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The Role of Christian Faith for Women Living with Disabilities and HIV in South-south Nigeria

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Degree of Doctor of Philosophy
The University of Edinburgh
April 2022
Abstract

This study examines the impact of Christian faith on women with disabilities and HIV in Nigeria, by investigating the extent to which faith enables women to face social, cultural, and religious exclusion and develop a positive sense of self. In most parts of the world, persons with disabilities, whether physical, sensory, mental or functionally-limiting conditions, are often faced with complex levels of discrimination as a result of religious and cultural stereotypes. Within many African communities, these stereotypes are often informed by society’s belief that disability is a curse from the gods or ancestors. Human immunodeficiency virus (HIV) has been described as the most stigmatising disease due mainly to the religious misconception that infection is due to illicit sexual activities. When women test positive for HIV, it is often considered to be their actions rather than those of their partners which are assumed to be the cause of the infection. They are therefore, often considered promiscuous by a patriarchal society that views women as inferior or second-class to men. Women with disabilities are at increased risk of HIV because of their vulnerability to rape and other gender-based violence. The health and social consequences of triple stigma of gender, disability, and HIV are enormous, often leading to marginalisation and exclusion. Yet research on the inclusion of women with disabilities and HIV and how they cope with the challenges of their daily lives, their complex identities, and their sense of religious belonging have been lacking. The research addresses the above observed lack with an ethnographic research methodology. This involves participant observation, interviews, and focus group discussions to gain understanding of the religious and socio-cultural lived experiences of women with disabilities and HIV. The research engages primarily with twelve Christian women living with disabilities and HIV who belong to the Bold Outstanding Ladies with Disabilities (BOLD) Hearts Network, a Non-Governmental Organisation (NGO) for women with disabilities in Nigeria. Interviews were also conducted with 73 persons comprising of Christian faith leaders, medical personnel involved in HIV treatment, members of disability and HIV Support groups, as well as staff of state AIDS agencies. The research was carried out in Port Harcourt and Uyo, two cities in South-south Nigeria with very high HIV prevalence in the country. The fieldwork was for 6 months (July to December 2019), with a 3-week pilot study in May of 2018. The research also draws on existing literature while being informed by the social model of disability as well as the views of African women theologians. The women involved in this research affirm that their relationship with Jesus Christ is central to how they live their lives. It transforms their identities, facilitates an improved self-image, and gives them hope in ways that enable them to face the difficulties associated with the stigma of gender, disability, and HIV. Stories were veritable means of sharing their experiences of exclusion but also of their resilience and creative endeavours at overcoming discrimination. Contrary to the minor role often placed on faith to address societal problems, this thesis demonstrates that faith can help women to reclaim their dignity and address sociological and medical challenges. It therefore offers suggestions for faith-based strategies in efforts towards response towards gender, disability, and HIV intervention in Africa, and globally. In recognising the importance of faith and spiritual life for marginalised persons, this thesis contributes to the interdisciplinary field of World Christianity.
Lay Summary

This study seeks to understand how women living with disabilities and HIV cope with the challenges in the society and in the church, and the extent to which Christian faith helps them to face their difficulties. In many African communities, women who have a disability and who live with HIV are faced with a lot of challenges. They are often treated with disdain and have trouble belonging to social or religious gatherings. This is because of the assumption that their disability is a curse from the gods or spirits and that HIV is transmitted through immoral sex. As a result, these women continue to be discriminated against and excluded as part of the social consequences of triple stigma: gender inequality, disability, and HIV. Although there have been many studies on HIV in Africa, there has been very little mention about women with disabilities and how they cope with the challenges of living with HIV.

For 6 months, I lived in Port Harcourt and Uyo in South-south Nigeria, to observe, interview and discuss with women with disabilities and HIV. These two cities have high HIV prevalence rates in the country. The women that I interacted with all belong to Bold Outstanding Ladies with Disabilities Hearts Network (BOLD), a non-governmental organisation in Nigeria. I also interviewed several health professionals, BOLD members, and religious leaders. The women with disabilities and HIV shared their stories of exclusion from the life of the church and community. They did not always feel welcomed by the liturgies of the church, or the women’s groups to which they wanted to belong. Many did not find supportive relationships in their families while all expressed how the friendships they had built in BOLD offered space for mutual empowerment. However, there were also stories of the many ways in which these women overcame these challenges because of their faith.

This research demonstrates that for these Christian women living with disabilities and HIV, their relationship with Jesus Christ is central to how they cope with the difficulties that they face daily. This relationship gives them a new sense of who they are, as women loved and accepted by Jesus. They find in Jesus Christ a friend and healer, who, they say can do all things for them. This understanding gives them hope to face their daily difficulties, to practice their Christian faith, and to support one another. They did not belittle faith as something that is unimportant to medical or sociological problems. Instead, they affirm that it is their faith that enables them to cope with the difficulties before them, whether in the family, the church, or the wider society. This study offers suggestions on ways to effectively engage with women with disabilities and HIV. These suggestions include the recognition that faith is fundamental to religious people, that women deserve to be treated as persons, and that balanced stories can be affirming for all concerned.
Dedication

To

Nyambura Njoroge –

my spiritual midwife, for your love, friendship, and mentorship across the oceans
Acknowledgment

My deepest gratitude goes to God Almighty, who through various people and institutions, helped me to start and complete my studies here at the University of Edinburgh, UK. I am very grateful to my Principal Supervisor, Dr Emma Wild-Wood whose kind guidance greatly shaped my thesis. It is thanks to Dr Wild-Wood’s constant encouragement that I participated and excelled in other aspects as a student, such as winning the 2020 University of Edinburgh Three Minutes Thesis Competition, as well as lecturing and tutoring in the School of Divinity. I am also grateful to my Secondary Supervisor, Professor Liz Grant, for her insightful feedback. I was blessed to have Professor Brian Stanley as my Personal Tutor during my Masters programme. I am thankful to him for his support, not only to apply for a PhD but also for sourcing for funding to make my studies possible. I thank Dr Alex Chow, for his gentle kindness and prayers. I acknowledge the institutional support that I received from New College, School of Divinity, Professor Helen Bond, Head of School, Robert Mckay, Jean Reynolds, Karoline McLean, Ming Cao, Louisa Grotrain and Dr Ulrich Schmiedel. I appreciate Professor Susan Hardman Moore and Dr Alison Jack, Principal and Assistant Principal of New College, for providing a Christian worship space that was spiritually enriching. I also benefited from the safe space at the University Chaplaincy, and I thank Reverend Harriet Harris, University Chaplain, and Reverend Ali Newell, (then Associate Chaplain) for that.

I acknowledge, with thanks, the financial assistance which made my studies and research possible. The University of Edinburgh, School of Divinity Scholarship and the Miller and Dalziel Scholarship, administered through the School of Divinity, paid for my tuition fees. The Faithshare Scholarship, World Mission Council of the Church of Scotland took care of my living costs as well as the provision of a comfortable accommodation in Edinburgh. The Redeemed Christian Church of God Travel Bursary and The Society in Scotland for Propagating Christian Knowledge Grant provided funds for my Field Work in Nigeria from August 2019 to January 2020. The John and Ian Baillie Scholarship, administered through the School of Divinity, was useful in defraying research-related costs. The School of Divinity Conference Grant facilitated my participation at academic conferences in my first and second years of study.
I would like to express a very special appreciation to the family of Reverend Dr Elijah and Favour Obinna, their children Finlay, Elspeth, Jessie, and Joshua. They provided a warm and soothing home for me here in Scotland. Elijah was particularly supportive and offered helpful suggestions for my work. I thank Jennie Chinembiri, Secretary, African and Caribbean Committee, Church of Scotland, for her constant love and support in managing the scholarships from the Church of Scotland. I appreciate Most Reverend Dr Miracle Ajah, His Eminence Nzie Eke, Rt. Reverend Solomon Okoro, Reverend Dr Okechukwu Kalu Iro, Rt. Reverend Marvelous Kalu, Reverend Dr Chika Nwankwo and The Presbyterian Church of Nigeria (PCN), for their support which enabled me to undertake this study in Edinburgh. Thanks to Session and members of Lekki Parish, Uyo Parish, Eleme Parish, and Woji Parish of the PCN, for their support and prayers. Uyo Parish graciously constructed a ramp in one of their church halls to make it disability accessible for the meetings with my research participants. I am very grateful to Bold Outstanding Ladies with Disability Hearts Network, (BOLD), for accompanying me throughout the period of field work, especially Ndifreke Andrew-Essien, Osaki Theresa Georgewill, Barivule Goni and Afiong Etim.

I am grateful for the friendship of Carol Finlay, Dorothy McMonagle, Mirella Yandoli, Audrey Graham, Ian Alexander, Thelma Stodart, Granny Irene Finlay, Claire and Sam Wilson, Stanley and Chidinma Okeke, and Ann Walker. Serving with Emma Mavin, Chloe Gardner, Axolile Qina and Matthew Baines on the New College Postgraduate Committee turned us from colleagues to friends and I am grateful for the opportunity it afforded for conversations about our research. Lucy Schouten, Calida Chu, James Dingjian Xie, Emmanuel Ossai, Arvin Gouw and Nuam Hatzaw enabled mutual support as we studied together at New College. I acknowledge the friendship that I enjoyed as a member of the Coordinating Team of RoofBreakers along with Tom Sutcliffe, Elaine Rumney, Carlo Crolla, and Ashleigh Milroy. I am grateful to the Lothian HIV Patients Forum who welcomed me into their space and broadened my understanding of how people cope with HIV infection within the Scottish context. My flatmate for three years, Mireia Vidal, deserves gratitude for being a family away from home. My fellow Faithshare students, Mimi, Nana, Ted, Sam, Emmanuel, Gyula,
Isaac, and Michael, provided a space for fellowship, prayers and sharing that were uniquely strengthening.

I appreciate the assistance of Nari Pedro, Librarian at the World Council of Churches (WCC) Ecumenical institute at Bossey, who always willingly made books available to me on request. Professor Ezichi Ituma was helpful in facilitating my access to the Main Library of the University of Nigeria, Nsukka, Nigeria. My many co-labourers in WCC, Ecumenical HIV and AIDS Initiatives and Advocacy were wonderful in their support and encouragement, always reminding me that my research mattered. Thanks to Nyambura Njoroge, the Programme Executive, to whom this thesis is dedicated, for being my ‘spiritual midwife,’ and seeing me before I saw myself. Thanks too to Professor Ezra Chitando, Ayoko Bahun-Wilson, Reverend Pauline Njiru and Professor Esther Mombo.

I am very grateful to South Leith Parish, Church of Scotland, the Minister, Reverend John (Iain) May, his wife Ann, and members of the congregation for their welcome and opportunities for service. Thanks to Iain for his availability and assistance in his capacity as Supervisor for my Ministerial Probation and in my service as Associate Minister for the Parish. I thank Penny Philipson and Alastair Chalmers for being great conversation partners as we served in the Parish Breakfast to the community team. I also thank the Granton Parish Bible Study Group, Church of Scotland, led by Reverend Ian Moir, including Barbara Gordon, Lesley Hamilton-Messer, Susan Leslie, Jimmy, Elizabeth and Jean McIntosh, for their prayers and fellowship. I acknowledge the support of many friends, whose belief in me, constant encouragement and prayers helped through some difficult times during this study. Among them are Elder Dr Kalu and Chief Mrs Hazel Uke Kalu, Kine and Mildren Osain, Ifeoma Ana, Nicole Ashwood, Francis and Miebaka Nemieboka, Charles and Miebaka Ngeribara, Ogbu and Hannah Ude, Chijioke and Nnenna Offia, Elders Urum and Uganze Eke, Uduma and Uzoechi Kalu, Elder Dr Uma and Elder Njanzi Eleazu, Elder Margaret Obinna, Ada Abam Uche, Dr Sara Fretheim, Lizzy and Martin Onuma, David and Oge Oka, and Gloria Ntieyong-Akpan.

