering from psychological conditions, leprosy, tuberculosis, or HIV/AIDS, which are all forms of disease with the capacity to evoke stigma. However, not all stigma leads to discriminatory actions, thus the need to avoid conflation of the terms stigma and discrimination (Deacon et al., 2005, p.50).

Deacon et al. (2005) argue that stigma does not have to lead to discrimination to qualify as stigma and suggest that, as well as being stigmatised by dominant groups, marginalised people can also stigmatise each other (Ibid.). This is true in the narratives of affected women who had their information leaked by other PLHIVs in the same Support Society

and their status was disclosed to other who stigmatised them (findings from my own study cohorts, 2014 field work).

Further, Deacon et al.(2005) explore how the blame model is utilised, arguing that “HIV/AIDS stigma revolves around the construction of blame and not simply the justification and continuation of existing inequalities between HIV negative and HIV positive people” (p.11). With reference to the blame model, stigma is fundamentally about the emotional response to danger that helps people feel safer by projecting controllable risk, therefore blame, onto out-groups (Deacon et al., 2006, p.18 citing Joffe, 1999). Thus, stigmatisation helps to create a sense of control and immunity from danger at an individual and a group level. These socially constructed representations only result in discrimination and the reproduction of structural inequalities when other enabling circumstances, such as the power and opportunity to discriminate, come into play (Deacon et al., 2006, p.18 citing Joffe, 1999). Parker and Aggleton (2003) acknowledged that stigma is largely influenced by prejudice, negative attitudes, abuse and maltreatment directed at the stigmatised persona.

Stigma is also seen as a major factor contributing to the global HIV/AIDS epidemic and thus needs to be fully understood and examined in order to develop interventions to address HIV/AIDS stigmatisation. The need to understand that stigma constructions are not fixed or static, but changeable, is advanced by Parker and Aggleton (2003), who argue that Goffman’s (1963) work has often been misread. These scholars offer an argument in which explanations of ‘negative attributes’ can be used to unravel a more complex reading of the relational dimension of stigma. They explain how stigma represents a ‘language of relationships’ and how it captures intersections of compounding influences of ‘power’ and control over ‘the others’.

4.3.3 Exploring the gaps in HIV disease stigma theorisation

From the above I rationalise that, whilst Goffman’s (1963) literature on stigma – which focuses on discreditable and discredited attributes – is useful for understanding the ways in which stigmatised individuals adopt strategies in the management of their spoiled identities and offers a generalised explanation, it is limiting. Additionally, I rationalise that there is a need to conduct gender analysis to examine how construction of stigma may be informed by gendered power imbalances and prejudices. I argue that both

contextual and gender analysis are useful, when examining the accounts of PLHIVs and their own experiences of stigmatisation processes.

In many respects, this moves our understanding beyond constructs of stigma as discredited and discreditable attributes to explore other explanations. Thus, my own contribution to stigma conceptualisation processes is to explore how gender analysis provides nuanced understanding of the structural forces and how they operate (from a cross-cultural non-Western socially and culturally diverse settings) such as the Gambia. It captures, the compounding factors presented in the research participants' narratives, unveiling a complex matrix of oppressions that affect women who are HIV positive. Deacon et al. (2006) contend that stigma is a social process, a social interaction, constantly changing and often resisted, rather than an individual attribute. However, they argue that, in an attempt to recognise the social and political aspects of stigma, researchers tended to define stigma with reference to its discriminatory effects. Alonzo and Reynolds (2005) define stigmatised people in terms of discrimination, suggesting that they are a category of people who are pejoratively regarded by broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanising benefit of free and unfettered social intercourse (Deacon et al., 2006, p.16, citing Alonzo & Reynolds, 2005, p.304).

4.4 Exploring the link between violence and HIV

The extant literature on violence and HIV suggests that intimate partner violence and non-intimate partner violence may be on both the direct and indirect pathways between fear of sexual, psychological and physical violence and actual experiences of violence, which can then lead to STIs, HIV/AIDS, unintended pregnancies and other harmful effects. Research by Jewkes et al. (2010), and by Dunkle and Decker (2013) also reveals that coercive nonconsensual sexual encounters may contribute to risks of unintended pregnancy, unsafe abortions, excessive bleeding, and increased risks of maternal morbidity and mortality rates, including other challenges of risks of psychological and emotional pain caused by their traumatic experiences.

I examine the literature which deals with violence as a direct link or precursor to HIV, and later how HIV contributes to a range of abuses and denial of rights according to findings of the literature on violence and HIV. Commencing on work by Dunkle and

Decker (2013) who highlight that there are obvious direct and indirect pathways from gender-based violence to HIV that can be attributed to violence as a precursor to HIV/AIDS amongst other effects. They stated that:

“Gender-based violence (GBV) affects 30-60% of women worldwide with significant consequences for mental, physical, and sexual health ... predominant among these health outcomes are sexually transmitted infections, including HIV.”

Dunkle and Decker (2013) further suggest that the link between GBV and HIV is multifaceted. As they traced cross-sectional global research conducted in Africa and India in the late 1990s, and contend that research has consistently found that women who had suffer physical and/or sexual violence from male intimate partners (IPV) were more likely to be vulnerable to sexually transmitted infections, including HIV, which may be the result of forced unprotected sex. HIV infections may be contracted through sexual assaults (which may be accompanied by threats of actual physical assaults) by intimate partners. The combination of physical, sexual, emotional and economic abuses of women has consistently been associated with increased risks of STIs and HIV (Dunkle and Decker, 2013)

These are interesting revelations, suggesting a strong association between gender-based violence and HIV, but it is equally important to recognise the complexity and multiplicity of pathways responsible for the intersection (Ibid.). For example, Dunkle and Decker (2013) traced a plausible biological pathway from gender-based violence to HIV, arguing that men who are physically violent are also physically more likely to be HIV positive, because they are at higher risk of engaging in risky sexual behaviour, with multiple and concurrent sexual partnerships, including transactional sex, and possibly substance abuse. Dunkle and Decker (2013) indicated that these men are, therefore, most likely to report symptoms of sexually transmitted infections and to be confirmed sero-positive.

Another issue is that their research also unveils another plausible causal pathway from gender-based violence to HIV positive status, which is attributed to repeated sexual relationships with infected persons who have contracted HIV, even where the sexual contact or relationship is not overtly violent. For example, in an unequal relationship of power, dominance and control, women may be unable to refuse sex; fear of abuse may

render a woman unable to refuse sex or unwelcome demands for unprotected sex, because the actual risk or violence, or fear of a partner using physical violence, reduces her ability to influence the timing and circumstances. This in turn may result in more unwanted sex and less condom use. In several instances, therefore, where sexual coercion and risks of abuse are present, the affected woman may be unable to use condoms for protection against STIs and HIV (Dunkle & Decker, 2013).

4.5 Stigma resistance and agency

In this section, I draw from Soldati-Kahimbaara's (2012) article, entitled *Immersive and counter-immersive styles of writing about HIV/AIDS* that narrates the challenges faced by the gay community in South Africa, which is similar to the Gambian context.¹² Soldati-Kahimbaara (2012) explores two novels from South Africa that capture the lives of PLHIVs as stories of agency and awareness creation, despite the silence surrounding extreme, violent forms of stigmatisation and victimisation when non-heterosexuals disclose. This essay shows how media and stories are revealing the power, prejudicial attitudes, and negative reactions of people towards persons with HIV/AIDS and the stigmatisation processes to which they are exposed in Southern Africa. A systematic review of VAW by Stangl et al. (2013) offers a useful catalogue of interventions to reduce HIV-related stigma and discrimination. I therefore contend that together PLHIVs and perpetrators of enacted discrimination can be encouraged to develop an agentic stance, and to confront stigmatisation ideologies in order to transform the manner in which perpetrators and instigators of HIV related abuses act towards persons living with HIV. This recommendation will be explored further in Chapter 8 of this thesis

4.6 Conclusions

From the discussion thus far, the literature on HIV/AIDS, provided useful insights on conception of stigma, offering a sociological perspective of the relational dynamics of HIV disease stigma and enacted discrimination. The study advances Goffman's conceptions of stigma as a 'discreditable and discredited condition' (Goffman, 1963) and I will use this theory to analyse the accounts of women living with HIV who are living

¹² I consciously did not include the perspectives of non-heterosexuals for fear of backlash and putting research participants at risk. Our national pronouncement on gay rights is restrictive and punitive. This is an acknowledged limitation of the study.

with concealable and non-concealable attributes, and how they manage their identities. In this literature review I teased out Chaudoir et al. (2013, pp.75-76) work, which in my view, offers another useful way to conceptualise stigma, for people possessing spoiled identities. I argue that the framework devised by Chaudoir et al. (2013) articulates how stigma can ‘get under the skin’, meaning it can lead to the concealment of a discreditable attribute by the possessor of a tainted persona, and that this may lead to psychological and physical health disparities (Chaudoir et al., 2013).

Other scholars such as Deacon et al.’s (2006) contribution to the literature review on disease stigma is relevant in defining stigma as ideologies. At the centre of the analysis lie the issues of power and privilege, and in certain situations people who contract stigmatised diseases are blamed and accused when their HIV status is known (Deacon et al., 2005). Many scholars and researchers, including Campbell and Deacon (2006), Parker and Aggleton (2003), and Goudge et al. (2009), indicate clearly in their work are intersections of power, social, political, economic, gender, and other overlapping variables are all capable of having an impact upon stigmatisation processes. In their view, they contend that stigma is a social process, a social interaction, constantly changing and often resisted, rather than an individual attribute. However, they argue that, in an attempt to recognise the social and political aspects of stigma, researchers tended to define stigma with reference to its discriminatory effects.

Additionally, the literature review has evidenced that global research has identified a strong correlation between unprotected coercive sex, physical and emotional abuses with links to sexually transmitted infections, including HIV/AIDS (Dunkle and Decker, 2013, Jewkes et al., 2010). These scholars traced a plausible biological pathway from gender-based violence to HIV, arguing that men who are physically violent are also physically more likely to be HIV positive, because they are at higher risk of engaging in risky sexual behaviour, with multiple and concurrent sexual partnerships, including transactional sex, and possibly substance abuse. Dunkle and Decker (2013) suggests that sexually violent men are therefore, most likely to report symptoms of sexually transmitted infections and to be confirmed sero-positive status. Unprotected and coercive sex may expose women to sexually transmitted infections and HIV. The need to develop understanding this social construction of stigma, within a specific ecological perspective (for example by examining the influence of gender and other simultaneously intersecting cultural, social,

economic and structural factors) might provide alternative ways of analysing and understanding stigmatisation processes.

In the Gambia, the link between HIV and VAW is an under-researched area of study and there is a need to centralise the voice of HIV sero-positive women and health care practitioners to deepen our understanding of the intersections of the two phenomena.

The next chapter, on the methodological approach of the thesis, is presented in two sections, A and B, which outline the data generation processes by which this research was undertaken during the six months of field work in the Gambia using a feminist participatory approach and thematic analysis to interpret the data.

CHAPTER 5: RESEARCH METHODOLOGY

5.0 Introduction

This chapter, on the methodological approach of the thesis, is presented in two sections. Section A outlines the participatory engagement process – a form of feminist political agenda which, in this case, tries to establish at the centre stage the voices of women living with HIV, and the field practitioners working with them in diverse settings such as health, gender and social development workplace, examining whether there is a connection between violence and HIV. Section B describes in detail the way in which the participants were recruited, the ethical issues of the research, the data generation process and the data analysis processes. The data corpus was analysed using social constructionist thematic analysis process (Braun & Clarke, 2006).

5.1 Section A

In Section A, below, I present the principles of the Feminist Participatory Research Approach (Maguire, 1996, 1987; Renzetti, 1997), followed by an overview of the Action Research paradigm, as advanced by O'Brien (2001). I give an in-depth explanation of how I adopted these two frameworks to generate data, with emphasis on rendering audible the voice, concerns and priorities of women living with HIV to develop insights into the ways they construct their experiences of gender-based violence. The main goal is to generate knowledge for the practical purpose of enhancing violence preventive support and care interventions in connection with HIV/AIDS.

5.1.1 Feminist Participatory Research Approach

I commence with feminist concerns that women's perspectives have often been silenced or ignored, and I have developed a keen interest in creating an inclusive process and encouraging women in the study to speak out without inhibition and fear on issues affecting them, as sisters living on the margins of society who suffer in silence (Hooks, 2015, 2000; Hess-Biber, 2012; Renzetti, 1997). When women remain silent (Human Rights Watch, 2002), they may be keeping secret painful issues that cannot be teased out without sensitivity and tact. I advance here an approach akin to that of Hess-Biber (2012) who observed that, in listening to women, we should be sensitive to gaps and absences in their speech, searching for "what meanings might lie beyond explicit speech" (Hess-

Biber, 2012, p.15); in doing this we provide support to them so that they feel safe to speak out. I will delve into key feminist principles, drawing from the contribution of feminist researchers. We are reminded by Renzetti (1997, p.133) “that there is no single, unified feminist methodology”, largely because there is “no single unified feminist theory”. She suggests, however, that there is a plurality of feminisms (Renzetti, 1997, p.133 citing Delmar, 1986, p.9), and she argues that there are key feminist research principles that could be useful as a guide in undertaking feminist research. Hence, in undertaking the current study, I am guided by a keen sensitivity to feminist concerns. Feminist researchers are concerned about power differentials between men and women in conducting social inquiry. Feminist social inquiry focuses on: (1) gender and women; is (2) committed to uncovering and understanding what causes and sustains women’s oppression, in all its forms within broader society; and (3) is committed to working individually and collectively to end all forms of women’s oppression (Maguire, 1987).

I believe the use of participatory research sits well with the espoused feminist values and central tenets which Renzetti (1997, p.133 citing Cook and Fanow, 1984) discussed in her feminist research, noting that she recognises the diversity of feminist methodological approaches, which inform my own project. First, she reminds us that feminist research promotes the need to focus on gender and to address gender inequality, and as such it implies a strong political and moral commitment to reduce this power hierarchy as a form of inequality. Second, feminist vision advances the goal of “describing or giving voice to personal, everyday experiences”, especially those of women and members of other marginalised groups. Third, in principle, feminist values in research are imbued with a commitment to social action with the goal of helping to bring about change to improve the conditions under which women and the marginalised live. Fourth, the researcher should adopt reflexivity to critically examine the impact of his/her sex, race, social class, and sexual orientation, and additionally, how wider social, political, and economic factors may influence the research process. The fifth principle is fundamentally linked to rejection of the traditional relationship between researcher and the “researched” in favour of approaches that avoid and minimise the hierarchical relationship between the researcher and research participants, making them “subjects” with more power and control in data generation and throughout the research process (Renzetti, 1997, p.133).

In response to the feminist aim of developing a co-operative, mutually beneficial, research process, I am guided by the feminist principles of generating data that allow participants

to actively participate, and to avoid hierarchical, ‘less extractive’ research processes. Hence, I opted for multiple data generation enquiry tools, including focus groups, participants’ self-administered journals/diaries and in-depth individual interviews, which allowed participants to creatively find their own ways to engage in the research process, without feeling pressured to respond to rigidly crafted questions that fail to account for their own lived experiences.

I rationalised that a collaborative project might extract rich, thick data (Geertz, 1973a), as women affected and infected by HIV constructed narratives by drawing on both their experiential and ‘situated knowledge,’ similar to a vision of ‘embodied objectivity’ that accommodates paradoxes and critical feminist reflections of the situatedness of their problems and experiences. As described by Donna Haraway, “feminist objectivity means quite simply situated knowledge” (Haraway, 1988, p.581) consistent with Harding’s conception of ‘strong objectivity’ (1993). I take inspiration from the scholarly contribution of Renzetti (1997, p.142), whose research adopted a feminist participatory model and methodological approach that meshes well with my own research goal of exposing the voices and lived experiences of HIV-positive women in order to create public awareness, and also, where feasible and realistic, I aim to utilise research findings to advance the transformative agenda of feminist research goals aimed at influencing policy and practice interventions. In so doing, I hope to address the problem of violence against women living with HIV/AIDS, an under-researched theme in the Gambia.

This goal is similar to Renzetti’s (1997) own approach of highlighting a research problem, which may be an under-studied phenomenon and may remain “hidden and ignored”, to draw public attention to it; she claimed, for example, that her goal was to explore battered lesbians’ experiences of abuse, and to attempt to empower them through research. While acknowledging the benefits of feminist participatory projects, Renzetti (1997, p.142) offers a cautionary note that, in pursuance of the transformation potential, we should tread carefully and must consider its applicability to our research projects. In a similar vein, while I believe it is essential and critical to aim for a feminist transformative agenda/goal in research, there is a need to explore how realistic, culturally appropriate strategies may be employed to remedy the identified research problem. Yet, while feminist scholars desire to have transformative goals, they should recognise that there may be inherent

difficulties in promoting change, because the proposed change may seek to dismantle the status quo of power and privilege.

In studying and understanding the contextual realities of the research participants, it is apparent that there may be barriers to engagement in transformative vision, thus sensitivity to the socio-cultural context was important when engaging the research participants in this project. My concern is that resistance, fear of negative consequences of ‘disclosure’,¹³ of abuse and violence, may serve as strong barriers, limiting research participants’ ability to break the silence. With this in mind, scholars researching sensitive themes are advised to must build trust and establish cultural sensitivity to the issues of shame and stigma often associated with affected women’s silence as survivors of abuse (Liebling and Shah, 2001; Human Rights Watch, 2002). Liebling and Shah (2001) research on sexual violence, with women from Uganda and girls from Tanzania, is referenced here to show why this is necessary, when conducting research on sensitive themes. The participants they studied in Uganda were female war survivors.

When researching sensitive themes, Liebling and Shah (2001) underscored the importance of building trust and establishing mutual reciprocal relationships. The non-governmental agency Isis-WICCE was able to build trust and forge strong relationships with local communities of the Luwero district before women in the study “spoke out” to researchers about their experiences. As a result, they recommend and call for researchers to use culturally responsive ways to conduct sensitive research, because some of the women “speaking out for the first time about their experiences of sexual violence found it helpful to narrate what happened to them” (Sherwood & Liebling-Kalifani, 2012, pp.87-88). Thus, it is important to recognise that there are circumstances that may limit research participants, rendering them unable to speak out, to share their experiences of abuse.

In my own research I will adopt a culturally sensitive, compassionate and confidential stance to engage participants in a research process that may spur agency, a process that minimises mistrust and inspires sharing of difficult narratives. I too hope to build trust

¹³ The concept of disclosure is placed in quotes because it is a slippery term and can have a variety of meanings. In the context of this thesis, I define disclosure as an action that is not coercive, an unveiling and making known (from participants’ free-will) to share something considered ‘secret’, a revelation of a sensitive issue based on an unfettered choice to share during interview and after being assured of confidentiality. It may be something that the participant would not normally unveil or share with others.

and establish relationships that engineer confidence and willingness for research participants to share their stories, and initiate/facilitate a process that avoids “expert-led” imposition and the objectification of the research participants (Renzetti, 1997, p.133). My own past working relationships – as a Women’s Rights Manager, health and social development practitioner involved in grassroots work and as a professional with previous experience working with HIV Support Societies, it is this work experience that enabled me to undertake this proposed study.

Hence, with regard to the above feminist guiding principles, and as I struggle to find answers to the many other questions as a novice researcher, I ask the following: 1.) How does my own epistemological positionality influence the study? 2.) What are the strategies that have been adopted to manage my own subjectivity and to avoid imposition of my values on the research participants? I refer to the writings of Hesse-Biber (2012) on reflexivity in order to address these questions, which are not easy to answer. However, in line with Hesse-Biber (2012, p.17 citing Hesse-Biber & Leckenby, 2004, p.211), who reminded us that reflexivity is a crucially important process in which the feminist researcher explores their positionality within research, I argue that:

“Feminist researchers are continually and cyclically interrogating their locations as both researcher and as feminist. They engage with the boundaries of their multiple identities and multiple research aims through conscientious reflection. This engagement with their identities and roles impacts the earliest stages of research design. Much of feminist research design is marked by openness to the shifting contexts and fluid intentions of the research questions” (Hesse-Biber, 2012, p.17 citing Hesse-Biber & Leckenby, 2004, p.211).

I rationalise that adopting this approach will reduce concerns about “power hierarchical relationship and may avoid imposition of ‘power’ by the researcher over the research participants” (Renzetti, 2009). Thus, in adopting this stance, to undertake a feminist participatory research process as advanced by Maguire (1996, 1987) and Reason and Bradbury (2008), I was concerned that the inquiry process should be one that promoted active engagement of co-research participants and research participants.¹⁴ The footnote

¹⁴ I have used the terms co-researchers and/or research participants interchangeably in this thesis. The term “co-researcher” is deliberately used to refer to the sixty women living with HIV who volunteered to jointly generate the data. I hope to continue working with them throughout all the action research phases which follow this doctoral programme. I also interviewed field workers from diverse multidisciplinary sectors, mainly from sexual reproductive health clinics, and rural and local community health care workers. In Action Research parlance, a collaborative project is one in which the research participants are co-

explains how I have utilised the term co-researcher and research participants interchangeably in the study. All eighty volunteers are referred to in this thesis as both ‘co-researchers’ and ‘research participants, interchangeably.

Additionally, I am guided by feminist claims that persons from the margins can contribute to knowledge creation based on their own lived experiences, not seeking to speak for them, but rendering audible and relocating their own voices from the margins to the centre (Hooks, 2000). From my work experience as a health and development practitioner, I have gathered knowledge that participatory approaches work if they are genuinely engaging and inclusive. Also, the literature from Freire (1978) espouses the need for people who experience oppression to be active in confronting the way structural injustice affects them through conscientisation and awareness creation processes (Freire, 1978). When reflecting on their epistemological response the researcher is reminded by Denzin (1986) that, “interpretive research begins and ends with the biography and self of the researcher” (Denzin, 1986, p.12). Under the next heading I explore in-depth my own positionality and subjectivity in the current study, striving to write a reflexive biography to explain how it might influence the study.

5.1.1.2 Researcher epistemological position and subjectivity statement

My own epistemological positionality is grounded in feminism, and in the current study is informed by a constructionist ontological paradigm. I also draw from feminist philosophy and key research principles guiding the manner in which research is to be conducted.¹⁵ This is because feminists have realised that, over the years, men have disproportionately dominated scientific research, and largely influenced most philosophical conceptualisation of the origins of knowledge. I position myself as an

researchers and, using focus groups, I engaged all of these categories of personnel (twenty individuals) in the cyclical process of reflection, action and reflection (on an on-going basis), to seek joint solutions to identified problem(s) through research. In the section dealing with the Action Research Process I have further explained how co-researchers were defined in the current study. This project defines women as co-researchers because we are all ‘learners and teachers’ in problem analysis, and as co-researchers they possess useful knowledge and experiences from which to make an informed contribution and recommendations suggesting the way forward.

¹⁵ Feminist researchers’ claims of representing others have been challenged and it is essential that I consciously reflect on the criticism that when we claim to be representing the voice of the marginalised and maybe we do so from our own privileged position of power. Thus, as a researcher conscious of this unequal power relationship in the production of knowledge and working with marginalised people, I ask the question: Who defines the marginalised or voiceless? In response, I suggest that it is the participants who must define themselves and name their own situation, not the researcher, as argued by Hinterberger (2007, pp.74-76).

indigenous, middle aged, female Gambian, studying abroad. First, I identify myself as a professionally trained health, gender advocate and community - based field practitioner. Second, I am as a budding feminist African scholar researching violence against women. I am particularly interested in developing an Afrocentric understanding of the nuanced social, cultural, religious, ethnic influences affecting women as I engage in collaborative social research on VAW and HIV, from a vantage point of affected women to unveil their contextual reality and thus develop better insights and deeper understanding of the situatedness (Haraway, 1988, p.581) of the problem of violence and HIV.

My own positionality is that of a culturally sensitive insider, who is aware of the critical gendered and embodied messages in our local language (parables, local proverbs and sayings) that are a part of the Gambian, ethnic, cultural and socially constructed gendered scripts that denigrate and objectify women. My cultural insider positionality provides me with an advantage in interrogating and clearly understanding complex interactions of ethnic, religious, and socio-cultural norms and practices that normalise and render women vulnerable to a range of abuses. I use these cultural insights and contextual understanding to demonstrate an interpretive competence and sensitivity when analysing my data.

The above reflexive analysis of my positionality is influenced by Sharlene Hesse-Biber (2012) essay on usefulness of reflexive accounts and examination of researcher positionality. She writes:

“Focusing on our positionality within the research process helps to break down the idea that research is the ‘view from nowhere’” (p.17).

Hesse-Biber (2012) believes it is important that feminist research practitioners pay particular attention to reflexivity, a process whereby researchers recognise, examine and understand how their social background, location, and assumptions affect their research practices. Thus, she writes that practicing reflexivity includes paying particular attention to the specific ways in which our own research agenda affects the research at all points in the research process – to include the selection of the research problem, selection of research methodological approach, methods, and data analytical tools and how the findings are disseminated.

It is evident that rendering transparent a researcher's subjectivity and assumptions is quite a complex process, and often a very difficult one to engage in. Where do I start? What do I choose to include? How much personal information do I need to expose as a way of demonstrating my declared epistemological positionality? These were key questions I struggled to answer, and am exploring as an on-going process, because I am the medium through which the research topic was selected and also through which the project was designed. The selection of a feminist participatory methodological approach was also based on, prior experiences and familiarity with use of participatory inquiry tools, to undertake research on gender-based violence and injustices which I believe are both gendered and structural, and my commitment to work with others to confront and seek ways to address the issues featured prominently.

My insider knowledge garnered from previous work experience tells me that most Gambian women growing up in rigidly structured patriarchal contexts (although I recognise the diversity and multiplicity of patriarchies as advanced by Hunnicutt, 2009) may experience difficulties articulating and breaking the silence concerning experiences of abuses in their lives, because of the shame and stigma. Armed with such information, the current project is designed to prioritise women's voice, even though it should be noted that both men and women were to be found in the Support Societies (an observed limitation of my research approach). I declare that the prioritisation of women's voices is a source of bias, but a stance I consciously opted for because of women's history of being silenced and their experiences of abuse which may not be visible, and normalised. I recognise the connection between all forms of violence, whether sexual, physical, emotional, or economic, which is the normalised basis of violence in the Gambia. Thus, my own subjective experience is useful as foreground knowledge about the fear surrounding disclosure of gender-based abuses before and after HIV diagnoses.

A brief background information may shed light on my subjective experiences. I recognise conducting research with women from diverse backgrounds to understand the intersection of violence and HIV, I straddle an insider and outsider positionality (Innes, 2009) work is useful in explaining the insider/outsider debate which enabled me to narrate my own insider and outsider status and positionality in the current research. As an indigenous Gambian woman, I have lived the experiences of being verbally threatened, emotionally and economically denied of my rights based on my gender, and at different trajectories of

my life, particularly as a married woman. My spouse has utilised his wealth and economic power to coerce and control me to conform to his wishes. I have experienced both moments of resistance and acquiesce as I struggle to define my own space and prioritise my needs but the process was not been easy because of the influence of peer pressure and other extended family members. I argue that, as a Gambian woman researching the problem of violence and HIV/AIDS, my insider perspective, and awareness of everyday violence as normalised in the Gambian context, is based on my own subjective experience and awareness, that I can theorise from the vantage point of ‘the subjugated’, as explained by Haraway (1988, p.583).

Like many other Gambian woman, we are constantly exposed to derogatory embodied messages and insults, for simply transgressing deeply embedded norms. Also, physical and corporal punishment of children, wife beating are normal and acceptable in many parts of the Gambia. Over several decades in my own life, I experienced gender-based psychological and economic abuses and I am aware of the normalisation and ‘silencing’ of a range of physical emotional and verbal insults against the girl-child and women at home (Human Rights Watch, 2000; 2002). As Human Rights Watch indicated in their reports (2000; 2002), many women suffer in silence and it is important to “break this silence” in several communities around the country. For several women in the Gambia silence is a coping strategy, it is explained as a form of peaceful resistance. However, there have been noticeable changes in attitude and practice with the introduction of policies, protective laws and preventive intervention that promote women and children’s rights as stipulated in the Gambia’s Women’s Act (2010) and the Gambia Children’s Act (2005) and various child protection policies and laws. The process of change is gradual.

Awareness of the sensitive nature of the research might shed light on those potentially difficult and sensitive themes that the research participants may choose to reveal, because research into sensitive topics can include areas which are considered “private, stressful or sacred”, or as Liebling and Shah (2001, citing Lee (1993, p.4) explain, themes that are sensitive and may “potentially expose stigmatising or incriminating information” needs sensitivity and awareness of the potential threats surrounding disclosure, or narration of women’s experiences. The potential for pain and harm to individuals and difficulty of assessing the number of affected women accurately are key issues to address (Liebling & Shah, 2001 citing Herzberger, 1993). For instance, in their study, it was difficult to assess

accurately the number of women who were raped during the Luwero civil war and the number of girls who were sexually abused and exploited in Tanzania, because there may be inhibiting factors that constrain women to speak about their experiences, which could be due to fear and the cultural sensitivities that surround sensitive themes.

To further clarify my positionality, although I consider myself as both an insider and an outsider, as an indigenous researcher, resident abroad but studying gender-based violence and its manifestations and effects in my home country, I am fully aware that even in a small country such as the Gambia, there are occasions where my nationality and gender are inadequate to qualify me as an insider. However, from past work experience of living in the rural communities of the Gambia, a country with a rich diversity of cultural norms and practices largely influenced by differences in ethnicity and location (rural and urban location) I am aware that there are significant differences between rural/urban geographic locations, and differences in class and religious belief which may need to be acknowledged here.

For illustrative purposes, I recognise differences between myself (the lead researcher) and co-research participants. Let me dilate on a difference that I, coming from a minority tribal group that does not practice FGM/C, and there are conscious adjustments I will make to suspend my beliefs when encountering women from diverse ethnic groups that practice FGM/C, early and forced marriages. While I do not share their cultural and gendered norm and belief systems and do not condone the practices of FGM/C, I acknowledge that there were instances when, speaking with women who had undergone the surgery, they may have been reluctant to discuss the matter with an ‘uncut woman’ such as myself because I was not one of them. In my past work experience I have encountered such feelings of alienation. They may have assigned me a devalued status as an ‘uncut’ or unclean ‘solima’, a local label assigned to uncircumcised women in the Gambia. It is important to note, however, that my awareness of stigma ideologies and understanding of local labels/metaphors gave me – an uncut woman – an advantage in developing clarity about their unwillingness to share their narrative with me. Thus, because I am an indigene, and have developed over time a deeper insight into their situation, I understand the reasons for some women’s refusal to discuss these forms of violence against women, especially themes on FGM/C.

I am a culturally responsive researcher, aware of and sensitive to the creative ways in which ethnic groups utilise jokes (declaring that I am a solima) and understand why they might not have wanted to share sensitive details with me. This admission to being uncut, in a culturally nuanced manner serves as an ice breaker. Additionally, my own familiarity with non-verbal signals which are understood by in-groups within our cultural context ('knowing the eye') was of value. These could have been missed by non-Gambians. I acknowledge the significance of naming my positionality, being informed by a social constructionist paradigm that takes account of the influence of wider social contexts and structural factors, and influencing research participants' accounts and experiences as well as feminist principles.

In summary, as I reflect on my own research agenda, I was interested in developing a cooperative research project, one that creates a platform to enhance discussion, and to jointly confront the problem of violence as research participants share experiences, affirming each other's views in a mutually supportive manner, while at the same time allowing the researcher to "see through the research participants' own eyes", to borrow a phrase from Bryman (2012, pp.399-400), as participants are encouraged to speak out from their own experiential knowledge. My assumption is that, when research participants are supported and trust built, hitherto 'silenced individuals' (for instance women living with HIV) may be willing to divulge sensitive and difficult issues that may reveal the underlying issues affecting them. Also, if they willingly choose to participate in focus groups, their interaction may help them to raise critical questions and may serve as a platform from which to forge collective force. They may even seek practical ways (or suggest solutions and priorities) to ameliorate the identified problems.

I have chosen to engage the researcher participants in a collaborative investigative process that will advance the inherent goals of feminist interventionist and transformative options in social research, which resonates with the viewpoints of scholars like Bell Hooks (2015, p.20), who advocate inclusive processes, and also Sandra Harding and Kathleen Norberg (2005, p.2011), who stated:

"Feminist researchers have insisted that their research projects have practical implications for the improvement of women's lives. Thus they have developed the controversial notions that research itself can contribute to producing

liberatory, transformative subjectivity in an oppressed or marginalised group and that this kind of engaged ... research can produce the knowledge that such a group desire” (Harding and Norberg 2005, p.2011)

It is my strong conviction and desire to create a platform of inquiry in which participants will frankly discuss this sensitivity topic under investigation. To realise this goal, I choose to adopt an action research approach.

5.1.2 Action research (AR): Why choose action research?

What is Action Research? According to Peter Reason and Hilary Bradbury’s Handbook of Action Research (2008), it is a:

“[P]articipatory, democratic process concerned with developing practical knowing in pursuits of worthwhile human purposes. It seeks to bring together action and reflection, theory and practice, in participation with others, in pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities” (Reason & Bradbury, 2008, p.4).

Action Research is concerned with the development of ‘living knowledge for emancipatory purposes’, where possible. Drawing on the work of Action Researchers, it is suggested that primarily action research focuses on seeking creative ways to turn “the people into researchers, because individuals learn best, and more willingly apply what they have learned, when they do it themselves” (O’Brien, 2001; Freire, 1978). Thus we all act as learners and teachers in the process of generating knowledge grounded on our own lived experiences.

Below I explore another definition of action research derived from the work of Rory O’Brien (2001), that action research is “learning by doing” and it is a form of collaborative project working with a group of people who identify a research problem, and do something to resolve the problem and also engage in assessment of the interventions to evaluate how successful their efforts are, and if not satisfied, try again. This process brings out clearly action research’s cyclical nature of systematic research,

involving phases in sequences of problem identification, reflection, action, and evaluation. The process can be repeated several times as the need arises.

O'Brien (2001), however, highlights key attributes of action research that differentiate the research process from common problem-solving activities by providing a more succinct definition that action “research aims to contribute both to the practical concerns of people in an immediate problematic situation and to further the goals of social science research simultaneously”. Thus, there is a dual commitment in action research to study a system and concurrently to collaborate with members of the system in changing it in what is together regarded as a desirable direction. Accomplishing this twin goal requires active collaboration between the researcher and research participants. As O'Brien argues, it stresses the importance of co-learning as a primary aspect of the research process (O'Brien, 2001 citing Gilmore et al., 1986, p.161).

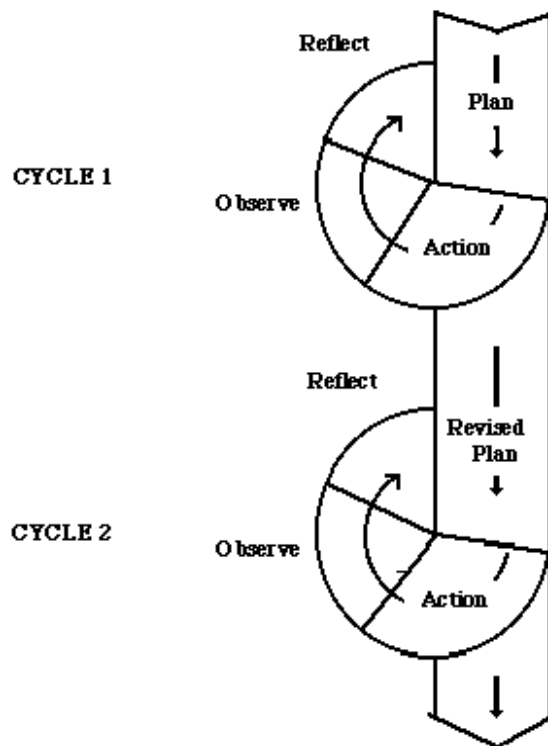


Figure 9: A pictorial representation of a simple Action Research Model (derived from O'Brien, 2001).

The above diagram illustrates the four critical phases of O'Brien's (2001) Action Research model: *plan*, *action*, *observe*, and *reflect*, with the cycle being repeated as the problems are investigated and attempts made to transform them. Historically, the key

proponent of the above is Kurt Lewin, who is considered to be the “father of action research” (O’Brien, 2001). He was concerned with addressing social problems by utilising participatory group processes to address change and manage conflicts generally within organisations. Following on from the above, I now present another model by O’Brien (2001) with adaptations based on the work of Gerald Susman whose own model involves a circular process of questioning and providing answers in order to engage in the phases: diagnosis, action plan, implementation of the plan of action, evaluation, and specification of the learning outcomes. The phases of the model are:

1. Phase 1: Definition of the problem
2. Phase 2: Explore several options for a plan of action
3. Phase 3: Selecting a course of action
4. Phase 4: Evaluating and studying the consequence of actions
5. Phase 5: Specify learning, identify learning outcomes, re-assessment of the problem and interventions adopted

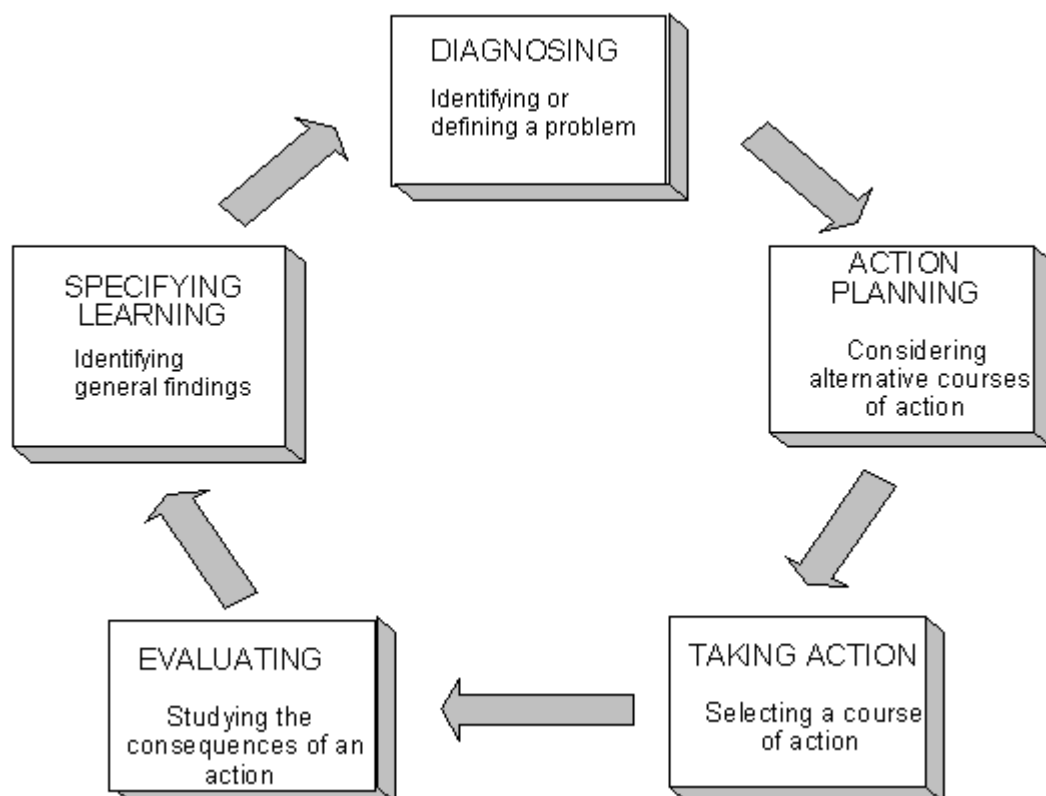


Figure 10: An adapted version of the Action Research Model (adaptation by O’Brien, 2001, sourced from Susman, 1983).

The above is a diagram figure 10 showing the action research cycle. As the initiator of the current study for my doctoral programme, I made a number of adaptations to the model described above because not all the phases of the Action Research model could be implemented during the main research phase. But did I gloss over the research process? No. Whilst I realised that it was important to address and transparently explore the dilemmas and challenges faced in the field, I register here that it was not possible to complete all the cycles, however, the cyclical nature of Action Research offers a built-in mechanism for making adaptations, as O'Brien (2001) writes:

“Much of the researcher’s time is spent on refining the methodological tools to suit the exigencies of the situation, and on collecting, analysing, and presenting data in an ongoing, cyclical basis” (O'Brien, 2001).

O'Brien (2001) suggests, Action Research is a scientific study, and accordingly, the researcher studies the research problem systematically and ensures the processes of investigation and intervention are informed by theoretical consideration. Furthermore, O'Brien (2001) notes that, unlike other disciplines, in AR the researcher makes no attempt to remain objective, but openly acknowledges their subjective bias. .

5.1.2.1 Application of the Action Research cycle

In the current research, I will be interviewing the research participants in order to bring out their real life experiences with the main goal of addressing their identified problems. The initiating researcher, unlike in other disciplines, makes no attempt to remain objective, but openly acknowledges her bias to the other participants. Whilst working through the phases explained below, I acknowledged my assumptions and bias: in providing support to the field practitioners and women through the pilot training; and in encouraging and supporting people to learn from each other. I wanted women in the study to be open, proactively engaging with problem identification, in critical reflection about the issues, and in examining the underlying problems and factors contributing to the problem, and to the seeking of solutions.

It was possible to experiment with in the pilot stage in two Support Societies in rural settings. The pilot stage offered opportunities for research participants to feel free to share and created safe spaces for in-depth and frank reflections on the problems of violence,

stigma and discrimination with keen sensitivity to the difficult nature of the topic under investigation. During the pilot we tested the checklist of questions for clarity and the research participants provided feedback for appropriate changes to be made. Also, for many of the women, I discovered that most of the participants had prior knowledge of the focus group discussion process.

The following stages were an adaptation of the cycles, in which I modified some of the phases to suit my own research and contextual realities. I attempted to follow the steps, but this was dependent upon situational feasibility, and I knew that where this was not possible the model was not a process ‘cast in stone’. Thus, I made relevant adjustments and plan to continue the Action Research cyclical phases as part of my post-doctoral work, after implementing the various phases in the field as documented below in the next section.

5.1.2.2 Definition of the problem of violence and HIV/AIDS

I was the originator of the research topic which I selected as part of my doctoral research project. My interest in researching the problem of violence against women and its intersection with HIV/AIDS stems from my professional interest in developing an understanding of the phenomenon. To do this I decided to conduct field work in the Gambia, working in collaboration with affected women, health care, gender and social development practitioners. The data was gathered using several tools as the project relied on research participants who played a critical role in generating the data derived during focus group interviews, from women’s journal entries, and from in-depth individual interviews. The discussions were lively as they examined the participants’ experiences, their subjective accounts of stigma, the effects and I probed to develop understanding of the root causes of abuses they experienced. Also the field practitioners made useful contributions in exploring the challenges and opportunities of working with PLHIVs (refer to Appendix 3A and 3B for the guided checklist of questions utilised during the interviews).

5.1.2.3 Analysis of the research problem and development of action plans

I was responsible for the data analysis, although some of the local dialects were translated into English for me. I carried out most of the analysis because I relocated to the United Kingdom from where I continued to compile the research findings. Following the

compilation of the final report, I conducted consultations and will follow up with a planned series of validation workshops in the Gambia to obtain final feedback on the key findings and recommendations as part of the Action Research process. In this way I will enjoin the research participants and key stakeholders to engage in collective postulation of several possible options, examining alternatives and solutions they would prioritise as part of the follow-up strategic interventions. Their input will be necessary in the development of plan(s) of action that might emerge after the series of validation workshops which will reflect upon and scrutinise my recommendations based on the findings of the research.

5.1.2.4 Taking action, selecting a course of action

Part of this process has already begun, as the participants mentioned the recommendations they felt most strongly about in their diaries, during the focus groups, and during individual in-depth interviews. It is a cyclical process of engaging women living with HIV in learning and sharing information to generate the datasets, and as part of the cycle of action research to validate the research findings and develop strategic interventions to find key solutions to the problem of violence as it is linked to HIV/AIDS. Since I am committed to continuing this process upon return to the Gambia, the action research cycle is cyclical.

5.1.2.5 Evaluating and studying the consequences of actions

Contingent upon the agreed strategic plans and outcome indicators that will be accepted, as the process continues, another research cycle will be implemented as part of an in-built mechanism to collate new data on the results of the interventions implemented. This is in line with data being collected and analysed at the 3rd and 4th phase in order to utilise the findings, and it must be interpreted in light of how successful the proposed remedial actions have been. In such a situation, the key actions which I envisage may include preventive, support and care interventions for women living with HIV.

5.1.2.6 Specify learning, identify general findings

At this point, the problem is re-assessed and the process begins another cycle. Not all of the phases have been completed in the current study. This phase is to be followed through in future, to explore the options, and to continue with the cycle. It is based upon the participants' desire to proceed, and if they choose to make changes I would accommodate

these new suggestions and input after I have held a series of validation workshops with them in the Gambia. According to the Action Research cycle of problem solving, reflection and action, it will be possible to use my doctoral research findings to engage in future interventions based on the input of other research participants, as explained by Rory O'Brien (2001). It was not possible in the course of the current research to complete all the proposed action research phases during the field work conducted in the Gambia.

5.2 Section B: Methods used

This section will describe in detail the way in which the participants were recruited, the ethical issues guiding the research process, the data generation, and the data analysis process. The data corpus was analysed using social constructionist thematic analysis (Braun & Clarke, 2006), as explained in the introductory chapter. In addressing the issues of voice and collaborative endeavour I was fully aware of the sensitive nature of research into violence, HIV and AIDS. The overarching goal influencing the selection of a method, and the guiding principles were informed by a quest for techniques that would best capture and represent women's concerns and experiences and also enhance their agency in transforming and reducing the incidence of VAW and HIV/AIDS. From the women and field practitioners' narratives and suggestions I will derive recommendations to prevent violence as it intersects with HIV/AIDS in the Gambia. Thus, the research utilised the following collection methods which included diaries, focus groups and in-depth individual interviews with a participant group of sixty sero-positive women in six Gambian HIV Support Societies, and twenty field practitioners working in the areas of violence and HIV/AIDS work in the Gambia.

5.2.1.1 Accessing research participants: Selection of women as co-researchers

The participants for this research were recruited purposively and through snowball sampling (Bryman, 2012, p.202) from Support Societies and also from an umbrella organisation of women affected and infected by HIV/AIDS, called the Mutapola Voices. The latter had a membership of women living with HIV/AIDS in various parts of the country, in decentralised regions in the urban and rural areas. Bryman (2012) describes snowball sampling as an approach to sampling, whereby the researcher makes initial contact with a small group of people who are relevant to the investigation of the research topic and then uses these contacts to establish contacts with others (Bryman 2012, p. 202). I also used an approach like this by inviting initially a range of potential research

participants who met the criteria listed below to volunteer as participants in the current study, within the Support Societies and they also assisted me to recruit other volunteers.

The inclusion criteria for this study involved identifying participants who defined or described themselves as persons living with HIV/AIDS who were registered members of a Support Society and/or Mutapola Voices. In order to participate, the women were asked if they were diagnosed with HIV, and if they believed they had experienced HIV stigma or abuse, and/or thought they might like to share their experiences (no age limit). A total of sixty women volunteered for the study. Due to the sensitive nature of the topic under investigation (HIV/AIDS and its connectedness to VAW), I was concerned that I may not recruit many women because of the sensitive nature of the topic, however I was in a position to recruit many more than anticipated. However, I was able to recruit sixty women living with HIV and I also managed to interview twenty field practitioners, making a total of eighty research participants. My insider status and prior professional contacts with the Support Societies enabled me to access seemingly hard to reach research participants. I was apprehensive as I entered the field, however as I built trust and established a relationship with the women and field practitioners (consisting of health, gender and public health care and clinical practitioners), we were able to conduct the interviews without inhibitions and fears.

Given the high degree of stigmatisation in the Gambia, and sensitivity surrounding HIV and violence research, I knew that I needed to build the trust and establish rapport with research participants (Leibling & Shah, 2001) and key 'gatekeepers' in order to invite them as volunteers for the research. Several of the HIV/AIDS peer educators, and community based care volunteers played a pivotal role in assisting me to meet most of the research participants. In the HIV Support Societies, I gained access to potential research participants after explaining my research intentions and proposals and building trust with the key informants and gate-keepers (the majority are men and are the Support Society presidents).

Initially, it was with trepidation that I embarked upon the six months' field work in the Gambia. I was nervous, and fearful that I may not be able to find sufficient volunteers. However, although I anticipated several challenges with building trust and accessing the women, after several visits to the Support Societies, I was eventually given the space and

time to invite potential research participants. After every session, I knew that I had answered their questions and allayed their fears and concerns about confidentiality and maintaining trust and confidence. If they were still concerned, I took time to explain their right to freely volunteer as co-researchers and that after enrolment they would have the freedom to rescind consent, even if initially they had freely given consent. This was an assurance they valued and they knew that they could subsequently withdraw at any time without explanation or fear of repercussions. The recruitment process was complete when I had enlisted sixty HIV-positive women and twenty field practitioners to volunteer as participants

5.2.2 Accessing key informants from a multi-sectoral team of professionals

I recruited a diverse group of field practitioners who are from the health sector (fifteen male volunteers and five females, a total of professionally trained personnel) who are health professionals, gender and social development practitioners, who identified themselves as professionals working with the affected women in the field of health, gender and social work, countrywide. Also within the within the Support Societies and through Mutapola Voices of Women living with HIV,¹⁶ who were recruited and interviewed were women living with HIV and identified themselves as HIV/AIDS peer educators and community home - based care volunteers, These HIV peer volunteers were found at the Support Societies and some of them were involved with HIV preventive work, and community home-based care and support interventions.

The recruitment of participants was possible because I was given the opportunity to discuss the project at monthly meetings at the Support Society locations. After several consultative meetings with the potential volunteers I was in a position to present to them the summarised versions of my research goals and objectives, and interview guide in vernacular. I informed them that I sought to engage them as partners during the research process and to elicit their views in a piece of participatory interventionist research. I also mentioned the ethical concerns and procedures prior to obtaining informed consent.

It may be relevant at this juncture to explain how I contacted colleagues I had previously known in the field. These were practitioners I knew as clinical and community social

¹⁶ One of the organisations was the Mutapola Voices of Women which is not a Support Society but an organisation of women who are infected and affected by HIV/AIDS in the Gambia.

workers, health care and HIV prevention professionals. Through them, using purposive sampling, and also by word-of-mouth, current members and staff of HIV Support groups and HIV peer counsellors would recommend health and gender or social work professionals to me to invite. I sent letters or called them to invite them to participate for interviews. This was for health care and development workers, working in non-governmental, organisations. With regard to the local community health care workers, I recruited them through snowballing as they volunteered to be interviewed based on their experiences and involvement in HIV and gender-based violence preventive work in the Gambia.

5.2.3 The use of interpreters and translators

During the field work, local interpreters/local language translators were selected from amongst the available volunteers (PLHIVs) and given basic instruction about prioritising the voice of all research participants. As I facilitated the interview process I was particularly determined to create a safe and engaging platform. As part of my ethical review commitment I discussed with all the research participants the privileged position of being present in the interviews and I ensured that all who took part signed confidentiality forms to protect identities and the information shared amongst the women (PLHIVs and field practitioners). Thus, throughout the research process, both in the field and after, I ensured that the data could not be linked to or identified with the participants by assigning pseudonyms, although some preferred numbers. Where I had to confer with my supervisors, confidentiality was maintained at all times. Interpreters were recruited from volunteers amongst the persons living with HIV, and were often peer health counsellors, or Support Society presidents and social workers I found within the organisations where the interview was taking place. Several PLHIVs could speak a number of local dialects, for example, Mandinka, Fulla and Wolof. Those who acted as interpreters were sworn to confidentiality and adhered to ethical norms and practices of anonymity. I was guided by research protocols detailing the participant information and ethical issues I had to address (Refer to Appendix 4) which was prepared in advance as requirement before ethical review clearance from the University of Sussex (Refer to Appendix 2), and at all of the Support Societies, which were made available for participants' scrutiny.

The volunteers finally were informed of their right to decline participation and I emphasised that there would be back-up social workers and peer HIV/AIDS counsellors, if needed for counselling support and that confidentiality safeguards would be in place. Ethical considerations continued to be observed during the fieldwork, and during subsequent follow up work and analysis. I ensured that my ongoing commitment to maintaining and preserving the anonymity and rights of participants was clearly communicated, as was their right to withdraw at any time. It was particularly important in all the interviews, but most especially in the FGDs, to remind participants before and after about the strict confidentiality of the information shared. Further, the study involved issues of confidentiality and record management and it was necessary to ensure strict adherence to the Data Protection Act of 1998 when processing participants' personal information to ensure the physical and technical protection of their identities and anonymity.

5.2.4 Ethical issues

The ethical review process I went through to gain clearance for this research (from the University of Sussex) was stringent and thorough (Please refer to Appendices 2 for the ethical review clearance certificate). Also, my reading of the World Health Organisation's ethical guidance (entitled *Putting Women's Safety First* (1999)), and training received in the past as a social work graduate on ethical issues for human subjects in social science research, clearly prepared me to deal with any issues and to make contingency plans as outlined in the ethical and safety standards and recommendations for researching violence against women in its various forms.

As the lead researcher collaborating with co-researchers, I acknowledge here that women who suffer violence and who attempt to disclose could become psychologically and emotionally distressed when recalling/remembering the events. Prior to each interview session and afterwards, I provided information about the support made available in-house to counsel and discuss any challenges. Additionally, the participants were given consent forms to sign before starting the interview and at the end of each interview an opportunity was created for them to ask questions and to contribute in areas they considered relevant. Alongside this, participants were reminded that they could talk to the social workers and peer health counsellors with regard to any potentially distressing information that they may have discussed or wanted to disclose. I reminded them about the potentially

stigmatising and sensitive information which we had shared in the focus groups and bound them to strict confidentiality and anonymity because the information learned during the conversation could be very private, incriminating or close to the heart of the interviewee (Leibling & Shah, 2001, p.3).

5.2.4.1 Anonymised participants' data and the location of the Support Societies

To avoid breach of confidentiality the names and exact locations of the Support Societies are not included for ethical and security reasons and also to avoid confidentiality breaches, and risks of stigmatisation and/or discrimination. I recognise that revealing their exact locations would affect them, therefore, I have anonymised the locations and names of the organisations.

Most importantly, the issue of confidentiality and respect for the rights of women to find safe 'spaces' in which they would feel free to talk was foremost as I negotiated access to the participants. Given the nature of HIV/AIDS and GBVAW as two high risk themes, the need to strictly follow ethical guidelines and to maintain risk reduction strategies was paramount. This situation is understandable given the high degree of secrecy and fear of unwarranted attention on the part of the HIV Support Societies. Also, it is a known fact that HIV/AIDS stigmatisation and discrimination are very challenging problems in the Gambian context, thus the need for enhanced sensitivity and to maintain safe anonymised confidential spaces was respected and recognised at all times as I gained access to research participants in the Support Societies through their gatekeepers. I was committed in maintain confidentiality and safety concerns of interviewees/respondents at all times.

5.2.5 The data generation process

This research is a qualitative study and it was conducted in two phases. The first was a pilot phase undertaken to test the participatory inquiry tools and sampling of the research participants to ensure that they were appropriate ways of generating data to answer the research questions, while at the same time avoiding a paternalistic attitude and consciously promoting the views of research participants, in order to capture the contextual realities. This was in line with the rationale, objectives, and feminist ontological and epistemological orientation of the research. Mason (2002) argued that "qualitative research is particularly good at constituting arguments about how things work in particular contexts ... rather than representing the full range of experience" (Mason,

2002, p.136). In the pilot study, I was interested in capturing the experiences of women who were living with HIV, through feminist participatory research. During the pilot phase, adjustments were made to the research protocols and guided checklist of questions (see attached Appendices 2) for the interview guided checklist utilised to conduct the study). The next phase was the main phase of the research which used focus group interviews, self-administered diaries/journals and in-depth interviews

5.2.5.1 The interview process

To commence the interview process, I developed strategies which differed depending on the interview context presented. As part of a ‘warm-up’ strategy geared towards opening up a safe unfettered platform for candid focus group discussions that empowered women and field practitioners to talk freely, I would sometimes turn to the posters on the wall, asking research participants to examine them and to talk freely about them. I would say for instance – Tell me, what does it say to you? The posters found on display at the Support Societies and on bill boards in local communities, proved to be very useful forms of ‘ice breaker’ before commencing the topic under investigation. Numerous opportunities were presented and explored as I collaborated with women in various HIV/AIDS Support Societies. During the interviews and throughout the field work I kept an audio journal and also wrote notes to track my thoughts, reactions and experiences.

This was useful in interrogating my own assumptions and subjectivity. I adopted a conversational style during the interviews which allowed the participants to talk freely and openly about their experiences. It also allowed me to probe and ask questions for clarity. The interview schedule and guided checklist of questions developed for this study can be found in (Appendix 3A and 3B). The development of this interview schedule was an organic process that occurred before and during the pilot phase. First, before going into the field I sent the interview schedule to my supervisor who helped me to review and refine it by developing key exploratory questions aimed at capturing the experiences of the research participants.

In addition to this, during the pilot phase and at the beginning of each interview I asked the participants to quickly review my exploratory questions and to add any areas that they felt should be included in the interview schedule. This was in accordance with the

principles of co-authoring interviews as recommended by Kvale & Brinkman (2009), to render the process participatory.

5.2.5.2 Managing multiple enquiry tools

This thesis is based on data generated from field work conducted in the Gambia, it is grounded in data related to HIV positive women's experiences with a focus on probing to reveal context specific complexities and challenges. Data collection methods included diaries, focus groups and in-depth individual interviews with a participant group of sixty sero-positive women from six Gambian HIV Support Societies across the rural and urban areas of the Gambia, and twenty field practitioners working in the areas of gender, health care services, community violence and HIV/AIDS. The use of multiple research methods afforded the flexibility to invite research participants to choose to be part of focus group discussions (FGD), individual interviews, and/or journaling data collection approaches.

While most of the sixty women who consented to participate in the study, opted for focus groups, four women who originally consented, failed to attend on the day of the scheduled interview. However, much later, while I was still in the field in the rural community, they contacted me to schedule new interview dates. The reasons for not attending were various; my field notes, and text messages sent to me by the research participants indicate that one could not attend because she had given birth and two others had recently been bereaved (one had lost a six-month-old baby and the spouse of another had died after prolonged illness with an AIDS-related opportunistic disease – pulmonary tuberculosis). This lady was in mourning and was traditionally required to be in seclusion, but I had reached her through snowball sampling and her strong conviction and determination to meet with me to share her story personally was humbling. I granted her wish and felt that she was courageous to meet me. One of the women sent her journal through another research participant. Some women opted to be interviewed individually because they felt the issue they wanted to discuss with me concerning their experiences was sensitive, and I respected their choice.

The flexibility of qualitative research enabled me to use diverse approaches to frame the interview encounter. I used unstructured and semi-structured interview techniques, in preference to surveys, to generate data. This, in my view, resonates with Oakley's (1989) observation, corroborated by (Bryman, 2012, pp.491-492 citing Oakley, 1989), that

feminists favour focus groups and qualitative research because it allows for a less extractive and more democratic relationship between researcher and interviewees. For instance, Bryman (2012) and Wilkinson (1999) identify FGD as a face-to-face interactive process with capacity to empower research participants. This form of interactive research is consistent with, and sensitive to, key feminist principles that deflect power away from the researcher, advancing a less hierarchical research relationship. Ann Oakley has written several articles and made a significant contribution to scholarly debate advancing the need for non-hierarchical relationships and a top-down approach. Bryman (2012, pp. 491-492 citing Oakley, 1989) suggests that the standard survey interview has limiting effects for the following reasons:

- “It is a one-way process – the interviewer extracts information or views from the interviewee.”
- “The interviewer offers nothing in return for the extraction of information. For example, interviewers using a structured interview do not offer information or their own views if asked. Indeed, they are typically advised not to do such things because of worries about contaminating their respondents’ answers.”
- “The interviewer-interviewee relationship is a form of hierarchical or power relationship. Interviewers arrogate to themselves the right to ask questions, implicitly placing their interviewees in a position of subservience or inferiority” (Bryman 2012, p.492).

Instead feminist researchers advocate a research process and principles that establish a high level of rapport between interviewer and interviewee, reciprocity on the part of the interviewer, fostering nonhierarchical relationship in the research process; and focusing on the perspectives of the women being interviewed (Bryman 2012, p.492)

5.2.5.3 The focus group interviews

The focus group discussions (FGDs) I conducted were with the field workers and also with sero-positive women during the field work in rural and urban areas. The focus groups took place within the Support Societies and were arranged by the residents of the Support Societies with key assistance from Mutapola Voices. I worked with a core of active participants who made phone calls, arranged the scheduled interviews, and generally dealt with the logistics for the fieldwork, enabling me to facilitate the interviews. In order to

gather and generate this data, I conducted ten focus group discussions with sixty HIV-positive women from six support societies within the rural and urban areas of the Gambia. Each FGD consisted of four to six women, and lasted sixty to ninety minutes. In addition, individual in-depth interviews were conducted with ten HIV-positive women who preferred this method of inquiry because of the sensitive nature of their experience and because they felt that they were not ready to share in FGDs.

The focus group interviews with field practitioners took place in their respective offices. Participants who volunteered were from government, the ministry of health, non-governmental organisations, community health care, and HIV and violence prevention programmes across the country. During the field work in the rural areas, I was in a position to conduct five focus group discussions with these field workers. Two of the focus groups were all-male and consisted of health and social development field workers. More male than female field workers participated in the study in the rural areas because there were low levels of trained female staff in the field. In the urban centres, two of the focus groups were recruited through snowballing. I made sure that the gender representation was balanced where feasible. Feminists are concerned with power relationships between the researcher and the researched. Mkandawire-Valhmu and Stevens (2010, p.688) recommend adopting a postcolonial feminist lens, centring voices of women from the margins to speak for themselves. It is essential to use research strategies that avoid hierarchical relationships and remove power differentials between researchers and participants (Wilkinson, 1999).

Sue Wilkinson (1999) suggested that there are numerous benefits to utilising participatory focus group discussions to conduct social science research with the vulnerable – in this study, HIV-positive women are considered as marginalised groups whose voices are made audible as they discuss their experiences from their vantage point. Further, Wilkinson (1999) argues that feminist researchers can use socially interactive contexts to generate a collective sense of meaning and negotiate identities through social interactions. In summary, some of the benefits of FGD, as reported by Wilkinson (1999), are captured in the points below:

- Focus groups in feminist research processes have the characteristic of creating social context and interactive processes to empower participants;

- They involve relatively non-hierarchical research relationships, a key aim of feminist and participatory research goals;
- Focus group interviews can generate new insights and collective meanings based on the interactive processes between research participants;
- The interactive nature of focus groups may trigger situations that call for action (spurring activism to advance social justice principles), as a result of feminist research (Wilkinson, 1999, pp.64-670).



Figure 11: Women engaged in a focus group. I was the facilitator.

In the figure above, participants allowed me to take the photograph as I facilitated a focus group. The interview process was an engaging one in which the participants were encouraged, with minimal interference, to explore the issues in-depth. This allowed them to take the lead, as I listened attentively to their accounts as co-researchers. To preserve their anonymity, I have disguised their images.

In this research, I was in a position to observe women working in an interactive process to define their individual and common everyday life situations and how abuse affected them as individuals living with HIV. Together they define their problems, probing each other's reasons for holding certain views based on their personal and group experiences. Participants were encouraged to explain their experiences and this enhanced individual and group agency, by rendering audible their voices, concerns, and priorities. This is one of the numerous benefits FGDs may offer as an interactive process during a research

encounter. Opportunities were created at the end of each FGD for participants to ask questions, to seek clarification, and to add new insights, especially if they felt that there were areas that was not covered by the focus group discussion, to reflect participants' concerns and priorities.



Figure 12: Women in a focus group discussing key aspects of their journal entries.

The photograph above shows several women engaged in an FGD as they discuss their journaling experiences. Utilising a feminist participatory approach to conduct social research offered me the opportunity to capture and explore women's daily experiences in depth, bringing out the complex interplay of socio-cultural factors and nuanced sayings, practices and norms that fuel VAW as it connects to HIV and AIDS. Using a feminist methodological approach allowed me as the researcher to prioritise their individual and group accounts and experiences. It demonstrated why Wilkinson, 1999) had documented the beneficial aspects of FGDs, which have great potential when used with women engaged in collectively constructing meaning, refuting, or validating and affirming experiences and making sense of a given phenomenon. Through these FGDs, I was in a position to identify jointly with the field workers, and also drawing from accounts of women in the study cohort, the policy and practice responses that best offered solutions to ameliorate the identified challenges which women prioritised and with which they grappled. In this way, the research offered the most relevant, contextually and culturally appropriate conclusions and recommendations.

I was able to conduct a maximum of two focus group interviews every two weeks, factoring in the necessary travel time up-country to visit Support Societies where the women who volunteered to participate in the study resided. What was evident during the FGDs was that adopting a postcolonial feminist research approach can significantly contribute to the exposure of critical information to develop our understanding of vulnerable women (hitherto considered ‘silenced’ and without agency and power). Women in my study cohort were very engaged and openly shared experiences, speaking out with in-depth understanding of their problems, and their voices were heard indeed. It is necessary to facilitate a conducive-non-hegemonic relationship to allow the research participants to respectfully interact and to bring out diversity and similarity of experiences. In my experience, FGDs do indeed advance a less hierarchal relationship (Wilkinson, 1999), although there are inherent challenges to implementing a democratic process when conducting research because of the tendency for some individuals to dominate the FGD. Participants can, however, overcome this by setting ground rules, and if the facilitator consciously ensures that all women have an equal opportunity to speak and all participants are enjoined to follow the rules.

Another difficulty is in transcribing the focus groups as participants speak simultaneously sometimes and when they do not announce their pseudonyms or chosen research numbers it is difficult to know who is speaking. Transcription of focus groups can be difficult when trying to identify the speakers and when speaker’s voice is not audible. Despite these identified limitations, I was able, conduct the interview and allow participants to take control while I moderated the process. Overall, I found focus groups to be a beneficial investigative tool with potential to advance key feminist interview principles with marginalised groups, as espoused by Wilkinson (1999) particularly when utilised in conjunction with diaries/journal entries (Seibold, 2000; Western, 2013), and in-depth individual interviews (Bryman, 2012).

5.2.5.4 The use of diaries/self-administered journals

Initially, thirty women living with HIV/AIDS were enlisted to keep a journal, although at the end of the three-month journaling period, only twenty of them were in a position to submit their journals for discussion in focus groups. They were encouraged to document and explain their experiences in their journals according to specific and simple instructions that were pasted inside the front covers, as follows:

“Please take 5-10 minutes daily to reflect on your experiences before and after you were diagnosed with HIV/AIDS. As you reflect, think about the various situations and challenges you faced. What were your experiences, needs and priorities in the context of HIV/AIDS and possible experiences of abuses, stigma and discrimination?”

Additionally, I guided them to select from their journal entries any excerpts they wished to discuss in a focus group, reflecting on the issues that mattered most to them. They were invited to examine the benefits of documenting their personal testimonies in diaries, and where feasible, to discuss any other issues and challenges they wished to talk about with other women in their focus groups.

More than thirty women volunteered to use the journal approach, whilst others declined due to literacy challenges. It was observed that the use of diaries brought to the fore serious challenges in terms of literacy levels, particularly for women from the rural and peri-urban communities, who had had little or no opportunity to attend school; some had been forced out of education in cases of early marriage. While many more women initially volunteered to journal their experiences, some could not find anyone to assist them even though they genuinely wanted to participate. Some of the women later declined to take part because they were unable to write. Others, however, took up the challenge and asked other women within the Support Society, who were also HIV-positive, to collaborate with them, coming together to write their stories at their own convenient place and time. I recognise here their courage, commitment to the process, ingenuity, and passion to freely document their narratives in these diaries despite the limitations of low levels of literacy.



Figures 13 and 14: A selection of journals/diaries.

The photographs above show the diaries women used and shared with others in the FGDs at the HIV Support Societies. By utilising diaries, women could speak through their own journal entries about their concerns and recommendations. They could explore ways to document and to confront the challenges (some of them for the first time), the myriad issues with which they grapple, and, where feasible, seek ways to suggest changes and make recommendations to transform the oppressive conditions in which they live from day-to-day – and this was crucial to the study. I found this exercise extremely useful because, through the use of journals, the rhetoric of divulging power to women became a reality as they took the lead role, controlling and recording the issues they deemed important. Similar work has been undertaken previously by Seibold (2000) and Western (2013), and the work of these scholars informed my own approach. Women's active involvement through the use of their own journals clearly had numerous benefits. I adopted a participatory approach, whereby I consciously and deliberately selected the inquiry tool of journaling as a good feminist participatory means of research, drawing on the work of these two authors Seibold (2000) and Western (2013, pp.1-2), whose use of journaling as a way of data generation was insightful, as they reflected on these benefits. By using journals, followed by focus groups, the participants validated their common and specific needs, recognising differences and also striving to engage in advocacy for future interventions to reduce the identified problems, in an approach espoused by feminist advocates (Harding & Norberg, 2005, p.2011). The next section documents the data analysis process adopted in this thesis.

5.3: The data analysis process

“Anyone faced with the prospect of eating an elephant would be daunted. Too big! Where to start! But faced with manageable pieces the prospect appears more comprehensible. So with vulnerability – faced with such a complex concept there seems little prospect of addressing it. But if analysed as a participatory process, some specific solutions will become apparent for any particular context” (Roger Yates, former Head of International Emergencies Team Action Aid UK).¹⁷

The above quotation teases out the central message at the heart of participatory vulnerability analysis, and is cited here to illustrate the challenge of creating meaning from a volume of data that captures the interlocking complexities of women’s experiences. By ‘breaking down’ the complexities into ‘manageable components’ (which equates to Yates’ explanation of dealing with a large volume of data, metaphorically described as the “elephant”), the researcher’s systematic organisation of the data into manageable chunks can greatly aid the analytical process. The need to describe the creation of an interwoven narrative that aptly and clearly presents the data, capturing it and representing it in a credible and trustworthy manner – one that justifies the time spent, the commitment to, and intensity of the work, and acknowledges the difficult circumstances of the participants’ engagement in this collaborative endeavour – has been the overriding goal of the chapter.

5.3.1 The challenge of adopting a feminist data analytical approach

While Renzetti (1997, pp.132-133) observed that there is no consensus on what constitutes feminist research, it is even harder to pinpoint what constitutes data analysis when undertaking feminist research. However, as I learned and gained experience by working through the process, this built my confidence, enabling me to finally settle upon a particular method based on my readings of the works of Bryman (2012) and Saldana (2013). This made it possible for me to explore the key principles of data analysis and how to undertake this process in a systematic and orderly manner. The data generated during this research was drawn from three main data sources whilst in the field – namely, FGDs, diaries, and in-depth individual interviews, which I analysed after transcription of the audio tapes.

¹⁷ Statement made by Roger Yates cited in a training manual entitled: *Participatory Vulnerability Analysis, step by step guide for field staff* (2003, p.3), Action Aid International publication.

5.3.2 Transcribing the multiple data sources

As previously mentioned, multiple data sources enable researchers to triangulate their data and the triangulation process introduces ways of validating the information which has been gathered using various data generation tools. The interviews were audio taped and transcribed into a written form to help me familiarise myself with the data corpus. The transcription process was a useful part of the initial data analysis process, as I listened repeatedly to the recorded interviews from focus groups, in-depth interviews and participant journals were transcribed verbatim. I adopted a simplified interview transcription convention developed by Malson (1998 citing Porter and Wetherell, 1987).