My family provided great support, encouragement throughout the period of my studies. Special thanks to my parents, Apostle Effiong and Deaconess Afiong Henry, for always being there for me, and reassuring me of their daily prayers. To my siblings, Henry and Gurjit, Maeyen and Bayo, Joy, Juliet, Godwin and Tammy, Samuel and Humble, Victoria and Samuel, Kari and Ehikioya, Imaobong and Timothy, my thanks for their continued love and affection. To my mother in-law, Dame Irene Fubara-Manuel for her love and encouragement and in-laws, Kalasisi, Alaye and Esther, Iso and Tima,
Tomina and Davidson, Ekine and Chimdi, Koju and Gloria, Pereye and Laurita, Sokari, Soso, and Asarama for their constant support and encouragement during my time of studies. To my namesakes, who gave me the motivation I needed to complete this thesis, namely, Jessica Obasi, Ini Edem Henry, Ini Henry, Jessie Obinna, Jessie Samuel Henry and Jessie Sunday Okuta. To my adopted grand-children, Komzie, Harriet, Jayden, Joshua, Jason, and Nene for their gentle love. I am deeply grateful to my children Tomina Eno, Otonyesia Idongesit, Datubo Mfon, and Chubby Kurom, for their incredible love and patient understanding. This second-chance at education away from home would have been so much harder without your constant words of encouragement as well as your care for your father. To Ezinne and Tony, Christy, Nnenne, Iboro, Sola, Violet, Josephine, thank you for your prayers. And finally, to my beloved husband, Ben, my partner for life, thank you for being amazingly supportive through all of this. May God’s blessing be with everyone mentioned here and those I may have missed.
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Acronyms/Abbreviations

AIDS: Acquired Immune Deficiency Syndrome  
ART: Antiretroviral Therapy  
BOLD: Bold Outstanding Ladies with Disabilities Hearts Network  
INERELA+: International Network of Religious Leaders Infected or Affected by AIDS  
HIV: Human Immuno-deficiency Virus  
NGO: Non-governmental Organisation  
PCN: Presbyterian Church of Nigeria  
UN: United Nations  
UNAIDS: United Nations Programmes on HIV/AIDS  
UNICEF: United Nations Children’s Fund  
WCC: World Council of Churches  
WCC-EHAIA: World Council of Churches-Ecumenical HIV and AIDS Initiatives and Advocacy  
WHO: World Health Organisation

Glossary

Owo edo owo: A person is a person  
Owo edo inyene: A person is wealth  
Mbuot idem: To trust  
Minini: Surrender  
Ebre: Play  
Nka Iban Isong: Women’s Society  
I dey kampe: I am alright  
Eke bot owo ukem ukem: All persons are created equal
Map of Nigeria showing all the States of the Federation, with Port Harcourt and Uyo starred.
Chapter One
Introductory and Historical Context

1.0 Introduction

This research investigated the role that Christian faith plays in the daily lives of women with disabilities who are living with HIV in the face of social, cultural, and religious exclusion. The fundamental inquiry therefore for this thesis is understanding how Christian spiritual knowledge and experience assist women with disabilities and HIV in Nigeria to cope with the challenges that they are faced with in their daily lives. Understanding religious or spiritual experiences of persons affected by health and other social issues is vital for appropriate knowledge and response.¹ This thesis offers a unique insight into the connection between gender, disability, and HIV, drawing on the social model of disability and the thoughts of African women scholars and theologians. It contributes to the African and global discourse of the distinctiveness of faith in the lives of women with disability and HIV. It therefore advocates for a better understanding of the stories of women living with both disability and HIV in Nigeria, as well as an appreciation of faith in their lives as important factors in all forms of intervention strategies.

Persons with disabilities, whether physical, sensory, mental, or functionally limiting conditions, are often faced with complex levels of discrimination due to religious and cultural stereotypes. These stereotypes pose different challenges and generally impede society’s efforts towards disability inclusion. A 2018 United Nations Population Fund study found that women living with a disability are up to ten times more likely to face gender-based violence than women who do not have disabilities, and therefore are more likely to face discrimination at various levels.² Human immunodeficiency virus (HIV) has been described as the most stigmatising disease due mainly to the religious misconception that infection is due to illicit sexual

¹ Kellen Kimani, Scott Murray, and Liz Grant, ‘Spiritual Issues of People Living and Dying with Advanced Heart Failure in Kenya: A Qualitative Serial Interview Study’, BMJ Global Health 1, no. 3 (18 November 2016).
activities. When women test positive for HIV, it is often their actions rather than those of their partners that are assumed to be the cause of the infection. They are therefore, often considered promiscuous.

Globally, women with disabilities appear to be at increased risk of HIV because of their vulnerability to rape and other sexual and gender-based violence. It has been noted that women disproportionately bear the burden of HIV due to their powerlessness and vulnerabilities within Africa’s patriarchal societies. Consequently, women with disabilities are more at risk of HIV infection due to poor education, gender-based violence or the inability to negotiate safe sex. The health and social consequences of the combination of disability and HIV are enormous, leading to marginalisation, inequality, and reversals of development, especially for women. Disability and HIV shape the life experiences of women already discriminated against due to gender dynamics in a patriarchal society such as Nigeria. This becomes more difficult with the added tensions between religion and indigenous cultural norms. The combination of their belief systems and affirming relationships has been identified as potentially a core strategy that enabled women to confront dehumanizing ideologies, beliefs, and practices.

To develop a rich case study, I focused on the membership of the BOLD Hearts Network (Bold Outstanding Ladies with Disabilities) or BOLD in Port Harcourt and Uyo. As explained later in this Chapter, BOLD is an NGO for women with disabilities. For over two decades, I have accompanied and befriended women with disabilities in Port Harcourt and Uyo. I watched their struggles with exclusion in the church and the wider society. Often, I wondered at the dexterity with which they continued to attend church and how they continued to profess their faith in Christ. I watched how they continued to seek empowering spaces and vocations, not just to survive but to flourish and add value to their communities. This thesis was therefore initially, borne out of a curiosity to use academic resources to investigate how these women were able to cope

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7 Kelly, *HIV and AIDS*, 12.
with the challenges that they faced? What was critical to them? How did they make sense of their evolving identities? How were they able to smile even when circumstances around them were not pleasant or inclusive? Why did they remain Christians even when the church was not as inclusive with issues of disability or HIV? Although I had not considered this thesis as advocacy, I realised that advocacy can be engaged with in different modes. Research writing, motivated by a curiosity to know for the purpose of change is an approach in advocacy, especially as it foregrounds the stories of a marginalised group, as such women with disabilities and HIV. This is discussed further in Chapter Three.

During my journey with these women, I had the privilege of gaining their confidence and trust. Some confided in me that they had tested positive to HIV. They shared their struggles with what they perceived as an added burden. They were confronted with a disease that has no scientific cure but one which brought a different level of stigma and estrangement, on top of those of disability. Beyond the medical difficulties of HIV and AIDS, were the sociological and psychological effects. These effects included the struggles with adherence to HIV treatment, the pain of non-disclosure to family and friends, the loss of identity as persons, as well as the economic impacts. Was it possible for faith to answer the questions posed by medical and social challenges? And if so, to what extent would the women’s voices and stories make a different in response strategies to gender, disability and HIV? Findings from the fieldwork revealed that for these women, central to their Christian faith is their relationship with Jesus Christ. It is the relationship with Jesus Christ that transforms their identities, helps them to reclaim their dignity, and enables them to cope with their daily challenges. Faith-based response is therefore critical to interventions for people of faith.

Analysed data from the field also revealed that these women’s understanding of faith as linked directly to belief in Jesus Christ informed their religious practices and relationships. It changed the way the women saw themselves and how they related to others. It transformed their identities and produced a version of themselves that was akin to an improved self-esteem which sought to give back to the community instead of just receiving. Through their stories, these women proactively struggled to change the narrative that rendered them valueless and instead projected themselves as persons
engaging in liberating relationships and economic independence. The themes that came through from the findings of this research are three-fold. The first is the unique place of faith for women with disabilities and HIV. This faith is integral to their relationship with Jesus Christ as healer, friend, and companion who gives them a new identity. The second is that the transforming power of their relationship with Jesus Christ enables them to negotiate and create liberating relationships in the family, the church, and in female friendships. The third is the creative use of Scripture, songs, prayer, stories, and testimonies. These spiritual resources serve as tools of worship but also provide support as they navigate different terrains of medical, sociological, and psychological challenges.

Among religious and non-religious people, spirituality has increasingly been recognised as a critical factor in identifying ways of addressing health or psychological issues. During the later twentieth century, international health organisations viewed faith with suspicion and ignored it as a private matter with limited impact on health and, therefore, on policy. Today, they acknowledge that a person’s spirituality can aid or destroy treatment processes. Frequently, religious leaders are being consulted on the ways and means in which faith can be used positively. However, engaging religious leaders or mere acknowledgment of the importance of faith for marginalised people, is not always a sufficient response in and of itself. This research demonstrates that religious leaders were not often as helpful as anticipated. Instead, due to a perceived lack of relevant training or fanatical spirituality, many religious leaders make church communal spaces unwelcoming for women with disabilities and or HIV. Furthermore, international organisations more likely pay lip-service to the impact of faith in addressing health and healing concerns.

This research challenges religious and medical actors to address the temptation to minimise the importance of faith for religious people, especially, Christian women with disabilities and HIV in its response strategies. It brings to the fore the importance of meaningful and liberating relationships with the divine and with humans in providing mutual support for persons undergoing similar circumstances. The women

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that I interviewed demonstrated a different response to oppressive systems such as patriarchy by identifying and concentrating on what works for them and choosing not to challenge or confront such systems. Their responses resonate with research carried out with other marginalised groups, ‘that creative resistance can come in various guises, not always necessarily as bold provocations but also in the form of more subtle negotiations and transformations.’ They engaged in a spirituality that subtly resists dehumanisation and seeks the transformation of negative attitudes, values, and beliefs. Based on the experiences of the women that I interviewed, this thesis suggests adaptable strategies that prioritise the foundational place of faith in response strategies for religious people and the recognition of the dignity of all persons as created equal in rights, duties, and dignities. It provides a space for the telling of women’s stories of their faith lives and allows for the voices of women living with disabilities and HIV, in Nigeria to be heard.

1.1 Research Questions
The main research question following from the aim and objectives is: What role does Christian faith play for women with disabilities and living with HIV as they navigate the challenges of their daily lives and negotiate their multiple identities?

Following from this, the research explored the following broad questions during interviews, focus groups discussions, informal conversations as well as observation of research participants.

i. What is the understanding of Christian faith for women with disabilities and HIV, and how is their identity shaped by this understanding of faith?

ii. How do women with disabilities and HIV cope with the socio-cultural and religious challenges of living with the stigma of gender, disability, and HIV?

iii. What are the support systems available for women with disabilities and HIV in church and society?


iv. To what extent do resources of faith impact or shape the lives of women with disabilities and HIV, and how are these resources used?

1.2 Aim and Objectives of the Research
The overarching aim of this research is to understand the role of Christian faith (personal experiences and institutional activities) in the lives of women with disabilities who are living with HIV, and how this faith helps them handle societal, religious, and cultural challenges in Nigeria. It sets out the following specific objectives:

i. To understand, through primary research with women in Nigeria living with disability and HIV:
   a. Interpretations of Christian faith and beliefs that influence the ways in which women understand and live with disability and HIV.
   b. The ways in which resources and practices of Christian faith influence how women deal with their complex response to gender, disability, and HIV.

ii. To understand the current global and African theoretical models and frameworks within the context of disability and HIV, as well as the ways in which faith communities have articulated these models and frameworks.

iii. To examine the multifaceted reflections towards disability and HIV within the faith spaces that the women engage with and identify factors that support or detract from inclusion and engagement.

iv. To offer suggestions for engagement with women with disability and HIV in dealing with disability and HIV interventions within Nigeria and beyond.

In seeking to meet these objectives, this research offers stories of the lived experiences of women with disabilities and HIV, whose voices are yet to be heard in Nigeria, and in Africa primarily.

1.3 Significance of Research
This thesis presents a scholarly narrative of the faith lives of women with disabilities and HIV in South-South, Nigeria. Its distinctive significance is that it addresses altogether the issues of gender (women), disability and HIV within Christian contexts.
In doing so, it offers faith-based perspectives to sociological and medical challenges embedded in disability and HIV for women in Nigeria. The thesis advocates that all actors in the gender, disability and HIV response locally and globally, take seriously the importance of faith as evidenced in the stories of my research participants.

With its focus on faith, gender, disability and HIV, this thesis responds to the call by African women theologians for the voices and experiences of women to be brought into theological articulations in Africa as well as to global feminist discourse. Whilst African women theologians have endeavoured to tell the stories of African women’s experience with patriarchy in church and society, the voices of women who live with both disability and HIV have been lacking. The thesis enables those voices to be heard and provides a resource for further research on faith-based approach to gender, disability, and HIV. As a study in Nigeria, it adds to the study of African Christianity, and part of the broader multi-disciplinary field of World Christianity. This thesis concentrates on faith-based creative strategies of handling difficulties instead of direct confrontation of persons assumed to be responsible for such challenges. In this way, it offers an alternative approach to how women cope by negotiating their identities and navigating oppressive spaces. The thesis demonstrates that engaging with coping strategies is not a weakness. Articulating effective means of dealing with challenges is in fact a different form of strength. It justifies the notion that women with disabilities can identify and focus on liberating spaces and relationships.