The Gambia has many spoken local dialects, and in the rural communities people communicate in Mandinka, Fulla, and various other tongues. There were some occasions when I needed the assistance of a local interpreter (some of the interviews were conducted in dialects which I did not understand; while I could speak, fully communicate in, and understand Wolof, Mandinka and Creole, I struggle to understand others like Sarahule, Fulla and Jolla) while at other times I did not need their help. Where I sought the assistance of translators, mostly from the Support Societies, I worked with the HIV peer counsellors, who were HIV-positive members of the Support Groups. I always emphasised to them the confidentiality of the work, and obtained their commitment to maintaining privacy and anonymity. I always impressed upon them that theirs was a privileged position requiring them to respect the rights of the participants and privacy of the data.

Undertaking a high quality qualitative research process that involves a true representation of the recorded stories requires familiarity with, and closeness to, the data. My engagement with typing and re-reading the transcripts, firstly line by line, quickly and in a progressive manner, and then thinking through this exercise to create my first impressions of the data, commenced in the field where I conducted the research. Each evening, contingent upon the availability of electricity (often there were power outages and it was not possible to charge my laptop), I would record my thoughts. When there was no electricity and it was too dark to read my field notes using candles, I used my Samsung Galaxy mobile phone as an audio-journal. I found the audio journal useful for capturing my thoughts, as a reflexive process. When there was electricity, I usually transcribed the audio-taped interviews and created written memos from my field notes. I

read and re-read the typed transcripts, becoming familiar with them, and eventually created initial categories, sub-categories and codes from the data. I was able to gradually build in potential themes and systematically engaged in the development of a central overarching theme to anchor my work. It was necessary to complete several cycles of coding, maintaining researcher reflexive practices throughout, using memos as a form of journaling.

5.3.3 The data analytical process using Thematic Analysis (TA)

In the current study I adopted thematic Analysis (TA), as advanced by Braun and Clarke (2006, p.81), and rationalised that the flexibility of the approach offers useful data interpretation benefits; I considered TA a good fit for analysing women's narratives of their lived experiences of violence and its intersection with HIV in a feminist participatory study. I also utilised TA to examine and analyse the datasets, in terms of the research participants' narratives constructing their experiences as women living with discredited and discreditable attributes. I adopted both a constructionist and a contextualist approach for generating themes in my datasets. Here I define a constructionist approach, as explained by Braun and Clarke (Ibid.), to be a method which examines the ways in which events, realities, meanings, experiences and so on are the effects of discourses operating within society. Braun and Clarke (2006) contend that thematic analysis is a method that can work both to reflect reality and to unpick or unravel the surface of 'reality' and they conclude that it is essential that researchers make clear their theoretical/epistemological positions for transparency purposes (Ibid.).

In view of the above, I adopted a constructionalist approach also concurring with the notion that there is no external reality discoverable through the research process. I instead utilise the accounts of the research participants as researchers to construct the interpretation of their 'social reality', which in my own research is a co-production process. It is the research participants' narratives which are interpreted by the researcher to construct their social reality.

I adopted a social constructionist approach (Bryman, 2012, p.710) to engage women as co-constructors of knowledge to involve them as co-research participants drawing out their own viewpoints and explanation as they construct accounts about their experiences, making their personal experiences of everyday abuse visible as a political issue where

feasible (Maguire, 1987, 1996; Oloka-Onyango & Tamale, 1995). The term ‘social construction’ is defined and utilised in the current study to offer research participants’ worldview as they construct their own understanding of their lived experiences. This is a process of collaborative endeavour that unveils a patterned narrative, evidencing situations of abuse and violation of rights (which the study seeks to unearth) which may be due to gender and / or diagnosis of a sero positive status. I consider the inquiry process to be a co-constructionist process, one that captures the research participants’ own worldview and my own interpretation of the data. Bryman (2012, p.710) defines constructionism or constructivism as an ontological position that asserts that social phenomena and their meanings are continually being accomplished by social actors, suggesting that constructivism is antithetical to objectivism. Also, Braun and Clarke suggest that constructionism “questions the idea that knowledge is an objective (or as objective as possible) reflection of reality, but instead sees our ways of knowing the world as tied to the social world in which we live” (2006, p.85). Hence, by advancing Braun and Clarke’s (2006) argument, that the constructionist perspective which I adopted, is aimed at deriving socially produced and reproduced meanings and experiences of the phenomenon, rather than focusing on individual psychological explanations, in the current study I am interested in capturing research participants’ version and explanations of the socio-cultural contexts and the structural conditions that may influence their individual accounts and experiences (Braun & Clarke, 2006, p.85).

A major challenge is how to use interpretive powers to represent lived experiences and voice without watering down their authentic voice and viewpoints (Fine, 2002), to paraphrase Braun and Clarke (2006, p.80) who suggest that our interpretive work in data analysis involves a process of carving out unacknowledged pieces of narrative evidence that we select, edit, and deploy to bolster our arguments (Braun & Clarke, 2006, p.80 citing Fine 2002, p.218). In line with Braun and Clarke (2006, p.81) who argue that the contextualist method of thematic analysis sits between the two poles of essentialism and constructionalism, which for my own study acknowledges the ways individuals (i.e. women living with HIV/AIDS) make sense and give meaning to their experience in terms of context and situatedness (Haraway, 1988, p.581).

By scrutinising the patterned responses from the datasets I was in a position to develop two key overarching themes and supporting subthemes from participants’ accounts of the

types of information management mechanisms adopted by persons living with both concealed and visible spoiled identities. I interrogated the datasets with regard to how they constructed their own version of disclosure related challenges and information control mechanisms, and documented the results as key findings in the final report.

5.3.4 Why select thematic analysis?

To provide a convincing reason why I selected Thematic Analysis (TA) instead of grounded theory or IPA, I make reference to Braun and Clarke (2006, p.80) argument that thematic analysis is different from analytic methods such as ‘thematic’ discourse analysis and grounded theory which look for patterns in the data but are theoretically bounded. I did not use grounded theory (Charmaz, 2002; Glaser, 1992), because grounded theory requires analysis to be directed towards theory development (Holloway & Todres, 2003) which was not my approach in the current study. I was interested in gaining a deep understanding of the phenomenon of violence and how it intersects with HIV/AIDS, which is in line with my stated research goal of adopting a feminist principle of prioritising the voice of marginalised women living with HIV/AIDS and their everyday experiences. This research is a qualitative approach that utilises Braun and Clarke’s (2006, p.78) work on Thematic Analysis.

It is also useful to note here that qualitative analytical methods can be roughly divided into two camps. The first is tied to a particular theoretical or epistemological position, and these include for example, conversation analysis and interpretive phenomenological analysis, which has relatively limited variability with regard to how the method is applied when conducting data analysis. The second method of data analysis is an approach “essentially independent of theory and epistemology” and can be applied across a range of theoretical and epistemological approaches. Braun and Clarke suggest that thematic analysis belongs to the latter and one of the benefits of TA is its flexibility. I also adopted TA because of its theoretical freedom. In essence, thematic analysis is widely used, but there is no clear agreement about what thematic analysis is and how one should go about using it (Braun & Clarke, 2006, p.79). At its best, it is branded as a method that has similarities with grounded theory as it examines the data during qualitative analysis to look for commonly recorded themes.

Utilising a thematic analytical process enabled me to identify, analyse and report patterns (themes) within the data (Braun & Clarke, 2006, p.79). It enabled me to organise and describe my dataset, and beyond the descriptive level, to interpret and construct themes derived from patterned responses to the research questions asked during the study. The participants' responses created rich and nuanced detail, bringing out various unexplored dimensions of the role of gender analysis and examination of interlocking structural forces and how, examining the relationship of power between women living with HIV/AIDS (perceived as individuals with tainted identities) and 'normal' (non-tainted) people in Gambian family and society. Interesting findings have been documented which unveil the influence of power dynamics and stigmatisation processes in a non-Western socio-cultural milieu.

My own data analysis was influenced by a feminist epistemological understanding and intersectionality perspective aimed at analysing various intersections that interact to influence the phenomena of VAW and HIV. For the current study, the analysis was inductive in that the data produced here was read and re-read in search of codes and themes that provide a patterned response to the research question. I referred to theories on VAW, after exploring the narratives of women and practitioners to observe patterns and also to explore their broader meanings and implications in my own study, as suggested by Braun and Clarke (2006, p.84 citing Parton, 1990). In many ways, I moved into a higher analysis of the themes adopting a constructionist paradigm (Braun & Clarke, 2006, p.84 citing Burr, 1995) in which I grounded my analysis based on interpretations of accounts of the participants, following a thematic analytical process.

Braun and Clarke (2006, p.83) argue that thematic analysis of the datasets can be done in two primary ways, in an inductive (bottom-up) manner or in a theoretical or deductive (top-down) way. An inductive approach means that the themes identified are strongly linked to the data themselves (Braun & Clarke citing Patton, 1999). They explain that with interviews or focus groups the themes identified may bear little relationship to the specific questions that were asked of the research participants (Braun & Clarke, 2006, p.83). They would also not be driven, because it is grounded on the data generated in the study. Inductive analysis is therefore a process of coding the data without trying to fit it into any pre-existing coding frame, or the researcher's analytic pre-conceptions. In this sense, Braun and Clarke (2006, p.83) rationalise that this form of thematic analysis is data

driven, however they also argue that researchers cannot free themselves of their theoretical and epistemological commitments. Figure 14 presents the stages adopted in this study, derived from Braun and Clarke's (2006, p. 87) guide to conducting a step-by-step thematic analysis.

Stages of data analysis	Description of the data analytical process
Phase 1: Data familiarisation	Transcription of the data, reading and re-reading the data, forming initial ideas.
Phase 2: Generating initial codes	Coding the data, examining interesting features of the data, adopting a systematic fusion across the entire dataset derived from focus group discussions, in-depth interviews and diaries.
Phase 3: Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
Phase 4: Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire datasets (Level 2), to generate a thematic map of the analysis.
Phase 5: Defining and naming themes	Undertaking an on-going recursive process of data refinement: refining the specifics and naming each pattern of responses (naming the key themes), by creating an overall storyline using coded accounts from research participants; examining definitions of what constitutes stigma, abuse, and violence in women's own lived experiences (see Appendices 5, this thesis).
Phase 6: Producing the report	Selection of vivid, compelling extracts as examples which relate to the research questions and literature. Presentation of a scholarly report.

Figure 15: Stages of thematic analytical process (adopted from Braun & Clarke, 2006). The figure 15 above represents the stages of thematic analysis, adopted from Braun and Clarke (2006, p.87). The stages identified in the table above are explored in detail below, commencing with the data familiarisation stage.

5.3.4.1 Stage 1: Data familiarisation

During this step, I transcribed the data utilised in the study. Writing the transcripts helped me to listen to the audio tapes and to examine how the participants had represented the meanings of their experiences of abuse in relation to HIV. To familiarise myself with the data I referred to my field notes and read and re-read the interview transcripts, and I listened to the voice messages I had recorded immediately after each session to capture my impressions, ideas, and thoughts about interesting features of the data corpus (i.e. the verbatim accounts of all verbal and sometimes non-verbal signals – pauses, silences and coughs). I spent considerable time viewing video documentaries of some of the focus group discussions, made during the interviews where permission was granted, and it offered various vivid pictures that aided my recollection of the non-verbal cues and interactions of the women and practitioners as they conversed during the FGD. I read the transcripts several times and coded the data by examining interesting features and asking questions drawn from my research questions, and related to theories of violence. The datasets were derived from the diaries kept by twenty women, the in-depth interviews with five women living with HIV, from ten focus group discussions with women, and interviews with health and gender field practitioners. This constituted the entire dataset which presented the predominant and important themes identified, coded and analysed from the data corpus.

5.3.4.2 Stage 2: Generating initial codes

At this stage I generated an initial list of interesting codes identified from the data. These constituted the most basic segments or elements of the raw data that could be assessed as significant responses to the research question on violence and HIV (Braun & Clarke, 2006, p.88). This coding process enabled me to organise the data into meaningful groupings, with themes derived from the coded data. In this study, I attempted to construct and interpret analytically the data which was coded using first of all a data driven and much later a theoretically driven analysis. I worked systematically through the entire dataset giving full attention to each data item, and identifying interesting aspects in the data items that may constitute repeated patterns (themes) across the dataset. I asked the following questions:

1. How are the participants constructing their responses?
2. What experiences are they narrating?

3. What are the key issues and effects of stigma in their lives?

The coding was manually carried out, writing notes on the edge of transcript itself, highlighting the data extracts, using markers and coloured pens to indicate potential patterned responses. In other instances, I used coloured post-it stickers to identify segments of the data which I had coded. At this stage I ensured that I had initially identified several codes and then matched them with the data extracts that demonstrated the codes, and then I collated them within each code from the data extracts. During this phase I searched for many potential themes as possible. I summarise the stage explained above as follows:

1. Code for as many potential themes and patterns as possible.
2. Code extracts of data inclusively and to try to remember the context in which the participants account were made.
3. The coding process was carried out exploring different themes that were illustrated by a data extract. I coded and un-coded, coded again, as many times as necessary to produce a thematic map which would serve as my interpretation of the data.

5.3.4.3 Stage 3: Searching for themes

Here I developed a long list of initial codes, identified across the datasets. I then collated them with the data extracts to support the initial codes. During this phase I refocused my analysis at the broader level of themes rather than codes (Braun & Clarke, 2006, p.89). Using Braun and Clarke's examples I sorted the different codes into potential themes, by collating them with the relevant data extracts. I reviewed the list of codes and began to analyse them, exploring ways in which they might combine to form overarching themes. At this stage I used a visual thematic map with brief descriptions to create a linkage/relationship between the codes, the themes and the different levels of themes. For instance, to link the codes and themes, I utilised an intersectionality paradigm to search for linkages between accounts suggesting stigma before and after HIV/AIDS diagnosis. Within this analysis, a theme is understood to represent some level of patterned or meaningful response that is informed by the research questions, and I decided to use the subjective experiences and accounts of research participants to generate these themes.

Braun and Clarke (2006) argue that thematic analysis offers an accessible and flexible approach to analysing qualitative data. I utilised verbatim words or phrases capturing something important about the data to infer themes and sub-themes, from the dataset, these are shown in the initial thematic map in (Figure 16, in Appendix 5).

5.3.4.4 Stage 4: Reviewing themes

During this stage I devised a set of candidate themes, and then refined them. Some of the themes were collapsed and merged into one theme and others were broken down into separate themes (Braun & Clarke, 2006, p.91). At this stage, the data analytical process involved reviewing and refining the themes on two main levels. During the first level, I read the collated data extracts and then considered whether the themes constructed formed a coherent pattern, using a recursive approach of reading the extracts to generate the themes.

The second level considered whether the theme itself was problematic or whether some of the data did not fit there – I had, in any case, to continually revisit and rework the themes in order to create new themes. In other words, I tried to find a home for those data extracts that did not work in an already-existing theme. Some of them I had to discard from the analysis. Once I was satisfied with my data themes, and was happy with my data interpretation, I had a candidate thematic map, and was then ready to move to stages five and six.

As part of this stage, Braun and Clarke (2006, p.91) suggest that the researcher should consider the validity of the individual themes in relation to the dataset, but also the process throughout this stage involved assessment, refining and re-working the themes by examining additional data extracts within which new themes were re-coded, adopting an ongoing organic process (Ibid.). Please refer to the second thematic map, which shows the two overarching themes and six supporting sub-themes.

5.3.4.5 Stage 5: Defining and naming themes

This stage began at the point where I felt that I had constructed a satisfactory thematic map of my data, as shown in thematic maps 1-3 (Appendices 5), depicting an accurate diagrammatic representation of the coded themes I had generated. At this point I was positioned to define and further refine the themes which I developed for my final analysis,

by identifying the key essence of each theme and how it was connected to the two final overarching themes. In order to do this, I went back and forth between the collated data extracts, scrutinising each theme and organising them into coherent, internally consistent accounts, supported by accompanying narratives (Braun & Clarke, 2006, p.92). I also examined how each individual theme could be fitted into the overall storyline that I was telling about my dataset. This was done in relation to the research questions, however I was cognisant of Braun and Clarke's guidance (2006) to avoid any overlap between themes (see Appendix 5). By scrutinising the patterned responses derived from accounts of abuse and violations of the rights as women living with HIV, I was in a position to develop two key overarching themes and supporting subthemes from participants' accounts of the types of information management mechanisms adopted by persons living with both concealed and visible spoiled identities, registering d challenges and information control mechanisms which would be explored extensively from the dataset and documented as key findings in the final report. Below is a summary of themes (overarching theme and supporting subthemes as seen in the final thematic map, below captioned).

Overarching Theme	Sub-themes
Overarching Theme: HIV stigma as discreditable and discredited attributes.	Presented in two separate chapters (Chapter 6 and in Chapter 7). PLHIVs adoption of concealment strategies: Accounts of women living with discreditable attributes: Sub-themes: 1.) "Keeping our secrets 'secret'" 2.) "They fear us we fear them", and 3.) "Self-stigma" (internalised stigma) Sub-themes: 1.) PLHIVs vulnerable to enacted stigma and discriminatory acts (multiple perpetrators and instigators) 2.) Accounts of confidentiality and ethical breach as sources of stigma 3.) Accounts of abandonment, social isolation and ostracism 4.) HIV 'stigma' is physical abuse, emotional & economic violence by perpetrators at home and in the community

Figure 16: A summary of the overarching theme and subthemes

The above figure 17 is a summary of the overarching themes with seven supporting subthemes for the data analysis process, to write up the final report that is used in the current thesis, but will also be used (an abridged version) to disseminate to the various stakeholders and also for future publications of the findings of the study. I presented a concise, coherent, logical account of the storylines derived from the data extracts within and across themes. I developed a strategy for constructing a narrative supported by data extracts which demonstrates the prevalence of the selected themes. The overarching theme: HIV stigma as discreditable and discredited attribute is evidenced by data extracts and subthemes which weave a common analytical narrative that illustrates the story of secrecy, fear and self-stigma and also evidence of enacted stigma and discrimination in the lives of women who possess discredited conditions of HIV. The analysis goes beyond the descriptive level and includes interpretation of the data presenting an argument and sets of propositions in relation to my research questions. Also, the analytical claims made in this report are grounded in an inductive thematic analysis that seeks to understand women's experiences of abuse and denial of rights in relation to a broader Gambian social context (Braun & Clarke, 2006, p.93 citing Frith & Gleeson, 2004).

Braun and Clarke (2006) citing Frith and Gleeson (2004) suggest that it is important to provide a clear sense of the scope and diversity of each theme (Ibid.), and in line with this I used a combination of analyst narrative and illustrative data extracts, and a combination of descriptive and interpretive analysis to present the final report, teasing out the patterns of responses that illuminate specific experiences, and accounts that capture intersections of abuse and structural violence and their effects. My interpretation of accounts of women's experiences formed the basis of the key themes generated in the study to reflect overlapping intersections of multiple factors impacting their health and well-being.

The final report examines how women living with discreditable and discredited attributes are also affected by interlocking forces of patriarchy, gerontocracy and structural violence collude to render them vulnerable to VAW and to produce negative outcomes for women and their dependents. Finally, the report examined the key priorities of participants in terms of treatment, support and care which formed the basis of my final recommendations that may inform policy and practice development.

A major issue of writing the final report was the challenge of representing the voices of the narrators, one that I overcame by sending my draft analysis to the co-researchers for validation and their feedback was included in the final report. I have been unable to include all the comments which I received, following the final submission of this thesis to the University of Sussex for my doctoral degree. However, I will endeavour to incorporate new commentaries and recommendations in the final report complied for follow-up action plans (according to the AR cycles), in so doing, thereby making their contribution, in validating, upgrading and finally allowing the report to be accepted as a true reflection of their research experiences. The participants' final recommendations will serve as useful for informing future interventions for prevention, support and health care service provision. The next are two research findings chapters 6 and 7. In Chapter 6, the socio-demographic data of the study sample will be presented, followed by the overarching theme and subthemes which will be presented in two Chapter 6 and also Chapter 7.

CHAPTER 6: RESEARCH FINDINGS, ACCOUNTS OF WOMEN LIVING WITH DISCREDITABLE ATTRIBUTES

6.0 Introduction

“Bat suu gibeesh borom ham” (Traditional Gambian Wolof proverb).

“The inertial mass of language is like the inertial mass of society. Women inherit their place as speakers inherit their words. We drag a vast obsolescence behind us even as we have rejected much of it intellectually, and it slows us down ... The gun of sex-biased language may be rusty, but it is there, and the greater danger is unawareness that it is a gun, and is loaded” (Obododimma Oha, 1998, citing Dwight Bolinger, 1987).

In a traditional Gambian social context, proverbs are used in everyday conversations. The first quotation above is an old Wolof proverb which literally means – when words are uttered (fired) their owners are aware of what they are saying. In the context of HIV/AIDS, words are used as metaphors to deliberately name, point out, degrade and dehumanise sero-positive women, in order to shame them. The second statement, by Obododimma Oha (1998) in her essay entitled: *The semantics of female evaluation in Igbo proverbs*, foregrounds the importance of words and how, as powerful weapons they can be fired – metaphorically speaking – at women. Proverbs can be adopted as conduits to communicate powerful, embodied gendered constructions and gender ideologies to specific targets. The loaded or derogatory messages are used to reach the target (i.e. the receiver understands its meaning and intention), which is to hurt and devalue women (Obododimma Oha 1998, p.87 citing Dwight Bolinger, 1987).

6.1 Overview of the data findings chapter

This chapter deals with the research findings first presenting a description of the socio-demographic data of the study sample, as useful background information on the research participants. Following this, I present an overview of the overarching theme and subthemes derived from the thematic analysis detailed in the methodological chapter of this thesis.

Overarching Theme	Sub-themes
Overarching Theme: HIV stigma as discreditable and discredited attributes.	<p>Presented in two separate chapters (Chapter 6 and in Chapter 7). PLHIVs adoption of concealment strategies: Accounts of women living with discreditable attributes:</p> <p>Sub-themes:</p> <ol style="list-style-type: none"> 1.) “Keeping our secrets ‘secret’” 2.) “They fear us we fear them”, and 3.) “Self-stigma” (internalised stigma) <p>Sub-themes:</p> <ol style="list-style-type: none"> 1.) PLHIVs vulnerable to enacted stigma and discriminatory acts (multiple perpetrators and instigators) 2.) Accounts of confidentially and ethical breach as sources of stigma 3.) Accounts of abandonment, social isolation and ostracism 4.) HIV ‘stigma’ is physical abuse, emotional & economic violence by perpetrators at home and in the community

Figure 16 A summary of the overarching theme and subthemes referenced again for recap.

Figure 16 is again repeated as a recap / summary of the overarching theme and seven supporting sub-themes. Here I delve into the findings from the women’s and field practitioners’ reported accounts of their experiences of living with discreditable attributes of HIV, followed by women’s accounts of living with discredited attributes of HIV.

First, I present the socio-demographic data which is a description of the women who were recruited for the research. The socio-demographic data presented below will serve as background information about their age, educational levels, marital status, experiences of FGM/C, and early and forced marriage. This is useful information that evidences how participants’ own constructed accounts of everyday abuses affects them before HIV diagnosis. It is hoped that it will illuminate my reasons for conceptualising “women’s suffering as never ending” (a common problem experienced by women) as they struggle with a range of abuses before and after HIV diagnosis. The traditional norms and practices of FGM/C and early and forced marriage exemplify key issues that are revealed by my research participants’ narratives.

6.2 Description of the study sample

6.2.1 Women's socio-demographic data

The socio-demographic data below was gathered prior to the in-depth interviews and focus groups. Some of the data was taken from women's reflective journals.

Age	Number (out of 60)	Percentage
21-25	3	5%
26-30	16	26%
31-35	12	20%
36-40	15	25%
41-45	10	16%
46-50	4	8%

Figure 17 Diagram representing ages of the study cohort (N=60).

The above table 18 captures the ages of sixty women interviewed in the study. The majority were aged 26-30 years (26%), followed by women between 36 and 40 (25%), those of 31-35 years of age (20%), those between 41 and 45 (16%), and those between 46 and 50 (8%), with the youngest age range being 21 to 25 (5%).

6.2.2 Data on educational levels of the study cohort

In the Gambia, the Government and its development partners prioritise women's education. The Gambia National Education for All Report (2014, pp.7-9) has registered significant gains in enhancing parity of education between boys and girls, but while women's enrolment in primary school is high, there is a serious gap in terms of enrolment and retention at higher levels of education. The findings reveal that many have had no formal education. Most had attended a madrassa (school of Islamic studies), but some of them left early in order to marry. It is important to note that most rural women have been denied access to school, or were removed for reasons of early marriage and as a result they experience serious challenges in life in terms of livelihood support, and have restricted choices and options for employment. The table below summarises the formal, non-formal and madrassa education of the study participants.

Type of education	Number (out of 60)	Percentage	Age at enrolment
No formal schooling – did not attend Madrassa	21	35%	-
Madrassa (now part of the formal educational system in the Gambia)	19	31%	3-7
Formal education	Number (out of 60)	Percentage	
Grade 1-6	12	20%	7-13
Grade 7-12	7	11%	13-19
Higher education (post-secondary education and training in professional skills, as a social worker, or as an HIV peer counsellor)	3	5%	19 plus

Figure 18 Formal and non-formal educational data for the study cohort.

The table 19 above provides data on the educational levels of this study cohort, and it presents a dismal picture of the enrolment of women and the various educational levels attained and estimated age of enrolment. Some women attended formal schools and at the same time took Islamic studies through a madrassa. Additionally, for many of the women in the current study their low literacy levels influence their subordinate status. Several of them claim that they are vulnerable to power abuse as they were denied educational opportunities, or withdrawn early from school. This affects their capacity to earn an income through employment that offers good wages. Many occupy low paid jobs and are economically dependent on others for basic needs. As a result, most are denied their socio-economic rights, and if they transgress patriarchal norms, they experience a range of emotional, verbal and economic abuses.

Despite the educational policies that encourage and protect the rights of girls, some of the women, living under rigid patriarchal conditions, still erroneously believed that they

could be denied an education. Many in this situation believe that they will be married off so do not warrant the expenditure of meagre family resources.¹⁸ The participants were concerned and mentioned that their lack of education and inability to read and write had a limiting effect on their lives. This is evidenced when, after HIV diagnosis, they face stigmatisation and enacted discrimination because they have to ask others to help them read their prescriptions or to tell them the appointment dates for follow-up treatment, support and care. The intersections of poverty, gender bias and equality are evidenced in their narratives. The next table summarises the types of marriage amongst the study cohort, how many of those were forced, and by whom.

6.2.3 Data on marriage

Types of marriage & instigators /abusers	Number (out of 60)	Percentage
Marriages (forced)	49	82%
Marriages (not forced); and 1 unmarried	10	17%
Instigators of forced marriages (father/uncle)	19	32%
Instigators of forced marriages (mother)	6	10%
Instigators of forced marriages (both parents)	9	15%
Instigators of forced marriages (others)	10	16%

Figure 19: Number of women reporting forced marriage, and its instigators.

The table above shows that 82% of women reported having been forced into marriage, and by whom they were forced. For many of my research participants, it is a virtue to suffer courageously and in silence. The women shared experiences which they viewed as

¹⁸ To increase enrolment and retention in schools, the Government of the Gambia has made education for girls free. However, there are 'hidden costs' (amongst them, uniforms, books, school lunches, transportation), which may still be unaffordable for poor families who live on less than \$1 a day. It is thus difficult to quantify the estimated cost, depending on the type of education attended (whether private or government-run public school). The norms and practices of early and forced marriage render girls liable to withdrawal from schooling.

a normal part of women's suffering as they are forced into marriages against their will. The suffering they endure is an extension of normalised violence, which is experienced as girls and carries on into this stage of their lives, a stage in which they have been diagnosed with HIV. The socio-demographics show that violence, as a precursor to HIV, remains a serious and perennial problem.

6.2.4 Data on FGM/C

The study demonstrates that incidents of early and forced marriage, FGM/C and a multitude of gender specific stigmas are forms of everyday normalised abuse that were suffered by this study cohort at the directives of multiple perpetrators and instigators.

FGM/C	Number (out of 60)	Percentage (%)
Women experience of FGM/C.	55/60	92%
Women who underwent FGM/C and virginity sealing (locally known as 'fata' in Wolof)	13/55 women who underwent FGM/C experienced fata/virginity sealing	22%
Had not undergone FGM/C	3/60	5%
FGM/C status undisclosed	2/60	3%

Figure 20: FGM/C statistical data for the study cohort.

The above table presents the statistical data for women who underwent FGM/C. The data extracts presented below will capture nuanced and context specific information derived from the focus groups, their journal entries and also individual interviews with women as evidence of participants' accounts of pre-existing gender stigmas (especially the negative labelling of girls as uncut or 'solima', and of unmarried women as 'seedless', 'barren', or

‘prostitutes’). The statistical data provided will be referenced in the discussion chapter to buttress the argument that there are pre-existing gender-based abuses which are normalised in the lives of women and girls, before and after HIV diagnosis. The data findings consist of one overarching theme and seven supporting subthemes. The main theme is: Stigma as discreditable and discredited attributes. The next table is a summary of the main theme and sub-themes. We shall examine the accounts and struggles of women living with HIV who are considered discreditable and also of those who have discredited attributes.

6.3 Accounts of sero-positive women living with discreditable attributes

I commence this section with a critical examination of the overarching theme and sub-themes generated by the thematic analysis in which women diagnosed with HIV have reported their vulnerability to a range of abuses and denial of rights. As shown in the summary above, for ease of presentation I have split the overarching theme of stigma as discreditable and discredited attributes into two separate chapters, with their supporting subthemes. I begin with women’s accounts of living with stigma as a discreditable attribute as they struggle to conceal their status using concealment mechanisms and strategies, to keep their secret and thus avert incidents of stigma and enacted discrimination. Depending on the disease progression, some individuals diagnosed with HIV can conceal their status, while others may not. Most of the women whose status is concealed describe the concealment strategies and mechanisms used to protect themselves. The sub-themes of secrecy, fear and self-stigma are examined below:

- Sub-theme 1: “Keeping our secrets ‘secret’”
- Sub-theme 2: “They fear us we fear them”
- Sub-theme 3: “Self-stigma” (internalised stigma)

6.3.1 Analysis of sub-themes

6.3.1.1 Sub-theme 1: “Keeping our secrets ‘secret’”

The main themes discussed will focus on concealment and information control to hide the HIV identity of PLHIVs and the subthemes of secrecy, fear and self-stigma associated with living with and/or possessing concealable ‘discreditable’ stigma, as described by Goffman (1963). Upon HIV-positive diagnosis, women construct narratives of creatively adopting concealment strategies so that they may live with the non-visible discreditable attributes as PLHIVs. I will also discuss themes of fear revolving around: fear of status

being revealed, self-stigma and distancing, and self-imposed isolation (internalised stigma) to reduce interactions in order to avoid discovery of being discreditable after HIV-positive diagnosis. These are subthemes constituting the patterned responses derived from the narratives of women; they are the stigma management and concealment strategies adopted as women work hard to ‘hide or cover-up’ their discreditable status.

In line with the literature by Goffman (1963), this study finds that the stigmatised person experiences a devaluation of her personhood due to local stigma ideologies. Women in the study explain how they are shunned, lessened in their life circumstances and experiences, and that this limits their access to and enjoyment of life enhancing opportunities.

We will now examine how this cohort of women attest to stigma as discreditable and discredited conditions in the household and within the community, how they explain their lives as women living with HIV, and what mechanisms are adopted to avoid exposure and becoming devalued or tainted. In the data extracts, I provide evidence that suggests a positive diagnosis makes them vulnerable to a complex web of suspicion, rumours, secrecy, and fear of isolation and ostracisation, and they adopt mechanisms to protect their concealed identities. There are challenges linked to disclosure related risks and vulnerabilities captured under the theme “keeping our secret ‘secret’”. The subthemes of secrecy, fear and self-stigma will be reviewed here to show how concealment mechanisms are employed by PLHIVs possessing discreditable attributes.



Figure 21: Secrecy and covering up – why should I disclose?

The figure above shows a woman ‘covered up’. This is closely linked to the common metaphor of cover-up and ‘secrecy’ which is evidenced in the conversations of women in the study cohort, and thus has been analysed as one of the key subthemes employed by women to conceal their identity as PLHIVs. This picture was taken with the permission of the PLHIV as she used her towel to cover her face, demonstrating that it is common to ‘cover-up’ non-visible stigmas associated with HIV.

PLHIV 002 asked a very pertinent question: “Why should we let others know about our status?” “Let our secrets be secrets”. “Others do not test so why should I disclose?”

The study has evidenced from the research participants’ accounts that women in the study cohort manage their discreditable attributes by adopting ‘secrecy’ as a concealment strategy and mechanism. As claimed by participant 008 during a focus group discussion:

“We keep our secret ‘secret’”!

When women test positive during screening for HIV, they are affected by disclosure related fears and concerns, hence they struggle to keep their diagnosis ‘secret’. Key subthemes of secrecy are overwhelmingly common in the narratives of affected women. These include the ways in which they hide when going to clinics, ‘hiding’ their HIV status to avert stigma and discrimination. Concealment is evidenced in reality and metaphorically drawing into focus the everyday struggles and challenges that women living with HIV experience, as they possess discreditable attributes. In other words, they refer to ‘secrecy’ as a concealment strategy that they adopt to avoid letting others know that they have been diagnosed with HIV. Participant 015 explained during a focus group how they cover-up and, as women living with HIV, hide to avoid revelation of their status. She answers through an interpreter:

“Well for me, the problems women face here in the Support Society due to HIV are mainly fear of abandonment and men not caring for their wives and it is a common problem. Other family members and relatives are also part of this problem as they instigate the husband, in the situations where there is rivalry between co-wives, they fight and many of us women when we test positive we avoid making our status known and we cover-up and hide and to avoid the bad experience of ‘chodiro’ [finger-pointing]. Because if your status is revealed you

have a problem. Many women are shamed and even ostracised. People run-away from them. They are called names and they suffer many forms of hardship.”

From the above accounts, women who are discreditable work hard to conceal and keep their secret ‘secret’ and to conceal their identity as part of an information control mechanism. The next data extracts are accounts of secrets being revealed without consent. Here the problem of poor education, of women’s inability to read and write due to their early removal from school, is critical, because illiteracy renders women dependent on others to read their prescriptions, inadvertently exposing them to enacted discrimination, as 066, 065 and 067 (three PLHIVs) explained during a focus group discussion:

066: “I have experienced my secret [HIV positive status] being revealed to others because of this lack of education. When you ask others to help [to read appointment dates and also prescriptions], you risk stigma. I went to a social gathering after my details were revealed to someone who read my treatment and prescription form and I experienced stigma. People started to finger-point and run away from me. I sat down at the food bowl and everyone ran away. I felt pain and anger.

“I refused to eat and I went home and felt really hurt. I did not reveal my prescription to others but the only person who read my prescription and appointment date leaked my secret to others and that’s why I was stigmatised at this naming ceremony. I was ostracised. I do not go to anyone’s home. I would rather stay at home than let them shun me further. I had to isolate myself. This stigma occurred because it is linked to my lack of education and the exposure of my HIV-positive status.”

065: “Well I have issues with this same point – namely ‘Musolloo la Karambaliya’ [meaning women’s lack of education is a challenge, in Mandinka]. Just look at this situation facing us now ... as uneducated women we cannot sign and cannot read or write on these consent forms; we need help. This affects us seriously, particularly when you need to read your prescription. In our lifetimes, the elders have not valued the education of women, but have insisted that we help our mothers. Now we go to the kitchen and this is affecting us.”

067: “I agree with what all the others say; lack of education is a major problem we face and it affects us as women with HIV. We are exposed when we seek help from others to read our prescriptions, and also our appointments for treatment.”