This thesis also highlights the dynamics of the various relationships that women with disabilities and HIV are involved in. Some of these relationships are perceived as oppressive while others have empowering possibilities. The women that I interviewed show how faith helps them to establish relational boundaries and to mobilise communal support for themselves. This creates an appreciation for the role of positive relationships as a tool of support for persons who may suffer exclusion, marginalisation, or psychological traumas. Although many of the faith resources that the research participants talked about in this research are common in Nigerian African Christianity, the intentional use of its resources to provide succour may be useful for

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12 Isabel Apawo Phiri, Devarakshanam Betty Govinden, and Sarojini Nadar, eds., Her-Stories: Hidden Histories of Women of Faith in Africa (Pietermaritzburg, South Africa: Cluster Publications, 2002), Of the twenty stories of African women, not one is of a woman with disability so disability perspective is missing from this collection.
theological and sociological enterprise. This thesis therefore suggests a faith perspective to the efforts in achieving the global international development goals which has provisions for disability inclusion and response strategies towards a world of justice and equality for all.\textsuperscript{13} It is within this interconnection between the local and the international, that the thesis proposes strategies that takes seriously the dignity and humanity of women living with disabilities and HIV.

1.4 Literature Review
The inter-relatedness of gender, disability, and HIV for women of faith in Nigeria, and across the globe needs to take its rightful place in literature. As will be discussed, whilst each of these issues have been attended to in some form with differing emphasis in different contexts, this thesis is unique in studying gender, disability and HIV in the Christian faith. Much of the literature on these subjects tends to address either gender and disability, or gender and HIV, but not gender, disability, and HIV in one piece, as this thesis does.

This thesis has been influenced by the writings of African women theologians in critiquing theological and gender issues that arose in the research. The seminal works of Mercy Amba Oduyoye are foundational. Although she has only infrequently written on the issues of HIV, Oduyoye notably sets the stage for African women’s engagement with theology and society. She offers a feminist theological approach and advocates for African women to confront patriarchy, challenge unhealing traditions, and appropriate only liberating texts from Scripture.\textsuperscript{14} It is most probably from Oduyoye’s challenge to make African women’s stories known that a compilation of twenty stories was published in 2002. The contributors were African women theologians and the stories concentrated on women’s roles within the church; it did not therefore capture the stories of ordinary women engaged in sociological and theological articulations from their lived experiences of abuse because of disability

\textsuperscript{13} ‘Sustainable Development Goals (SDGs) and Disability | United Nations Enable,’ accessed April 28, 2019, https://www.un.org/development/desa/disabilities/about-us/sustainable-development-goals-sdgs-and-disability.html. The SDGs contains five provisions that directly speak to disability inclusion which is an improvement from the absence of disability in the Millennium Development Goals (MDGs). For information on MDGs see https://www.un.org/millenniumgoals/.

and or HIV. Reading the stories of women from many contexts was helpful in my writing. However, my fieldwork approach in this thesis brings the voices of ‘ordinary’ African women to the table; often non-theologically trained and non-ordained.

Earlier in its formation, the Circle took on the challenge of HIV and AIDS in Africa, and particularly its effects on women as a serious task for research and publishing. Perhaps due to the institutional location of the authors, or the depth of the countries’ burden with HIV, much of the writings from the Circle were centred more on Southern Africa with secondary focus on Eastern Africa. For example, are the works of Musa Dube, Nyambura Njoroge, Musimbi Kanyoro, and Isabel Apawo Phiri. Although writing from different contexts outside of Nigeria, they all bring helpful lenses to the HIV and AIDS discourse in African Christianity. This thesis has benefited from these resources.

From Southern Africa, Musa Dube’s works have been categorical and reflective of her professional training as a Biblical Scholar in maintaining that the Bible must respond to human struggle for liberation from HIV and AIDS oppression. Isabel Phiri’s works have been drawn from her engagements with Circle members to articulate an appropriate response to HIV as the holistic mission of the church. Paula Sue Grimes in her study on ‘HIV/AIDS and Women with Disabilities in Zimbabwe’ points out the risk factors and institutional efforts connected with gender, disability,
and HIV in Zimbabwe.\textsuperscript{24} Her research participants were women in Zimbabwe, with ‘pre-existing disabilities or who become disabled as a result of HIV,’ a description that fits one of my research participants.\textsuperscript{25} Her research offered no information on the spirituality of her research participants. She did not examine how they coped with the social and spiritual challenges of disability and HIV beyond the difficulties of assessing medication.

Within the East African context, Nyokabi Kamau’s book titled \textit{AIDS, Sexuality, and Gender: Experiences of Women in Kenyan Universities} focuses on the challenges of AIDS-related stigma and discrimination experienced by women in the Academia.\textsuperscript{26} Kamau’s research participants did not disclose their HIV status. This means the direct voices of those infected are lost in the narratives. This could either be termed a weakness or a deliberate choice of Kamau’s work. It makes it difficult to know whether the voices were of those infected by the disease or those affected because a family member or friend is infected. Her research participants were also all within the University settings in Kenya, presenting a homogenous setting in terms of status, career, and education. Kamau has become a significant research dialogue partner, for although her research did not mention the issue of disability, it provides a unique perspective to HIV and sexuality discourse. However, Kamau underplays the critical role of faith in providing succour even whilst acknowledging that women she interviewed considered their faith to be an important part of their support system. This is a critical departure from this thesis which acknowledges that faith is central and critical to the coping strategies of women living with disabilities and HIV.

Melissa Browning’s book on \textit{Risky Marriage: HIV and Intimate Relationships in Tanzania}, has been a very useful resource.\textsuperscript{27} Her research in Tanzania focuses on women who were or had been in marriage relationships and who were also infected with HIV. She argues that marriages need not be a risk factor for Christian women if the church takes seriously its responsibility for ensuring that marriage is a safe and

\textsuperscript{24} Paula Sue Grimes, ‘HIV/AIDS and Women with Disabilities in Zimbabwe’ (M.A., United States -- Oregon, University of Oregon, 2012), iii.
\textsuperscript{25} Grimes. ‘HIV/AIDS and Women with Disabilities’, iv.
\textsuperscript{26} Nyokabi Kamau, \textit{AIDS, Sexuality, and Gender: Experiences of Women in Kenyan Universities} (Eldoret, Kenya: ZAPF Chancery, 2009).
flourishing place for women. However, her focus was primarily on marriage; she therefore did not discuss the other forms of relationships that women find ‘risky’ and from which they navigate safe spaces. Nyambura Njoroge, in her current role as Programme Coordinator (as at time of writing) of the World Council of Churches, Ecumenical HIV and AIDS Initiatives and Advocacy (WCC-EHAIA), has made both theological and ecclesial responses to HIV and AIDS, often calling attention to the disadvantaged place of African women. In all these works, the place of advocacy is prominent which is important for my work although the lived experiences of women with disabilities and HIV are missing.

Sinenhlanhla Chisale noticed the missing voices of women with disabilities. Chisale says the Circle are ‘guilty of silencing the plights of WwD (women with disabilities)’ because despite their robust attention to African women, the ‘African woman with disabilities experiences of culture, HIV and AIDS, and religion are lacking.’ However, her work focuses on motherhood and, much like Browning, fails to adequately discuss the gendered roles of women beyond marriage and reproductive responsibilities. Chisale’s proposal for a theology of disability for Africa women is apt. In the sense that disability theology, has been described as the ‘attempt by disabled and non-disabled Christians to understand and interpret the gospel of Jesus Christ, God, and humanity against the backdrop of the historical and contemporary experiences of people with disabilities,’ then this thesis contributes disability theology for Africa. It also learns from and critiques Micheline Kamba’s expose on the theology of healing, which is discussed in Chapter Four.

In West Africa, African women are rising to the task of addressing the challenges that HIV impacts on women and girls. Nigerian Circle members have joined the conversation on gender and HIV but have equally not included the voices

31 Michelle Kasongo Kamba, ‘Developing a Holistic Educational Programme through Contextual Bible Study with People with Disabilities in Kinshasa, Democratic Republic of Congo: IMAN’ENDA as Case Study’ (PhD, Pietermaritzburgh, South Africa, College of Humanities, University of KwaZulu-Natal, 2013).
of women with disabilities. Ruth Oke’s PhD thesis is not focused on women but on the effects of stigmatisation for persons with disabilities in general and the advocacy for inclusion. Kunbi Labeodan, like other Circle members mentioned above, seeks the churches’ response to HIV and AIDS, in its role as a place of ‘encouragement and comfort.’ The Circle’s focus on the church should be critiqued, especially because many people, like the women that I interviewed find alternative spaces for encouragement and comfort outside of church institutions. Dorcas Akintunde’s work examined stigma from the stereotypical opinion that HIV is driven by homosexuality.

Another related work is Celine O. Osukwu’s dissertation, titled ‘Disability, HIV/AIDS and Gender in Nigeria: A Critical Analysis.’ In her study, she evaluated the efforts and policies of the Nigerian State towards a gendered-HIV response that includes Disability concerns. Although Osukwu’s work does not analyse faith-based contributions in Nigeria, her analysis of the strategic response of the Nigerian government to disability and HIV is beneficial to my research.

Osukwu also provides the closest scenario to this research as both - her research and mine - are based in Nigeria and seek an improved inclusion of persons with disabilities in public spaces. However, as useful as her work is, it is a literature-based study and does not capture the personal stories or experiences of women with disabilities. Also, while she argues for a gendered approach to disability response, she focuses on both men and women with disabilities, and addresses policy change outside of the control of persons with disabilities. Diseye Mary Dasimaka’s PhD falls within the ambit of Osukwu in its public policy approach. She examines the role of faith in shaping development outcomes of HIV and AIDS with evidence from faith-based organisations.

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32 Ruth Oluwakemi Oke, ‘Situating the Stigmatisation of the Haemorrhaging Woman within the Context of the Experiences of People Living with HIV and AIDS in Ibadan, Nigeria’ (PhD, Ibadan, Nigeria, Department of Religious Studies, University of Ibadan, 2016).
36 Dasimaka, ‘Faith and Development Outcomes’.
A few male theologians have supported the Circle’s pursuit of gender justice in HIV and disability response. Top on this list are Ezra Chitando’s edited volumes; some of which he co-edited with female theologians. Compassionate Circles: African Women Theologians Facing HIV, edited with Nontando Hadebe, brought together stories from five different African countries on HIV as it affects women and children, as well as the church’s responsibility in HIV response. Another of Chitando’s edited volumes with Nyambura Njoroge, focused on African women’s sexuality and the multiple challenges that arise from issues of sexuality. Recognising the role of men in HIV response, he co-edited a volume with Sophie Chirongoma on Redemptive Masculinities: Men, HIV, and Religion. Adriaan van Klinken engages with the writings of African women theologians to argue for a re-evaluation of men not only as perpetrators in the transmission of HIV but also as partners in its mitigation. Both Chitando and Klinken’s useful resources are, however, not drawn from the direct experiences of women, with and without disability.

I have gone through all this literature, and it shows that the scholarship on religion, gender, disability and HIV in Africa, really needs a substantial study of Nigerian/African Christian women’s responses to the lived realities related to triple discrimination of gender, disability, and HIV. None of the literature mentioned above sufficiently offered a critical investigation into how women living with both disability and HIV positive status use their faith to cope with the challenges that they face. My thesis identifies the lacuna in the Circle literature and provides an account of African women coping with the challenges of gender, disability, and HIV, and the influence of faith in their lived realities, in a way that no other literature has done.

1.5 Background of Study
1.5.1 Port Harcourt and Uyo in South-south Nigeria
Nigeria has the largest population in Africa and the eighth largest population in the world. It is situated in West Africa sharing boundaries with Benin, Chad, Cameroon,

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and Niger.\textsuperscript{40} It has 36 States and is divided into six geo-political regions. Nigeria is a ‘multi-religious, multi-ethnic, and multi-cultural society’, and predictably this creates tensions between religious, ethnic and cultural ideologies and beliefs.\textsuperscript{41} Christianity, Islam and African Indigenous Religion compete for the devotion of Nigeria’s religious population. It is a nation of more than 200 million people with a significant number facing disability and HIV.\textsuperscript{42} Fifteen per cent of the population live with a disability, the majority of whom are women.\textsuperscript{43} Nigeria is also the country with the second-highest burden of HIV, with more than 2 million people infected, of whom about 60 per cent of whom are women.

The South-South region comprises six states: Akwa Ibom, Bayelsa, Cross Rivers, Delta, Edo and Rivers. Together with Abia and Imo (south-east) and Ondo (south-west), these nine states form the Niger Delta region of Nigeria and the nation’s oil producing region.\textsuperscript{44} About eighty percent of Nigeria’s annual earning is dependent on oil production and export and is derivable from the Niger Delta.\textsuperscript{45} Yet it is one of the most under-developed areas of the country with oil spills and gas flares posing a threat to the wellbeing of the citizens worsened by government inaction.\textsuperscript{46} Akwa Ibom and Rivers States, the States of this research, account for over 50\% of the crude oil production as well as having natural gas (Rivers) and coal, limestone, salt (Akwa Ibom).\textsuperscript{47} The result of these is high commercial activities in all parts of these states. With large migration rates as people move from the rural areas to seek employment opportunities in these two urban areas, over-population is the result. Both States boast population figures of more than six million with the State Capitals accounting for about

\textsuperscript{43} WHO (2011) estimates that 15 per cent of any given population are people who live with a form of disability.
\textsuperscript{44} Nkem Emerald Osuigwe, ‘Crude Oil, Conflict and Christian Witness in Nigeria: Baptist and Pentecostal Perspectives’ (The University of Edinburgh, 2010), 15.
10% of the population. There is sporadic youth restiveness due to the quest for resource control, and an upsurge of militancy, which is not diminished by the high level of religiosity.

It was not because of the economic and political capital status of Uyo (Akwa Ibom) and of Port Harcourt (Rivers State) that these were chosen for this study. Two main reasons informed the choice namely that these two neighbouring states combined have the highest prevalent rate of HIV burden in the country and they are both predominantly Christian States, this being Christian faith-based research. It is pertinent to mention here that there is a strong influence of cultural and indigenous belief systems in the practice of Christianity causing a tension that is most adversely felt by women due to patriarchal domination. For many of the women in these two cities, therefore, the exercise and integration of their faith, is crucial to living in these religio-cultural contexts.

Uyo, as capital of Akwa Ibom, is described as the ‘treasure base of the nation’ due to its crude oil reserves. It has a population of over eight million people and is part of the Ibibio ethnic group, constituting the fourth largest ethnic group in Nigeria. The Ibibio cultural folklore including songs and dances provide a platform for socio-cultural interactions. It has been noted that pre-colonial social interactions embedded in the ethos of friendship and family facilitated peaceful co-existence among Ibibio people. Seasonal plays and masquerade displays characterised the communal life of the Ibibios. Storytelling as a means of oral tradition was a regular part of socialisation and continues in many forms to provide narratives of the lives of the people. During this study, storytelling was a crucial form in which the women that I interviewed shared their experiences including the joys, sorrows, and challenges.

It has been noted that ‘the Ibibio are happy, cheerful people, warm and hospitable to strangers, proud of their homes and heritage’ and grounded in the values

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50 Ivan Ekong, ‘The Ibibio Concept of Peace and Its Implications for Preaching: A Practical Theological Study within the Akwa Synod of the Presbyterian Church of Nigeria’ (Ph.D., South Africa, Stellenbosch University, 2014), 55.
51 Ekong, ‘The Ibibio Concept of Peace’, 56.
It is no wonder then that proverbs that promote community and mutual care are enshrined in Ibibio indigenous culture. An African concept of community is embedded in the equality and dignity of all persons valued beyond human wealth. A popular Ibibio proverb is *eke bot owo ukem ukem* meaning, all persons are created equally. Here the proverb recognises that humans are created by a higher being, but the emphasis of the saying is on the equality of all created beings, much like the Biblical image of humanity as created in the image of God. Based on available proverbs on the concept of community in Ibibio, there appears to have been better levels of inclusion and acceptability for women and for those with disabilities in the past. Many African indigenous traditions offer positive life affirming beliefs and practices, that promote the dignity of persons, and by extension, persons with disabilities. Historically, and from proverbs now almost extinct, there appears to have been greater levels of inclusion which is currently missing possibly due to colonial and missionary interventions.

Another ideal that seemed to have been ignored by the missionary and colonial interventions is the women’s group that ‘used indigenous methods to fight for justice, liberation, and restoration for the Ibibio womenfolk’s dignity in a male dominated world.’ To do this, Ibibio women formed and belonged to women’s social groups such as *Nka Iban Isong*, (Women’s society) or *Ebre* club to carry out social and judicial functions with the objective ‘to safeguard women against the tyranny of the men folk.’ During another research project examining the African concept of community for disability engagement, I encountered women who expressed that with the advent of Christianity, belonging to such women’s groups was perceived as anti-Christian and insubordination to the husband or father by the woman. African women theologians have noted how Christianity has promoted the departure from affirming indigenous

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52 Ekong, *The Ibibio Concept of Peace*, 55.
54 Ekong, ‘The Ibibio Concept of Peace’, 56.
56 Ekong, ‘The Ibibio Concept of Peace’, 60.
58 Personal Interview with Affiong Effiong, Afaha Offiong, 20 July 2019.
cultures and rather tended towards stereotypes that support the dehumanisation of women. They therefore call for a critique of cultural and Biblical norms that are tools of domination of women while seeking to ‘identify and promote what sustains and enhances life,’ Within Ibibio culture, there are still issues that are judged to disadvantage women.

Both religion and culture speak against witchcraft and are more likely to call the woman a witch than a man. Although Uyo is predominantly Christian, many Christians including adherents of indigenous religions still believe in the power of witches and its ability to affect the destiny of persons. Often women and children are accused of being witches, being possessed by witchcraft or adversely suffering from the attack of witchcraft. Many believe that witchcraft could cause disability. Whatever the belief in or about witchcraft, the person involved suffers exclusion, abuse, or even death. As discussed in Chapter Five, some of the women that I interviewed in Uyo spoke of the fear of being labelled witches due to their disability. Their reality seems contradictory for people who live in communities enshrining the values of hospitality and welcome of all persons (including strangers). Like African women theologians call for liberating norms for women, Christian disability advocates call for a rethink of all religious doctrines, ethics, and attitudes (emanating from both African Religions and Christianity) that militate against the full participation of persons with disabilities in the mainline activities of any given society…retaining those positive beliefs and values that foster the creation of inclusive societies

While the above advice by African women theologians and Christian disability analysts are worthwhile, they are often addressed to theologians and the elites who may have the recourse to power or theological acumen, and not to the average African women struggling to survive.

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During fieldwork in Uyo, I attended the commissioning of the south-south administrative office of the National Agency for the Control of AIDS (NACA) of Nigeria in October 2019. Three things stood out in my observation: the announcement that Akwa Ibom is a Christian State; the male-dominated leadership of NACA, and the large number of female attendees at the event. First, the Master of Ceremony (MC) proudly said that Akwa Ibom State is a Christian state, and there would be no Islamic or traditional prayers. In what was a national event, the MC went ahead to sing and clap to Christian songs, while most who were able rose to sing and dance to the beats. When I asked a member of INERELA+ (Network of religious leaders infected or affected by AIDS, if there was any connection between the assumed religiosity of the State and the high prevalence of HIV. This was his answer:

It is because we are so spiritual, that is why we pretend to be holy. Let me give you an example, condom use is lowest in Uyo because no one wants to be seen taking free condoms. So here, if you put out a bowl of condoms, you will come and meet two bowls. But in Calabar, if you put out two bowls of condoms, you will meet none. The numbers there in Calabar are low, but here in Uyo, it is rising every day.\(^6\)

The above quote highlights instances where the religiosity of a community can impede their response to the reality of HIV and AIDS. Uyo is, like many cities in Nigeria, full of churches and Christian fellowships in every nook and corner of the town. Religious language plays out in informal and formal conversations as many people defer to their faith for several reasons. It is no wonder the women that I interviewed turn to their faith for succour. What was surprising was how central and formative their faith is to their realities and relationships.

Like most Nigerian-African societies, the family unit is the basic aspect of communal socialisation for the Ibibio people from which it extends to the wider society. It has been noted that ‘in pre-colonial Ibibio ... social interactions and alliances were formed through four institutions, namely: friendship, ally, grandparent/child relationship.’\(^6\) Within clans, people trace their relationships back to the family lineage and persons are described by their relationship to others in the community. A typical

\(^6\) At the event, a faith leader called to give ‘exhortation’ had admonished that the people must return to the teachings of the Bible as prevention to HIV infections.
\(^6\) Ekong, ‘The Ibibio Concept of Peace’, 56.
family unit consist of a man, his wife or wives, and children. Extended members of the family derived their relationship as connected to the nuclear family. The family setting is highly patriarchal, often extending patriarchal norms to the broader society. The male, man, husband, or father is often the head of the family and dictates what happens in the family. The girl-child is expected to be married and therefore usually not given a place of permanence in her family of birth. Consequently, unmarried women are seen as abnormal in Ibibio society; and are excluded from family meetings, with the exception of women who have some economic means and can contribute meaningfully to the health of the family. For women, if poor and or with disability, being unmarried is a taboo to the family and a challenge to the individual woman.

Many of the characteristics of the life for the people in Uyo obtains in the neighbouring city of Port Harcourt. However, there were some peculiar incidences that shaped the response and experiences of the women I interviewed in Port Harcourt. Most prominent was the ordeal of militancy that the people of Port Harcourt suffered over a decade ago, but which effects were still being felt in the city. Between 2006 to 2009, Port Harcourt was described as a ‘war zone’ due to conflicts over resource control as militant groups sought to have a say in what happened with the gains of oil exploration in Rivers State. Whilst women suffered greatly during this period, female groups also surfaced, not only to challenge the male groups but also to find alternative sources of peaceful resolution of the conflict. In many conflict areas, women became peacemakers and peacebuilders. They did this through religious gathering and spiritual practices, in ways that demonstrated women’s ability to find alternatives confrontation or challenge of male actions.

But oil has also been blamed for the destruction of the family structure in Port Harcourt, and more broadly, in the Niger Delta. It has been argued that ‘with oil came a promiscuous lifestyle and that has made the Niger Delta most of the time not to have a normal family setting.’ It is true that with oil came migration of persons, from

67 In Abonnema, Rivers State, one of the hot spots of the conflict, the women, led by the King’s wife, rallied the women into a community prayer forum, which they believe brought about a divine intervention to the crisis. Today, that community prayer is still ongoing, known as Ama Teke (the town prays) attended by all persons including the Council of Chiefs.
within and outside Nigeria, to the Niger Delta for commercial purposes. As capital of Rivers State, Port Harcourt is at the ‘heart of Nigeria’s hydrocarbon industry and the leading city in the Niger Delta in terms of its economic clout and political importance.’ Migration means many families are separated and new forms of family relationships are formed. However, it is not clear whether that is the reason for abnormal family settings. What was clear during the interviews, however, was that many of the women expressed that the family space was a contested space in which they had to navigate the various in-family relationships to find the support and sense of belonging that they needed.

As one who has lived in both Port Harcourt; like Uyo, it has a predominantly Christian population. But unlike Uyo, it would not readily be conceived of as a Christian State. Apart from the presence of a significant number of Muslims, culture, and religions (indigenous and Christianity) are significant players in the lived experiences of the people here as well. The conflict of how to be ‘Christian’ without being alienated from indigenous cultural practices is always present. For Kalabari women for instance, their spirituality still touches the two poles of cultural dictates and religious compulsions. The new mother who is dressed and celebrated at the village square on Saturday, with all the traditional regalia, adorns her head-cover and goes to church for ‘mother-child thanksgiving’ on Sunday. Her identity is shaped by its contested realities, and she must learn to draw from both wells. Her spirituality must be authentic to her indigenous experience. Among many ethnic groups in Port Harcourt, like the Kalabaris, are women groups and societies that meet to provide welfare to women and create spaces to enjoy traditional dances and songs. Coincidently, many of my research participants were from the riverine areas where the reverence and/or fear of ‘mammy water’ is rife. However, there were no discussions about fear or the effects of these cultural beliefs among the research participants.

Another significant challenge that was being faced by the residents of Port Harcourt, including my research participants, was an environmental pollution caused by the black soot. Between 2016 and late 2018, Port Harcourt witnessed the presence

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of black soot as it fell in tiny particles without any smell or immediate medical effect. It settled quietly on surfaces and was inhaled unconsciously in the natural act of breathing. A noticeable presence of black soot was in the blackened surfaces that in turn made everything dirty. So, getting the soot out of the hands, something easily done by others became a herculean task and mattered more to women with disabilities due to supposedly feminine need for hygiene and society’s expectation for the woman to be clean. For some, looking ‘dirty with black soot’ was not good for their businesses which in turn adversely affected their income and financial independence. The women that I interviewed reminisced about the sociological and psychological challenges that they faced. They shared how living in fear of the possible side-effects of the black soot on their already frail health due to HIV increased a dependency on their spirituality. Although this was not part of the main challenges of the women that I interviewed for this research, it is instructive to note that often, women with disabilities face challenges incidental to their disabilities and gender that calls for the inclusion of their peculiar experiences in all response strategies.

In both Port Harcourt and Uyo, there was a resilience in the women who live with both disabilities and HIV, to overcome the difficulties incidental to their conditions of disability, health, and gender, and to build a supportive community for mutual flourishing. Whether single or married, divorced, or widowed, the women in my study demonstrated how faith provides succour and liberating tools to transcend the challenges imposed by religion, culture, and society.