Several of the women narrate similar problems linking poor education and low literacy rates as a limiting factor that affects them. They find it difficult to keep their secrets, because they are dependent on others to read their prescriptions and remind them of their appointments. This exposes PLHIVs to risks of their secret being discussed with others

without their consent. The issue of education has been prioritised by co-researchers to form part of the study recommendations to inform interventions for health policy makers and practitioners to review – as strategic interventions to end HIV related stigmatisation. The intersection of poor education, disclosure and revelation of HIV status to others make a compelling narrative that emphasises the need for HIV stigma reduction strategies to focus on women's education through adult literacy and continuing educational projects.

In a one-to-one interview, participant 031 is positively diagnosed and said she had concealed her status, only disclosing selectively to her immediate family. Her children were supportive:

Interviewer (I): "I am looking at the diary you have submitted to me and also the socio-demographic data you have filled in. I can see that you did not undertake FGM at all because it is not your culture as you mentioned. Also you mentioned about challenges with your education. Please tell us a little bit more about your life before and after HIV diagnosis as captured in the diaries."

031: "I did not write this diary myself, I obtained help to do the writing. Well... in terms of ability to read and write I believe it has many associated challenges. With illiteracy you are dependent on others to read anything in writing for you. You cannot have secrets and 'sutura' [meaning confidentiality]. It is always a challenge, thank God for me I educated my daughter and she now helps me. She reads my prescriptions and dates for the appointment to the clinic for HIV. She directs me on the days to go for treatment and then I will be in a position to obtain my medication on time and also take it too as prescribed. With this assistance I can access my treatment and receive appropriate care. I know without my child's assistance my privacy and confidentiality would have been compromised. It would have been a major problem for me to go out there to try and look for outsiders to read and tell me about my clinical appointments. My status would be discovered by others and I know how this may lead to stigma and discrimination. Since I have been diagnosed only a few members of my family know about my status. I did not disclose except to my two sons and my daughter. I also told my elder brother.

"For my daughter I told her about my status. She goes to school and has been educated about HIV. One night I told her about HIV and explain to her that I live with the virus. I also obtain food rations and medication from the HIV access and care programme. With this explanation, I was able to show her and disclose to my daughter. I select those I tell about my situation because I am aware that with disclosure the possibility of abuses and violence exists. So I do not even relate with wider family members. I make my life private because I fear that my family members may react to my illness."

As the woman above explains, PLHIVs adopt secrecy and find ‘strategic’ information control mechanism to ‘pass’ as HIV-negative, cognisant of the real risks of disclosure based on the lived experiences of those who choose to disclose. Fear of stigma and enacted discrimination are part of the struggles and the real life experiences that affect women and need to be addressed. For many people testing, knowing their status, and disclosure have been painful and challenging. Thus, many choose not to test, and those who test prefer to conceal their status from others. The next section examines the sub-theme of fear and shows how PLHIVs adopted responses and strategies as they anticipated incidences of stigmatisation, resulting in avoidance and fear.

6.3.1.2 Sub-theme 2: “They fear us we fear them”

The sub-themes of fear and avoidance are part of the women’s narratives as they strive hard on daily basis to cover-up their sero-positive status to family and others. Many talk about fear of being ‘discovered’. Threats and fear associated with disclosure make it a difficult process for many. Additionally, the fear of stigma and enacted discrimination by an intimate partner and other family members adds to the constant struggle women experience as they manage to live with discreditable attributes. A major challenge that women experienced upon HIV positive diagnosis is how to overcome the constant fear of their status being known to others. The next data extract is from an in-depth individual interview with Fatou Manjang, a woman living with HIV whose account captured the sub-theme of fear. She disclosed only to her spouse and in strict confidence, but she feared the husband’s constant threats and manipulation. She explains:

“After disclosure, I felt vulnerable as I live in fear of the frequent threats and manipulative tactics used by my husband”. [She explains how her spouse would shout, threatening her and saying: ‘I will leave you, send you back where you come from’] “This caused me a lot of pain and anger but I could not do anything, I felt trapped in the body of a PLHIV.”

Some women did not share their HIV-positive status with anyone, as the next data extract indicates. In an emotional narrative, the speaker is a female PLHIV who revealed the challenges and struggles associated with non-disclosure, of hiding her positive status from others. This female, a PLHIV and HIV peer counsellor, drove home the point that fear, associated with a lack of economic support upon disclosure, is a real problem to married

women. She explained how women's dependency and poverty render them vulnerable. For most women, marriage is their only hope of survival:

"It is difficult to disclose if you are poor and you have HIV, nobody wants to marry you again and if you are not married you cannot feed yourself. We depend on our parents, later on our husbands, to feed us so we stay quiet and keep our secret..."

"If I disclose to my family they will spread the news throughout the village, they will call me names. Some members of my family go about spreading bad things about me – they will abuse me verbally. I have never told anyone about it ... However, I experience self-stigma. My fear is I do not want anyone to know so I am constantly on the lookout, which is truly very difficult to do ... [pause for a while, becoming very emotional] HIV is a lifetime thing – when will it end?"

My research participants' need for constant surveillance to avoid enacted stigma is very challenging and emotionally draining. The next data extract is from a focus group as women shared sections of their journal entries. Jonkong is a female PLHIV, and she explained how PLHIVs adopt concealment mechanisms to hide their positive diagnosis and how this affects them when going for treatment:

"... The situation just explained is realistic because women have to hide to survive with HIV. We hide when going to the clinic – we send someone else who is a peer counsellor to 'secretly' bring our treatment of antiretroviral drugs (ARVs) and other medicines when they visit us during community home-based care visits. We find it difficult sometimes to come to the clinic ourselves. We may not have the fare to pay for transport, and even when we collect the nutrition support rations it is difficult to transport the food back home; *we hide it* with shop keepers and take it in small quantities ... if we didn't do this, we would risk being suspected, even abused and divorced if our husbands found out where we got the food rations ..."

Food rations of oil, rice and other assistance are given to PLHIVs as support interventions to meet some of their basic food needs. However, the challenges mentioned above may affect women and hinder their access and utility of this life-saving assistance. Several of the affected women are economically marginalised and they are in need of the food assistance, however fear of stigma is a major challenge they grappled daily. Fear is a common sub-theme and this fear forces affected and infected women to constantly devise strategies to avoid being discovered and subjected to stigma and enacted discrimination. The ability to conceal discreditable attributes of being HIV-positive depends on the

degree to which the disease is visible. Some women in the study disclosed to family members they trusted and did not experience stigma. But others did experience stigma.

Participant 039 reported that initially she had been ill and had a cough (although she had not disclosed, she had a discreditable attribute). No one knew about her positive diagnosis, yet she feared that her coughing may trigger suspicion. Tuberculosis may be an indication of opportunistic infection associated with HIV/AIDS. Yet she did not disclose but feared being singled out and stigmatised ('chodiro' is locally used to indicate finger-pointing and stigma, it is an embodied construct). She said:

“Before, when I was looking very ill and I feared being pointed out – ‘chodiro’ – because I am aware of how they treat others, I was worried, because I was coughing and I feared people would start to spread rumours about me being an AIDS patient ... but now I am improving with medication. I am feeling much better now and I do not notice anyone treat me differently. Before it was very bad and I was ashamed and feared anyone knowing I had HIV.”

6.3.1.3 Subtheme 3: Accounts of experiences of self-stigma/internalised stigma

Pryor and Reeder (2011) and Chaudoir et al. (2013, p.76) explain that ‘self-stigma’ broadly describes how individuals respond to possessing a stigma. Self-stigma is a common term amongst PLHIVs in this study. Many claim that they experience self-stigma, and that fear is closely linked to self-stigma. PLHIVs live in fear of what others may think about them, fear of being devalued and shamed, or experiencing finger-pointing [the chodiro’ experience]. Some women adopt restrictive/controlled strategies to avoid social encounters and risks of being a target of stigma and enacted discrimination.

The anticipated stigma and fear of being ill-treated, shunned, and devalued by other family members and friends, may trigger a desire to ‘keep safe’ from discrimination by adopting mechanisms of concealment. Self-stigma, triggers self-imposed restrictions on family relationships. The next data extract, taken from a diary entry by participant 092, is revealing in terms of self-stigmatisation. The writer of the journal is a 38 year-old PLHIV with seven children, had been diagnosed with HIV seven years previously and indicated that she had encountered self-stigma and also enacted stigma from her family, although she was the first to stigmatise herself. She added:

“I thought that was the end of my life and began to distance and exclude myself from social gatherings. I refused to go out for fear of finger-pointing by my family

and others. Later, other family and community members began to stigmatise me because of the way I isolated myself.”

Mother Joofen, is a PLHIV, who explained her experience of internalised stigma, stating:

“After hearing the messages on the radio, I was afraid and I experienced self-stigma. I did not experience enacted stigma or discrimination from others but because of the negative labels that only bad and loose women contracted the disease, I experienced self-stigma.

“There was a point when I would hear about AIDS on the radio and would immediately turn off the radio ... it was affecting me, I asked how did I become a loose woman? When was I playing around? ... My husband knew me as a virgin ... and this negative message affected me ... and I have remained faithful to him.”

Persons living with discreditable attributes may be influenced by several factors, including stigma ideologies and local stigma constructs. This may trigger feelings of shame and refusal to reveal to others that they have a HIV positive diagnosis. To conceal their status, many reported ‘social isolation’ as part of concealment mechanisms/strategies which are problematised in the study. However, some women reported information control measures to hide their status. As co-research participant 004 living positively with HIV for several years explained how she adopted strategies of information control to keep her identity intact:

“I do not want people to know. I know how they treat others [people whose identity is revealed] and I limit the information I share about myself. When I go to the hospital, I do not tell them where I am going. I keep this information to myself. It puts a lot of strain on me and it is difficult to cover-up”

6.4 Conclusion

From the participants’ accounts, we see how PLHIVs control and manage information to conceal and avoid discovery of their discreditable condition. Women who live with non-visible ‘hidden’ discreditable attributes worry about how to maintain their ‘secret identity’ or to pass as ‘normal’. However, the emotional and psychological toll of living in constant fear, and experiences of self-stigma, have negative consequences. PLHIVs living with discreditable attributes adopt key information control mechanisms to limit their social contacts, as women’s aversion to stigma and discrimination. This concludes the section on discreditable attributes, and in Chapter 7, I will now present the findings concerning women living with discredited attributes.

CHAPTER 7: HIV-POSITIVE WOMEN LIVING WITH DISCREDITED ATTRIBUTES

7.0 Introduction

This chapter presents the second part of the findings which reflect Goffman's (1963) generalised conception of 'stigma' in terms of discreditable attributes and also attributes that are deeply discredited. In the preceding chapter, which dealt with the theme of women living with discreditable (concealed) attributes and their struggles, I explained the three subthemes of 'secrecy', 'fear' and 'self-stigma' as the first part of the study findings.

In this chapter, I will demonstrate how women living with HIV who possess (non-concealable) discredited attributes experience stigma and enacted discrimination. They are vulnerable to a myriad and continuum of HIV stigma-related abuses as revealed in their constructed accounts of stigmatising encounters in their daily lives. By scrutinising and presenting appropriate data extracts I have analysed the main theme of women living with a discredited and/or tainted identity, similar to Goffman's treatise (1963, p.13), and have generated five sub-themes to present my findings, which advance Goffman's conception of discredited attributes. I draw on gender, conceptions of power and examine their usefulness to offer a nuanced account of the context and situatedness (Haraway, 1988) of the stigmatising realities as alternative ways to make sense of women's experiences.

7.1 Accounts revealing women living with discredited attributes

In presenting the findings it is important to note that in the Gambia, as mentioned in the previous chapter, deeply ingrained in people's consciousness is a fear of HIV as a contagion associated with looming death. The thesis asks: What are the local stigmatisation ideologies and local metaphors? What are the research participants saying about their own experiences? How is this linked to VAW and what are the risks and effects in the lives of PLHIVs? Is there a gendered dimension to the problem? I argue that conceptualising stigma as a discrediting attribute requires that I use my interpretive skills and understanding of the social context to examine the narratives to capture the range and mosaic of abuses as discriminatory actions meted out to women who are HIV-positive and who cannot conceal their identity. The construction of stigma ideologies includes deeply embedded ideas and notions of HIV as a threat and 'danger' to others (particularly

during the manifest stage). For clarity, the findings of this study are consistent with the literature on stigma (Goffman, 1963; Alonzo and Reynolds, 1992, p.4-6). They trace the trajectory of the diseases of HIV, and also show how the stigmatised persona may experience feelings and reactions from others which also make them feel dehumanised. This affects their ability to have free and unfettered access to social life encounters with others or enter into social relationships without the ever-present fear of being stigmatised.

The fear of disclosure for women living with discreditable attributes has been extensively covered in the previous chapter. But why is disclosure so important in the context of HIV? The next interview situates the voice and personal testimony of a health field practitioner as she underscores the dilemma and associated benefits of disclosure and the risks women face. The narrative below is the viewpoint of a prominent gender specialist and health field worker with several years' hands-on work experience in reproductive and sexual health education, care and activism. She is an avid gender activist in defence of the rights of women. This is her opinion with regard to HIV disclosure. She stated that it was critical to disclose, however she underlined that there are challenges and dilemmas, and highlighted the need to reduce VAW:

“Disclosure is very important and critical because HIV for now does not have a cure scientifically. And because scientifically there is no cure for HIV, it means it is something you are going to live with for the rest of your life, and this means you need somebody that is going to support you – a treatment supporter ... it is not easy to be on HIV drugs throughout your lifetime.”

She further explains:

“You need that love and care; someone who is willing and able to be behind you, to coach you, to give you time, all the encouragement for you to continue taking your drugs. And we know drugs come with their side effects. HIV drugs are not an exception. So you need the family to be there for you, so that when you have side effects they know what you are going through and they can support you. The likelihood is if you do not disclose you are on these drugs and you have side effects, they will take you to the health care providers and they will not know. They may even take you to the traditional healers. Disclosure is very important in terms of HIV ... be able to find someone you can disclose to, to obtain treatment support for the side effects of ARVs [antiretroviral drugs].”

Numerous attempts have been made to find creative ways of reducing disclosure related stigmatisation and discrimination. While disclosure of HIV for support is deemed useful,

affected women and community carers agree that, for some women, it may be dangerous to disclose without support. The next section (7.1.1) examines how accounts of women living with discredited attributes manage their condition, under these subthemes.

7.1.1 Sub-themes illustrated by data extracts. The sub-themes are:

- Accounts revealing living with discredited attributes: HIV perceived as a contagion;
- Accounts of PLHIVs' experiences of HIV/AIDS; adopting containment strategies: PLHIVs vulnerable to enacted stigma and discriminatory acts (multiple perpetrators and instigators);
- Accounts of confidentiality and ethical breach as sources of stigma;
- Accounts of abandonment, social isolation and ostracisation;
- HIV 'stigma' is physical abuse, and emotional & economic violence by perpetrators at home and in the community.

7.1.1.1 Sub-theme 1: Accounts revealing living with discredited attributes: HIV perceived as a contagion

HIV stigmatisation is influenced by HIV/AIDS stigma ideology that evokes situations in which persons living with HIV are perceived to possess a contagion. The issue of posing a risk to others causes PLHIVs to be isolated and containment strategies utilised to avoid contracting HIV (a common theme in the narratives of PLHIVs). Drawing from Alonzo and Reynolds' (1995) work entitled: *Stigma, HIV and AIDS: An exploration and elaboration of the stigma trajectory*, I rationalise that when the women manifest visible signs of HIV/AIDS, for example wasting and prolonged illness, this may trigger stigma and enacted discrimination. The next data extracts are indicative of the widely held beliefs of the 'threat' and danger of HIV contagion to others (especially during the symptomatic stages of the illness).

Participants 039 and 023 are PLHIVs whose first-hand experiences of stigma were linked to early 'social messaging' on HIV and AIDS. The excerpt reveals a lack of understanding and misconception of HIV/AIDS.

039: “I believe it is the earlier message about HIV as a deadly disease that makes people fear us – if you listened to the radio and television at that time you would hear Jaliba [a local popular musician] singing about the deadly nature of HIV and that it had no cure. Before I was diagnosed with HIV, before I was ill for a prolonged period, I was also afraid of anyone who had HIV.”

023: “It is important to change the messages and educate people on how HIV is contracted... to stop fear and the perception that HIV is ‘Alabalal’ and ‘Turobangoo’ [causes seedlessness and is a deadly disease], and that the effect is imminent death from HIV/AIDS. This is why HIV is perceived as a death sentence.”

039: “Before, when I was looking very ill I feared being pointed out – ‘chodiro’ – because I am aware of how they treat others. I was worried, because I was coughing and I feared people would start to spread rumours about me being an AIDS patient... but now I am improving with medication, I am feeling much better, and I do not notice anyone treat me differently. Before it was very bad and I was ashamed and feared anyone knowing that I had HIV.”

The extracts above provide insights into the experiences of HIV disease progression and the manifest illnesses of AIDS. When PLHIVs possess non-concealed (discredited) attributes evidenced by the visible signs and symptoms of body mass wasting, excessive coughing due to tuberculosis, and dermatitis, it inspires fear of the risks of contracting a contagion. The issue of internalised fear and self-stigma is evident and will be addressed as a common subtheme above in 6.3.1.3 depicting the subtheme 3, which focus on the accounts of experiences of self-stigma/internalised stigma. The issue of self-stigma is deepened as Pryor and Reeder (2011) and Chaudoir et al. (2013, p.76) explain that ‘self-stigma’ broadly describes how individuals respond to possessing a stigma. Self-stigma is a common term amongst PLHIVs in this study as carriers of a contagion or ‘perceived threat’ to others. As comments of PLHIVs 039 and 023 are indicative of fear of anticipated risk and danger of contracting HIV, as an incurable and deadly disease. Both fear and rumours about patients harbouring AIDS and imminent death spread like wild-fire in the context of HIV.

The next data extract registers how, due to family relationships that are characterised by competition and rivalry among co-wives, affected women are at risk of enacted discriminatory practices. The speaker reported that her co-wife’s daughter spread rumours about her, and this created a great deal of pain and instability in her life. It can be difficult to trace and identify the origins of rumours, however they affect women’s interpersonal and social relationships.

For 003, stigma is very real, as explained in a focus group discussion:

“Yes it is real. Let me explain first, I am a second wife, the daughter of my co-wife went about inquiring in the health centre where I get my treatment about me. She works at the Basse Health Centre. She sees me there and makes enquiries about my health status and leaks out information about my frequent visits to the hospital – also I was very thin and weak so they suspect HIV and AIDS. My co-wife’s daughter said to people ‘Look at her she is ill and most likely has the big disease’ [sasa baa in Mandinka a local dialect]. It is true then that I was very thin, so ill that **** [health care worker and counsellor’s name deleted] helped me and counselled me. That time I was also pregnant.”

Further, she was forced to engage in a physical fight with her co-wife’s daughter in public.

Interviewer (I) “Why did they abandon you?”

003: “It has a lot to do with the rumours spread by my co-wife’s daughter. I fought with her before the hospital entrance when she accused me of having AIDS, and she challenged me in front of others and talked about my illness as AIDS, always. Because of my co-wife’s daughter and the rumours, she spreads.”

PLHIV 003 claims that everyone knows her status because of the rumours. In an in-depth interview, she explains how her co-wife’s daughter exposed her:

“She would sit under the tree and talk about me and spread rumours about my imminent death caused by AIDS. People feared me and started running away from me for fear of catching the big disease.”

I: “Did people say anything negative to you? How have they treated you since then?”

003: “They say hurtful and slanderous things to me and question how I got the disease. Where did I get it from? They ask, insinuating that I was promiscuous. It caused me pain and I am emotional about this rumour. It hurts me.”

Women living with discredited attributes may also try hard to hide and conceal their HIV status. However, the discussion shows how rumours and the spreading of false and negative information to discredit and shame PLHIVs has affected most of them. In this section, this research overwhelmingly uncovers how HIV/AIDS related abuses against women occur under the pretext of HIV stigma and discrimination. We will explore how early messages are linked to local metaphors of HIV as a contagion that is feared because

it is perceived to be capable of causing ‘seedlessness’ (‘touraubangoo’ and ‘kurangangoo’, a deadly disease in the Mandinka local dialect). Many of the research participants describe relational contexts and challenging scenarios that point to their unending struggles as they navigate everyday interactions with others who devalue them, as advanced by an HIV Support Society President who is a PLHIV:

“When people suspect you and learn about your HIV-positive diagnosis they change their attitude towards you and some may even abandon you, ostracising and shaming you. It’s a difficult life. Stigma affects us.”

Another PLHIV said:

“My own mother, my friends abandoned me. No one cared to talk with me. I had nowhere to go, and I only talked to my own children – my four-year-old. I was thrown out and had nowhere to go ... [Sighs]”

She further elaborated:

“My mother was the main culprit, she treated me very badly. When I tested positive my husband denied it and sent me packing. He drove me away, to go back to where I got the disease from ... I returned home to my family compound but my own mother was unwelcoming. The rumours about my illness had reached her. She refused to have me at home. She sent me out of the home upon arrival, I had no place to go. I went to my uncle’s home, stayed for one year, and again was thrown out by my uncle and his wives – they fought with me, we fought, and fought often and I went to the district chief to report it ... The chief asked me to leave them and to keep the peace ...”

When women become tainted by an HIV-positive diagnosis, many experience economic hardship, housing and food insecurity. PLHIV 031 reported abandonment by her spouse and the reasons why she experienced serious economic hardship, a negative consequence of abandonment. I asked her:

I: “Why do you think he abandoned you?”

031: “Well I can’t tell. I know that I didn’t see him again he just left but I faced several years of economic hardship and difficulty in obtaining food to feed my family because I was too ill to work. My young sons tried their best to help with our survival needs. My daughter was a pillar of strength. Without her I could not have coped.

“I was later referred to the Support Society where I found others who had lived with the virus for several years. At first I was apprehensive and later with counselling support and care I began to change and improve my health. Other

members of the Support Society explained how they would go to the Support Society to unburden and discuss their worries and concerns as they lived with the virus. I was living far away from the Support Society and could not go there often due to transportation challenges.”

7.1.1.2 Sub-theme 2: Sub-theme 2: Accounts of PLHIVs’ experiences of HIV/AIDS: Discriminatory acts (multiple perpetrators and instigators).

When women cannot conceal their identities, they are at risk of being tainted and devalued by family, close friends and other community members. Many of the women during the interviews claimed that, when their positive status became known, family members adopted mechanisms to control and contain them. The first sign of trouble is when a spouse and/or close family member runs away from and refuses to care for them during a period of prolonged illness. This is particularly evident when rumours and negative information start to circulate, and others begin to devalue and avoid them, using verbal and emotional forms of assault and denial of basic needs such as food.

Several of the women in the study reported feelings of self-consciousness, due to problem of ‘self-stigma’. They explained how they fear and reaction of persons when they know they possess a discredited attribute, as explained by (Pryor & Reeder, 2011). Several of the affected women narrate enduring negative reactions to HIV as they acquire a negative label. When they cannot conceal their identities, they experience a number of challenges. The next data excerpt is taken from a discussion with PLHIV 030 concerning the diary she kept. She opted for a one-on-one in-depth interview because of her emotional pain and the shame she experienced from enacted stigma. She lost her twins because she passed the HIV virus to them and they died in early infancy.

030 “I did not receive treatment [early] because I was told by my husband not to accept my HIV-positive diagnosis. I was denied access to treatment by him and much later when he abandoned me, I learnt that he had known about his own positive status, yet he refused to let me receive treatment.”

I: “So after nine years you mentioned you became ill. What happened next?”

030: “After nine years I was very ill and was admitted to hospital. I received help from the doctors and nursing staff and also from some members of a Support Society for PLHIVs. People in my family did not visit me. No one did. My mum and dad were not alive. My mother’s co-wives treated me badly, my step sisters treated me badly. They treat me bad. It pained me. I now learnt that as long as you are alive you experience numerous challenges and see many things in life... [The

Mosque call to prayer was loud and disturbing at this point]. [Sighing, very emotional but wanted to continue with the discussion] ... they all treated me badly when I fell ill.

“My little children were the only ones helping me. They bathed me and dressed me. I was too weak to do anything. The family as a whole deserted me. I felt ashamed. My family treated me badly. My brother brought money to feed me, but they would refuse to spend the money on me. I was denied food and I was losing weight and becoming very ill. I was isolated. I was treated badly, denied access to food and care. My food was sometimes thrown at me in a very degrading manner. I was treated very badly by my own relatives, my blood sister. They refused to eat with me.

“They called me names, I was [living] with the virus and they did not want me to spread my illness to them. Everyone, including my sister, shunned me when I stayed with her. After a while she received a call from my family who asked her to drive me out. I was thrown-out because I have the virus. They feared being infected [coughing, coughing].”

I: “Now let’s look at your socio-demographic data and diary entries. Tell me a little about your life.”

030: “I was given away and married off at the age of 10 by my uncle. I was forced to marry. My breast was not out [her breasts had not developed] and I had my first period in my marriage.”

I: “How did you feel?”

030: “I feel my life was affected. In this first marriage it was my husband’s mum and sister who did not allow me to go with him to [****name of foreign country deleted] where he was living for a few years after our marriage. They believed if I went with him ... to [****] I was strong headed and would control him. I would be the only one my husband cared for, therefore I should stay back with them. During the first few years of my marriage I got pregnant but had a miscarriage. After many years the marriage ended since we did not see each other and he was in [****]. He later came back to made amends but I refused to join him [go back to him] since he left me and disappointed me.

“For the second marriage, I was in love with my husband and we got on well. I chose him and I had children with him. I had three pregnancies and all these children were negative. It was during my pregnancy with the twins that I tested and was tested positive with HIV. The twins were also positive, all boys. We all tested positive.

“The twins died and they were born faulty. Their bodies were damaged, they went to the toilet frequently and their stools had blood. The twins bled in their mouths, their eyes, their skin peeled, they looked pathetic and not fully matured. The twins died later.”

I: “Did their death affect you?”

030: [Sighs] “Yes very much their death affected me. I was denied access to treatment. My husband denied I was ill with HIV. It was much later I discovered that in fact he knew he was positive and he refused to accept and denied that we were both HIV-positive. After the twins I was pregnant again; my child was also born and it was the same thing, the child was damaged. He died later.

“He [her husband] said if we tell and accept that we are positive, then people will start to shy away from us, they will refuse to come near us, not eat our food ... I guess he had a fear of being stigmatised... well for me this was the main issue.

“I did not know why my husband denied that I was HIV-positive. I also did not realise that he knew he was also positive but hid it away from me. After nine years with the HIV virus it was taking over my body. I did not have treatment. It was later when my husband abandoned me and left our matrimonial home that I knew my husband was on treatment, but he denied me treatment. I was very ill, vomiting, diarrhoea, skin infections [‘pecha’ ‘pecha’, meaning rashes everywhere], even inside my vagina, everywhere was affected from my head to toe, and fluids came out, oozing out of my body. I could not do anything.”

I: “How do you see all that?”

030: “Ah, hmm, for me I am very surprised. I wonder how? How you can make your wife ill then you deny her treatment and then you abandon her when she becomes too ill? You are not concerned about the welfare of your children. I take care of them, then what type of a person are you?”

The above are difficult questions 030 have raised, clearly with no easy answers. Her account resonates with other women’s stories who narrate very difficult issues concerning denial of the right to access treatment, and emotional pain and suffering due to the loss of children following transmission of HIV from parent to child; and resulting in still births. As family members failed to assist them for fear of contracting the disease, as they exhibited ill-health and were further weakened by the manifestation of HIV/AIDS symptoms (particularly those women who suffered delayed access to testing, treatment, and care), many spoke of an inability to cope without outside help from Support Societies and other non-1 community home - based care and support projects.

7.1.1.3 Sub-theme 3: Accounts of confidentiality and ethical breach

In this study, oftentimes PLHIVs claimed that they were suspicious that ethical breaches in privacy and confidentiality might have occurred at the health settings, or when they had trusted someone who may have failed to keep their ‘secret’ (narratives common in FGDs). Such unexpected disclosure of status could in fact be the main source of stigma.

PLHIV 011's narrative from an in-depth interview attests to the negative impact of confidentiality breaches with regard to stigma and the spreading of rumours.

"I returned home and that time I deteriorated, my illness worsened. I was very ill. After a prolonged illness and poor response to treatment I was tested and found that I was positive and started receiving HIV treatment. I began to feel better..."

"A man wanted to marry me but I told him I was not feeling very well, I was ill. However he insisted and finally we became husband and wife."

Later, due to rumours, the couple experienced a rift in their relationship. Stigma causes numerous interpersonal conflicts and is a major source of abuse experienced by PLHIVs, and it affects both the individual and their family. The next data extract is from an in-depth interview with 011 who explains how she perceives confidentiality breaches and their negative impact:

011: "My second husband said he knew I was ill and at first my illness did not worry him. It was much later, when people began spreading rumours about my prolonged ill health and frequent visits to the health facility, then we started having problems. We had fights and arguments often..."

"I think in the health care settings it is the nurses who leak my condition to others. It is those people who are supposed to cure us who disclose our status to others. I think this is bad – I feel bad when others know about my status. I also think it is bad; they need to maintain confidentiality about patients."

I "When you experience this and you think your 'secret' was brought out and disclosed to others how this perceived breach of confidentiality does make you feel?"

011: "Nurses breaching confidentiality in a close-knit society such as ours is causing us HIV patients many problems. For me, I experienced finger-pointing, 'chodiro'. It hurts me. If you want to go out you feel ashamed, you have to hide, and the people I used to do business with I can't anymore. Because the people I used to work with [as a petite trader] are the ones that are now stigmatising me. They are afraid of my ill-health. They fear my illness."

The data extract above shows how a PLHIVs experienced rumours and how rumours affects them. Perceived confidentiality breach and the fear of rumours remains as a burden to several women in the study. It is a challenge to keep information about their positive status hidden from family and friends. As a result, mistrust and adoption of 'secrecy' also take a serious emotional toll on affected women's mental health and well-being. This anxiety also has emotional and psychological effects and may cause breakdown in family

relationships. At the home level, it causes a deepening of the cycle of fear, and of perceived and real threats of stigma, due to rumours and breaches of confidentiality.

The above interview shows how rumours and confidentiality breaches are a heavy burden on women who are devalued and live with discredited attributes. Another critical issue is that confidentiality breaches can have negative outcomes and fuel interpersonal conflicts and rifts between husband and wife. Rumours of HIV affect women who become ostracised, rejected, and adopt self-imposed social controls to reduce contact with others. These measures limit their social interactions and as a result they feel trapped and face emotional, social and serious economic and survival challenges.

7.1.1.4 Sub-theme 4: Accounts of abandonment, social isolation and ostracisation

Enacted stigma and discrimination may take the form of social isolation, ostracisation and being shunned. Below we discuss the subtheme of abandonment as an example of the stigma effects on women as they struggle with the challenges of the discredited attribute of HIV contagion. In the Gambia, local metaphors are commonly used to describe HIV as '*touraubangoo*' and '*alabalal*' (i.e. HIV is locally known as a killer disease), even though medical advances and treatment show that women can live for several years with the virus, and with the advent of antiretroviral treatment HIV is now properly managed as a chronic disease. However, the notion of the contagion, the killer disease lingers in the psyche of most Gambians. These subthemes are commonplace, occurring at home and in social gatherings. The study brings out stigmatising contexts in which HIV-positive women state that people run away from them, will not share their meals, and other stigmatising actions, as captured below in the narratives of PLHIVs.

The next data extracts explain numerous challenges associated with women's experience of ostracisation and social exclusion. These are mundane forms of abuse which deny women the right to access food, and other basic needs. The extracts reveal how PLHIVs possessing discredited attributes are affected when family members stop sharing their food because of their tainted sero-positive status. In the data excerpt, 026 and 030 are two women, both living with HIV; one is an HIV peer health educator, an advocate for the food and social rights of PLHIVs. Both are members of the Network of HIV-positive women, Mutapola Voices of Women, and they explain in their journals:

026: "...my own family stopped sharing food with me in the same food bowl.

They run away from us all... They stopped sharing food. I was diseased... I was given separate feeding utensils..."

030: "My own mother drove me away after I went to her... she drove me away and I had nowhere to go... during that time they don't eat with us anymore... I was separated from the family food bowl..."



Figure 22: Food bowl politics – family members sharing the food bowl.

The figure depicts the sharing of food at home and at social events where people eat together at the same food bowl. However, many are denied by family members the sacred principle of sharing basic food (indicating oneness and togetherness) in the family. At home and in social gatherings, this experience is traumatic and very painful. The politics of the Gambian food bowl, which documents subthemes of ostracisation and social exclusion, is clearly revealed in numerous women's reports of people 'running away' because they fear contracting the deadly disease. I provide a contextual analysis of the politics of the food bowl and how it focuses upon social control measures and exclusion of persons living with the virus.

Participant 002 is a PLHIV who stated in a focus group discussion:

"Since I have had this diagnosis, that I am positive, I have not had problems with my husband, but have had many issues and problems with other family members and neighbours who stigmatised and discriminated against me. People stopped eating with me from the same bowl at home, and they did not stop at that but also excluded my son. Family members talked about my illness and went to the extent of stigmatising my son and saying 'do not play or eat with him, his mother is ill.' I felt very bad. It caused me a lot of pain."

With an HIV diagnosis, and when women manifest non-concealable signs and symptoms such as excessive coughing and prolonged illness, family members are unwilling to share or to touch food or items which have been touched by infected women and their children. They often leave the food bowl when ‘infected women’ join them and this has been described as a shameful and degrading experience by the affected women, as recorded in a diary entry by PLHIV 025:

“I experienced economic abuse or isolation as a form of violence. When I disclosed to my husband he failed to give me ‘fish money’ to cook and when I managed to find something to cook he would not eat due to my HIV-positive status ... I experienced secret violence (not verbal but he would shun me, not talk to me, not eat my food...).”

Often in the traditional Gambian context, family members share meals from one communal food bowl. Men eat together and women and children share the same food bowls. In such contexts, a woman’s role is clearly delineated according to the gendered division of labour and her assigned role as a mother is to cook and feed her family. Indeed, she may be valued because of her ability to implement her gendered role and in the case of HIV she feels dehumanised when she prepares food and no one eats it, or when she is not allowed to cook, and is even excluded from sharing in family and communal meals shared during social functions like weddings and naming ceremonies, as the next data extract suggests:

005: “For me, I did not experience physical violence but I experienced emotional forms of abuses when I tested positive and was very ill. There were rumours [chodiro], people talked and discussed me, because I was frequently sick. Also, when I cook family members refuse to eat my food, because of my HIV. They say I have AIDS – the big disease. This is very painful. It brings shame to you as a woman.”

Revisiting the situation of the PLHIVs, their main concern is with family members and the way in which they are ostracised from normal family/social activities such as sharing family meals. Affected women feel excluded and this brings pain and psychosocial effects of shame and feelings of isolation for women. The negative effects of social isolation and ostracisation are themes covered in the next account by 079. For example, basic food and house rent and increased debt and anxiety over basic survival needs create stressful situations for women living with HIV, especially when illness and fear of stigma limits

their ability to engage in economically viable activities to meet their own basic needs. As 079 and 039, both PLHIVs, indicate:

079: “I was too ill and couldn’t work or obtain money to pay my rent or buy food. I had owed rent for months. I went to the Support Society who helped to pay my rent... since I was too ill I used to sell iced water but stopped for fear of stigma, and also I was too ill... I am a petite trader. I have numerous problems and the biggest challenge is food and rent... I eat dry bread sometimes... My son is now living in the city, he has no work. I also borrow and take credit from the shopkeeper next door. Sometimes I cannot pay the bills and it causes a lot of anxiety. Often I go to [****name of Support Society deleted] to eat when I am very hungry...”

039: “I am a farmer and when I fell ill I stopped farming because I was very ill. As my disease progressed I experienced family members and other people calling me diseased, suspecting AIDS. I experienced chodiro – but I will not respond. Food is definitely our main problem, sometimes I can barely find one meal a day. People are afraid to eat with us, to touch us and live with us...”