1.5.2 BOLD Network as Case Study

Women’s groups have tended to devote more time to dialogue and to building relationships than mixed gender groups have done…. An inclination toward engagement, toward listening and struggling to establish positive relationships seems characteristic of such initiatives.

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niger-delta. Sunday Orji’s short article provides a good summary of the black soot and its effects (immediate and eventual) on the citizens who live and inhale the soot.

This thesis uses Bold Outstanding Ladies with Disabilities Hearts Network (BOLD) as its case study. In 2018/19, it was the only established network of women with disabilities in Port Harcourt and Uyo in south-south Nigeria.\textsuperscript{72} It was formally inaugurated in December 2016 after over two years of periodic meetings. By late 2014, male and female persons with disabilities met together in what they referred to as a time for ‘fun, food and talk.’ These initial meetings were limited to those within Port-Harcourt city in Rivers State, Nigeria. As the meeting progressed, female members found the space unconducive to share concerns that were peculiar to women especially concerning sexuality, relationships, and gender dynamics.

According to the Secretary of the Network,

\begin{quote}
although we (men and women) are disabled, disability in women poses different if not more challenges, especially when you talk about love and acceptance. The men do not seem to understand what we were facing as ladies.
\end{quote}

Upon further enquiry, she explained that the men did not seem interested in gathering to discuss challenges of any kind. They easily dismissed concerns raised by the women and made sweeping comments that the women were complaining too much. Many of the male attendees were married or in romantic relationships and were unable to understand the relational difficulties that the women were feeling. She said this made the ladies leave the meeting feeling low and downcast. Their feeling was akin to what most women with disabilities often feel within disempowering situations ‘that they (women with disabilities) do not count, that they are not important, that they are not whole human beings or valid members of the …community’\textsuperscript{73} There was food at these meetings but there was no fun or talk for the women, and they discussed this disenfranchised state with one another. Although, the logistics and food preparations for the meetings were often done by the women, they did not feel a sense of belonging in that space.

\textsuperscript{72} The Co-ordinating Team told me how they had tried to reach out to similar networks in the south-south; and while there were networks for persons with disabilities, there was none for women alone. As an ex-officio member of the Joint Association of Persons with Disabilities in Rivers State, an umbrella body for all disability groups and persons, only BOLD is an all-women group in Port Harcourt.

Consequently, in 2015, the ladies decided to have a separate meeting without the men. They did this in the hope of having a group that was for women to freely discuss issues that are peculiar to women. It aligns with the opinion that women ‘share the basic experience of what it is to be a woman… and this creates a special depth of understanding.’ For BOLD, it was not just about being women, it was about being women who were living with a visible disability, because they had not always claimed welcome among women’s groups. According to the Network profile, ‘the aim of the meeting was to create a safe, conducive, and relaxed environment where women with disabilities could come together for experience sharing, proffering solutions and being a support to one another.’ Following this ‘sisters-only’ group set up, the number of attendees gradually increased from 15 to over 30 ladies attending statutory quarterly lunch meetings. Small groups of between 3 and 5 would meet as the need arose, either just for snacks or to carry out a support activity for another member.

At its Christmas party in December 2016, the women reached a resolution to formalise its meeting and to establish a network called ‘BOLD (Beautiful Outstanding Ladies with Disabilities) Hearts Network.’ The Secretary explained that the meeting chose to use the word ‘ladies’ instead of ‘women’ as women sounded old and past the socially acceptable marriageable age. She said members had suggested other names such as ‘nothing do me Network,’ ‘I dey kampe Ladies,’ ‘Disabled Daughters of Zion,’ ‘Faith and Love Ladies,’ etc. However, the vote was cast on the name Bold Outstanding Ladies with Disabilities Hearts Network. It was to be a support group for ladies with disabilities that would span across Africa but with initial focus on Nigeria. The meeting set up a coordinating group of five persons to arrange the legal framework of the Network and to extend membership to ladies outside Port Harcourt. The aims of the Network include:

To connect, build and reach out to women living with disability.
To eliminate isolation and seclusion among women with disability.

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75 Pidgin translation to English: Nothing is wrong with me Network.

76 Pidgin translation to English: I am very fine Network. This is a popular slang in Nigeria to show that one is fine and fearless and needs no favours.
To support, develop and mentor women with disability and disability-related issues.\textsuperscript{77}

With the use of the social media (FaceBook, WhatsApp, Instagram, etc), Bold Network has attracted membership from across Nigeria, notably in Uyo, Benin, Abuja, Lagos, and Jos. Membership is open only to females with disability. Others without disability are invited to meetings and events as friends of the Network. Many of the members are within the low-middle economic class with a literacy rate showing a minimum of basic Primary education in the 18-40 age bracket with a good number of university graduates. The coordinating team attest to having over 125 women who have registered through its online FaceBook page, but attendance at Port Harcourt quarterly meetings were between 20-30 members per meeting. When I asked some members of the BOLD co-ordinating team what the Network means for them, these were some of the responses:

Well for me, BOLD is a place when we special ladies can interact and learn. It is also a place where anyone who feels isolated in her dealings with disability can come in and know that she is not alone. It helps to know that disability is not associated all the time with negativity.\textsuperscript{78}

For me, BOLD is a place to meet, share and receive support for struggles as a woman with disability. BOLD helps me to know that I am not alone in my struggles.\textsuperscript{79}

I have always had support from this body, whenever I am in difficult situation to make right decisions and also in carrying out mini projects as it concerns persons with disabilities.\textsuperscript{80}

What members of BOLD got from the creation of this network was a place in which they felt they belonged and within which their concerns mattered. For women who often felt excluded in many communal spaces, whether church or community, BOLD offered a safe place for belonging and use of their resources. A person’s sense of belonging is intricately tied to their identity and of vital importance in many areas of their lives. It is the ‘subjective experience of being valued by or important to others

\textsuperscript{77} BOLD Profile, Unpublished.
\textsuperscript{78} Personal Interview, Fidelia, 20 March 2019
\textsuperscript{79} Personal Interview, Angel, 20 March 2019
\textsuperscript{80} Personal Interview, Nelly, 20 March 2019
and experiencing a fit between oneself and others around him/her.\textsuperscript{81} When the female members unanimously decided to leave the combined space of women and men, they were responding to some form of patriarchal subjugation, that defied any opportunity of belonging. The men were perhaps acting upon internalised patriarchy where gender dynamics often create an unequal and unjust society. Whether intentional or not, the women felt silenced by the men. The women’s response was to leave that group and start one that offered a space for ‘sisters’ who shared similar concerns. And here we notice a different kind of practical feminist response; not of confrontation but of exploring a different space means of flourishing.\textsuperscript{82} I have argued in Chapter Five, that this act of exploration of liberating spaces is not cowardice but strength in identifying affirming places and relationships.

Nothing in the profile of BOLD describes it as a religious organisation nor is religious belonging a pre-requisite for membership. It may be assumed that because Port Harcourt and Uyo are predominantly Christian States, that this accounts for all BOLD members, as at date, identifying as Christians. As such all their activities and ideals are grounded in their faith. A typical meeting, no matter where it is held, has the rituals of a Christian fellowship meeting. I will illustrate with two meetings that I attended.

In December of 2018, I was invited to the BOLD Christmas party at the home of the Chair of the Co-ordinating Team. This meeting had a dual purpose of a business meeting and an end-of-year Christmas get-together. The gathering was scheduled for 2pm so members would not have to travel late into the evening due to the state of insecurity in Port Harcourt. People started arriving at about thirty minutes before the time. As the venue filled up, so did the chatter of greetings of welcome, jokes and laughter. Ladies arrived smiling and happy. A few attended with their carers and some called for help with transferring to their wheelchairs as they arrived in hired taxis. The Chair called the meeting to order with ‘Praise the Lord oohh!’ When she failed in

\textsuperscript{81} Meji\textsuperscript{a}s, Gill, and Shpigelman, ‘Influence of a Support Group for Young Women with Disabilities on Sense of Belonging’.

\textsuperscript{82} Wendell, Susan, ‘Towards a Feminist Theory of Disability’, in The Disability Studies, Reader, ed. Lennard J. Davis (New York; London: Routledge, 1997), 261. Susan Wendell notes the choice women with disabilities have to make whether to seek full integration and equal power with men ‘as a goal’ or ‘whether to preserve some degree of separate culture, in which the abilities, knowledge and values of women/the disabled are specifically honoured and developed.
stopping the private conversations, she bellowed ‘Ladies, Praise the Lord ehhh!’ Whilst ‘Praise the Lord’ is a popular call to worship in many Pentecostal/Charismatic fellowship, it was the signal of the start of the meeting for BOLD.

The programme for the day began with singing of Christian songs popularly tagged ‘praise and worship.’ This was followed by opening prayers, introductions, testimonies, Bible exhortation (preaching), business meeting (an evaluation of the current year, and plans for the next year), prayers, food, announcements, photographs, closing prayer and dismissal. The meeting also provided the opportunity for economic empowerment as attendees discussed and advertised their business products and ideas. Those facing economic difficulties shared those concerns, others told stories of how they overcome their economic challenges, while others proffered possible advice. This singular meeting provided the space for social, economic, spiritual, and health support for BOLD members. The meeting lasted for about three to four hours with lots of giggling and laughing and jokes.

The second example was my meeting with the Coordinating Team at the start of my fieldwork in August 2019. It was decided to hold the meeting at a Fastfood indoor catering facility in Port Harcourt. We chose a large facility assuming that it would be disability accessible, but it was not. After two hours and five attempts at five other catering facilities, we finally found a place with enough room for two wheelchairs and two pairs of crutches. The entrance ramp was so steep that the two security guards had to practically carry the ladies in wheelchair into the hall. Once inside, we walked or wheeled to place our orders and have them served. Here again, in that open eating place, the Chair called the ‘meeting’ to order with ‘ok, ladies, let us pray.’ During the prayers, she thanked God that we were finally able to find a good accessible venue for our meeting, for safety of BOLD members, for BOLD activities as well as asking God for a successful meeting that day. After the prayers, she laid out the agenda for the meeting as follows: welcome to Mama Jessie, Briefing by Mama Jessie on her PhD project, BOLD input/responsibilities to the project, Prayers for the project, prayers for other, eating time, closing.

The difficulties encountered in Port Harcourt were worse in Uyo. Whilst the hotels and restaurants advertised accessible facilities, these were usually limited to one entrance that was often very steep and unsafe. To have an enlarged meeting of BOLD,
we had to appeal to a church to build a ramp and rail into its multi-purpose centre for our use. With the approval of the church authorities and input from members of BOLD, an acceptable ramp and rail was ready within a fortnight. For the meeting of the coordinating team, we used the home of one of BOLD members. It did not matter where the meeting was held or the challenges with accessibility, prayers, and other spiritual activities such as songs and forms of dance formed part of the meeting agenda. Their spirituality was never dampened by the difficulties faced. I observed that the joy of meeting together, discussing the project, sharing a meal, or just having a conversation seemed to make up for the attendant difficulties with accessibility.

The commonality of church practices, rituals and resources was obvious as everyone knew the songs and prayer items mentioned. The exhortation was from the Bible, and a few women brought out small-sized Bibles from their purses or bags, opened them and joined in the reading. They had come with Bibles even though the call was for a BOLD Network meeting and not a church fellowship meeting. There was no talk of denominational affiliations, church names were not mentioned at these meetings, and hymns from church hymnaries were not used. I had mentioned that BOLD does not identify itself as religious, however, these features resemble what has been described as ‘grassroot ecumenism’ representing cases ‘when people come together despite their religious differences.’

Although Richard Werbner’s study centred on intentional communal co-operation in the conduct of funerals in Botswana, he noted that grassroot ecumenism, amongst other inclusive factors were ‘through the cultivation of an interdenominational repertoire of hymns and rites; … shared ideals of unity and love, salvation, peace, and consolation; …practical co-operation based on shared everyday assumptions…. ‘ These factors were present in the meetings of BOLD even though the purpose of the meeting, such as research for this thesis, formed a greater part of the discussion.

In BOLD are members of mainline churches such as Presbyterians, Anglicans, Methodists, Lutherans, Salvation Army; Pentecostal/Charismatic churches such as The Apostolic Church, Assemblies of Church, Rivers of God, Mountain of Fire and Miracles, Redeemed Christian Church, Winners Chapel, as well the Roman Catholic

84 Werbner, 'Botswana's Ecumenical Funerals in the Making'.
church. When these women gather, they unconsciously lean into what is commonly known and acceptable to enjoy their spirituality. Unlike the people in Werbner’s study, in all the times I attended their meetings, there were no polemics, or unwanted religious expressions. It does seem therefore, that the Circle would gain from BOLD, women without theological training but who are able to contribute to African women theologising from their unintentional grassroots ecumenical endeavour. Within this setting, they address the issues that are important to them, whether it is their faith, their sexuality, relationships, or support strategies for their daily lives.