When women are diagnosed with HIV they experience a mosaic of abuses and denial of rights. These may include ostracisation and social exclusion as a form of containment strategy adopted by others who fear contracting the virus. Frequently family members fear them and they are shunned and asked to stop cooking family and communal meals. In the Gambia, a woman is considered tainted and feared as a contagious person if known to harbour the virus. They may be denied fish money – an allowance to prepare food for the family.¹⁹ To further illustrate this point, 009 brings to the fore critical issues depicting the theme of everyday struggles for survival as unending, due to family and social ostracisation and the effects are negative effects of stigmatisation.

009 explained through an interpreter, her own experiences as she deteriorated and at this stage of the disease progression and she might have been in a manifest and symptomatic stage on HIV/AIDS. However, due to her emotional distress and mental health challenges, she was labelled negatively and treated harshly by family members.

009: “She was seen by her family as a ‘mad woman’. She was having vaginal discharges and numerous problems with her health.”

¹⁹ Fish money refers to the daily subsistence finances that a husband or intimate partner or an influential household head provides for a woman to prepare meals. They use the funds to shop for food and basic household items and consumables.

The translator explained how 009 was treated at home by the relatives:

“For two years she was tied up in a house – locked up in a hut with a very heavy piece of wood [even 5-6 people could not carry it] and they tied it to her. Like a slave – sitting in one place she was tied and fed there, hoping she would calm down. She would be left like that for a long time. They hoped the spirits within her would calm down. The ropes round her hands were hurting her. They were afraid that she would escape ...”

She explained about 009’s experience of physical assault, food deprivation and isolation from the family:

“They locked her up. She was in this hut. They dug a hole and that is where she passed your stools – they tied her up as a form of restraint. They did not provide food or water for her; she was isolated and treated badly. Everyone feared her and did not want her released.”

“They held her and took her to marabouts [spiritualist/traditional healers]. They used ‘safaras’ [local traditional spiritual medicines/concoctions]. She was taken from place to place, to different marabouts. Later she was taken as a last resort to the hospital. She said she actually received good treatment with good people caring for her in the hospital [‘boroo kendeya’, while admitted in hospital. At this stage she was diagnosed with HIV].”

The role of non-intimate partners in causing abuse to PLHIV is revealed here. In the context of multi-generational households and extended families live in family compounds. Women who disclose their positive status experience various problems. The narrative below shows how 101 tested and shared her sero-positive test result with her brother, but the wife of her brother stigmatised her by calling her names, singing [songs she composed about her] and verbally assaulting her:

“When I tested positive, I disclosed to my brother and he also told his wife. My own brother’s wife was the one singing [composed songs to hurt and shame her] and accusing me about my HIV positive status. My husband was ill, and my brother’s wife stigmatised me, she would spit when I passed by her. She would compose hurtful songs and sing about me and my illness.

“She would deny her children access to my room. She would tell them that HIV killed my own husband ... The verbal abuses; the finger-pointing ... the family moved me from the main house to the back of the compound, to a place where there is an old and dilapidated hut, where garbage is thrown. I was ostracised ... I

was made fun of and ridiculed by this woman. I continue to face her each day and the problem is unresolved ...”



Figure 23: Dilapidated and isolated living conditions. A hut with poor sanitation.

The figure shows a mud hut where a PLHIV 064 was relocated, abandoned and ostracised, away from the main family dwelling. Social isolation within the family was common as part of the women’s daily struggle with housing insecurities if suspected of harbouring the disease.

“After my husband died I was asked to vacate the family house. It was my husband’s house. He built it, the roof and everything to shelter us was taken off and we were forced to sleep outside ... yes it was my in-laws who threw us out from the main family house”.

Other women who are less fortunate experience eviction and many of them have great financial challenges to pay their overdue rents. As a PLHIV Nanding [pseudonym] in her diary documented:

“I was evicted by the family and I left peacefully to avoid further trouble and resettled in the Kombos. I owe several months of rent and my landlord is very unaccommodating. We experienced problems and live in constant struggle to find the rent ... I am not working and this is the main problem, my children are young and cannot work too”.

The situation described in the data extracts above is not unique to Nanding, several other PLHIVs have experienced similar challenges of overdue rentals, as a result of late unemployment, poverty and economic marginalisation. Most of the women seeking assistance from the Support Society are poor. Many of those women face several complex

survival challenges when they experience eviction from their marital home upon the death of the spouse, when they are abandoned, divorced and ostracised. Some of them have managed to find their own rented accommodation after being thrown-out by family members. However, of the women who managed to rent their own homes, a high percentage document in their journals/diaries that they owe months of back-rent. Prolonged illness, frequent hospitalisation, and abandonment by spouses and other family members are referenced here as the main reasons why they owe their landlords rent.

Some of them owed over six-month' rent and often tenants are asked to pay in kind. When they refuse transactional sex in exchange for rent, they are abused verbally or asked to leave the rented house, as another PLIV said, she was harassed regularly and asked for sex in lieu of rent:

“I knew I was diagnosed with HIV and I was concerned about transmission of the virus. My landlord harassed me often and asked for sex in lieu of rent. I owe him several months of rent but I refuse to have a relationship with him ...”

Another PLHIV admitted similar problems and said:

“My own situation he forced me [the landlord] and we had a fight, I sustained injuries to my arm and had to report the matter to the Support Society. They intervened to resolve the conflict”.

Generally, the majority of women struggle with effects of economic challenges and associated risks of finding safe and affordable housing for PLHIVs. As a woman, the risk of sexual harassment remains an unexplored problem associated with poverty and dependency. In addition, enacted stigma and discrimination of PLHIVs in the current study, unveil the negative aspects of living with a devalued (discredited) status of HIV. These findings were also corroborated by health care field practitioners and peer health and community educators involved with their care. The stories have unravelled the complex web of challenges that women have lived with a discredited condition as they struggle against and suffer the effects of stigma and enacted discrimination. I was interested in presenting the views of clinicians and I asked the next focus group, a group of clinicians, about the problems of the women they offer care and support to in their professional capacity.

I: “From your work settings and experiences what do you think are the key issues affecting women living with an HIV-positive diagnosis? What are the issues these women are vulnerable to as they live with HIV?”

Lovely: “I am 113 for me in our African tradition and because of concept of HIV we think HIV that when a woman has contracted HIV [because] it is believed she has been promiscuous or she has been living a bad life. So that would lead to stigma because here HIV is attached to people who are like sex workers [...] or the lady has been living a free life. That is one reason why women in Africa are vulnerable to stigma, discrimination and violence. Because if that woman is a married woman and then she is found to positive and the husband is negative the family members will think that maybe this lady has playing out having sex with other men this can lead to divorce, and maybe the husband would even maltreat her, and she will be faced with domestic violence. So for me I think one of the reasons is because they think that the woman has been living a ‘free life’...”

I: “Thank you Lovely,, I would like to ask have you ever experienced dealing with a woman in your work situation who has complain that she has been treated badly or has been stigmatised, because of HIV As you have just explained?”

In response another health clinician, I believe in God [pseudonym] said:

“Oh yes many of them, many of them most of our patients that we see here because in fact that is one of the problems we are having with disclosure. Because when a women is found to be positive she finds it very difficult to disclose, because she is afraid for what the outcome will be... because one thing is stigma the next thing she will be faced with violence because they might treat her anyhow. The husband may send her away, even if she is not married family members might just ehmm... [Ehmm] maltreat her saying she has been living a bad life. Women are afraid to disclose. Anyhow so we are facing a lot problems with disclosure because the stigma because they believe there is a saying that only promiscuous women are infected with HIV”.

7.1.1.5 HIV stigma is physical abuse, and emotional and economic violence by perpetrators at home and in the community

Women tell of hostility as their status becomes known and discredited attributes of stigma (non-concealable signs and symptoms of the disease, such as coughing, TB, and weight loss) evoke negative reactions, including insults, accusations of promiscuity and the adoption of social control strategies that isolate and malign them. In addition, some women in the study report physical abuse, such as beatings. The next data extract is a painful narrative from a focus group, where participant 103, a Mandinka woman, explains that her spouse beat her “like a donkey” – ‘akeh bussa com fallow’:

103: “I married my husband as a young girl. Later, after my husband had travelled for five years, I fell very ill for a long time. My husband travelled to [**** name of country deleted], and he eventually returned home to the Gambia. He was very ill too. He too tested HIV-positive. At first everything was OK between us, but later my husband was influenced largely by his mother and immediate family members. We had many difficult moments staying together at this point. Our relationship can best be described as very challenging – it became strained because of the frequent physical beatings and accusations by my husband. He beat me several times and accused me of giving him this disease. In fact, I sustained physical injuries and reported to the hospital for treatment due to his beatings. He beats me like an animal – even a donkey could not suffer worse because he always accused me of giving him the disease. His mother was the main culprit behind all these accusations.”

I: “Hmm ... we have listened to her story and I want to know from your own various experiences what do you think of this explanation?”

101: “Well from my own experiences what we just heard is painful and it should not have been like this because no one knows ... he could have infected the wife without knowing it ...”

One research participant, Nyima, who I describe as an active co-researcher, revealed how she had provided help to other women to overcome various problems. Although still overcoming her own personal struggles of having lived with HIV for twenty-seven years, she now has a mission and has decided to take an agentic stance to help others, stating:

“I have found a platform from which to speak out and engage in HIV prevention and advocacy work.”

Furthermore, Nyima said:

“Opportunities abound to help others because you have lived the experiences of self-stigma and enacted discrimination. She who wears the shoe knows where it hurts most.”

Like many other PLHIV volunteers, Nyima, Mother Joofoo, and Mama Sarahule are all part of a very strong and empowered group of women in the Mutapola Voices community and home-based care project. There are too many of them to document all their stories, but they capture the trajectory of change from being diagnosed with HIV, to learning how to cope, and becoming resilient and helping other newly diagnosed PLHIV to cope. They gradually being strong, active and vocal in claiming their rights as members of a network of women living with HIV.

Women in the current study cohort have narrated accounts to show that violence and a range of economic, emotional, physical and psychological abuses have been problematised before and after HIV diagnosis. VAW is a precursor and sequel to HIV.

The next data extract is from a key informant, a gender specialist and advocate, an indigenous Gambian consultant Ngata [pseudonym], during an in-depth individual interview, deliberated on the issue of gender-based violence against women as a contributing factor to HIV/AIDS. She explains:

“I consider violence, most of the time, a cause of HIV/AIDS, because when you look at the culture in the Gambia, we live in a ‘culture of silence for women’. Women are not supposed to speak up, they are meant to take instructions from their husbands and from males in their family, and this allows the opportunity for these men in their lives to abuse them, and to also control their bodies. And this starts from childhood, where in most of the Gambia young women are subjected to FGM, which is a decision obviously by the family and not the young women themselves since they’re too young to make that kind of decision ... Much later most decisions are made for them in terms of who to marry; usually somebody they are not in love with, and who they are told they need to listen to and do what they want them to do. And that creates a problem, because these gendered norms and roles in society then influence the way women are perceived as ‘objects’ and not as ‘subjects’, so to speak ... without their own sense of agency.”

During the individual interview with Ngata, she further clarified that while patriarchy was a system that devalued women and promoted male dominance and control of men over women, certain influential women colluded with the system. For example, it is insightful to learn that elderly women (the aunties, grandmother, mother-in-laws, sisters-in-law, aunties and other highly respected female elders) all played very significant roles in sustaining the system of patriarchy. She posits that women colluded with men and sustained patriarchal norms and practices.

In her analysis, Ngata clearly brings out intersections of power and privilege accorded to elderly and influential women, clearly revealed how women’s role as instigators of abuses is affecting other less powerful women. Here we register that men are not the only perpetrators of domestic abuses. The oppression of women by men and the role played by women as gatekeepers of patriarchal norms and practices borders on questions of power and an inability to take an agentic stance in matters concerning their lives.

Women's marginal position in decisions related to their lives as subjects is often denied within the patriarchal and traditional family.

In the study, women living with discredited and tainted attributes are devalued by negative labelling and accusations of leading a promiscuous lifestyle. I now present a data extract from 045 which informs the reader of the subtheme of abandonment and being thrown-out, ostracised and isolated from the family home. It is based on the notion that women are promiscuous, thereby justifying the accusation, and blaming them for their own predicament. The data extract is from a focus group discussion with a number of health clinicians. During the discussion 114 states:

“OK I am ‘General’ well ... *ammm* pertaining to the question I would like to agree with what 113 have said before. The notion that HIV and AIDS is mostly attached to promiscuous women, a bad woman some who plays around. These are women who play around especially the sex workers. So ... if anybody who has it you are pointed as one of them. So ... you see so that's why you are being stigmatised. Anywhere you are seen you are being pointed out as a sex worker, a bad woman and so nobody would want to associate with you. So that is why it is always difficult for HIV positive women to come out [to disclose]”.

The next excerpt is taken from an in-depth interview with forty-three year old HIV-positive participant 013, who stated:

“I say for many people in the Gambia in polygamous relationships women are not given their due respect. I was given away in marriage at 16 years, my husband died of HIV, this is my second marriage and I disclosed but he accepts and loves me, but not everyone is lucky.”

She further explained:

“My first marriage was a difficult issue for me. It was a forced family marriage, I was forced to marry him as a second wife at 15 years of age. In that marriage my husband married and divorced, married and divorced all the time up to ten wives. I was the only one left during the time he died of TB. I was not in love, I will never like him today, never liked him ever not in this life and not in the next world. I will also never forgive him for the poverty life and hardship he left me with after his death. I never wanted the marriage and it is this marriage that left me suffering up to today. I am suffering with my children. I was given away to suffer, my family has money but I was given away to a relative I am still not fully recovered from the effects of my poverty life with that first husband. We never had enough food because of this large family and his frequent marriages to other women.”

She continues:

“Food insecurity was my main challenge and even a bed for us to lie down was a problem. I suffered from poverty and lack. We never found enough to feed my family, never. My former husband provided nothing for me. Now you see we are very poor and I cannot find adequate housing, during the rains you will feel sorry for me, rain enters everywhere is leaking in this grass thatched roof. I suffer with my children am still suffering, I was in bondage, after diagnosis with HIV we stopped having any sexual relationship, and he had several women about ten of us, all left eventually and she was the only one left to care for treated him. He treated me badly but I stayed in the marriage until he died. She reported to her family but they insisted she stay in her marriage - he was a family member. She stayed at the former husband’s home. I cannot disagree with my parents [elders in the family] and if they say I stay in the marriage I have no choice but to adhere to their orders. I am still living in this marriage home and my new husband visits me. He helps to care for my family.”

The following data extract is suggestive of a range of abuses, best described as physical abuses affecting women. During a focus group discussion, she explained how she was aware of a range of abuses meted out on PLHIVs by family members. Key examples of physical abuse included a PLHIV whose own sister scalded her with hot water then visited her in hospital and assisted her before she passed away. Nyima stated:

“I did not experience violence myself, however I have helped several women who have been discriminated and physically abused. For example, a PLHIV was scalded by her sister in the presence of her mother. She told her to go and die with her AIDS. She sustained extensive third degree burns as a result of the scalding with hot water. She suffered and was in great pain. I helped her during her admission in hospital but she later died from the extensive injuries she sustained.”

There is evidence to suggest that, after HIV/AIDS diagnosis, violence can take the form of mundane or visible acts of abuses. HIV diagnosis may exacerbate violence in the lives of women. Both the women, and field workers in community home-based care programmes were in agreement as they provided stories of HIV positively diagnosed women being discriminated against and exposed to mundane forms of abuses and also overt forms of abuse and physical and economic violence. On one hand the overt forms of abuses may include reports of endless physical beatings, and physical fights with their co-wives and co-wives’ children who stigmatised them. Other women narrate stories of being locked up and isolated, and exposed to a range and mosaic of abusive HIV enacted stigma and discriminatory practices. On the other hand, the mundane forms are

abandonment and social isolation. When women are diagnosed with HIV they experience a mosaic of overlapping abuses and denial of basic needs to housing, food and other rights. The containment efforts imposed on them may include ostracisation and social exclusion as a form of containment strategy adopted by others who fear contracting the virus. Frequently family members fear them and they are shunned and asked to stop cooking family and communal meals. Thus, I argue that if a woman is considered tainted and feared as a contagious person, they will experience abandonment and in her diary a PLHIV who has been diagnosed with HIV, aptly explains how she experienced hardship as a result of abandonment. The husband “simply left and never returned”.

Initially, he did not eat my food anymore with us [the newly diagnosed PLHIV] but goes over to her mother and other relatives to eat. He later abandoned me and did not provide any assistance, he did not give us fish money, nothing. I have no conjugational rights even if I need him he never comes home, never support us, yet he has not divorce me. He merely discarded me like an old wrapper. He simply left us to fend for ourselves ...”

Based on perceptions of risks and the contagious nature of the virus, PLHIVs are vulnerable to enacted stigma and discrimination. A PLHIV expressed concerns when she was treated badly during a naming ceremony as she was isolated. As she entered the event people stated to move away from her, she felt the effect of the overt social isolation. She narrates how people do not want to sit near or share food with them, being treated like a ‘leper’ or ‘outcast’ because they are considered to live with the ‘contagion’.

She said:

As I entered the place where the naming ceremony took place, people did not want to sit next to me. I felt like I had faeces rubbed all over my body. I asked them why they are running away. Why are they treating me like a leper? I felt very bad and fought back assaulting them verbally.

Several of the research participants express how at market places, at the water collection points (the village wells) and many other social spaces, PLHIVs experience stigma and discrimination (the chodiro experience) when they are known as ‘positive’ and many perpetrators and/or instigators of enacted discrimination erroneously think they are infectious to ‘others’ and thus treat them differently. However, there are several of the women who have disclosed to a limited number and consider the experience positive and

empowering, consistent with findings of previous studies by (Denton et al., 2012). Yet, in some extreme situations, some of them experience physical abuse, are abandoned, divorced, verbally assaulted at home and in the community, and denied forms of assistance and basic needs such as food, housing and economic support. Hence, being diagnosed with HIV has implications of fractured family relations and breakdown in social networks and support. As a result of abandonment, being-thrown out or divorced, as depicted in the accounts of my study cohorts who experiences of economic struggles, food and housing insecurities, including the emotional and psychological traumatic experiences of living with discredited stigmas. The problem is unending and remain unresolved as many of them revealed in their stories during the interviews.

7.2 Conclusion

The purpose of the study is to investigate the link between violence against women and HIV/AIDS in the experiences of Gambian women. My quest was to render audible co-research participants' voices and subjective experiential knowledge as a contribution to our understanding of the intersections of the phenomena of VAW and HIV. They have spoken and their contribution unveils a sociological perspective on the social construction of HIV ideologies and how stigma manifests as mundane and overt forms of abuses. The actions of perpetrators are revealed through various practices of everyday normalised abuse and adoption of social distancing and control measures by 'othering' PLHIVs in HIV/AIDS disease stigmatisation processes.

The findings of the research document that perceived threats are experienced by PLHIVs living with discreditable attributes. Also, many of them live in fear associated with disclosure, which is difficult because of pervasive threat of stigma and discrimination. Additionally, the fear of stigma and enacted discrimination by an intimate partner and other family members adds to the constant struggle women experience as they manage to live with visible 'discredited' attributes. A major challenge that women experienced upon HIV-positive diagnosis was how to manage the information concerning their positive status.

I have used the preceding two chapters to present my study findings. I utilised a feminist participatory approach and combined the action research process of data generation to prioritise the voice of women with reports derived from key informants from a team of

multidisciplinary health, gender, women's rights and social development advocates to identify the findings of the study. There are interlocking structural factors and systems of oppression that contribute to women's vulnerability to a wide range of abuses, which in turn may expose them to the risk of contracting STIs and HIV. By utilising a thematic data analytical process, I came up with one overarching theme, that HIV stigma is both a discreditable and discredited attribute, and eight supporting sub-themes. These unearthed context-specific complexities and challenges related to a range of stigmatising acts of discrimination experienced by sero-positive women living in the Gambia.

The analysis revealed themes of isolation, ostracisation and exclusion that clearly capture women's perceptions and conceptualisation of the stigma to which they have been subjected by close and trusted family members. Also, some describe self-imposed sanctions due to fear of stigma, limiting their social interactions and adopting concealment strategies (secrecy, fear, self-stigma, avoidance and self-imposed isolation) to prevent exposure to stigma and discrimination. Women living with visible (non-concealable) or tainted attributes experience associated risks of stigma and enacted discrimination. Thus, it is important to understand the context and situatedness of the propositions made in the next chapter 8 to appreciate why the intersection between violence and HIV/AIDS cannot be explained by any single theory, given the complexity and fluid nature of the phenomena under investigation. The next chapter will focus on the contribution of the research to key propositions based on the findings of the study, the study recommendations for future interventions and research, study limitations, and dissemination of the key findings.

CHAPTER 8: RESEARCH PROPOSITIONS, RESEARCH CONTRIBUTION, RECOMMENDATIONS, STUDY LIMITATIONS AND DISSEMINATION OF RESEARCH FINDINGS

8.0 Introduction

I commence this chapter with the discussion on the research findings for women living with HIV and possessing either discredited (non-concealable stigma attributes) or discreditable (concealable) attributes. The chapter focuses on a number of key propositions based on key findings of the current research. In addition, I will discuss the contribution of the thesis to the sociological debate on violence against women and intersection with HIV. This will be followed by the study recommendations for future interventions and research, study limitations and dissemination of the research findings.

The current study had two main objectives:

- To create a platform where women are supported and encouraged to discuss their lived experiences.
- To utilise the findings of the study to address challenges identified by research participants, to recommend interventions for preventive, care and support services.

I sought to unveil the experiences of women living with HIV and to reveal the connection between violence and HIV.

8.1 Discussion on the propositions

A strong correlation between violence and HIV/AIDS has been acknowledged in research for a long time. However, few evidence based studies have been conducted in the Gambia that focus on the lived experiences of women with HIV, and of the health care practitioners working with them. By adopting a feminist participatory approach to the analysis of extensive qualitative data, the chapter seeks to render audible research participants' voices on their experiences of HIV and vulnerability to violence. The current study has evidenced that there are multiple, interlocking structural factors and systems of oppression that contribute to women's vulnerability to a wide range of abuses, which in turn may expose them to the risk of contracting STIs and HIV.

In addition, this study has unearthed context-specific complexities and challenges experienced by HIV sero-positive women in the Gambia. These will not be explained by

any single theory, given the complexity and fluid nature of the phenomena under investigation. As a way of making sense of my data, I present a number of propositions below, then expand upon them in the remainder of the chapter under these key headings: 1). HIV stigma as a ‘discrediting and discredited attribute’ representing a language of relationships; 2). the idea of stigma *as* violence due to compounding underlying forces of patriarchy, gerontocracy and structural violence, 3). multiplicity of perpetrators; 4). agency and resistance to pre-existing gender and HIV stigmatisation processes.

8.1.1 HIV stigma as a ‘discrediting and discredited attribute’

Drawing from Goffman’s thesis, stigma is a ‘discrediting and discredited attribute’ representing a language of relationships, whereby the possessor of a stigma confirms and internalises the usualness of the stigmatising constructs, often invoking negative traits and imagery. The stigmatised persona is constrained and functions within social limiting boundaries (Goffman, 1963). Consequently, the stigmatised person experiences a devaluation of her personhood, she may feel shunned, lessened in her life circumstances and experiences, and this limits her access to life enhancing opportunities (Goffman, 1963). Hence, it is argued that a stigmatised person may experience feelings and reactions from stigmatisers that dehumanise and affect her ability to have free, unfettered access to social life encounters with others or enter into social relationships without the looming fear of being stigmatised (Alonzo & Reynolds, 1992, p.4-6; Goffman, 1963). Generally, the findings of this study are consistent with the literature on stigma (Goffman, 1963; Alonzo and Reynolds, 1992, p.4-6) who trace the trajectory of the diseases of HIV, unveiling the stigmatisation process in the Gambia as a form of negative reactions from others who devalue women living with HIV. Stigma discredits and accords a tainted attribute to women living with HIV, Thus affecting their ability to have free and unfettered access to social life encounters with others or enter into social relationships.

Below, I have analysed Alonzo and Reynolds’ (1995, p.306) essentially distinct phases of the illness trajectory in terms of Goffman’s conceptualisation of stigma (as discredited and discreditable) and in relation to my own examination of the HIV illness trajectory as presented in the current research participants’ accounts.

- (1) At risk: In the PLHIVs accounts rumours and suspicions that are not founded on any tangible or concrete evidence is a problem especially when women frequently visit the HIV clinics or treatment centres.

Thus, the subtheme of rumours and fear is central in this thesis. When women are suspected of being a risk to ‘others’ who are not yet HIV positive, they are at risk of being discriminated against and abused (fear of verbal abuse, finger-pointing, name calling, the ‘Chodiro’ experience) abounds in their narratives. Thus, I rationalise that when PLHIVs manifest signs and symptoms of coughing or wasting and have non-concealable attributes, fear of enacted stigma and discrimination affects PLHIVs. Fear is a common subtheme in their accounts.

(2) Diagnosis: When a PLHIV is diagnosed with HIV and it is not known, the management of information and how she conceals her positive status ‘to pass’ is important, yet she may constantly engage in surveillance to avoid the risk of disclosure (themes of secrecy, concealment, avoidance, constant surveillance to control information in order to avoid stigma and discrimination; fear of discreditable attributes being discovered is a common theme at this stage).

(3) Latent: common in the narratives of women are subthemes of self-stigma, PLHIVs living with a deep sense of avoidance, of shame, fear of being ill-treated, shunned, and devalued. PLHIVs have a strong desire to keep safe from others who may know about their discreditable status. Thus, to avoid discrimination they adopt mechanisms of concealment, ‘self-imposed’ secrecy, exclusion and isolation from family and friends.

(4) Manifest: living with discredited attributes evoke social isolation and containment strategies adopted by others. Participants narrate subthemes of abandonment, shunning, social isolation, being thrown-out, as “people do not want to sit near or share food with them”; few of them claim to be treated like a ‘leper’ because they are considered to harbour the ‘deadly virus’; some experience physical abuse, are abandoned, divorced, verbally assaulted at home and in the community, denied forms of assistance and basic needs such as food, housing and economic support.

Furthermore, the literature also suggests that “socially constructed views on AIDS can be assimilated and internalised by HIV infected persons, resulting in “self-stigmatisation” (Pryor & Reeder, 2012). Several women discuss the subtheme of “self-stigma” and its emotional and psychological ramifications. The current study has evidence from the participants’ account subthemes of internalised fear, this form of fear is consistent with

scholarly writings of (Chesney & Smith, 1999; Lee, Kochman & Sikkema, 2002) who explore how internalised HIV/AIDS stigma may cause adverse behavioural and emotional reactions as affected individuals' experience of fear of revealing their HIV status to others. Fear affects several women living with discreditable and also discredited attributes. For several of the women in the study this takes the form of anticipated fear and may result to 'self-stigma' (Pryor & Reeder, 2012) and internalised stigma. The effects are delayed testing, failure to test, and fear to seek early treatment, causing delays to access treatment, support and care services.

Several affected women in the study indicate that they experience various stigmatising encounters and discriminatory actions meted out on their personhood as discredited and tainted individuals living with HIV. For instance, some of them narrate how they are subjected to mundane forms of stigmatisation – finger-pointing', 'name-calling', being 'thrown-out' and people 'running-away' from them. Many explain vividly how they experienced a wide range of stigmatising encounters at home and locally in the community. As a way of exploring a more complex analysis beyond Goffman's thesis of stigma as discreditable and discredited stigma attributes, I will also explore how, by using gender and intersectionality analysis, other alternative explanations may shed light into women living with HIV and the link with VAW. I argue that there are pre-existing gender stigmas interlocking with HIV-related stigmas to yield alternate insights for understanding the co-researchers' accounts of stigmatisation, particularly when they possess non-concealed, discredited or tainted identities.

8.1.2 The idea of stigma *as* violence

The overarching theme derived from the thematic analysis reveals that women living with HIV experience challenges of living with discreditable and discredited stigmas. I argue that there are underlying factors deeply engrained into the society and need to be examined further. From the research participants' accounts, it is plausible to suggest that patriarchy, gerontocracy and structural violence are underlying factors that best explain the accounts of women's experiences of abuse and how it renders them vulnerable to other sexually transmitted infections including HIV. However, these the underlying (often hidden) factors that trigger and sustain gender-based violence and its link to HIV are often unexamined and they perpetuate the problem of VAW. In this research I will examine how before and after HIV diagnoses women living with the virus experience enacted

stigma and discrimination through the lens of patriarchy, gerontocracy and structural violence.

8.1.2.1 Patriarchy, gerontocracy and structural violence

In my analysis of violence against women and girls in the Gambian socio-cultural context, I have made use of patriarchy, gerontocracy and structural violence as useful conceptions to explain the phenomenon of VAW and HIV intersections. The first concept is patriarchy which is defined here as both an ideology and a systemic force in which gendered power and control by men over women and girls is a key factor in VAW. I prefer the definition offered by Hunnicutt (2009, pp.554-555) who advances the thesis of “varieties in patriarchal structures – that is, a range of different patriarchal manifestations among cultures and clan”. Intimate partner violence is an issue fundamentally related to gender and specifically to the patriarchal domination of men over women (Lawson, 2012, p.573), and this is certainly the case in the Gambia. Although my research narratives echo Millet’s (1969) construction of VAW as a visible use of force or “coercive power” utilised by men over women (Hearn, 2014; Millet, 1969), in my own research, the findings suggest that VAW in the Gambia is enacted by multiple perpetrators. The incidence of a range of abuses takes on a culturally specific form of violence (mentioned earlier as female genital mutilation, forced and early marriage, and virginity sealing and removal) before HIV/AIDS diagnosis. These practices are influenced by elders and peer pressure to accept and belong to a group as evidenced the accounts of the research participants.

The second concept is gerontocracy derived from the participants’ account suggesting how gerontocracy— in other words the rule of elders is at work. These elders include both sexes⁹ elderly men and women, especially those involved in family, religious and ethnic leadership positions in our society) who possess influence, power and control over women and whose (economic, social, political and religious) powers and rule are visible (Chant & Touray, 2012, p.3 citing Saine & Saine, 2012, p.319). In many ways these elders are the power brokers, influencing religious, cultural and traditional norms, values and practices and making decisions about marriage and major traditional practices that mark significant milestones in the lives of women and girls. My participants’ accounts reveal how dominant influential elders in the patriarchal family force young women and girls into child marriage and practices of unprotected, coercive marital sex. Drawing from the data presented on marriage practices of the study cohort, I will now demonstrate the how

my argument evidence that there are pre-existing gender stigmas interlocking with HIV-related stigmatisation and enacted discrimination, is unveiled in the study.

The importance of marriage is revealed by the narratives of women in this study cohort. I make reference to the next quote which embodies women's views, suggesting that "They are concerned with family honour and tradition, not considering the effects of violence on our lives." (PLHIVs account explaining stories that unveil troubling issues concerning traditional practices that focus on preservation of family honour and tradition which women and girls endure). These practices include forced marriage, vaginal sealing to preserve virginity, honour and the dignity of maidens. For illustrative purpose I draw from the reports of women concerning first the practice of FGM/C, early and forced marriage practices to evidence why I argue about the patriarchal and gerontocratic powers in the Gambian socio-cultural contexts.

Apart from the role of family elders forcing women and girls to succumb to FGM/C, peer pressure plays a significant role in encouraging women to undergo FGM in the Gambia. Amie Cham, a PLHIV, explains how women succumb to FGM/C:

"Fear of being called 'solima' – meaning the 'uncircumcised' – was central to [my] decision to have FGM done. Not wanting this form of stigma and name-calling [I] succumbed to pressure from [my] peer group and friends. Also [my] grandmother forced [me] to do FGM/C."

I argue that pre-existing gender stigmatisation is evidenced from the accounts of my research participants who describe being called such names as 'solima' [meaning uncut woman] and devalued. The role played by peers and elders to pressurise girls to succumb to prevailing norms is evident in their narratives. This excerpt from a focus group on FGM/C reveals the problems of FGM and fear of negative labelling. For instance, the next data extract is derived from a focus group discussion includes a detailed narrative on FGM from family pressure to undertake FGM/C. The role of culture and ethnicity are important factors to examine by 102, 100 and 103, all PLHIVs examining issues affecting them in a focus group discussion at a Support Society:

Interviewer (I): "On the topic of FGM, I appears all of you have experienced female circumcision except 102 and I would like to discuss this more to find out what your opinion about FGM is. Would you like to comment on this topic?"

102: “For me ‘FGM’ we do not do it. It is not in our culture. It is not a practice in my ethnic group, not our tradition. My second husband is from [**** name of country removed] they are Fullas and they carry out FGM/C on their girls [daughters]. Even before my husband died, my husband did not want my girls to be circumcised, however, my husband’s family- the sisters-in-law would pressurise me to take my daughters to undergo FGM. My daughters also tell me that someday they will hide and secretly join the other girls in the community to be circumcised, but I do not support them.”

I: “Why did you not support them to undergo this circumcision?”

102: “Well it is not my cultural practice. I do not think the practice is good. For us, because it is not my cultural and ethnic group’s practice, if you do it then your people will look at you differently.”

100: “Well if I knew about the negative effects and risks and if I had the power to make decisions I would not do it. For example, I hear what 103 has just mentioned about how a woman who is not circumcised is better [in terms of her sexuality] than a woman who is circumcised. Well this is new knowledge to me [laughter and giggling].”

103: “What do you really think? Are you convinced in reality about this? If you have not heard this argument before what would you say?”

100: “Hmmm, well you know, during the time I was very young I was verbally abused by my peers, that I was a ‘solima’, someone who was uncircumcised, and that peer pressure forced me to go and be circumcised. Then it was because in this place where I lived the predominantly ethnic group where Mandinka and all my peers experienced FGM so I did it too. I got hurt by the word, ‘solima’, ‘solima’, ‘solima’. It hurt me. This was the insult other girls threw at you when you played with them and the word ‘solima’ pressurised me to join other girls in the community and have circumcision done to me.”

103: “As I listen to this conversation I think, upon reflection, that if I had known then what I know now I would not have undergone FGM and I would have resisted it. Well now, you know, what has past has past and I think about the present now. If I have a daughter now – I have a male child you know – but if I have a daughter, I will not circumcise her now.”

The following examples are taken from the narratives of those who experienced problems due to FGM/C. Some participants were coerced, tricked and lured by elders (especially female elders and influential gatekeepers of traditional practices), for instance their grandmothers. Others were too young to recall the experience. The thirteen women in the study cohort reported that they underwent FGM/C surgery and experienced virginity sealing. Not all women report problems, however; there were many PLHIVs who said

they were unable to make linkages between FGM and health or sexual reproductive challenges. Their accounts are documented below, taken before the commencement of a focus group as they captured their socio-demographic data. Some of the women in my study cohort reported being sealed, experiencing pain, and trauma, and also the shock associated with excessive bleeding after unsealing of the virginity seal during their wedding night. As Binta Bah, a young PLHIV, confirmed:

“Yes, I underwent FGM twice. I was sealed ‘fata’.”

According to her report, she experienced extreme pain and bleeding, and later, several other difficulties as a result of FGM. She also underwent early and forced marriage at 13 years-of-age.

“Yes. It hurts me a lot, I am not happy” [pause, as she was crying].

Others underwent FGM and stated:

Mariama Mendy: “Yes at 12 years of age. I experienced bleeding, and during my first wedding night [I suffered] pain and sustained injuries.”

Fatou Manneh: “Yes FGM at four years old.” She had “scar tissue from sealing (‘fata’).”

Jarga: “Yes as a baby, [I] was sealed.”

Amienatto: “I underwent FGM at 11 years of age. I suffered a lot during FGM. It was done on two occasions and I experienced pain.”