An area in which BOLD support for one another has been strong is in the affirmation of their sexuality. It was their inability to discuss issues of sexuality and relationships that prompted their desire to leave the male-female space to form a female only BOLD space. Persons with disabilities are often regarded as asexual. They are considered as not having the ‘same sexual urges as non-disabled people’. This way of regarding persons with disabilities is worse for women. Bold members observe that whereas men with disabilities can convince women of their sexuality and can have relationships, women with disabilities are more likely to be abused as a ‘test’ of their sexuality and then discarded. Writing from their experiences as women with disabilities, Salome Muigai and Celine Osukwu state how women with disabilities are often treated as though they are sub-beings who are incapable of having and maintaining healthy heterogeneous relationships. In responding to its aim to eliminate seclusion and isolation, BOLD members intentionally encourage visits among its members and constant communication through social media. Furthermore, the specific challenges involved in finding and keeping intimate-partner relations are discussed freely and experiences shared to help others exercise caution and assertiveness in negotiating sexual relations.

It is no wonder the BOLD’s first conference was a discussion on their sexuality. In June 2017, BOLD, in partnership with World Council of Churches (EHAIA and EDAN programmes) and the Presbyterian Community Services and Development (PCS&D) of the Presbyterian Church of Nigeria, organised its first national

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conference. The theme of the conference was ‘Women with Disabilities and Sexual Reproductive Health.’ Talks and sessions were focused on female sexuality, HIV and AIDS, female assertiveness, and female self-image. Many of the attendees took part in the HIV voluntary testing and counselling. The conference rose with the slogan ‘Bold ladies, Bold Heart’ to give impetus to its members in tackling the daily challenges of disability.

The Secretary of BOLD mentioned that the conference helped the members to further build their confidence and affirm the two dimensions of their sexuality. These dimensions are acceptance of their humanity as defined as made in God’s image on one the hand, and that which includes the ‘basic needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive and sharing thoughts and feelings’ on the other.\(^88\) Oduyoye says the ‘sacredness of sexuality has to do with the sacredness of the whole of a person’s humanity’ and that it is a collective responsibility to ‘safeguard the divine image which we are.’\(^89\) The appropriation of their humanity and personhood resonated during the fieldwork and participants credited this to their faith as the source of their inspiration. It was at this conference during which I acted as consultant, that the thought of writing the stories of women who tested positive to HIV, was further nurtured. This was especially as I was privileged to have women willing to share their lived experiences with me as well as have the world hear their stories in pseudonymised format.

For BOLD, sharing their stories is to ‘share the basic experience of what it is to be a woman (with disabilities) … and this creates a special depth of understanding.’\(^90\) Scholars who research the role of support groups agree that support groups are efficacious especially when such groups are based on ‘shared experiences and/or ideals such as faith.’\(^91\) According to Lakesha N. Anderson,

> Effective support is most likely to come from socially similar others who have faced or are facing the same stressors…

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\(^{90}\) Pearson, ‘A Support Group for Women with Relationship Dependency’.

empathy and sympathy from similar others is a crucial condition
for seeking and acceptance of coping assistance.\textsuperscript{92}

Anderson’s quote above further aligns with Susan Hayward’s opening quote in this
section and resonates with my research participants in various ways. As members of
BOLD, they identify and face similar challenges in the same societies. Their efforts
to build sustainable relationships is an intentional one to create avenues for mutual
support.

1.6 Organisation of the Chapters
This thesis comprises seven chapters. The first two chapters provide the background
of the research and explores its key concepts of gender, disability and HIV within
Nigeria’s Christian faith expressions. It introduces BOLD Hearts Network as the case
study for this thesis and makes a case for the distinctiveness and originality of this
study in addressing the issues of gender, disability, and HIV altogether. These initial
chapters also highlight the global and Nigerian burden of the concerns of the research
and why women are more disproportionately affected by the stigma associated with
gender, disability, and HIV in Africa in general, and Nigeria in particular. It does so
by engaging with sociological, religious, and cultural dimensions of this subject. It
further discusses the writings of African women theologians and scholars on the
tripartite relationship of gender, disability, and HIV. It therefore responds to
understanding the ways in which faith communities articulate African-based relevant
theoretical models. Following from select literature in conversation with research
participants for this thesis, Chapter two makes a case for the integration of faith-based
perspectives in tackling social consequences of gender, disability, and HIV.

Chapter three draws on social science research plan and concentrates on details
of the methodology for this qualitative research. It takes seriously the interpretation
of the data as well as the process of data collection, analysis, and the parties in the
research process. It also provides information about the researcher’s role in the field
demonstrating the uniqueness of faith-based ethnographic research on sensitive

\textsuperscript{92} Lakesha N. Anderson, ‘Functions of Support Group Communication for Women with Postpartum
Depression: How Support Groups Silence and Encourage Voices of Motherhood’, \textit{Journal of
Community Psychology} 41, no. 6 (2013), 709–24.
subjects such as disability and HIV. The reflexivity of the researcher, ethical issues and theoretical framework for the research were also discussed. It foregrounds further discussions on the results from the field work.

The next three chapters discuss the findings of the research with prominence given to the voices of research participants. Chapter four attempts a response to the research objective of understanding how women’s knowledge and interpretation of faith influence their ability to live with the realities of disability and HIV. Research participants understood their faith as a relationship with Jesus Christ as healer; and explained how that understanding is central to the profession and practice of their faith. A crucial aspect of healing for these women is a transformed identity that enables them to seek out and engage in liberating relationships. It is a demonstration of women’s Christian faith and personal relationship with Jesus Christ. A part of this chapter was used in a book chapter on disability and healing in Africa, to be published by Tearfund.

Following from Chapter Four, Chapter Five turns to the theme of relationships for women as research participants expressed the importance of relationships in their lives. The chapter demonstrates the extent to which relationships provide support and succour for women as they handle the challenges of gender, disability, and HIV. The chapter investigates how women navigate the different relationships in the family, negotiate relationships in society and the church, as well create empowering relationships in friendships and support groups. It advocates for faith to be seen as a public good in offering the relational support to address societal-instigated problems.

In chapter six, the research objective of understanding faith resources and practices available to women and how these resources are utilised to deal with the multiple challenges that they face, is examined. The identified resources are Scripture, Songs, Prayers, storytelling, and testimonies. Whilst these are not innovative resources and are popular in Nigerian African spirituality, research participants provided peculiar examples of ways in which these resources are understood and used to engage with stigma and discrimination, while seeking issues for affirmation. It demonstrates that women value faith in and of itself, and that these resources further their relationship with Jesus Christ, to reclaim their dignity as women of faith.

Chapter seven is the last chapter which summarises and concludes the thesis. It highlights the lessons that should be considered by churches, faith communities,
theologians, medical and international development organisations for faith-based strategies in gender, disability, and HIV intervention. These suggestions include the recognition of faith as integral to lives and healing processes for religious people, the dignity of all persons, and the significance of women’s stories in changing the dominant narratives. It argues for the active recognition that faith is not circumstantial but fundamental for women who have accepted and experienced Jesus as both friend and healer.

1.7 Conclusion for Chapter One
This chapter provides the basis for this thesis. It explains why this research is important and shows how I will examine the way in which women in Nigeria cope with the challenges of disability and HIV. My findings show that the many aspects of faith provide women with the support and succour that they seek. To prepare the ground for a proper understanding of the findings from the data of this research, I attempted a brief historical background for the study, endeavouring to discuss the context of study, the case study used to drive the research question(s), as well as the deliverables of the thesis. In attesting to the validity of faith to offer succour and support to handle difficult challenges, the women interviewed for this study demonstrated their reliance on their Christian faith to avail them of tools with which to face the difficulties of their daily realities. While not ignoring the influence of patriarchy, religious or culturally induced stigma and social difficulties associated with the concerns of gender, disability, and HIV, they demonstrated a choice for personal negotiation and navigation with oppression rather than confrontation or challenge.

In this way, they own and exercise discretionary self-acquired power from their faith to cope with the multi-layered difficulties that they face in the family, the church, and the society. Women in this study bring a distinctive contribution to African Christianity by engaging with faith from their lived experiences with disability and HIV within the context of tension between religious and cultural belonging. Although they proved that identities are informed by relationships, the women that I interviewed demonstrated that with proper support, relationships, vertically, with the divine, and laterally with humans, can inform empowered self-esteem that allows for communal co-existence.
Chapter Two

Discourse on Gender, Disability, HIV and Faith

2.0 Introduction
This chapter explores the concepts of gender, disability, HIV, and faith, expounding on how they are understood for this thesis. It examines the conceptions and misconceptions around gender, disability, and HIV within predominantly patriarchal societies of Port Harcourt and Uyo. It brings into thematic conversation writings of African theologians (females and males) and the experiences my research participants shared during the interviews. This thesis prioritises the writings and voices of African women and broadens the reach of the Circle of African Women Theologians with the stories of ordinary African women who are often disadvantaged for being women.

I take this approach, not because I agree with all the writings or views of the Circle, or that the women who participated in my research do. I do this because for a long time, African women have accused men of writing women’s stories and discussing women’s concerns without appropriate input from women. This approach enables the voices of women who are unable to challenge discriminating religious and cultural systems to be heard. The chapter provides a preliminary discourse on how the women that I interviewed, found creative alternative ways of living life fully despite prevailing misconceptions and exclusive conditions in the family, the society, and the church.

Faith is critical to engaging with the concerns of my research, even when interpretations of faith are informed by experiences with patriarchy, gender norms, and health concerns. The chapter demonstrates that while faith should be integral to health strategies, articulation of life-giving theologies with respect to equality, health and healing is important when responding to issues of gender, disability, and HIV. Faith is therefore the place to start in articulating the four core concepts of this thesis.

2.1 Understanding Christian Faith
The term ‘faith’ in a Christian theological context, is often used to refer to ‘the body of truth which fully incorporates the teaching of Christ’ and to, ‘the human response
to the revelation of such a body of truth.  

93 The women who participated in my research tended to focus more on the second meaning by discussing their response to faith and by understanding ‘truth’ as embodied in the figure of Jesus Christ. However, they introduced the element of relationship as crucial to faith, and in this case relationship with Jesus Christ. They would answer my questions about faith with words liked, ‘my faith is about my relationship with’, or ‘because of my faith, I can…’ This thesis prioritises the women’s understanding of faith as their response to the truth they found in a relationship with Jesus Christ. I have examined their lived experiences as women whose faith informs their religious practices, and social relations. Using the words of Meredith B. McGuire, examining the women’s understanding of Christian faith is about how as ‘ordinary people’, they practised, experienced, and expressed’ their spirituality.  

Consequently, I have used spirituality to refer to the ways in which the exercise of faith resources such as prayer, songs, Bible reading, etc affects their engagement with life’s challenges. I have used belief as a declaration and/or expression of confidence in God, in the sense in which the women used the word.

The ways I used these concepts do not constitute a universal understanding. Nevertheless, like some scholars, I am using ‘faith’ in a sociological way as an empirical category, rather than in a normative theological way.  

94 Within Christian religious circles, faith is generally understood as a strong belief in the person of Jesus Christ, whose crucifixion and resurrection lie at the heart of God’s presence and work in the world.  

95 Christ, at the centre of faith for Christians, is the ‘personal saviour and personal friend of those who believe in him,’ … ‘the healer of those who are sick, both spiritually and physically’.  

97 For my research participants, Christian faith involves three aspects; a belief in the person of Jesus Christ, the ways that belief is practiced in everyday life and how their social relations in the family, church and society are

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impacted because of that belief and practice. It is in this understanding of faith that is operational in this thesis, and discussed in greater depth in latter chapters, especially Chapters four, five and six.

For many Christian people in Nigeria, their faith is integral to how they live and how they deal with challenges. Yet faith is often overlooked when responding to these issues. How faith can be understood and integrated in societal response strategies have been my passion and shapes my engagements in local and international scenes. On 9 June 2016, I made the following contribution at the United Nations 2016 High Level Meeting on Ending AIDS at a Side Event on ‘The 90-90-90 Goal and Human Resources for Health.’

My name is Jessie Fubara-Manuel, representing the World Council of Churches, Ecumenical HIV and AIDS Initiatives and Advocacy. Faith-based organisations have never been absent in HIV interventions. Reaching the 90-90-90 target is ambitious but achievable. It would require effective collaborations and partnerships with all HIV responders and faith-based bodies as critical HIV response actors. Whereas UNAIDS, PEPFAR and of course Global Fund have worked strategically with faith-based organisations over the years, this partnership is not reflected in the documents outlining the processes to achieving the 90-90-90 target. Faith-based organisations have the platform, the population mass, the grass-root reach, the Human Resource in terms of its volunteers and the faith-language to transmit the HIV intervention message appropriately and sensitively. For ownership and accountability of this target, faith-based organisations need to be named and incorporated in its execution process. 90-90-90 is not just about numbers, it is about people, and people are majorly people of faith.