From the data generated in the study, of the sixty women interviewed, the findings indicate that many experienced FGM/C, early and forced marriage. The study captured data sets that also evidence the difficulty young girls experience to resist coercive sexual encounters, particularly during the removal of the virginity seal on their wedding night. The socio-demographic details of women (in Chapter 6, section 6.2.3 indicating the data on marriage, show that for the study cohort, early and forced marriages occur with women

and girls married off early, 82% entering into forced marriages, 17% in marriages which were not forced, and 1% in marriages the foundations of which were undisclosed.

The research unveils that there are multiple instigators and or /abusers in forced marriages and coercive sex. The role of peer pressure and influence, respect for elders and stigma associated with the unmarried status of young women is further explored below. The role of elders and influential decision makers as perpetrators and instigators of this sexual violence clearly brings out the context of patriarchal and gerontocratic powers (two interconnected underlying factors influencing women and girls' vulnerability to coercive sexual abuses in marriage) in the study. This data presents a picture of women in a subordinate position, with men and elders in control with regard to decisions about whether or not to marry-off their daughters early. Incidences of forced marriage and marital rape, and sexual violence in marriage are normalised. The risks of coercive and unprotected sex are described in another PLHIV's story.

In her diary/journal entry, a PLHIV Adama [pseudonym] recorded that, at 16 years of age, she had no option but to accept forced early marriage because it was her family's shared and religious belief that "marriage is a blessing from God". She expressed the view that a woman's value and respectability is closely linked to marital status and her ability to endure pain in silence in her marriage. She shared her diary entry, which was written with the help of another, literate PLHIV, because having been denied access to education she could not read or write. Through a local language interpreter/translator she again shared her story with other women during a focus group interview. She revealed the sexual and physical abuses she endured and later resisted. As the interpreter explained:

"She had bad experiences with her first husband in the form of forced sex during her period, beatings, and physical abuse [She discussed at length in the FGD the risk of HIV transmission during her period]. When she refused to have sex, there was a family discussion and the husband decided to marry a second wife."

She further suggested that married woman who fail to comply with the wishes of their husbands and in-laws are shunned by their peers. After her first marriage she was divorced, then she married a second time, but was abandoned by her husband because she refused to become a second wife. Women share stories of being in polygamous relationships, being forced into normalised forms of sexual abuse as wives. Marriage is

valued in the Gambia and women who are unmarried seek desperately to find suitable husbands to avoid negative labels.

Often women and girls have limited or no choice when their elders give them away in cases of forced and early [child] marriage...

The role of women (mothers, grandmothers, fathers' sisters and mothers-in-law) as chief architects/instigators of sexual abuse is often not fully examined and is shrouded in silence. In the issue of forced coercive sex, this is also true for several of the women who experience early and forced sex in marriage. I thus refer to the next data extract is an account by Jainaba, a PLHIV, of how her own parents and elders were complicit in forcing her, under sedation (a traditional herbal concoction), to have her vaginal seal removed, and then forced her into her first sexual encounter with a man she did not love, through a family arranged marriage:

“I was forced. They [parents and elders] drugged me and then forced me to marry him. I was in great pain after the seal was removed. That same night he took me forcefully, I was forced.”

Several of them discuss themes of polygamous and intergenerational marriages, with men older than their wives. Cross-generational sexual relationships, multiple and concurrent liaisons, often render them vulnerable to Sexually Transmitted Infections (STIs) and HIV. The study brings into sharp focus the role of women as instigators of coercive sexual encounters, particularly when young brides are forcefully given away without their informed consent.

Ngata, a gender advocate and scholar, clearly brings out this invisible dimension in the following account, taken from an in-depth individual interview:

“That’s what I am saying. I think it’s important as feminists when we theorise, that we get it right, because most of the time we talk about patriarchy – males do this and that ... when in actuality it’s the women that enforce the laws of patriarchy. If they had not created patriarchy, they’re doing a good job of enforcing it, because it’s not like it’s the men who come and say ... OK, even if the man says I want to marry this woman and the woman says no, any sane man would say ‘I don’t want to be married to her either’, but they don’t do that, they go and tell the woman you have to marry him, and it’s the women who enforce this, not the men that are pushing for it ...”

Ngata during the interview further suggests that:

Ngata: “Also when you look at women being used ... as chattels in the sense that if you want to get married your family would ask the in-laws for so much dowry so the man’s family feel like they own you. You’re a slave to them, you’re property, you are no longer a subject, and you’re an object. They use you accordingly and violence is not just experienced from the spouse, I want to clarify that. Most incidents of family violence come from the women, the sisters-in-law and the mothers-in-law.”

I: “This is rather interesting because also what I am getting women to say in the field, women are complaining that it is just not the husbands, but the pressure comes from the mothers-in-law, the sisters-in-law and the co-wives, forcing their husbands to become violent especially when they’re sero-positive.”

Ngata: “Definitely you see women pushing men to hit their wives telling them ‘oh they now think they’re “uppity” they now think they are “too liberated” so you have to bring them down a notch or two’. We see that ... like the mother-in-law, the sister-in-law and the co-wives as you said, since we live in a polygamous society and there’s a lot of competition, so every wife wants to see the other one suffer.”

The effects of violence against women and girls has been researched and findings from WHO & UNAIDS (2013, p.3) report suggests that violence against women is a widespread and costly public health challenge, deeply rooted in gender inequality. In the Gambia, respect for elders is a norm. Teenage girls who respect their parents exercise little power and control. They acquiesce and succumb to pressure from their parents, uncles and/or grandparents. The findings of my study is evidenced as the literature on violence indicates that adolescent girls (15-19 years of age) and young women (20-24 years of age) are most vulnerable, because this cohort registers high levels of intimate partner violence in their lifetimes, with prevalence rates accounting for 29% and 32% respectively (WHO & UNAIDS, 2013, p.3). It is a phenomenon that violates women’s human rights and VAW exists in all parts of the world. This report argue that violence against women has serious consequences for women’s health and causes fatal and non-fatal injuries, unintended pregnancies, induced abortions, sexually transmitted infections (STIs) including HIV. VAW causes serious psychological and mental health challenges such as post-traumatic stress disorder (PTSD), depression, anxiety, and suicide among others (WHO & UNAIDS 2013, p. 3).

Similar findings of the negative effects of gender-based violence by Liebling-Kalifani et al (2007) revealed that sexual violence and torture experienced by women during the Luwero civil war in Uganda, caused considerable health and serious damage to their

reproductive organs, resulting to experiences of chronic abdominal pain. Women were also infected with sexually transmitted infections and many were left with serious gynaecological health challenges. They argue that the psychological, physical and social aspects of women's experiences of pain are closely enmeshed and impact directly on women's identities and through the process of narrating their experiences in the study the women reflected that they were able to break the silence about their urgent health needs as well as "giving meaning to their pain" (Liebling et al. 2007, pp. 12-13 citing Obbo, 1989; Bendelow, 2000).

When women are diagnosed with HIV there are local HIV metaphors, sayings and proverbs central to stigmatising processes. As I dug deep in order to tease out answers to questions about the intersections of the two subthemes of 'secrecy' and 'fear' and how this may affect the women living with discreditable non-visible stigma, it is evident that narratives of secrecy and fear are unveiled as patterned responses of perceived threats of and anticipated stigma. Some of the women narrate subthemes of fear and suffering as a normal part of womanhood. Women are socialised to suffer in silence, and secrecy surrounds their lives causing under-reporting of abuses before and after HIV diagnosis.

The gendered nature of the stigmatisation process is clearly unveiled in my research and it draws from Corbin's (2012) contribution in which the author's use of intersectionality analysis, as recommended in her essay entitled: *Intersections of context and HIV/AIDS in sub-Saharan Africa: What can we learn from feminist theory?* I argue that this essay is useful because it made it possible to develop clarity about the context. Her essay shows how valuable it is to use intersectional analysis to capture the complex interacting forces and rationale behind Gambian women's experiences. Such a framework allowed me to examine the intersection of religion, ethnicity, women's economic dependence on men and elders in the family due to patriarchy and respect for elders' rule and dominion, a prevalent norm of the Gambian cultural milieu.

As mentioned earlier in the preceding paragraph, influential elders (gerontocratic rulers) take decisions on behalf of young maidens on marriage, sealing and unsealing of virgins, which in my view is aimed at controlling the bodies and sexuality of women and girls and a form of rights violation. Yet, though many in the study explain how religious beliefs are critical in understanding the justification for the continuity of FGM/C for instance,

research has failed to evidence this. The quotation below explores how Islam is used to justify FGM/C, however religious explanations are limited in perpetuating the practice:

“[Gambia is ...] an Islamic-majority population, and where religion is thought to be a significant reason for practising FGM, understanding the connection between religion and FGM in The Gambia is crucial. FGM predates the major religions and is not exclusive to one faith. FGM has been justified under Islam, yet many Gambian Muslims do not practise FGM and many agree it is not in the Qur’an” (28 Too Many, 2015, p.44).

Religious, socio-cultural peer pressure, coercion and ethnicity explanations have been utilised to justify the continuation of FGM in the Gambia. The practice is normalised and there is evidence of tolerance towards VAW, however, I argue that it constitutes the denial of a woman’s rights to her bodily integrity. FGM/C, for example, is also an act of violence against women and the data referenced in this chapter are indicative of these interconnected variables and the propagation of FGM. The 28 Too Many report (2015, p.19 citing MICS, 2010) shows that a combination of interacting factors largely influence the practice of FGM/C, forced and early marriage.

It is also clear that an unexplored area is the role of structural violence and how it plays a significant part in our analysis and understanding of the multiple inequalities that interact to negatively affect women in the current research. Johan Galtung (1996) conception of structural violence is also relevant in understanding how women’s exposure to various social structures and social injustice, is linked to the prevailing systemic forces affecting them. Structural violence and direct violence are said to be highly interdependent, and to include family violence and various forms of gender-based violence.

8.1.2.2 Structural violence: poverty and economic marginalisation

I will now explore the third concept of structural violence affecting this cohort of PLHIVs. Poverty and social exclusion and the economic marginalisation of women are evidenced in the women’s narratives, particularly those of women living in resource poor and peri-urban and rural areas of the country. For example, rural women are most marginalised, especially those women who are uneducated, do not own land and property and have little in the way of economic resources to use as coping strategies. Many of the women lack

access to basic needs (food, adequate shelter and education), and this stems from gender and structural inequality. In addition, research has evidenced that gender-based violence perpetrated by men against women and girls is a serious public health problem (Jewkes & Lang, 2015). Women's narratives in the current research are consistent with the findings of research on violence against women, indicating that not only are violence against women and HIV driven by gender inequality, but entrenched gender inequality leaves women more vulnerable to its negative impact and consequences, which in turn further marginalise them (WHO, 2017, p.1).

Similarly, I find Kabeer's (1999), definition of gender inequality very useful and that it reflects the "ways in which women are different from men, in terms of their biological capacities and in terms of the socially constructed disadvantages women face relative to men" (p.37). My findings reveal that gender relationships are framed and influenced by the broader social structures such as gender ideologies, institutionalised norms, values and practices of a given society. These structural forces determine how masculinity and femininity are defined and who has influence and power to decision making processes, access and control of resources. Women's economic marginalisation and poverty imposed upon them structurally, all compound with their assigned gendered roles to create gender constraints and overlapping inequalities for women. Several of them are poor and experience serious economic dependency and survival challenges, especially when they are abandoned, thrown-out and divorced. Some of the women who experience prolonged illness and delays in accessing medication due to the delayed assistance from relatives and sometimes the spouse who refuse to accept their diagnosis, result to late / delayed commencement of antiretroviral treatment.

Gender unequal relationships affect women who are rendered 'powerless' affects women who are marginalised and dependent on others. It is important to register here that some of the PLHIVs have found new ways of economically engaging in micro-enterprise and small scale economic activities as they receive support, treatment and care and have improved their health status²⁰. The issues of gender inequality and structural inequality has been evidenced as critical issue affecting women. There are observable power

²⁰ Some of the Support Societies receive support to involve in income generation activities tie-dye, small scale poultry and vegetable gardening to assist members. These economic activities are very useful and need to be scaled up to include many more PLHIVs to alleviate poverty and economic marginalisation.

imbalances (economic power, access and control of resources and power to make informed decisions) because of the tradition assigning power to men as patriarchs in the family. The women in the study cohorts generally possess less power, than their male counterparts, men remain the bread-winner and head of households. This situation affects many PLHIVs, who are dependent on them. Thus, when more economic power is wielded by men, women in abusive relationships who are dependent may find it difficult to leave those abusive relationships. These findings are consistent with research that examine how gendered norms and practices of inequality interact with structural violence (poverty, lack of power and exclusion) to render women vulnerable to a range of abuses, including partner violence (Heise, 1998, 2011; Fulu & Miedema, 2015, pp.1431-1432). They demonstrate how multiple factors may interact as determinants and causative elements of violence against women and girls.

Thus, I call for interventions that examine and address the prevailing gender inequality between Gambian women and men. Gender inequality may result in double standards in the legal treatment of men and women, neglecting the protection of women from men's violence. Many incidents of domestic violence in the Gambia may not be reported due to silence, and stigma associated with the domestic abuse of women, and fear of unjust treatment by the legal system may present barriers to women's utilisation of services, especially when the police also come from a male-dominated patriarchal worldview and system.

Furthermore, I acknowledge the limitation of a focus on gender as the sole explanation, choosing also to examine how other forces and powers (such as the rule of elders over the younger generation) contribute to the utilisation of power to subordinate and control women and girls in the Gambia. For instance, in the Gambia there are narratives from affected women who speak of elders removing girls from school and denying them the right to complete their education beyond primary level as a result of early and forced marriage. This has a negative impact on their capacity to secure the prerequisite knowledge, skills and training to understand HIV preventive measures. Also, their lack of skills restricts their ability to find employment and to earn their own independent income, consequently spurring a cycle of dependency on men and elders.

In addition, studies on gender inequality have revealed that illiteracy and low levels of education imposed upon women and girls have long lasting effects in virtually every other aspect of their social life, particularly when negotiating key decisions that affect their life chances (Fulu & Miedema, 2015). Thus, it is crucial that interventions to prevent VAW examine and unveil the underlying factors that fuel gender-based violence. This also means that understanding who are the main perpetrators and instigators of VAW is critical for proper redress and justice.

8.1.3 The multiplicity of perpetrators

In the literature on HIV and violence, violence is a precursor and sequel to HIV. Intimate partner violence accounts for the prevalence of gender-based violence. Yet, in the Gambia, the link between patriarchy and gerontocracy in the research shows that men are not the only perpetrators of violence against women. Coercive force, power and control are utilised by multiple perpetrators and instigators of abuse, before and after HIV diagnosis. Referencing theoretical explanations offered by Messerschmidt (2012) and Jewkes (2015), which reflect the patriarchal power of masculinity (Messerschmidt, 2011) and also the gerontocratic power of elders, I argue that gerontocracy intersects with patriarchal power in the subjugation of Gambian women, particularly women living with HIV, who are subjected to mundane and violent acts of discrimination. These women often suffer silently and endure the negative consequence of physical injuries, emotional and psychological traumatic experiences, and economic deprivation.

Apart from elders and intimate partners in the immediate family, PLHIVs also evidenced that there are other equally powerful and influential leaders (religious, ethnic and cultural traditional leaders), powerful individuals in the Gambian community, who are to be reckoned with in rendering women vulnerable to gender-based abuses and its normalisation and tolerance. Hunnicutt (2009) argues that in patriarchal societies and systems, age, class, and race may align with patriarchies and both men and women are complicit in maintaining the system of oppression. This was certainly true in my research which showed evidence of women elders (mothers-in-law, fathers' sisters, senior co-wives and traditional FGM/C practitioners - 'Nyansingbas') who in many respects violate the rights of women and girls through enforcement of harmful traditional and cultural norms and practices of FGM/C, early and forced marriage and a full range of gender-based abuses within the community.

In the Gambia, older women occupy some position of respect and status in their respective patriarchal family systems, creating an incentive to uphold traditional ideologies (Hunnicut, 2009 citing Kibria, 1990). The social context of the women reveals complex family arrangements on gendered lines, especially in patriarchal family and extended and intergenerational household arrangements such as those of Gambian patrilineal families. The nature and structure of the family in which several of the affected women live suggests that men as the elders and family head are very influential. This study also brings into sharp focus not only the role of men as family household heads, but clearly shows how other influential community elders (in-laws, aunties, cultural and religious leaders) rule over the younger generation and women in particular, within intergenerational settings.

These are the perpetrators and instigators of normalised and naturalised domestic abuses. In such environments, women and girls are socialised to respect elders and men, and they know the implications of transgressing the social norms. In social contexts where there are rigid rules about gender roles and expectations, transgressing them may result in gender-based abuses which needs alternatives forms of masculinity modelled by boys and men to change (Jewkes, 2012; Lapsansky & Chatterjee, 2013). In the Gambian social settings, similar observations have been documented where PLHIVs respect the wishes of their parents and stay in bad and ‘bitter marriages’. The responses of the study cohort in the research conducted in the Gambia suggested a level of tolerance and acceptance of domestic violence. For example the MICS suggests that in the Gambia children 2-14 years old experience psychological and severe physical punishment and a number of parents and caregivers of children of this age cohort believe that “in order to raise their children properly, they need to physically punish them” (MICS, 2012, p.155) and almost 90.3 percent of children age 2-14 were subjected to psychological or physical punishment by their mothers/caregivers, including other household members (Ibid.).

Furthermore, Gambian women and girls experience a continuum of abuses in their everyday lives and it is my contention that these forms of stigmatisation constitute normalised violence. Following HIV diagnosis, women fear being judged morally because HIV is a sexually transmitted disease and, often erroneously, affected women are branded as promiscuous. Indeed, the findings suggest that HIV-positive women are

overwhelmingly labelled prostitutes. Across the board, the research shows that fear of survival without male support and powerful and economically empowered family members is a critical part of the narrative that explains intersections of poverty, gender inequalities and other structural factors affecting PLHIVs.

To further illustrate that stigma is violence my research findings are consistent with findings evidencing a range of abuses affecting PLHIVs whose own experiences are gendered. I restate here that, my study participants show how physical, sexual and emotional abuses are more common for women living with discredited attributes. In a study by Denton et al. (2012), women confirmed that there were incidences of discriminatory acts in which certain members of Support Societies were subjected to and this represents in my view human rights violations,. This included explicit acts of violence such as being scalded with hot water, beatings, and injuries sustained from fights. Several of the women in my study reported daily experiences of stigma and discrimination which fits the definition of violence against women and girls (mainly economic, physical and psychological) abuses.

8.2 Interlocking factors of patriarchy, gerontocracy and structural violence

Through an intersectional analysis it was possible to examine how stigma is gendered before and after HIV diagnosis. I therefore make reference to gender as a culturally specific construct (Gupta, 2000, pp.1-2). Hence, in the Gambia it is important to interrogate how in patriarchal and patrilineal society, certain families adhere rigidly to gendered norms and practices that negatively affect women. The participants' accounts have explained also how religious, ethnic and socio-cultural factors all interact and contribute to men and elders in particular utilise power, dominance and control over women and girls. This constitutes the basis for discussion of my own practical contribution to the sociological perspective on VAW and its intersection with HIV; the recognition that there are underlying and interlocking factors of patriarchy, gerontocracy and structural violence. For instance, the three overlapping forces/powers (patriarchy, gerontocracy and structural violence) are critical in exposing women to experiences of violence before and after HIV diagnosis. This is a key contribution of the study, bringing to the fore the need to address the fact that both patriarchal and gerontocratic powers are interlocking forces that negatively affect women. Also, I recognise that structural

violence stemming from gender unequal opportunities for women compared to men, lack of freedoms, education and access to economic power affects them disproportionately.

The context of the stigmatisation needs to be properly understood because it differs from Western contexts in many respects, because the social context where my own research takes place, there are deeply embedded gender ideologies of the ideal standard of good womanhood. Maintaining these standards through traditional practices of FGM/C, early and forced marriage constitutes a violation of rights, although many describe it as traditional norms and practices. Yet, in the name of tradition, women may acquiesce and accept traditional norms and practices that subject them to a continuum and mosaic²¹ of everyday normalised VAW. These everyday forms of violence are exacerbated by positive HIV diagnosis. My research participants presented narratives of pain, physical, emotional and psychological harm. They also felt isolated, shamed and devalued in many respects, but their stories also showed that women actively resist the stigma and abuse that ostracise them, seeking solidarity with other affected PLHIVs. The significant role played by women living with HIV as HIV peer supporters cannot be overemphasised.

As part of the stigmatisation process, my participants' accounts capture a range of normalised violence including denial of food and housing and other basic needs. Also reported were physical fights between co-wives, emotional assault, and in some cases sexual harassment and abuse by multiple perpetrators, especially when women are widowed (death of a husband from HIV), divorced, abandoned and need urgent assistance to feed, house and take care of their dependents. Yet, I argue that stigma and enacted discrimination can be resisted and change is possible.

8.3 Agency and resistance gender –based abuses and HIV stigmatisation processes

A major contribution of this thesis is how it unearths the ingenious ways in which Gambian women deal with everyday normalised violence, both before and after HIV diagnosis. In a social context where traditions, cultural norms and practices take precedence and where women and girls are expected to acquiesce to these, even when

²¹ The term 'continuum of abuses' is an adaptation of Kelly's (1988) continuum of violence depicting a range of abuses occurring in sexual violence whilst 'mosaic of stigma' is my own coinage to describe the intersections, layered range, and complex web of incidences of enacted discrimination (verbal, emotional, psychological, economic, and physical abuses, and the denial of rights) described by participants in this study.

aware of their damaging effects, women still find creative and ingenious ways to navigate the daily life challenges they face. Women understand the hierarchical relationship and dominance of men and elders, yet they are shrewd and adopt strategies that are less confrontational and adversarial. While some women simply leave and just do not look back, they move on with their lives, and take care of themselves, others claim that, although they recognise that men have overt power, they also have their own subversive powers. As some of them claim, ‘they make the best out of the worst situation’, not giving up but creatively using passive non-violent forms of resistance as a form of adaptive mechanism to engage in fewer fights.

Some report that they go out and meet other women through family and social gatherings. These include naming ceremonies, weddings and a host of women’s social functions where they celebrate as women and where men do not exhibit their power. In the HIV Support Societies, peer counsellors assist them and provide the voluntary support they need. I see these as useful arenas, as natural platforms to engage women for change, using music and various entertainment to deconstruct negative gendered and sexist scripts. These trends are observable in other studies conducted elsewhere in Africa and show how women accept the normalisation of VAW (Maman et al., 2002, pp.1333-1334). Women may also internalise notions that VAW is normal, and this needs to be confronted, scrutinised, and an agentic stance adopted where feasible with both men and women in order to develop strategic interventions to ameliorate and to prevent practices that violate women’s rights and the normalisation of VAW.

8.4 Evidence of preventive interventions to challenge VAW and prevent HIV

In the Gambia, the government and its partners are guided by international and legal protocols that advocate women’s reproductive, social and economic rights (i.e. women’s access and control to land and agricultural inputs, and also protection of their reproductive rights), as captured in the Convention on Elimination of Discrimination Against Women (CEDAW Article 14). Also in the Gambia, for instance the Gambia National Policy on Women (2010), the Women’s Act (2010) are all progressive legal documents developed to offer protection of women’s rights with regard to protection of women’s sexual and reproductive rights, promotion of women’s equal access, and ownership and control of land and other productive resources. For instance, there are several ongoing initiatives that address sexual violence which includes the national action plan and development of a communication strategy on gender-based violence. Also the Gambia has passed the

Sexual Offence Bill (2013) which seeks to punish offenders for sexual violence, harassment and other threatening behaviours against women and girls. But as noted by Sherwood et al (2013) the practical implementation of the bill has not been fully studied. In my view, the ongoing work by UNICEF Gambia, UNFPA, UNDP concerted efforts and interventions for child protection services and advocacy against FGM/C, early childhood development and prevention of early marriage practices and other initiatives (UNICEF Annual Report 2015, pp.6-7) are critical interventions aimed at advancing the rights of women and girls against all forms of abuses. Similarly, the interventions by GAMCOTRAP, Network against Gender Based Violence and other partners who provide services to survivors of gender-based violence, and they providing valuable support and care services. However, they need resources and capacities through training and support to undertake outreach services and increase coverage in remote and hard to reach communities to enhance prevention and care services for survivors of sexual abuses, countrywide.

Equally, important is the need for national governments and development partners to protect women's rights, to engage in gender equality interventions by ensuring that women gain equal rights and access to economic resources, including land rights, and other essential property rights is problematised here and the potential for HIV prevention interventions emphasised (WHO, 2017, p.1). Thus, I also argue that the need to address the intersection of VAW and HIV commences with the micro level (in the family) and moves to the macro-levels of society (Heise, 1998, 2011) drawing from the ecological paradigm to conceptualise VAW and also to offer researchers a useful lens through which to explain how the family is a strategic point of entry for addressing problems associated with various forms of violence. The family can be reached through community radios, using (phone-in programmes, through music and role plays, story-telling and other interactive development communication messages) to alter negative and harmful norms and practices against women. Interactive media initiatives for young men and women can serve as safe spaces and platforms where the youth through peer-based support groups can ask questions, about masculinity, their health and well-being, and gender concerns that affect their lives. I will recommend here World Health Organization (2017) offer a consolidated guideline on sexual and reproductive health and rights of women living with HIV which is useful in preventing gender-based abuses and HIV/AIDS. These are valuable resources that could be used as guidelines together with the creation of safe

platforms and local community avenues to involve them in critical dialogue and to incorporate serious and communication campaign messages that emphasise positive masculinity, promote gender equality and respect for women, and to bring out positive role models and behaviours that challenge and change norms and practices that devalue women and girls in the society. These forums can also teach participants about sexual reproductive health, basic information and knowledge sexual transmitted infections, HIV prevention, treatment, care and support services and where to access these services. The need to link violence and HIV and other negative effects of violence is vital

While I recognise that the Government of The Gambia have engaged in HIV prevention, support and care services since the first cases of HIV in 1986. Programmes also include support for HIV testing and treatment. Studies have consistently shown that early testing for HIV and early commencement of Antiretroviral Therapy (ART) have potential to prevent HIV transmission by reducing the viral concentration in the blood and genital secretions (Whiteside, 2008); they are useful because they empirically demonstrate the benefits of initiating antiretroviral treatment (ART) to stop the spread of HIV infection. Whiteside (2008, p.28) writes that sexual intercourse is the most common source of transmission of the virus; almost 75-85% of people are infected this way and this includes both homosexuals and heterosexuals. However, in the Gambia, heterosexual intercourse predominates, as documented in the National Health Policy strategic documents in the country (2012-2020). I argue that HIV infection is for life and what is often not appreciated is that an HIV infected person can be re-infected with new strains of the virus, thus damaging their prospects for survival (Whiteside, 2008, p.25). By using the ecological paradigm and intersectionality theoretical analysis I could examine and develop an understanding of the contextual realities of the phenomenon of VAW and its link to HIV/AIDS. There are multiple perpetrators and instigators of a range of everyday normalised violence against women and girls and survivors need to prompt care and services, access justice and protection. According to Sherwood et al. (2013) the evidence suggest that providing services to survivors of violence must include emergency contraceptives, to prevent unwanted pregnancies and abortions. It is critical to offer an integrated and comprehensive approach to prevent women's vulnerability to negative health consequences of rape especially in contexts where abortion is illegal and women may risk seeking abortion services from unsafe environments (Sherwood et al, 2013). Current HIV/AIDS preventive interventions are useful, however there is a need to address

the gender dimensions of the projects and to enhance preventive work that avoids new strains of the virus appearing in persons living with HIV. This requires the provision of female condoms which they have access and control, the promotion of women's rights from sexual violence and justice for survivors of a range of abuses.

The Government of the Gambia has adopted a cooperative and coordinated response to an integrated approach to HIV prevention, treatment support and care services. They emphasise the use of the three ones principle that focuses on one agreed HIV framework of intervention in the Gambia, for all partners who intervene in HIV prevention, support and care work. Furthermore, by utilising one national coordinating authority (the National HIV/AIDS Coordinating Programme and National AIDS Secretariat) function as the implementing arm of the Government to engage in decentralised programming for HIV/AIDS preventive and support interventions, it is possible to promote a comprehensive and an integrated approach in seeking solutions to the HIV challenge in the Gambia. Thus, as a robust, holistic, and strategically focused mechanism to prevent transmission of HIV, it is vital to promote gender equitable and gender sensitive interventions and social justice and to meet the unmet reproductive concerns and basic needs of survivors of violence and marginalised individuals.

The Government has the mandate to work within a broad collaborating framework with multi-sectoral partners for funding and resource management, as well as implementation of programmes, using an integrated monitoring and evaluation system.

The current projects undertaken by government health care services and collaborating partners (NGOs, civil society and grassroots organisations) provide resources to promote public education and use behaviour change communication messages to encourage HIV testing so people can find out their own HIV status. With an HIV-positive status, affected and infected individuals are helped to access universal treatment, support and care. These interventions are aimed at preventing the spread of the virus. Public awareness campaigns and HIV preventive work are widely used in schools in the Gambia to prevent the spread of HIV/AIDS. These activities are supported by condom distribution and interventions that encourage condom uptake by sexually active individuals. Additionally, these individuals are targeted to encourage behaviour change and support of the 'Abstinence,

Be faithful and use a Condom' (ABC) and Know Your Status strategies, which are central to HIV/AIDS prevention.

The national HIV preventive programmes gauge the level of public awareness about HIV prevention and of messages to prevent stigma and discrimination of PLHIVs. Other programme interventions aimed at preventing the spread of HIV include the 'Parent to Child Transmission' control measures which are considered strategic in the fight against new infections.

The Government of the Gambia and civic society organisations, non-governmental partners are taking measures to stabilise and reduce the prevalence of HIV/AIDS and providing treatment, care and support to people living with HIV/AIDS. The government has also taken measures to protect the rights of people, and in particular the Constitution has extensive provision on Fundamental Human Rights which protects the rights of PLHIVs. Despite all of this, however, HIV related stigma and discrimination persist (Denton et al., 2012). A number of key players are addressing HIV stigma and discrimination, and the role of NGOs and grassroots organisations as strategic allies of the government, supported by National HIV/AIDS Control programming and the National HIV/AIDS Secretariat who disseminate preventive messages, is visible. Local artists and drama groups are amongst those key players in the Gambia adopting various Behaviour Change Communication (BCC) messages and grassroots educational approaches to enhance HIV prevention interventions and also end stigma and discrimination against persons living with HIV/AIDS. However, what is less known is the effectiveness of current interventions in preventing stigma and discrimination and also to what extent gendered issues are being problematised.

Additionally, there are strategies to prevent HIV and other sexually transmitted infections and also to reduce the social and personal consequences of HIV/AIDS. In the Gambia, the National Health Policies document adopts partnership interventions with international organisations such as UNAIDS and various non-governmental organisations, and local community based organisations collaborate to develop health interventions concentrating on the reduction of the HIV/AIDS disease burden on persons living with HIV and providing increased access to treatment, support, and care services. The interventions include partnership efforts to provide testing and treatment in various decentralised

regions of the country and within the health system. This involves developing fully equipped facilities to conduct the HIV tests, provision of voluntary counselling, the offering of support, and access to prophylactic and antiretroviral drugs (ARVs). Other preventive activities include blood screening to ensuring that blood bank safety is strictly observed. Since HIV is found in the blood and body fluids of infected people, exposure to blood and blood products presents a maximum risk of infection and that is why there is so much concern around blood safety and hygiene, both in health care settings and in the community.

8.4.1 Legal instruments offering protection and prevention of VAW

I have explained in (Chapter 2 the Government of the Gambia in collaboration with various partners), adopted and implemented key policies and legal framework and interventions aimed at offering protection and securing rights of women. These interventions, including the passing of the Women's Act (2010) to help advance gender inequality, were the creation of the Sexual Offences Bill (2013) and the Domestic Violence Bill (Faal, 2013). The Government of the Gambia and its partners (non-governmental agencies, civic society organisations and local community based groups) have made significant strides in influencing and designing policies, national laws, and undertaking programmes to mainstream gender in various development initiatives. Yet, there remain the perennial challenges of confronting the health and gender issues as it is critical to address the underlying structural problems closely linked to patriarchy and gerontocracy, as critical areas to address if the gaps in prevention of the link between VAW and HIV intersection is to be narrowed. The need to engage on a long – term basis the local family and community elders, ethnic and religious leadership to examine and challenge prevalence of practices of FGM/C, early and forced marriages, and also other forms of abuses rendering women and girls vulnerable to STIs and HIV is central to this approach.

I argue that although good work in these areas are currently being implemented more work needs to be done through research to assess the impact and also to deepen intervention and decentralise service is a main gap. Gender-based violence is shaped by strong gendered expectations, norms, values and practices, and this is evident from the narratives of the study cohort. My findings demonstrate that the influence of culture in patriarchal and gerontocratic norms is deeply entrenched in the rural and resource

constrained communities (MICS, 2012). Also, in these rural communities, there are practices of FGM/C, early and forced marriage and virginity sealing which render women and girls vulnerable. More needs to be done to translate these instruments into the local language and to educate and train women and men, boys and girls to adhere to and respect these laws or expect punitive sanctions. The research has evidenced the accounts of research participants that affected women's dependency on family members and significant others for care and support renders them vulnerable to experiences of everyday normalized and naturalized violence. Moreover, the literature on violence and HIV intersections claims that the perpetrators of violence in intimate partner relationships are men. Evidence from the Gambia, in the context of polygamous relationships and extended family households where intergenerational families live together, indicates that HIV stigma abuses are multiple. The need to advance more democratic and egalitarian outcomes in the social relationship between young women and their elders is a critical part of this process. The adoption of multilevel socio-culturally responsive approaches to promote agency and resistance to everyday normalised violence on the part of the women and others who are influential and can be relied on to promote agency and transformative processes through dialogue and engagement in preventive processes,

8.5 My research contribution to knowledge

The key contributions of the thesis are to the sociological debate on VAW and HIV, and it also offers recommendations for practical application in preventive, care and support services where feasible, and for future research. This section differs from the previous chapters in many respects as it shifts away from theoretical explanations of the intersection of VAW and HIV to offer practical tools to anchor advocacy, preventive, care and support work. As outlined in the introductory chapter, my quest was to render audible co-research participants' voices and subjective experiential knowledge as a contribution to our understanding of the intersection of VAW and HIV. The co-researchers have spoken and their contribution unveils a sociological perspective on the social construction of gender and HIV through various practices of everyday normalised abuse and adoption of social distancing and control measures. The current study has revealed how the stigmatisation process in the Gambia, is capable of 'othering' of PLHIVs and devaluing them as women living with HIV struggle with everyday life of 'discreditable' and 'discredited' attributes. It brings of the situatedness and contextual

realities of poverty, dependency and precarious living for these women and their dependants, when they are abandoned, ostracised and marginalised in society.

In my own current study, I commenced this thesis by opening with the voice of PLHIVs, here again I emphasise that they have broken the silence and spoken out. They have also prioritised their needs which will form the basis of my recommendations below in section 8.3 of this thesis.

The experiences of the research participants recounted in my thesis provide a contextual and situated description of stigma and discrimination. Thus, by adopting ecological and intersectional analysis to examine the data, it is possible to derive results from the study that illuminate the interlocking powers of elders and other perpetrators of a range of abuses (both male and female elders as perpetrators and instigators), aimed at containing women living with HIV, and many report being denied access and rights to food, shelter and various essentials of life. These findings are also consistent with other empirical research conducted by, the African Gender and Media Initiative (2012), Dunkle et al. (2004), the International Center for Research on Women (2007), Njororai, Bates and Njororai (2010), and the UNAIDS Global HIV/AIDS Report on violence and HIV/AIDS (2013). The current research is insightful in revealing that women living in low socio-economic conditions are vulnerable to poverty and potential exposure to gender-based violence and oppression.