My contribution at the June 2016 UN HLM on Ending AIDS, was a contribution to the voices of many African women scholars, Christian Health actors, and theologians on the need to apply faith resources in tackling HIV and AIDS. It was also in furtherance to the quest for faith communities to contribute to health interventions on the premise that faith response is strategic to addressing the constantly

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98 Jessie Fubara-Manuel, *Giver of Life*, viii. This book was a contribution to the World Council of Churches 10th Assembly.
99 The 90-90-90 target is as follows: By 2020, 90% of all people living with HIV will know their HIV status.; By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy; By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression. For more information see, http://www.unaids.org/en/resources/909090.
changing face of health in Africa. In July 2016, at the 2016 International AIDS Society conference, UNAIDS noted the challenges of faith responses to the AIDS epidemic by stating that,

A strong faith response is critical to achieving the Fast-Track Targets by 2020 and to ending AIDS by 2030. Yet effective mobilisation of that response faces many unique challenges…there are often perceptions of conflict between religious values and health priorities.100

UNAIDS acknowledges that a faith-based response is important to ending AIDS. Yet its call for HIV research is barely faith-inclusive due to the perceived conflict between faith and health. The inclusion of persons with disabilities, especially women, in its response strategy is however a welcome development. It calls for a “person-centred, disability-inclusive HIV response that allows for increased participation of people with disabilities (particularly women) and integrates rehabilitation within the continuum of HIV care.”101 UNAIDS acknowledgment for the participation of women with disabilities in HIV response is helpful as only the voices of those directly affected can make meaningful contribution to policy formulation and implementation.

Christian women living with disabilities and HIV who are HIV responders and who embody life-giving theologies can bridge the gap between religious values and health priorities. As is demonstrated in this thesis, religious responses, whether to gender, disability, HIV, or other justice-related issues, are not always positive, especially for marginalised people.102 The influence of faith on religious people means that beliefs inform behaviour, attitudes, and actions. When such beliefs or its interpretations are negative, then it breeds negative attitudes and actions. Women’s understanding of Christian faith and the interpretation of belief systems is necessary for a faith-based response to the challenges of gender, disability, and HIV. Often this

understanding and articulation of Christian faith is more within the realm of experience than intellectual engagement.

Telling the story of her Christian journey, Mercy Oduyoye speaks about the experience of being saved. She gives this narrative as something that occurred within the Christian rituals of Sunday school, campus fellowships and morning prayers. She describes Jesus as the one who saves and ‘proclaiming the divinity of Christ is in the dimension of faith.’ According to Oduyoye,

The Christ of Christianity touches human needs at all levels, and Africans are but ordinary members of the human race feeling the need for salvation….. salvation through Jesus Christ as Saviour and Redeemer.

Oduyoye presents Christ as the centre of Christianity (or Christian faith) and portrays him as the one who is concerned about the needs of humanity, within which the imageries of saviour and redeemer are enacted for the Christian who believes and needs salvation. In one of her seminal books, Hearing and Knowing, Oduyoye demystified the technical nature of Christian theology or spirituality by describing it as what is done ‘whenever people reflect on their life situation in the context of the (Christian) gospel.’ Oduyoye’s ecumenical journey was envisioned in this understanding; that the Christian faith could be interpreted for the liberation of all persons (male and female), when the Christian gospel becomes the context of reflection. Her story highlights the difference that the Christian gospel can make for people who accept it and are guided by it. Christian spirituality becomes the mirror with which Christians consider life’s choices as an ongoing endeavour.

The Circle published a collection of stories of the faith lives of many African Christian women in Her-Stories: Hidden Histories of Women of Faith in Africa. Many of those stories were crafted in the assumption that the story tellers are religious people who understand what Christian faith means for them and who look to God for help.

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104 Oduyoye, Beads and Strands, 18.
105 Oduyoye, Beads and Strands, 19.
107 Oduyoye, Beads and Strands, xi-xiv. Oduyoye provides a brief of her Christian and ecumenical journey.
Fulata Lusungu Moyo tells her story in Chapter Nineteen. As a woman liberation theologian, Moyo uses singing and dancing to tell her story of faith, in the belief that it is the ‘will of God for women and men regarding their being in equal terms in the image of God.’ She speaks of God who is ‘protector,’ having heard ‘God’s audible voice of love and being,’ and felt ‘God’s embracing touch and assurance.’ Moyo conceives a Christian faith of equality because of a collective belonging to God, in which she finds support and protection from God.

I asked Moyo for a direct definition or personal understanding of Christian faith. This was her answer:

My Christian faith is about a living love relationship between my God who created us so that we can be in a living dynamic relationship of love with the God community of three in one. I understood my faith encounter (dramatic conversion) as a direct encounter with a powerful God, who defied even death. Most of my writings assume this understanding even when they might not articulate it.

Moyo is a founding member of the Circle. I use her story to broaden our knowledge of what the Christian faith could mean for African women. It has divergence and common components. For some like Moyo, it is about relationships, primarily with God, as creator, as protector, based on the death of his son, Jesus Christ. Though Moyo does not use the name of Jesus, the reference to the defiance of death, makes Jesus central to her encounter, much as Oduyoye’s understanding earlier in this section.

Moyo also mentions the ‘community of three in one,’ a deeply theological understanding of the trinitarian concept in Christianity, which is outside the scope of this thesis to consider. However, her perception of Christian faith as one of relationships resonated with the experience of my research participants, although they did not speak of the trinity or any dramatic conversion. Jesus Christ was central to the Christian understanding of my research participants, but it was the imagery of healer and friend that was most pronounced. This could perhaps be explained by their need

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109 Moyo, "Singing and Dancing Women’s Liberation", 393.
110 Personal Interview, Fulata Moyo, 30 October 2019. I had to interview Fulata Moyo after it was increasing difficult to find direct description of faith by African women theologians or faith leaders.
of healing and support which Jesus is able to provide. This further illustrates how the understanding of Christian faith may have some commonalities among Christians but often different in individual experiences.

Moyo’s dramatic conversion in 1980 is explained further as an experience that happened after a,

feeling of utter remorse because of my sins. I accepted the liberation of Jesus Christ as my personal saviour. Flowing in the traditional born-again life of the time, I dressed modestly and tried to dance to the tune of the Christianity of that day, when even your hairstyle had to show that you were a born-again Christian.\(^\text{111}\)

Moyo’s further describes of her understanding of Christian faith in relation to Christ as liberator from oppression and saviour from sin. Following her conversion, everything about her changed, even her dressing. She was now a born-again Christian, and one whose entire life was mediated by that experience. Her sense of spirituality followed the traditional Pentecostal-Charismatic practice of her time.

Ogbu Kalu deepens our understanding of the born-again phenomenon that characterised the Christian life with the explosion of the Pentecostal and Charismatic movements in Nigeria in the 1970s\(^\text{112}\). Whilst the mainline churches, or missionary established churches such the Presbyterians, Methodists, etc, struggled with this new phenomena, Pentecostal worship with its singing, dancing, speaking in tongues, etc flourished among many African Instituted Churches\(^\text{113}\). These churches ‘created a religious space for themselves in the quest to access a spirituality that sustains and is faithful to the mandate of the scriptures.’\(^\text{114}\) Conversion within Christianity by persons already considered Christians became the norm; and older people gradually joined these Pentecostal spaces. The experience of being born again, being saved, or accepting Jesus Christ as one’s Lord and personal saviour was everywhere.

\(^{111}\) Moyo, “‘Singing and Dancing Women’s Liberation’: My Story of Faith’.


\(^{113}\) Kalu, ‘Who Is Afraid of the Holy Ghost?’

For many who were seeking answers to numerous problems, the Pentecostal call to conversion was timely. According to Kalu, many were,

invited to be born again and receive the power of the Holy Spirit, manifest the charismata, and come under the cover of the blood of Jesus which protects from witchcraft attacks and empowers one to gain the rich promises in Scripture. To be born again is a bridge-burning experience that deconstructs and repackages with a new identity. Testimonies are encouraged as narratives of the biographical reconstruction.\textsuperscript{115}

Kalu does not give a definitive description of what the Christian faith or the Pentecostal Charismatic experience within Christianity means. He offers helpful explanations of what happened with or to people who subscribed or accepted this new form of spiritual expression. If anyone had been asked what Christian faith meant, the answer would have been that it was the faith that brought drastic change in the belief and lifestyle of the believer. From Kalu’s explanation, it was also the faith that protected people from witchcraft attacks. It was also an experience that enabled a new identity that signalled the end of a previous identity. The discourse of the term was often in the verb form, rather than in the noun. It was about what was received and what was done to a person within that religious understanding.

To retain their members, especially women and youths, from the lure of the Pentecostal-Charismatic embrace, missionary-founded churches mentioned earlier, began to engage with the ‘Pentecostal spirituality, liturgy, and theology.’\textsuperscript{116} Pentecostal modes of worship became the norm in many Nigerian-African churches; a phenomenon that Cephas Nath Omenyo refers to as ‘Pentecost outside Pentecostalism.’\textsuperscript{117} Many people in the southern part of the country self-identify as Christians with Christianity adjudged as the ‘fastest growing religion in Nigeria.’\textsuperscript{118} It is common to find a blended form of worship ritual in almost all the churches in Nigeria, especially among the Christian South.

\textsuperscript{115} Kalu, Who Is Afraid of the Holy Ghost?
\textsuperscript{117} Kalu, ‘Holy Praiseco’
\textsuperscript{118} Obinna, ‘Nigeria’, 189-200.
The implication of this is that many in the southern part of Nigeria, where this thesis is based, live within a similar Pentecostal-Charismatic influence. They sing similar songs, have similar prayer patterns, and engage in similar church activities. Their Christian faith and identity appear wrapped in the same cloth. On one hand this clarifies what is observed in Chapter Six, where, though members of BOLD come from different church denominations, faith resources of Scripture, prayer, songs, storytelling, or testimonies are utilised knowledgeably. On the other hand, it highlights the complex nature of faith understanding where individual Christian identity and practice is dictated by a collective identity. This scenario agrees with McGuire’s description of ‘lived religion.’ According to her, ‘although lived religion pertains to the individual, it is not merely subjective. Rather, people construct their religious worlds together, often sharing vivid experiences of that intersubjective reality.’

There was a merging of individual practices by the women within communal BOLD space that allowed for mutual enrichment and support that I observed as embedded in a safe environment.

Research participants spoke of being saved, giving their lives to Jesus, and Jesus coming into their hearts. While not often in dramatic circumstances, this encounter with Jesus informs the way they can meet the challenges of disability and HIV in the society and church. This faith encounter is about relationships, vertically and horizontally. Women relate with God through Jesus Christ, in that they believe that the salvific properties in the work and being of Jesus can solve a mirage of problems, just like the stories of the Circle members. As I observed during fieldwork, women with disabilities are owning their right to reclaim their dignity and live wholesome lives.

The women in my study spoke about being able to lean on Jesus trusting that he would always be a travel companion through the ups and downs of life. This provides a focus to understanding the way that faith is expressed. Their understanding of faith becomes the key to demonstrating their response to the challenges of gender, disability, and HIV in the church and society. For women who struggle with dependable relationships, as is discussed in Chapter Five, women find in Jesus a dependable ally in a world of oppression and marginalisation. The women in my study

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align with the Circle’s obligation for communal faith practice where the good and justice they seek is for all of humanity. For the women that I interviewed, however, such a faith community is only possible when there is prior mutuality between women without and those with disabilities. Gender inequity is not just about men and women, it is also about women and women.

2.2 Gender within Disability and HIV Debate
In Chapter One of this thesis, I described how gender misconceptions and stereotypes make women, and especially, women with disabilities vulnerable to HIV infection. I argue here that gender as a concept, is not negative, it is the contextualised application of gender, based on cultural, religious, and social interpretations that problematise the concept of gender. Esther Mombo describes gender as the relationship between men and women and how society appropriates power, duties, and expectations to each gender. According to Harriet Bradley,

> Gender refers to the varied and complex arrangements between men and women, encompassing the organization of reproduction, the sexual divisions of labour and cultural definitions of femininity and masculinity

It is the complexities of gender and its direct influence on relationships between men and women that make gender worth discussing for this thesis. As will be discussed in Chapter Five, relationships are critical for my research participants, and often how they chose to manage or negotiate any relationship is dependent on the power structures and gendered roles. These gender roles are often embedded in relationships within the society. However, because much of society views the female as lesser and second-class, the female is susceptible to ‘gender discrimination’ when compared to males.