Also the issue of child and early marriage is critical and needs to be questioned and resisted. The age differences between young women who are given away in marriage to older men has serious gender and power differentials between the couples. Younger women find it difficult to negotiate safe sex or use condoms, especially with older and more powerful husbands, consistent with research by Schaefer et al, (2017) where the age differences between couples affect young women's ability to negotiate safe sexual practices.

In addition, my research findings are similar to those of VanTyler and Shields (2013), who reveal how HIV/AIDS brought social disruption and profound changes to micro-contexts and the family, which had previously sustained the fabric of African life. These findings correlate with my own work as most of the women in the present research experienced fracturing of family and social support networks, being ostracised, shunned,

divorced by spouses and/ or thrown-out of their homes by their own mothers because of HIV (VanTyler & Shields, 2013, pp.4-8).

This thesis has shown how feminist participatory research is pivotal in centring the voices of women who are often marginalised. Their narratives, validated by field practitioners, illuminate key themes around women's accounts in the conceptualisation of everyday normalised violence and the intersection with HIV. Violence is a precursor and sequel to HIV. My own research contribution is to evidence how women living with discreditable and discredited attributes of HIV stigma manage to conceal or to subvert incidences of stigma and discrimination. However, women who cannot hide their status risk experiencing abuses. This stigma is violence (they experience a range of economic, psychological, sexual harassment and physical abuses) due to their discredited attributes and devalued status as women living with HIV. Across the board, the common problems reported by the participants in a series of FGDs and from journal entries are summarised below as a result of the negative outcomes of stigmatisation and enacted discrimination of PLHIVs:

- Poverty, food insecurities and risks associated with malnutrition;
- Abandonment, social isolation, poor and inadequate housing, with several women experiencing inability to pay rent;
- Experiences of emotional, physical and risk of sexual harassment and violence contribute to harm (physical debilitating injuries, burns, fractures, and emotional and psychological traumatic experiences).
- Inadequate and sub-standard housing affects majority of abandoned, divorced and ostracised women.

Without adequate shelter, for example, women are defenceless against malaria (pandemic in the Gambia) and its complications, and also against various other opportunistic communicable diseases. Shelter is essential, but most are faced with escalating debts as they borrow money for food and rent. Some women are isolated and, when evicted from the marital home, live in poor sub-standard and insanitary housing. Interventions are urgently required to prevent waterborne diseases that compromise PLHIVs' resistance and expose them to conditions such as gastrointestinal infections which cause diarrhoea.

The findings of this research reveal that, before HIV diagnosis, the study cohort were involved in several small scale economic or survival activities, on a daily basis. Some of the women were economically independent and they were able to overcome gender marginalisation and the effects of poverty through economic empowerment activities. However, fear of HIV stigma and actual enacted stigma and discrimination, curtailed their normal economic activities and nullified their efforts. Women confront new challenges which are gendered. Participants report discriminatory acts of abandonment, divorce causing family disruption, and complete breakdown of economic forms of support, love and care. The outcome is destitution and precarious living for most of the women and their dependents.

The fear of being separated, divorced, or abandoned has been problematised, as basic needs such as food and housing remain a challenge for many of the participants. The effects of economic violence cannot be overlooked as they touch the core of women's survival and livelihood. Based upon the narratives, women struggle to overcome poverty and their dehumanised existence is a common concern. Most of the women find it difficult to even collect water from the well without being discriminated against, finger-pointing, being laughed at or shunned. Others stop selling food as food vendors for daily subsistence, because no one buys from them. They are isolated and feared because of HIV. Several of them narrate how prolonged illness has robbed them of work. Many of the women without work, and whose livelihood activities stopped due to stigma, are unable to pay overdue rents. Some landlords harass PLHIVs who owe rent; as PLHIV 054 said, she was harassed on a daily basis and may be asked for sex in lieu of rent. The potential for spreading HIV to the uninfected is evident here. Most women are blamed for contracting HIV and some experience abandonment, divorce, and other challenges as they are forced to become 'homeless', of no fixed abode. The complex intersection of illness, poverty and structural violence is clearly visible from their accounts.

The majority of the women who use the services of the Support Societies are poor and live insecure lives, for those who lack education and occupy low waged jobs experience gender inequality, and are forced to depend on men and elders. This dependency exposes many to risks of early and forced marriage, sexual coercion, and unprotected sex with the attendant risks of STIs and HIV. It is evident from the accounts of the participants that, upon being diagnosed with HIV, many poor and marginalised women experience

abandonment, divorce and fractured family relationships. PLHIVs begin to experience lack of compassion and support from trusted family members and friends, and their isolation and ostracisation render them dependent on Government and NGO support for their treatment and care services.

8.6 Recommendation: Offer support to secure basic needs of food and housing

HIV stigmatisation deepens poverty and the economic marginalisation of women. Many of the women suffer from poverty, food insecurity and poor nutrition further compromising their health and well-being. Therefore, I recommend food vouchers and cash transfers to support economically disadvantaged women and their dependants. In addition, there is need for access to emergency security, such as safe housing, adequate food for enhanced nutritional standards to promote health and wellbeing, antiretroviral drugs (ARVs), and other drugs to treat opportunistic infections such as Tuberculosis. This was accorded the highest priority by my participants.

Another recommendation, is to help build local capacities for fund raising and resource mobilisation to finance projects within the Support Societies and wider community health projects to undertake Partner Management and Stepping Stones preventive interventions within established HIV home-based care interventions are essential in order to secure sustained levels of funding for the proposed interventions. This will be proposed as an integral part of programming to achieve long-term meaningful change.

Almost all women using the Support Societies and Mutapola Voices projects clearly highlighted the benefits of accessing antiretroviral drugs, multivitamins, antibiotics and nutritional support for themselves and their dependents. The above are the kinds of economic, social and psychological support and care services they identified as high priority services that need to be continued within a broader attempt to address structural violence and gender inequity. I recommend strategic interventions for alleviation of food insecurities poverty and economic marginalisation of affected PLHIVs, through income generation and direct cash transfer and support mechanisms.

8.6.1 Adopt an integrated model of health, gender, and social justice

As a central thrust to my recommendations, I propose an integrated approach adopting culturally sensitive strategies and interventions to provide support to affected women. What I am recommending is an approach also proposed by Garcia-Moreno and Temmerman (2015, p.186-187) who suggest that the interventions that address VAW must be implemented under a coherent and systematic policy framework that empowers women socially and economically (Garcia-Moreno & Temmerman, 2015, p.186-187), thus in my view addressing the structural violence. Studies have evidenced that an integrated health and justice approach is particularly needed to respond to the needs of affected women and dependent families. The health system and health-care providers (particularly, but not only, sexual and reproductive health services), programmes and information, can support disclosure, provide treatment, care and support, referral and follow-up, and create documentation. Furthermore, national and local health policies and programmes should ensure that health services meet the minimum requirements for addressing violence against women in accordance with WHO guidance (WHO, 2013). They should involve: policies, training and support for health professionals so that they can recognise and respond to partner and/or sexual violence, including first-line psychological support and physical health care; post-rape care, including emergency contraception, safe abortion, STI and HIV prophylaxis, and psychological support; and violence prevention, recognition, and care information in all education activities (Garcia-Moreno & Temmerman, 2015, p.186-187).

8.6.1.2 Adopt journaling for psychological support within the Support Societies

I again recommend support for establishment of journaling sessions within the Support Societies as a critical part of health and social justice interventions, to discuss women's experiences of abuse, to find ways to counsel them, and to offer concrete realistic support to them, as they define their problems. This approach is in consonance with on-going Action Research principles of repeated action, reflection, action, as a change process (Seibold 2000; Western, 2013). I therefore make the following recommendations. The use of journaling and drama is a good start. Many of the participants may benefit from alternative approaches where drama and creative art could be explored as avenues through which to express themselves and discuss the issues affecting them, within the HIV Support Societies.

There is a need to seek collective ways to synergise and address their identified problems. In the focus groups, several of the participants talked about self-stigmatisation or internalised stigma, thus there is also a need to promote the psychological, emotional and physical inner strength to develop resilience and resistance to stigma (Liebling & Baker, 2015). I argue that this process requires support and capacity development of affected individuals to make the conscious transition away from positions of ‘helplessness’ to be supported to address unresolved challenges.

There are many benefits to using journaling sessions to create safe platforms to document and share stories, to resolve the myriad issues in women’s daily lives. They need support to rebuild their shattered lives and to enable them to shift from a position of vulnerability to active agency. There is a need to enable them to receive adequate health care, to access justice, and to address the problems of ‘abuse’ which they experience because of HIV. The need to work with the HIV Support Societies and local community groups and networks addressing gender-based violence is prioritised by the research participants. They will require training and capacity building to equip them with the relevant knowledge and skills to help HIV peer volunteers respond to the needs of the support groups.

Another intervention could address the connections between violence and HIV/AIDS in order to develop meaningful, preventive, support and care services to ameliorate the identified problem. An integrated approach could engage the community for long-term preventive and transformational work using Stepping Stones as a scalable model in the Gambia.²² I advocate for holistic preventive interventions to strategically engage key stakeholders and influential community, cultural and religious leaders to dialogue and seek culturally responsive options to address VAW and HIV through long-term engagement in education, public awareness, and advocacy work, to connect local to national levels, and subsequently involve affected women in broader universal activism for transformative and social justice work, back up with research on evidence based inquiry.

²² The Stepping Stones programme has been used in the Gambia and the results are promising. Refer to (Shaw, 2002; Paine et al., 2002) reports *Before We Were Sleeping but Now We Are Awake: The Stepping Stones Workshop Programme in The Gambia*, pp.128-40. Also refer to Welbourn, A. (1995) Stepping Stones – A training package on HIV/AIDS communication and relationship skills.

8.7 Work with influential men and young boys to model gender equitable norms and behaviours

There is growing awareness of the value of encouraging and supporting men and boys to challenge gender-based violence as it intersects with HIV. Current interventions, for example Promundo's project (2017) aims to prevent gender-based violence and violence against children by working to model alternative norms that transform harmful effects by engagement of men and boys in partnership with women and girls to 'create a world free from violence' by exploring masculinities and gender equality issues, in prevention of sexual and gender-based violence. They also conducted research on child and adolescent marriages in Brazil, amongst several other studies. The research by Taylor et al. (2015) brings out context specific issues affecting young brides in Brazil and through their own perspectives, it was possible to model projects that change norms, attitudes and practices associated with child and adolescent marriage in Brazil. Their research findings highlights that change is possible if we understand the reasons why certain traditional certain norms surrounding child and adolescent marriages are influenced complex factors. For instance, parents' concern for marriageability of their daughters, and avoidance of shame and preservation of family honour. Poverty, and economic factors may also account for the problem. My own research findings resonates with key findings by (Taylor et al. 2015, pp. 12-13), unveil how focus groups and in-depth-individual interviews with girls (aged 12 to 18) and men (aged 24-60) was successful in documenting structural issues and parents' concerns for marriageability. Through better understanding of the underlying challenges, Promundo's proactively involved in programme development using the research findings for advocacy and training campaigns to promote nonviolent attitudes and behaviors related to the promotion of gender equitable values and norms.²³

Previous evidenced based work conducted in the Gambia by Paine et al. (2002) in which a Stepping Stones programme was evaluated documented promising results. The project was acclaimed to positively address gender-based violence, gender unequal relationships between men and women and registered a reduction of sexually transmitted infections

²³ For a context specific research on adolescent and child marriages in Brazil, refer to a useful literature by Taylor, A., Lauro, G., Segundo, M. & Greene, M. E. (2015). "*She goes with me in my boat.*" *Child and adolescent marriage in Brazil*. Results from mixed-Method Research. Rio de Janeiro and Washington DC: Promundo and Promundo-US. Promundo's projects are diverse and can be explored and accessed from this website. <http://www.promundo.org>

and HIV (Shaw, 2002; Paine et al., 2002) in communities where the programme was implemented.

Other initiatives we can learn from include projects similar to ISIS-WICCE's 3rd Peace Exposition: Zero tolerance for sexual and gender - based violence, held in Lira, Uganda (2012) the Peace Exposition as evidence of good work being undertaken at community levels to secure safe platforms to enjoin key influential stakeholders concerned with gender-based violence preventive work to engage in meaningful dialogue for transformation of the status quo. These key influential stakeholders met with women and girls who are survivors of various forms of gender-based violence, including partnership with civil society organisations, grassroots women's organisations at national and local leadership (individuals representation of different cultural, religious, ethnic representative and interests groups) to discuss issues confronting women, focusing on gender and social injustices and gender-based violence. Drawing on the interventions adopted by Promundo's work and several others globally aimed at challenging, redefining and re-imagining masculinities and resisting VAW to borrow from (Lapsansky & Chatterjee 2013, pp.41-43) I propose interventions that are based on holistic and integrated approach to promote agency and resistance and model alternative spaces to enable people challenge and resist traditional practice that normalise violence. I recommend that together policy makers, activists, health practitioners we can utilise our individual and collective powers to forge synergies for action together with religious and cultural leadership to spearhead the process of engaging men and women through public education and awareness creation.

The process must come from grassroots activism and be owned by men, women, boys and girls at various levels of society. Here the central principles of agency and support for women to find their own ways of resisting VAW is important, without imposition of our own values as middle classed, Western educated advocates. I recommend that by adopting an integrated approach such as Stepping Stones, both genders can be encouraged to engage (at family, community and national levels) to dialogue for change, interrogating norms that perpetuate and sanction gender unequal relationships, violate women's reproductive rights, their health and well-being.

It is true that there are several promising interventions such as Stepping Stones conducted in the Gambia (Medley et al., 2013; Shaw, 2002; Paine et al., 2002) and partner management approach reported in my own study, scaling up programmes and interventions in rural and resource poor communities is a major barrier. The perennial problem of securing funding for preventive work is hampered by economic challenges experienced by poor countries. While programmes such as Stepping Stones that trigger change getting several communities to engage a wide range of stakeholders and involve them in dialogue and community interventions in order to create a critically aware and responsive masses, require massive investment and long-term engagement for transformative processes to occur. To advance heightened gender sensitivity, to encourage social actors to commence the difficult yet necessary process of challenging and changing hegemonic gender relationships, it requires on-going support, training and capacity development for activism and preventive work. Also, they would be encouraged to explore and suggest new ways of relating to women in non-violent ways. It is time for women and men to work together and enjoy their rights for peaceful co-existence, will contribute to gender equality and HIV prevention efforts as part of the intervention effort for couples.

Another less visible issues, is the silence on multiple perpetrators of violence against women in the Gambia. My study reveal that HIV disease stigmatisation in the Gambian social milieu, men are not necessarily the sole perpetrators/instigators of abuses of women's rights before and after HIV diagnosis. My research participants made reference to acts of discrimination couched in the language of stigma to describe verbal, physical, emotional and in some cases sexual harassment and abuse by intimate partners, but while the literature on violence and HIV intersections have already demonstrated that the perpetrators of violence in intimate partner relationships are men. Evidence from the Gambia, in the context of polygamous relationships and extended family households where intergenerational families live together, also contribute in rendering visible the multiple perpetrators which include elderly men and women and influential family and household heads or powerful persons who exercise dominance and control over women and girls in the family. Some reported co-wives and their children, mothers-in-law, and others in the family and within the community stigmatising them. The family and social locations of PLHIVs define how women experience enacted discrimination. Most of the perpetrators

and instigators of VAW live within closely-knit households and communities, so PLHIVs may be exposed to various degrees of stigmatisation by people they trust.

This raises pertinent questions about the role of men and women as culprits and accomplices in the enactment of violence against women living with HIV and it is critical that we address this in preventive frameworks and to assist affected women to deal with unresolved emotional and psychological issues confronting them. The need to build resilience in the face complex challenges of living within difficult circumstance where PLHIVs are vulnerable to stigma and enacted discrimination (Liebling et.al, 2014). Liebling –Kalifani et.al, 2007, pp. 2-4) own research reveal that 54.2% of women who were abducted, forced into marriages, during the decade of civil war in Kikamulo sub-county, in Luwero, Uganda, the findings of the research registered that a number of the affected women experienced problems of post-traumatic stress, as well as physical and gynecological health difficulties including headaches, physical aches and pains, genital and abdominal pains, palpitations, chest pains, anxiety, lack of appetite and ulcers (Liebling –Kalifani et.al, 2007, p.2). The study concluded that based on the findings of women's experiences of sexual violence and torture, many of them suffer from considerable damage to their reproductive organs and the effects of their experiences has resulted to chronic abdominal pain, they argue that women's reproductive powers were re-shaped through multiple rapes, impregnation and destruction of fetuses, hence the need to address the physical, psychological, and social aspects of the women's experiences and dealing with pain is critical and it is closely enmeshed and impact women directly. The need to break the silences on the range of abuses they have experienced is part of the health needs as well as giving "meaning to their pain" (Liebling –Kalifani et.al, 2007, p.13).

In this current project, my research concern was aimed at rendering audible the 'silent voices' of women living with HIV who are survivors of violence. To understand how they construct their narratives of abuses as a result of HIV stigmatisation and enacted discrimination. It is hoped that the findings will be utilised to promote agency and action which will assist them to secure survivors' rights and justice. The thesis concludes that context specific and culturally specific and Afrocentric approaches, grounded in women's everyday practices of agency and resistance, are necessary in the Gambia.

Furthermore, the emotional and psychological trauma and negative effects of everyday stigmatising abuses and denial of women's rights need to be understood and accorded due attention. The need to search and initiate safe platforms to encourage dialogue and to challenge existing gender inequalities and structural injustices is currently being addressed globally. A very informative and useful reference literature is published by Liebling and Baker's (2010) work on the global health and justice paradigm and these scholars' contribution on gender-based violence prevention work using a holistic and an integrated approach that emphasise the interventions aimed at addressing women's rights to health, social and gender justice.

There are inherent tensions and barriers to the prevention of violence against women and girls because of fear of backlash. To circumvent this potential backlash, I suggest that it is possible to bring out explicitly a gendered dimension that not only captures clearly the effects of violence on affected women, but also showcases how various categories of women are affected by violence and also to create safe communicative platforms to engage men and women, boys and girls to dialogue and also examine how men are affected by their own misuse of power and control of women. It is possible to utilise recommended interventions by World Health Organisation (WHO) & London School of Hygiene and Tropical Medicine (2010) evidenced-based violence prevention model and suggested actions to prevent intimate partner and sexual violence against women

These interventions could incorporate collaboration and the forging of strong partnerships with key influential elders in the family and religious and cultural leaders (men and women, and also young boys and girls) who are willing to engage in preventive processes towards challenging and eventually preventing the occurrence of everyday normalised and naturalised abuse which is fueled by male dominance and control of women and girls.

I also argue that there are intersecting underlying factors (patriarchy, gerontocracy and structural violence) that contribute to women's experiences of violence and abuse and render them vulnerable to HIV. In addition, alongside the more visible gendered forms of violence which intersect with HIV/AIDS, stigma should be seen as an 'everyday' practice of normalised violence, particularly when women who possess discreditable attributes of HIV, and who may struggle to keep their HIV status concealed, need support to prevent stigma and discrimination and to build their resiliency (Sherwood & Liebling-Kalifani, 2012).

The cohort of women in my study who possess discredited attributes (visible and non-concealable attributes of HIV) revealed that they suffered from enacted stigma and discrimination. The effects of HIV related stigma evidenced by my study cohort include a range and mosaic of emotional, psychological and verbal forms of abuse, and aggressive and violent tendencies which isolate and ostracise them. They report physical fights, threats concerning sexual favours, and coercion by landlords when they experience difficulties paying rent. Most of the research participants discuss constant surveillance or avoidance to keep off perpetrators of stigma and discrimination, particularly at home where women live with co-wives, mothers-in-law and other extended family relations. Many women report self-stigma, social isolation, verbal insults, and other social control mechanisms imposed on them as women living with HIV, including blaming, name-calling ('prostitutes'), shaming and finger-pointing – forms of ostracisation adopted by perpetrators to devalue HIV-positive women. These attempts, identified by the women, aim to segregate and contain the spread of the virus from the 'infectious' to others who deem themselves 'normal'. HIV stigma ideologies and pre-existing gender stereotypes and stigma interlock to produce complex stigmatising and harmful forms of enacted discrimination against stigmatised women living with HIV. Some of the PLHIVs indicate in their accounts that with early diagnosis, enhanced access to treatment, support and care, they experienced better health outcomes and feeling of well-being. Treatment with antiretroviral (ARVs) and other drugs that fight opportunistic infections such as tuberculosis. ARVs reduce the viral load and prevents progression of HIV to AIDS symptomology as evidenced by the manifest stage in the HIV disease trajectory (Alonzo & Reynolds, 1995). This feeling of enhanced well-being builds their resilience and prevents internalised and / or feelings of self-stigma (Pryor & Reeder, 2011).

8.8 Recommendations for future research

The conspicuous gap in research undertaken in the Gambia when compared to other sub-Saharan African countries highlights the urgency of conducting large-scale studies that take into account both men and women's experiences as PLHIVs to examine gendered differences. First, I recommend three follow-up quantitative and qualitative studies to examine the effect of structural violence and unequal gender relationships between men and women, examining the socio-cultural, economic and political dimensions that may make men and women vulnerable to gender-based violence. As Kabeer suggests it is

useful to understand how certain structural factors (economic, political, cultural factors) imposed by dominant groups determine the rules, norms, who have access and control of resources, which in many ways are defined along lines of gender, class, race, caste, and so on may pose as constraints (Kabeer 2016, p.297). Second, using both qualitative and quantitative data collection methodologies, there is a need to conduct evidenced-based study to examine the extent to which coercive and forced sexual relationships (examining early marriage, unprotected and coercive sex) may render women vulnerable to sexually transmitted infections and HIV, because there is limited research addressing this area in the Gambia.

In the current study, I adopted a qualitative approach but now propose that, for future research, both quantitative and qualitative investigations be undertaken to further expose the best practice that reduces women's vulnerability to stigma and discrimination. In addition, I would recommend the scaling-up of Stepping Stones as a form of preventive intervention aimed at challenging hegemonic gender norms and addressing gender inequality and VAW prevention, and it would be reasonable here to recommend other interventions like Partner Management to reduce VAW ²⁴ as it intersects with HIV. As part of the action research cycle and methodological approach, for future research, it would be useful to explore how, after implementation of the Stepping Stones Project, the use of diaries and journaling strategies might assist support and care interventions. In addition, it would be useful to evaluate and share best practices on the utility of Partner Management Interventions. Further research is needed to investigate the prevalence of HIV in prisoners who are vulnerable to abuse, especially gender-based violence in the Gambia.

Such evaluation would gauge the outcomes, using participatory vulnerability assessment tools (PVA), to determine the effectiveness of the proposed strategies/interventions in preventing stigma related violence. These findings could inform theory formulation and be shared as useful interventions, because I argue that what is largely missing are theories of change to spur preventive actions, working with researchers, scholars, and local Support Societies and grassroots movements.

²⁴ The scaling up of this intervention is important and urgent to prevent VAW as it connects with HIV/AIDS as findings from previous studies reveal its benefits in preventing VAW and STIS.

8.9 Study limitations

First, this study has limitations because it uses a purposive sample limited to women who were prepared to disclose their HIV-positive status and who also chose to share their experiences concerning the nexus between violence and HIV. These women were found in the Support Societies. The insights and knowledge gained from this research could be limited and may not be generalisable to non-HIV-positive women and to the wider population of women who may experience violence but are not clients of the HIV Support Societies. Second, the research could only study the experiences of stigma, discrimination and violence in affected women who chose to disclose, who had already been identified as HIV-positive, and who could volunteer and give consent to participate, making themselves available and accessible to the researcher. The research could have missed out on women who are afraid to disclose, yet face similar (or perhaps even worse) challenges.

The current project is designed to foreground gender, to prioritise women's voice, even though it should be noted that both men and women were to be found in the Support Societies (an observed limitation of my research approach). I declare that the prioritisation of women's voices is a source of bias, but one I prioritised because of women's history of being silenced and their experiences of abuse which may not be visible. The need to include men for comparative analysis in other studies is highly recommended to capture their views on the differences between men and women living with HIV.

Another identified limitation is that this thesis did not interview women in non-heterosexual relationships. As mentioned in the literature review on violence against women (Chapter 3), I was aware that I may encounter challenges when seeking persons willing to disclose and share narratives about their experiences of violence in non-heterosexual relationships, because of the laws against homosexuality in the Gambia, so this particular limitation was anticipated. Notwithstanding the above limitations, this study has contributed in a unique way to capturing the contextual realities of affected HIV positive women and the views of field practitioners in the Gambia. It has opened up dialogue spaces for future collaborative engagements and studies.

8.10 Dissemination of research findings

In line with the action research approach, I propose the following dissemination plans. As mentioned in the research methodological section of Chapter 5, the Action Research cycle

will involve a series of consultative meetings to disseminate the thesis report (abridged version 15,000-20,000 words and video in local ethnic dialects and in English to help co-researchers obtain feedback and to validate the findings). It is critical that relevant others provide input and recommendations to influence the next cycle of the action research process. Hence, the report will be disseminated to the following:

- The Ministry of Health and Social Welfare and Education;
- The Women's Bureau;
- The existing HIV/AIDS Support Societies at decentralised levels of the Gambia (rural and urban areas);
- Mutapola Voices of Women;
- National AIDS Secretariat (NAS);
- The Network for Prevention of Gender Based Violence;
- Action Aid International, The Gambia;
- Key informants who participated in the study;
- Catholic Relief Services (CRS);
- The Association of Non-Governmental Organisations (TANGO) in the Gambia, an international, non-governmental, civil society organisation that is interested in the report and would like to forge partnerships with Support Societies to work on future interventions.

8.11 Thesis conclusions

This research has evidenced that Gambian women and girls from birth to full maturity are subject to a range of compounding and multi-layered dimensions of structural socio-economic, political, cultural and other factors that have a negative impact upon sero-positive women. This study has shown that there exists an interconnectedness of stigmatisation, enacted discrimination and various other forms of physical, economic, emotional and sexual abuse which are made natural and then accepted as everyday normalised violence. Women's narratives concerning their histories of violence before HIV diagnosis are essential in understanding how everyday normalised violence is exacerbated in the context of HIV after diagnosis. Violence is a precursor and sequel to HIV. Stigma is violence and from the research participants accounts it covers a range of economic, social, physical and psychological acts of a range of abuses affecting PLHIVs. The recommendations may help to frame our policy and interventions at several different

levels, where feasible. Culturally specific and holistic and integrated approaches are necessary, which are grounded in women's everyday practices of agency and resistance and, in particular, address the fear of dethronement (loss of power, privileges and prestige) amongst men and older members of society. There is urgent need to address the physical, psychological and emotional as well as the justice and women's rights issues. The seeds of hope can be sown now through commitment and active involvement of all stakeholders. There are opportunities to move beyond limited instrumental interventions, to more holistic, sustainable efforts, challenging the status quo that normalises violence against women and girls.

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Appendix 1: Enlarged map of the Gambia

Appendix 2: University of Sussex Ethical Review Certificate of Approval



Social Sciences & Arts Cross-School Research Ethics Committee

CERTIFICATE OF APPROVAL

Reference Number:	ER/AC527/1
School:	LPS
Title of Project	Gambian women, violence and its intersection with HIV/AIDS: agency through feminist participatory research
Principal Investigator: (Supervisor)	Agnes Campbell Nee Kallay (Bendelow)
Expected Start Date:*	02/09/2013
<p><small>*NB. If the <u>actual</u> project start date is delayed beyond 12 months of the <u>expected</u> start date, this Certificate of Approval will lapse and the project will need to be reviewed again to take account of changed circumstances such as legislation, sponsor requirements and University procedures</small></p>	
<p>This project has been given ethical approval by the Social Sciences/Arts Research Ethics Committee (C-REC). Please note the following requirements for approved submissions:</p> <p>Amendments to research proposal - Any changes or amendments to the approved proposal, which have ethical implications, must be submitted to the committee for authorisation prior to implementation.</p> <p>Feedback regarding any adverse and unexpected events - Any adverse (undesirable and unintended) and unexpected events that occur during the implementation of the project must be reported to the Chair of the Social Sciences C-REC. In the event of a serious adverse event, research must be stopped immediately and the Chair alerted within 24 hours of the occurrence.</p>	
Authorised Signature	
Name of Authorised Signatory (C-REC Chair or nominated deputy)	Professor Stephen Shute 03/06/2013

Appendix 3A and 3B: Interview guided checklist of research questions

Interview guide checklist of questions with PLHIVs women in Support Societies

Preamble:

Earlier, during the pilot phase we jointly discussed and agreed on the various types of ‘abuses’ you may have experienced (at home or in the community) in which you all agreed what it means and what you consider as abuse / or VAW from your own personal experiences as women living in the Gambian context. Am I correct? Now let us try and bring into our mind (to recall) how in your own situation it happened? Tell us in the focus groups what happened before and after HIV diagnosis giving examples. It may be different or similar for each woman and I want to register here I also know it is very painful and difficult, if you are ready to talk about your experiences then we can commence.

As a reminder again, please note we have in – house social workers and HIV peer educators. Please do not feel obligated to talk. You are free to share and to listen or withdraw at any time freely without any repercussion. It is your right to participate or not to participate. Just to recall what we define VAW to be from your own explanations I have compiled the following to organise what we generally described as VAW:

Physical violence (experiences of physical fights with injuries sustained, slapped, kicked, beaten, pushed around, shoved, and the perpetrators may use any weapon to cause physical threats of violence with intent to harm.

Sexual abuse (used forceful sexual advances, without your consent to sex or intimate relationships even when you say no/refuse);

Emotional and psychological violence (includes use of abusive language, derogatory name calling and finger pointing; publicly shamming/ and embarrassment to your person; in front of ‘others’, includes acts of isolation and denial of your rights to access food, clothing, shelter, and your children; including shaming and shunning by others).

Economic violence (for example - denial of fish money and or/food; refused or denied access to your children; refused or withhold support such as material and financial, or housing or other basic needs –in case of abandonment, divorced and using extremes forms of isolation and lack of support).

Well today as we open this conversation let us recall if any one of you experience these situations in your life and explain how you were it occurred what triggered it Please explain giving examples, where possible as we converse together in this focus group, for the purpose of structure we can for example:

1. Describe your experiences/ how did it happen, who was responsible?
 - a. Experience(s) of VAW **before** you were diagnosed with HIV/AIDS;
 - b. Experience(s) of VAW **after** you were diagnosed with HIV/AIDS.
2. Have you ever felt being treated differently since you tested positive?
3. Tell us what happened and who were/are the perpetrator(s) and what was/is your relationship to them?
4. How did this abuse and /or violence affect you? In what way and what did you do?
5. When you were first diagnosed as HIV positive did you tell anyone (ascertaining disclosure)? For example did you tell any family member(s) – like husbands, in laws, co-wives, sisters/brothers, and own parents.
6. What were your experiences?

7. What do you think of the services you received at the HIV Support Societies, or at health care facilities? Did they address your needs when you seek help? How did it help you? Let's discuss the kinds of assistance and interventions do you think you currently need, providing specific and concrete examples of care and support services you consider to be most urgent and helpful.
8. What are your suggestions and recommendations - for care and preventive measures to end violence against women as it links with HIV/AIDS?

Finally, I appreciate all of you sharing and us learning about your experiences from all as we engage in this discussion. Please remember that we have in place a follow up care, you are invited to come to talk with us; please remember the ethical and confidential issue we discussed and please let's adhere to our commitment not to discuss any of the issues we talked about outside this group! Thank you.

Appendix 3B: Checklist of questions for practitioners and policy makers

1. From your work experience and personal viewpoint are there any linkages or connections between women's experiences of violence (VAW) with HIV/AIDS in the Gambian context?
2. How do you explain the incidences of VAW and HIV/AIDS in your area of work?
3. What do you think are the contributing factors? Please describe any other factors you consider relevant.
4. What are your organisational responses manifested in policies and practice interventions when dealing with VAW as it links with HIV/AIDS?
5. What are your recommendations for interventions in terms of prevention, support and care responses assist affected women and families?

(N.B. Where feasible probe and encourage – to offer concrete examples) which they think is useful based on their work experience as the way forward for enhanced care, support services? Any relevant recommendations.

Thank you for your contribution and time.

Appendix 4: Consent form for research participants



CONSENT FORM FOR PROJECT PARTICIPANTS

PROJECT TITLE: Gambian women, violence and its intersection with
HIV/AIDS: agency through feminist participatory research

Project Approval

Reference: ER/ AC527 / 1

I agree to take part in the above University of Sussex research project. I have had the project explained to me and I have read and understood the Information Sheet, which I may keep for records. I understand that agreeing to take part means that I am willing to:

Be interviewed by the researcher:-

- 1) I understand that any information I provide is confidential, and that no information that I disclose will lead to the identification of any individual in the reports on the project, either by the researcher or by any other party.

- 2) I understand that (data will be coded and anonymised) to prevent my identity from being made public.
- 3) I understand and consent to keep all information shared and heard in the focus group discussions as strictly confidential.
- 4) I understand that I will be given a transcript of data concerning me for my approval before being included in the write up of the research and also I agree for it to be published in doctoral thesis and other publications.
- 5) I consent to the tape recording of focus groups and videotapes (blurring of identities) being utilized during the interview process but it shall be done in such a way that our identities will not be distinguished. It shall be technically blurred for anonymity and confidentiality of our identities.
- 6) I consent to any disclosure of illegal acts of violence to be reported to the authorities and professional counsellors who will deal with it appropriately according to the institutional ethical standards and responsibility.

Interview Clause

<p>I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.</p>
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<p>I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.</p>

Name:

Signature:

Date:

Independent witness to participant voluntary and informed consent

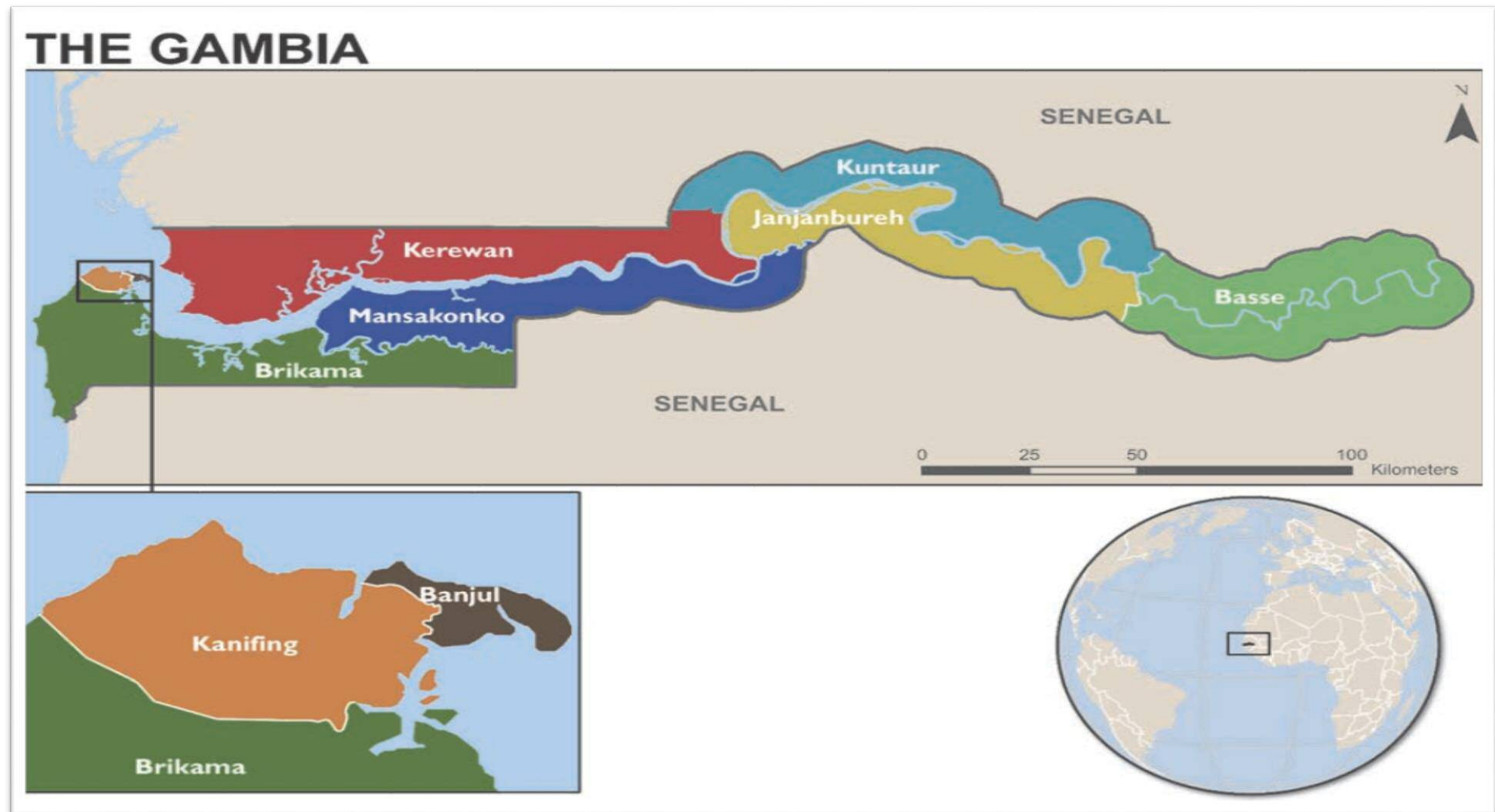
I believe that _____ (name) understands the above project and gives his/her consent voluntarily.

**Signature of
Witness:**

Address

Date:

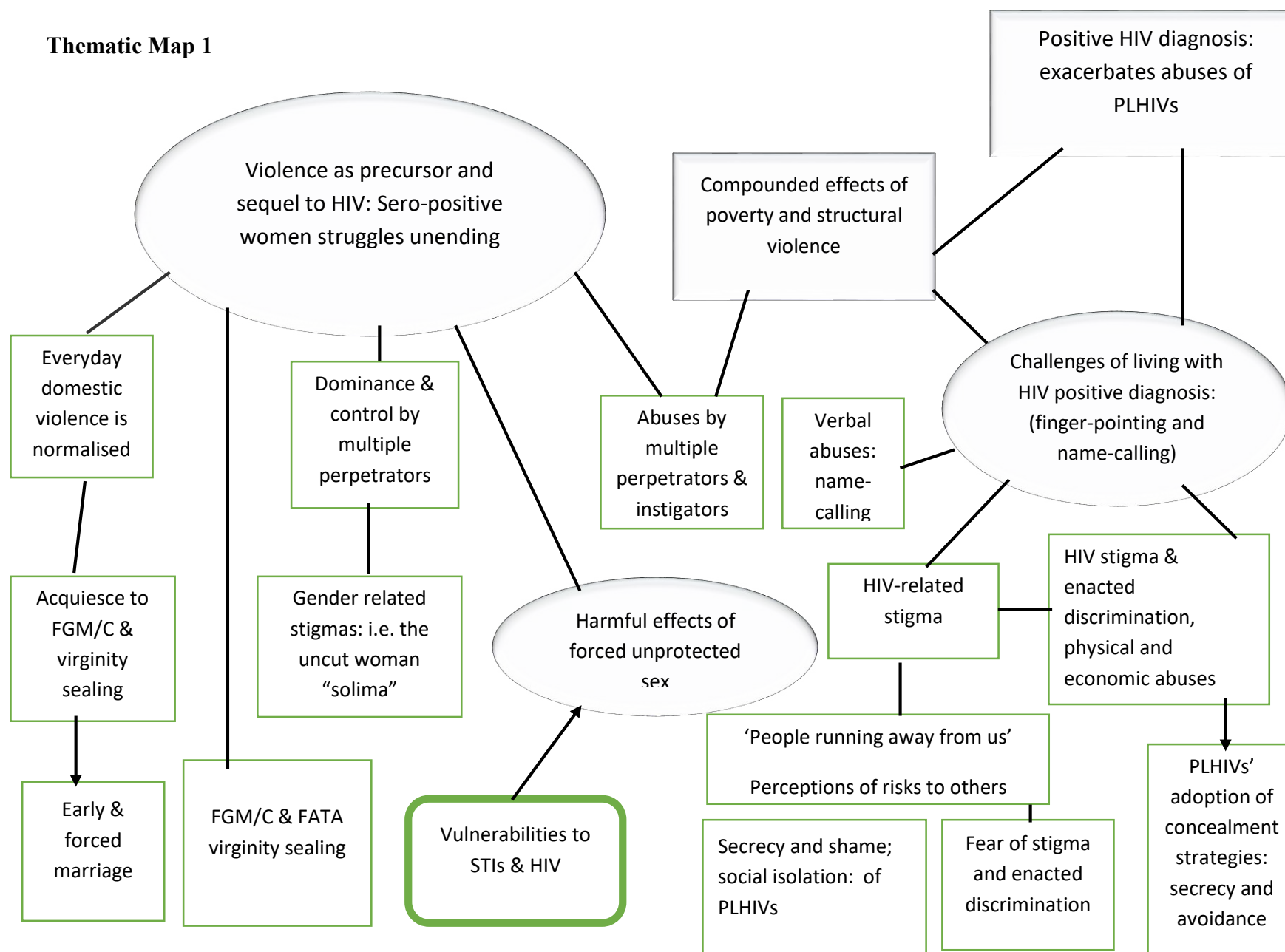
Appendix 5: Thematic maps, summary of main theme and sub-themes



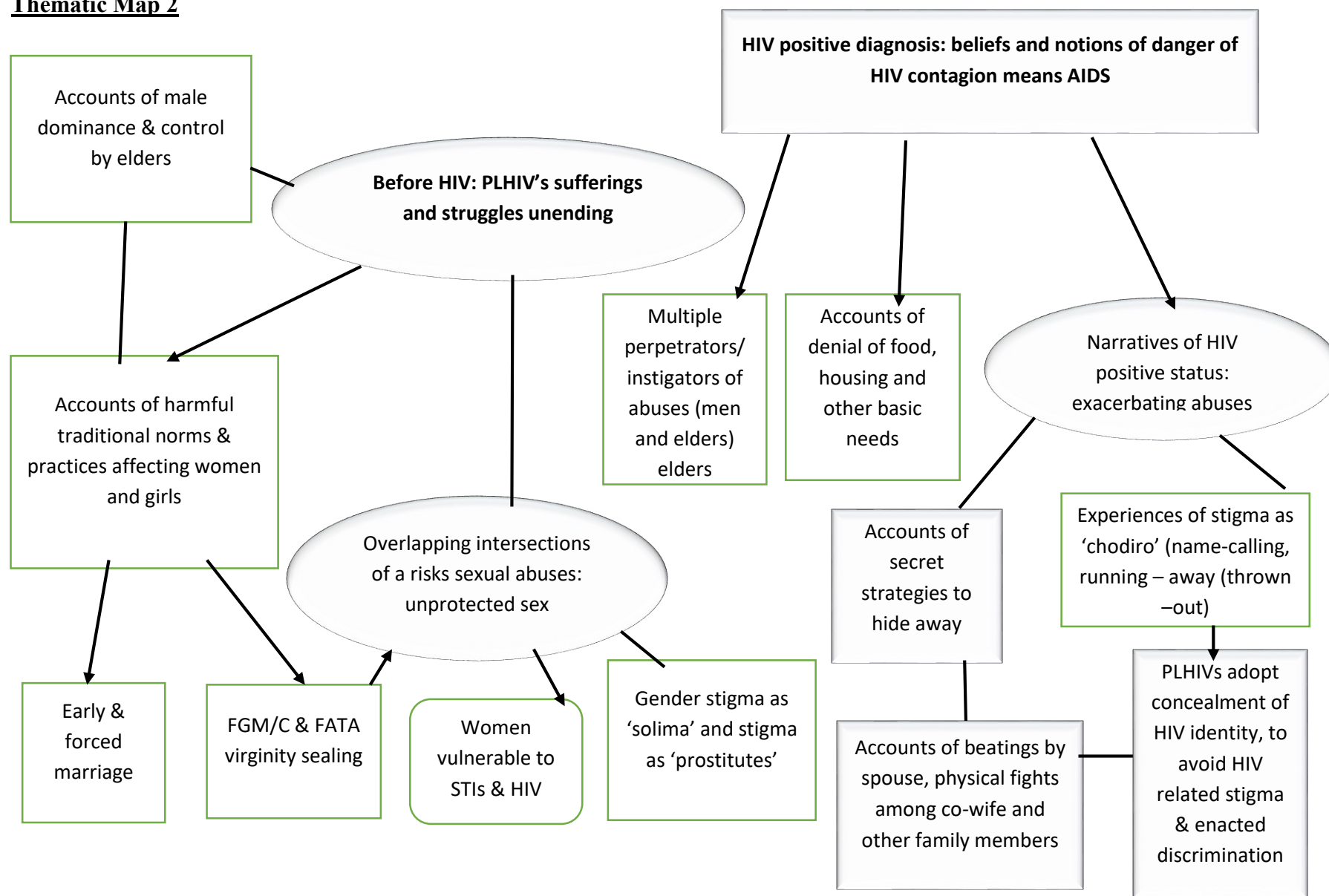
Appendix 1: Enlarged map of The Gambia

Appendix 5 Thematic analysis presenting the three main thematic maps and summary of the main theme and sub-themes:

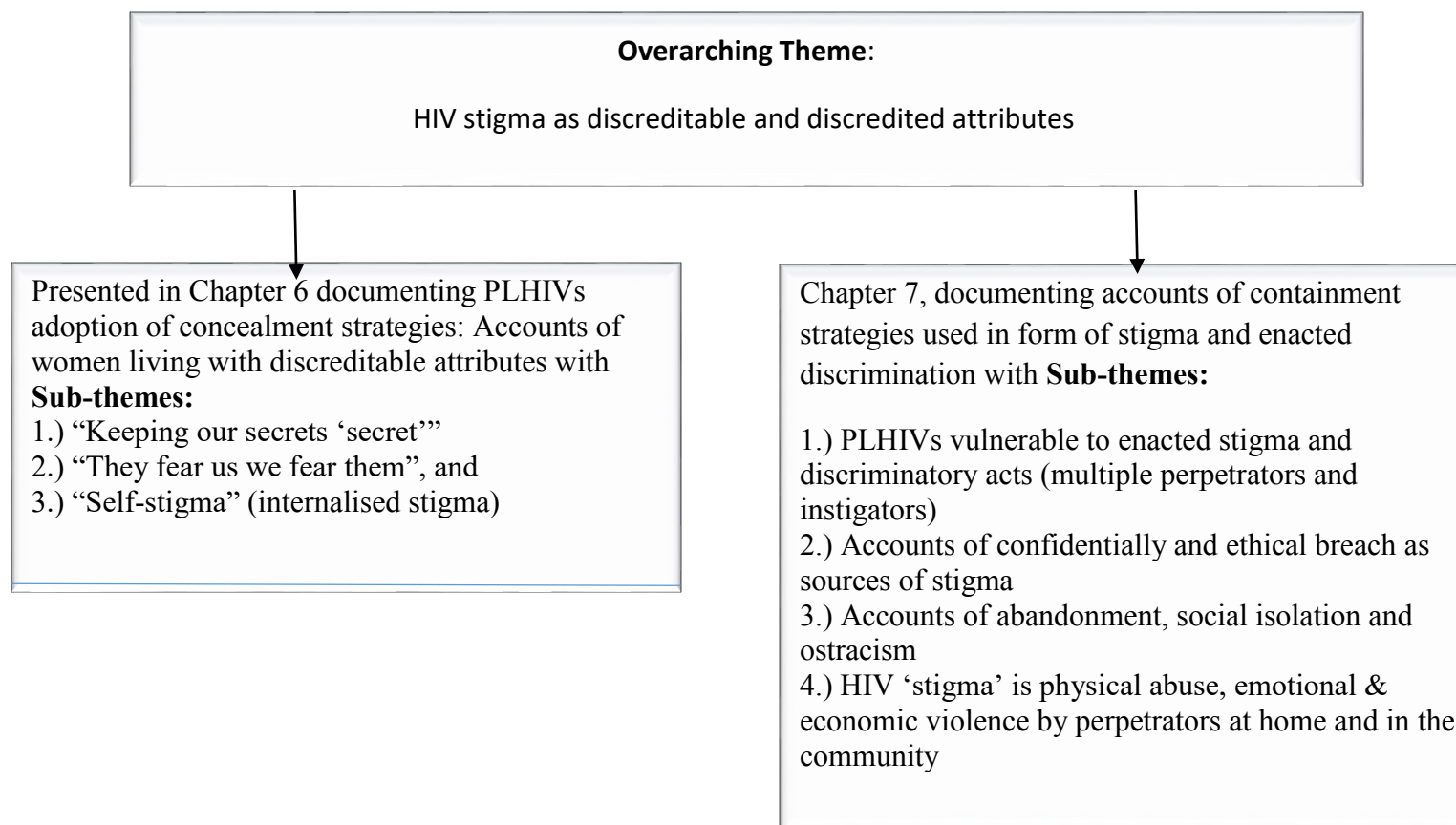
Thematic Map 1



Thematic Map 2



Final thematic Map 3



Overarching Theme	Sub-themes
<p>Overarching Theme: HIV stigma as discreditable and discredited attributes.</p>	<p>Presented in two separate chapters (Chapter 6 and in Chapter 7). PLHIVs adoption of concealment strategies: Accounts of women living with discreditable attributes:</p> <p>Sub-themes:</p> <ol style="list-style-type: none"> 1.) “Keeping our secrets ‘secret’” 2.) “They fear us we fear them”, and 3.) “Self-stigma” (internalised stigma) <p>Sub-themes:</p> <ol style="list-style-type: none"> 1.) PLHIVs vulnerable to enacted stigma and discriminatory acts (multiple perpetrators and instigators) 2.) Accounts of confidentially and ethical breach as sources of stigma 3.) Accounts of abandonment, social isolation and ostracism 4.) HIV ‘stigma’ is physical abuse, emotional & economic violence by perpetrators at home and in the community

A summary of the overarching theme and sub-themes

Appendix 6: Sample of data extracts (coded interview transcripts)	(Page 257)
<p>Data extract sample 1: A focus group discussion with health practitioners</p> <p>I (Interviewer): “From your work settings and experiences, what do you think are the key issues affecting women living with HIV positive diagnosis?”</p> <p>113: “Well ...In our African tradition, and because of the concept of HIV, we think that when a woman has contracted HIV she will be labelled and called names that she has been promiscuous or she has been living a bad life. So that would lead to stigma because here HIV is attached to people who are sex workers [...] or if the lady has been living a free life. That is one reason why women in Africa are vulnerable to stigma and discrimination or violence. Because if that woman is a married woman and then she is found to be HIV-positive and the husband is negative the family members will think that maybe this lady has been playing out, having sex with other men. This can lead to divorce, maybe the husband will even maltreat her, and she will be faced with domestic violence. So for me, I think one of the reasons is because they think that the woman has been living a free life ...”</p> <p>I: “Thank you 113. I would like to ask, have you ever experienced dealing with a woman in your work situation who has complained that she has been treated badly or has been stigmatised because of HIV, as you have just explained?”</p> <p>116: “Oh yes, many of them, many of them, most of our patients that we see here, because in fact that is one of the problems we are having with disclosure. Because when a woman is found to be positive she finds it very difficult to disclose, because she is afraid of what the outcome will be... because one thing is stigma the next thing she will be faced with violence because they might treat her anyhow. The husband may send her away. Even if she is not married, family members might just, ehmm..., maltreat her saying she has been living a bad life. Women are afraid to disclose. Anyhow, so we are facing a lot of problems with disclosure because of the stigma, because there is a saying that only promiscuous women are infected with HIV.”</p> <p>Ron: “I think basically the exposure out here is ... hmm, it is more or less linked to the... hmm... socio- cultural makeup, and if a woman discloses that she is HIV-positive, especially to the husband, instantly the husband thinks that she has been playing around. She is accused of ‘cheating’ more or less without the</p>	<p>Code assigned (I used ‘direct phrases and verbatim quotes’ (in-vivo coding) see highlights in blue).</p> <p>Social context of HIV stigma as name-calling (verbal assault) of female PLHIV</p> <p>Negative labelling ‘free and promiscuous’ life</p> <p>Stigma associated with women: ‘accused of living a ‘free life’.</p> <p>HIV diagnosis associated with risk of divorce/ maltreatment /domestic violence.</p> <p>Difficulty surrounding disclosure /fear of outcome</p> <p>Problems and risks associated with HIV (being sent –away)</p> <p>Accusations of HIV positive women, being ‘promiscuous’ and ‘cheating’</p>

<p>husband even having a good understanding of other ways of being infected ... And the other thing also is that, because of some strict religious rules and taboos, it is difficult, very difficult indeed, for HIV status to be disclosed, and especially for women's positive status to be accepted ... in some settings, the women are affected as they come from closely-knit families and communities."</p> <p>I: "Can I ask here why it is difficult for them to reveal that in the Gambian setting?"</p> <p>116: "Well in cases where women cannot disclose, when they come together we find a creative way to let the husband know that we asked him to come because the wife came and complained of certain sexually transmitted infections, common ones women experience ... but we will not mention that it is HIV. We reason with them and explain ... well you know how sexual infections are contracted ... so you see we want to send both of you for tests [speaker takes a deep breath] and one of the tests is the HIV test and we do not want to do the test for your spouse behind your back and that is why she was asked to invite you so that both of you can now go for the test. If he accepts it now gives us an opportunity to counsel both of them together again [clinicians explained to me that strategy is a 'cover-up' to pretend that the clinic is testing her for the first time to deflect blame]. We will then seek their joint consent and find out how they want their counselling conducted, whether as a couple or separately. But once the partner is there, preferably it is done as a couple."</p> <p>I: "Elaborate a little bit more about the concept of partner management. What exactly takes place?"</p> <p>113: "Okay as my colleague 116 has just said, well it is true. It is lack of understanding that leads to the introduction of the partner management approach here at [**** name of clinic deleted]. It is one of the ways that we use here. When a woman is positive, we tell her to bring her partner/husband to be counselled. HIV is transmitted through sexual intercourse, so her partner might be infected with the virus and so we ask that she brings him. This way that partner will be tested too ... "We counsel them together, pretending a test has never been done for HIV for the woman... We give them a slip of paper and when the staff see that slip of paper they understand that it is a partner management slip. We know that the partner needs counselling support and testing...here at [**** name of clinic removed for anonymity & confidentiality purpose] we offer an opportunity for the woman and man to come together and the counsellor will manage the way in which the information regarding the HIV-positive investigation is handled"</p> <p>114: "They will then be supported through the couple counselling and when the results come out, since you have done pre-counselling as my colleague has just said [116 has already explained], here you will not make it known that the lady</p>	<p>Religious norms and taboos associated with promiscuity (difficult to disclose HIV status)</p> <p>Strategies of Partner Management explained (couple counselling).</p> <p>Concealment strategies: Partner management (promote safety and deflect blame and accusations of women).</p> <p>Clinicians use partner management strategies (couple counselling to avoid stigma and other negative effects) upon HIV diagnosis</p> <p>Interventions to minimise risk of stigma [Pretend test done first time]. Avoiding blame (discreditable attribute hidden/concealment).</p> <p>Conceal HIV positive status / secure support from spouse for prevention of abuse</p>
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<p>already knows her status. So you prepare them together so that the partner is ready for any eventuality...”</p> <p>I: “... However it is assumed he does not know. Is this the way to minimise disclosure related risks?”</p> <p>113: “Yes, to minimise risks of stigma we put it in a way so that the husband or the partner will not know that the woman concerned already knows of her positive status and we pretend this is the first time they are being tested [pretending it is the first time for the woman], and when the results come we counsel them. But if the husband is negative and the woman positive that is another challenge we experience ...”</p> <p>114: “Well let me come in here. In situations where the wife is positive and the husband is negative we just...we continue counselling. You see those couples need more counselling support, especially the husband, to prevent abuse and to secure the husband’s support. Well yeah, because most of them, especially the men, when they are negative they tend to give the wife trouble. Some of them will end up divorcing the wife, but we have some understanding ones who will say: despite this she is my wife and I am going to take care of her... this is the time when she needs me the most ... and I will make sure she is with me till death do us part.”</p> <p>113: “The couple will then be supported in the partner management programme – through couple counselling – and when the results come out, since we have done pre-counselling as my colleague has just said [116 has already explained], we will not make it known that the lady already knows her status. So if they agree to be counselled together again – post HIV test counselling – then we prepare them together to be ready for any eventuality...”</p> <p>I: “... However it is assumed he does not know? Is it a way to minimise disclosure related risks?”</p> <p>113: “Yes, to minimise risks we put it in such a way that the husband or the partner will not know that she has already discovered her positive status. Maybe sometimes he will say: it is because you know, that is why you want to bring me here. So we do a general counselling again and send the tests to the lab [as if it is the first time for the woman], and when the results come back we counsel them and help them over several sessions.</p> <p>I: “Can any other person explain why it is a challenge for women to reveal their status that in the Gambian setting?”</p>	<p>HIV-positive women risk experiencing trouble</p> <p>Effects of HIV positive risk being divorced (negative effects of HIV)</p> <p>Couple counselling/partner management to avoid other negative outcomes from disclosure</p> <p>Minimise disclosure-related risks Fear of stigma / risk reduction strategies (to avoid stigma) concealment</p>
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SAMPLE FROM DATA EXTRACT 2

A focus group interview transcript (translated by the president of [**** name of a rural Support Society deleted] who is a man and the only one available to translate in four local dialects and he assisted me as the local interpreter because I was not fluent in two local dialects of this region. He is also HIV positive and a peer counsellor/community home-based care worker for [****; an NGO]) from a discussion with four women living with HIV, namely: 013, 011, 116 and 115. (Please note that I interviewed 013 first during this focus group and because of her emotional state she withdrew and I conducted an in-depth individual interview later, when she was ready).

I: Before the short break for your afternoon Muslim prayers, we discussed the topic of marriage and its importance. Again I examined your socio-demographic data sheets and it is interesting to note that most of you in this group have been married at least twice. Some are widows, others divorced and remarried. 013 you talked about the challenges, let us hear your views on this issue...

013: You see when you are HIV positive and it is revealed you do not have anyone to marry you. With this HIV and stigma, you cannot find a husband, you cannot marry. People talk about you and discriminate against you. Marriage in the Gambian context is important. If, as a woman, you do not marry, you are stigmatised. Also, when you die they dump [bury you without ceremony] you like a small boy or small girl. A woman who is not married and dies as a Muslim in this rural community will not be buried with respect to dignify your life here on earth. You may be dumped into the grave without prayers and denied any of the ceremony or respect accorded to the dead. Yes, no respect is accorded to you.

I: Hmm ... are there any other problems that you have experienced in marriage?

015: Several, I mean we cannot cover all the problems in one seating, you see marriage is valued ere in these rural areas, if you're not married you have a problem you seek ways to solve it to find suitable husbands to avoid being called a bad woman these are the types of difficulties, the bad image you are assigned.

015: Well you see often women and girls here in these rural areas we have limited or no choice when their elders give them away [against their will] to marry. It is just respect for parents' wishes. We listen to our elders even if we know it is forced marriage" [interruption as multiple voices are heard and ... voice of 015 continues well ... let me finish this ... [interruption] as I was saying after your husband dies, you can remarry many times, and you know to prevent shame and bad name.

If HIV status known,
difficult to marry.

Negative talk

Stigma associated with
unmarried women

Unmarried women treated
negatively /with disrespect
even unto death

Marriage valued in
Gambian social-context

Women and girls limited
choice

Respect for elders/listen to
parents/ marriage
frequently occurs after
death of spouse

<p>[Interruption ...but Let me add here ... name of speaker not audible] before this, for many young girls you have limited or no choice when our elders give us away, here they do not call it forced and early marriage, well it is normal to marry at young age in our local village here.</p> <p>I: Just clarify this point here about early marriage.</p> <p>As I said, our elders, mothers, grandmothers, our fathers and uncles give us away when they think we are ready to be married, it brings pride and honour and they will say they raised up their daughter very well. She has a good husband and children. Children are also important and valued. Without children you are shamed by your peers. You gain status in marriage.</p> <p>The president of the Support Society (PS as the pseudonym): interprets for PLHIV 013 saying: Here, in this Support Society, we deal with issues of women facing difficulty because they do not have a husband. Without a husband you lack respect and if you die you are not accorded respect. It affects your children. They are also stigmatised.</p> <p>011: Well now I hope you understand why women are marrying, marrying and marrying many times, because marriage leads to respect for the women, here in these rural areas.</p> <p>015: I agree, when a woman dies, elders will ask, “Is she married?” If she is not then she is merely dumped [buried] like a child.</p> <p>I: Hmm ... let’s talk a little bit more about HIV</p> <p>PS: When I first came out here to this rural community, you could not tell who had HIV; it is a secret then, not one would make themselves known in the community. It was my return home after I had been away from the Gambia for 17 years. I had travelled a lot around the world, I had spent many years away, and I had adopted a different life style. I set up this Support Society here for people like me, men and women.</p> <p>What many people are claiming here in the Gambia is that if you are not married then you lack social status and respect. Well I understand that but wonder about my religion and I know what the religion says about marriage. If you can do it yes, marry many but only if it can work. If you cannot marry many wives, then stay with only one. The religion says you can marry two to three only if you can (i.e. if you can afford to); if you can maintain them economically, and you are fair and physically strong and marry a woman to honour her. The religion does not force anyone to marry many women. Polygamy is more cultural, not a religious obligation in my understanding. People mix up culture and religion you know ... these are misconceptions, marriage, and male dominance, well I guess the issues are not clear to many. I</p>	<p>Choice restricted</p> <p>Elders’ power & influential role in marriage decisions</p> <p>Married women gain status.</p> <p>‘Unmarried’ - you lack social status</p> <p>Importance of marriage</p> <p>Unmarried women experienced devaluation of social status.</p> <p>Men must afford to maintain all wives according to religious norms</p> <p>If not do not marry</p>
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<p>say for many people in the Gambia in polygamous relationships women are not given their due respect.</p> <p>013: I was given away in marriage at 16 years and my husband died of HIV. This is my second marriage and I disclosed but he accepts and loves me. My first marriage was a difficult issue for me. It was a forced family marriage, and I was forced to marry him as a second wife. In that marriage my husband married and divorced, married and divorced all the time up to ten wives. I was the only one left at the time he died of TB. I was not in love, I will never like him, never liked him, not in this life and not in the next world. I will also never forgive him for the poverty and hardship he left me with after his death.</p> <p>I never wanted the marriage and it is this marriage that has left me suffering up to today. I am suffering with my children. I was given away to suffer. My family has money but I was given away to a relative. I am still not fully recovered from the effects of my life of poverty with that first husband. We never had enough food because of his large family and his frequent marriages to other women. Food insecurity was my main challenge and even a bed for us to lie down was a problem. I suffered from poverty and want. We never found enough to feed my family, never. My former husband provided nothing for me.</p> <p>Now you see we are very poor and I cannot find adequate housing. During the rains you would feel sorry for me; rain enters everywhere, leaking in through the grass thatched roof. I suffer with my children, am still suffering. I was in bondage, after diagnosis with HIV. We stopped having any sexual relationship, and he had several women, about ten of us. All left eventually and I was the only one left to care for him. He treated me badly but I stayed in the marriage until he died. I reported it to my family but they insisted I stay in the marriage – he was a family member. I stayed at my former husband's home. I could not disagree with my parents and if they said I should stay in the marriage I had no choice but to adhere to their orders. I am still living in this marriage home and my new husband visits me. He helps to care for my family.</p> <p>Observation commentary: From a separate in-depth interview with participant 013 (a 43 year old HIV positive woman), she loves this man and he is her own choice. He provides for her, but even if he didn't, she would still love him</p> <p>I: How do you help affected women? What kinds of support are in place for affected women?</p> <p>000 [Speaker's s name inaudible] Well, here in the Support Society we hear the women's cases of abandonment. When women have HIV they are driven away and thrown-out because of HIV and we respond in any way we can. We just help ... if we can.</p> <p>PS: We blame religion for everything, but it is our culture, tradition. We see how, for instance, women suffer FGM or cutting, the misunderstanding surrounding the religious</p>	<p>Poverty and hardship</p> <p>Early marriage at 16</p> <p>forced to stay in marriage /difficult marriage</p> <p>Multiple wives and concurrent relationships/polygamy</p> <p>Forced to stay and suffer in marriage respect for elders /</p> <p>Marital bondage</p> <p>Negative effects of food insecurity, poor housing</p> <p>Arranged family marriage</p> <p>HIV diagnosis - women experience abandonment, driven away because of HIV diagnosis</p>
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<p>explanations of this practice, and this makes the situation for many women very difficult.</p> <p>015: In the Gambia, we need our men to respect their wives, but this is not the case, women suffer. They need to respect and love them unconditionally. Also, we should not force them to marry against their will.</p> <p>I: What, in your view, do you think are the problems HIV women experience living with HIV? Please ask the women, say it in the local dialect. (.) Long pause</p> <p>[PS interprets and explains to women, probing and encouraging them to speak. They discuss in Sarahule, another local dialect, then...]</p> <p>PS translates in English: Well, the women are saying the same thing as me. I am concerned about the situation of Gambian women, especially us rural people, how men and others treat women, if they are the first to test positive. For example, I observe our culture and I see that women are doing more than men are doing. They are burdened with care of the family and have many children, more than they can care for. It becomes a source of conflict in the home. Women cannot cope with the burden. Now with HIV the story is even more compounded.</p> <p>I: Please ask 013 if she wants to add something.</p> <p>013: Well yes, during the pilot, I already told you, just as [name deleted] has explained, and others, you have heard women's experiences of pain, and the problems are too many. We sometimes do not know where to start. I think it is too much you know it is a big burden ... [long pause....silence].</p> <p>[Observation commentary from my field notes: Long pause and silence, she got emotional and we pause to allow her to gain composure, this was a difficult interview].</p> <p>PS: interjects saying "this is what women are saying locally. Here women say they experience problems. Their role as women is overlooked and they contribute a lot to the family, but despite all this they have no power or voice. Women are not allowed to speak and challenge these things that are forced upon them in the name of religion. Many of the girls here in the rural areas are not educated. They help their mothers with too many responsibilities, including cooking, cleaning, and going to the farm. They are overworked but many find it difficult to open up and share because of our culture. Many are not free to share because of the taboo. If you do you are accused of "breaking the silence and washing one's dirty linen in public".</p> <p>I: What are the reasons for the silences?</p>	<p>FGM/C religious justification / [but argues] it is 'cultural'</p> <p>Women's right need to be respected</p> <p>Concerns about rural Gambian women</p> <p>Women overburdened with care</p> <p>Too many issues confronting women/ burden of pain</p> <p>HIV diagnosis compounds burden</p> <p>Women experience too many difficulties in life/ silent suffering</p> <p>Overburdened situation of rural women</p>
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<p>PS: They teach women to “knowing the eyes” [locally meaning to understand non-verbal forms of communication look at ones eye and read meanings from their look; women are taught to read meanings i.e. the non-verbal cues]in the bush where they go for circumcision]. There they teach them how to be good wives to men, they can be seen but not heard. They know men have more power, and cannot argue with their husbands. Marriage is a blessing.</p>	<p>Silencing of women</p>
<p>In there [in the bush where circumcision takes place], women learn about respect for their husbands, how to respect elders in our family and they just do what they are told. For example, female circumcision.</p>	<p>Women internalise ‘silence’ Awareness of non-verbal cues</p>
<p>My wife comes from [deleted name of county]. There, women do not undergo female circumcision and when you have a sexual relationship you notice the difference, and I can compare her with the other Gambian woman I have married. My wife who was not raised in the Gambian context is different from my Gambian wife. They are different and she has experienced challenges with me in our sexual relationship. Also, she does not accept the way I want her to have freedom and she finds it difficult because of our socialisation process; the way women are marginalised runs deep here in the Gambia. It is difficult to change.</p>	<p>Socialisation: silence part of notions of good womanhood (learn how to understand non-verbal cues) Contextual and cultural differences</p>
<p>I: Well, let’s hear what the women are saying here. Ask them for me, I want you to ask them again, as women living with HIV, what are the main concerns? Do they have any problems?</p>	
<p>011 attempts to answer through an interpreter [language barrier]: Well for me, the problems women face here in the Support Society due to HIV are mainly abandonment and men not caring for their wives when they are diagnosed, and these are common problems. Other family members and relatives are also a problem as they provoke the husband to be abusive towards the wife. In situations where there are several wives [co-wives] the wives fight, and when many of us women test positive we face abandonment. Many are shamed and ostracised. People run away from them. They are called names and they suffer hardship.</p>	<p>Abandonment / lack of care Non-intimate partner & intimate partner abuses</p>
<p>The Support Society president interprets and explains: She mentions that here at the community level, we see women suffering a lot. They experience problems and hardship on a daily basis. For example, they have economic problems, and lack of money even to buy food becomes an issue for several women when abandoned because of HIV. Many suffer from stigma [Chodiro].</p>	<p>Fights among co-wives, shamed and ostracised Name-calling/shame Running away Experiences of shame & ostracisation</p>
<p>You heard what 011 and 013 said in their different interviews and this is a big problem for women and their children. We provide community home-based care and offer assistance to PLHIVs. Some of their conditions are so bad; they live in deplorable states, and for many, poverty, abandonment or rejection by family. The fear of HIV is the cause of their problems. For many of them,</p>	<p>Women suffer economic challenges as a result of stigma [the chodiro experience].</p>

<p>food is a main problem, and the lack of care from family members.</p> <p>You hear that 011's situation is also serious, that food is her main problem; but she has had other survival issues and many challenges. For her it is access to treatment, it is a problem of money. Her children suffer because she was abandoned by her husband. Feeding them and caring for them are just examples of her many problems. There are numerous records of women who have passed away since 2007. These are women who have been abandoned and thrown-out, disgraced by husband and in-laws. Even with the little help we give them, it is not adequate and eventually they die. Many do not survive without treatment and proper care. I have records to show you. They delay treatment and fail to have tests early so the HIV, the virus, weakens them and spreads the spirit of the virus, in their immune system.</p> <p>I: What do you mean by the spirit of the virus, just for clarity?</p> <p>SP: What I mean is, many of the PLHIVs, both men and women, hide and do not test. If they do then the virus is contained. But not testing spreads it and fear of disclosure remains a big problem. Here in the rural area people are afraid of this deadly disease. Many are afraid to test because of stigma. They progress steadily to AIDS and die. These are our concerns, the stigma and discrimination causes fear, fear of testing and fear of disclosure, people live secret lives. They hide rather than seek treatment. I take my motor bicycle to help carry their drugs. Those who are too ill may not have transport fares and we arrange transportation for some of them, if we have fuel. As many will explain, men have problems but women suffer more. It is very important to address fear because it helps us fight HIV. It is crucial to deal with fear, to arrest fear, just to stop the virus from spreading....</p> <p>I: Well this has been a long discussion and a difficult one. I can see it is getting dark. I may call on you again, so these are my contact details. If you want to share something you think was left out of this interview then please feel free to call me, or just to ask questions. I thank you all for your contribution. PS please ask the women if they have any questions to ask me please.</p> <p>[PS: Interprets in local dialect and gives back their responses in English.</p> <p>Following a long silence, there were no answers or queries, so the interview was terminated and I asked that participants be reminded about care; if they have any sensitive matters to talk about they can speak to the peer counsellors or social workers.</p> <p>I: I believe you have commenced a very useful process which I will follow up with the president of this Support Society.</p>	<p>Women experience food problems</p> <p>Abandonment</p> <p>Food insecurity/problem of finance</p> <p>Concerns with food and survival issues</p> <p>Failure to test /delay treatment /disease progression from HIV to AIDS/some succumb to death</p> <p>Not testing / fear of disclosure/fear of stigma</p> <p>Pervasive fear</p> <p>PLHIVs hiding /secrecy/ fear</p>
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