Gender is a social construct. It is unfixed and varying across cultures and peoples. Gender could be and is often constructed towards inequalities between men and women. Miranda N. Pillay refers to this as the ‘gender power-relations’ that is akin to the ‘theology of hierarchy, of male headship, of power and dominion based on

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120 I recognise that in Nigeria and much of Africa, gender is still constructed with male and female descriptions. The broad application or understanding of gender to cover gender-neutral or genderless groups is not used officially in Nigeria. Hence, this thesis stays within the male-female dichotomy of gender.

separateness.’ There is an inherent note of injustice in gender because of its reliance on male dominion over woman without recourse to shared responsibilities. Ezra Chitando argues that there is a conspiracy between patriarchy, religious and cultural norms to perpetuate the vulnerability of women to HIV. It does appear that according to Pillay and Chitando, men are religiously, culturally, and socially constructed to exercise power over women.

The Circle continues to view a social construction of gender as “inherently unjust,” to the woman in the era of HIV and AIDS, especially within the African continent. Women are often exposed to harmful sexual practices because gender inequalities define the power structure in the man-woman relationship. According to Mercy Oduyoye,

Gender can and does destroy hospitality and hence human relationship and community health. The relationship can move from being healing circles in a wounding world, to a prison of gender definition. Communities in which one’s gender as a female takes precedence over one’s humanity can generate dehumanisation and marginalisation.

Oduyoye’s quote above speaks about gender stereotyping where the misconception that the man is superior to the woman is popular and generally upheld. It therefore fails to be a concept that promotes a community, such as Pillay alludes to above, one that is “affirming and nurturing and for which all contribute their gifts” whether they are female or male.

Oduyoye notes that in Africa, “women’s experience of being persons is largely in relation to others – as mothers or as wives.” This is problematic for the woman, in that her identity or social status is dependent on her relationships – as mothers or as wives – and not on any personal achievements or qualities of her own. This is even

124 Dube Shomanah, The HIV & AIDS Bible: Selected Essays. 100.
126 Mercy Amba Oduyoye, Beads and Strands, 54.
127 Mercy Amba Oduyoye, Hearing and Knowing, 122.
though women play critical roles in the life of religious and social communities. In Port Harcourt and Uyo, Nigeria as in much of Africa, often, a woman without a man – a husband – is considered incomplete and unsuccessful no matter her economic standing. On the other hand, a woman with a man was not seen or considered at all, she was lost in her husband. She took his name and was expected to change her lifestyle to that of the man. This way of thinking breeds stigma for the female gender. It denies the woman of her identity as a person with values and skills outside of domesticated roles.

The fact that gender norms are ingrained in society’s sub-conscious could explain the game of ‘house.’ When children play ‘house’, the boy-man-husband sits and gives orders while the girl-woman-wife scurries around like a squirrel busy all through the game. At meetings, in church or society, men sit in front and make the decisions while the women clean and serve without complaint. It has been argued that people are unconsciously conditioned to these accepted norms and roles. African women theologians like Teresia Mbari Hinga has joined the voices of other Circle members to speak against the sense of unconscious conditioning of gender inequality. She argues that,

Notions of manhood and womanhood are learned rather than innate. The insight that gender is socially constructed implies that there is no such thing as a generic woman or a generic man. Gender essentialism is therefore a fallacy. This implies also that much of the behaviour that is manifest as sexism and gender violence is learned behaviour, acquired through the various strategies by which society transmits its notions of manhood and womanhood.  

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129 As a child in the Uyo environ, I played this game heartily and the boy who played husband was younger and smaller than me in size. I remember my father asking me not to participate in that game anymore. I did not give any reasons.


This argument that learned behaviour can be unlearned is the premise upon which the Circle has based its pursuit for gender justice. Ogbu Kalu supports this notion as he says:

> Gendered relations are not viewed as either natural or immutable, but rather as products of sociocultural and historical forces that are created and are constantly re-created by humans; therefore, these forces can be changed by human agency.\textsuperscript{132}

Kalu understands that this process of unlearning or re-creating gendered relations is a difficult one because it is ingrained in every fibre and institution of society, whether secular or religious. It must be recognised that this is a difficult task for the church, because, as observed during the field work, members of churches are also members of the communities. However, the onus may not be removed from the church (and society) to change the dynamics and the stereotypes that inform gender inequality, be it in the church or in the wider community.\textsuperscript{133} It is argued that the church has a role to play to confront the narratives on stereotypes and affirm the dignity of all human life.\textsuperscript{134} This mode of thinking agrees with the social model theory that drives this thesis; the responsibility on society to recreate a more inclusive processes of socialisation.

Unfortunately, the church itself is not always so placed. Women in this study did not find the church a safe place. Unlike contexts where issues of sexuality and HIV are preached from the pulpit, this was not the case for the women with disabilities and HIV.\textsuperscript{135} Oduyoye has noted that churches,

> Most often take the form of patriarchal hierarchies, accept the material services of women but do not listen to their voices, seek their leadership or welcome their initiative.\textsuperscript{136}

For the research participants, however, the double stigma is that the church rarely accepts anything from them and do not listen to their voices. Inequality fuels exclusion.


\textsuperscript{135} Van Klinken, \textit{Transforming Masculinities in African Christianity}, 107.

and loss of dignity for women which the Circle seeks to address, but its attempt appears lacking without the inclusion of all women.\textsuperscript{137}

During my fieldwork for this thesis, the women I interviewed shared stories of the different forms of relationships they were having with the men in their lives as fathers, husbands, brothers, male neighbours, or community members. Some, especially the singles, said they outrightly ignored patriarchal tendencies or sexist practices that disrespected their person. Others, majorly the married ones, said they navigated and managed attitudes or behaviours that they found unwholesome. In both responses, the women exhibited a resistance that enabled them to reclaim their sense of personhood. Perhaps, my research participants accepted like Finn Mackay that there is ‘no society or nation … where women as a group have had power and control over men in every sphere of life, including their personal affairs’\textsuperscript{138} Their responses to the men, therefore, were based on the level of capacity available to navigate or negotiate male patriarchy whether in the family, in the church, or in the larger society.

Some of the women in my research, explained the motivation behind their course of action in ignoring patriarchy. It is true that women suffer various types of patriarchal domination everywhere, but it is also true that there has been some gender progression in terms of women in leadership in many church spaces.\textsuperscript{139} In discussing the issue of patriarchy, these women opined that the continuous negative narrative of men’s domination, while true, may not always be helpful. While it describes the realities of many African contexts, it does not appear to help the holistic attitude of dealing with disability and HIV. I could argue that the demand for positive masculinities of the men must be accompanied by positive femininities of the women to create affirming spaces in spite of the men.\textsuperscript{140} The extent to which men may be socially constructed with the help of faith-based strategies is still being explored. The

\textsuperscript{138} Finn Mackay, Radical Feminism: Feminist Activism in Movement (Houndmills, Basingstoke Hampshire; New York, NY: Palgrave Macmillan, 2015). 4-5.
\textsuperscript{139} Ogbu Kalu, African Pentecostalism. 149.
\textsuperscript{140} Helen A. Labeodan et al., eds., Positive Masculinities and Femininities: Handbook for Adolescents Adn Young People in Faith Communities in Nigeria (Geneva, Switzerland: WCC Publications, 2019). This WCC handbook, the result of workshops with adolescents and young people in Nigeria seeks to respond to the ‘challenge of negative masculinities and femininities that are undoing responses to HIV.’
research participants’ lack of discussion on patriarchy in Chapter Five buttresses this point.

Many male scholars, such as Adriaan van Klinken and Daniel Jordan Smith, have wondered about the extent to which patriarchy should be blamed for women’s domestication and vulnerability to HIV infection. On the one hand, they argue that the “masculinities that inform critical male behaviours are often maintained by both men and women.”141 On the other hand, is the assertion that “social contexts … shape men’s performance of masculinities.”142 Both positions agree that there is need for a positive social construction of masculinities in its relation to gender justice or equality. What these male scholars ‘frown’ at, is what is referred to as the “simplistic” way in which all of Africa’s problems are blamed on “bad men and a crisis of masculinity.”143 Njoroge argues otherwise as stated in the quote below:

Patriarchy is a destructive powerhouse, with systemic and normative inequalities as its hallmarks. It also affects the rest of the created order. Its roots are well entrenched in society as well as the church – which means we need well-equipped women and men to bring patriarchy to its knees.144

Njoroge’s argument supports Kalu’s that patriarchy is found in both church and society. If patriarchy is truly the ‘government of the fathers’ as Kalu states, then should the onus not be on the ‘fathers’ to work towards re-creating positive masculinities.145 For Esther Mombo, the Circle needs to find ways to ‘rediscover the dignity and respect of humanity,’ stating that irrespective of the multi-religious nature of the Circle, all members agree that male domination is evil.146

The solution to gender inequality, according to Pillay, should be based on a ‘theology of community, mutuality and relationship.’147 It is the collaboration of men

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143 Smith, To be a Man is Not a One-Day Job, 147.
146 Mombo, ‘Doing Theology from the Perspective of the Circle of Concerned African Women Theologians’.
147 Pillay, ‘Luke 7:36-50: See This Woman?’
and women in the engagement on HIV prevention, care, and support in the presence of an African patriarchy system in church and culture.\textsuperscript{148} This would entail not normalising the danger of patriarchy being used to excuse men’s domineering tendencies that put women at risk or deny women support. It would mean engaging actively with the leadership potentials of women, not only for gender-specific roles, but also to appropriate personal freedom while allowing for interdependent relationships.\textsuperscript{149} This should be applicable to all persons, with or without disability.

As will be discussed in the next section, women with disabilities have felt left out of the struggle for gender justice in respect to women. Wairimu Muigai asks the question “are the disabled a third gender or a genderless group?”\textsuperscript{150} Muigai asks this question because, according to her, “when social justice pushes society to acknowledge the needs of persons with disabilities, it becomes difficult to deal with these needs at the gender level.”\textsuperscript{151} Muigai’s quote suggests a further exclusion of women with disabilities from the discourse about women. For example, when Kalu analysed the roles of female leaders in a quest for gender justice, there was no caveat that no woman with disabilities was mentioned.\textsuperscript{152} There seems to be a generalisation that women’s issues automatically include those of women with disabilities, something that my research participants disagree with. I could argue, as will be discussed in Chapter Four, that one of the reasons that most of my research participants claim an identity from their personal faith is the failure of the church or society to pursue the path of justice on their behalf. Disability is therefore another concept to consider in terms of how it is understood and what it means for women to live with HIV.

\subsection*{2.3 Disability among Women Living with HIV}
There are multiple complexities of disability in terms of the very concept and the way it impacts on women especially women living with HIV. As will be discussed in Chapter Three, in addition to living with HIV, all the research participants for this study had a disability. They shared how often, disability, especially visible disability,
becomes the defining identity for them because of their obvious impairment.\textsuperscript{153}

Although it has been argued that there is no explicit and/or formal definition of disability, it is often perceived as inability to function in ways that are considered ‘normal’ to those without disability.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) in its Preamble recognises:

| that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in the society on an equal basis with others.\textsuperscript{154} |

The CRPD’s description allows for a broad contextualised understanding of disability especially when viewed from the perspective of the persons with disabilities.\textsuperscript{155} It recognises the role that society’s inability to provide enabling facilities plays in disabling persons with impairments.

Section 57 of the Discrimination Against Persons with Disabilities (Prohibition) Act 2018 of Nigeria provides two interpretations for persons with disabilities:

(a) a person who has received a Temporary or Permanent Certificate of disability to have a condition which is expected to continue permanently or for a considerable length of time which can reasonably be expected to limit the person’s functional ability substantially, but not limited to seeing, hearing, thinking, ambulating, climbing, descending, lifting, grasping, rising, any related function or any limitation due to weakness or significantly decreased endurance so that he cannot perform his everyday routine, living and working without significantly increased hardship and vulnerability to everyday obstacles and hazards;

(b) a person with long term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder full and effective participation in society on equal basis with others\textsuperscript{156}

\textsuperscript{153} Fubara-Manuel, \textit{Giver of Life}, 60.
\textsuperscript{155} Grue, ‘Inclusive Marginalisation?’.
Like the CPRD, the Nigerian understanding of disability recognises the fluidity of society’s actions and barriers that cause exclusion as experienced by persons with disabilities.

Samuel Kabue describes disability from the perspective of persons with disabilities as,

the disadvantage or restriction of activity caused by contemporary social organisation which takes no or little account of persons who have physical impairment and thus excludes them from participation in the mainstream of social activities.\(^{157}\)

Kabue’s description of disability, as well as the Nigerian and CPRD’s, align with the social model of disability. Barring repetition, the social model places on society the burden of dismantling physical, environmental and social barriers that disable persons with various types of impairments, whether visible or invisible.\(^{158}\) For this thesis, these three definitions of disability have two advantages. They draw attention to invisible disabilities that are not easily recognisable to the public, or which could be the result of chronic illness such as stroke, or diabetes. This makes disability something that could happen to anyone and therefore should be perceived as part of life.\(^{159}\) They also buttress the fact that a person’s inability to perform certain acts could be primarily related to the lack of assistive devices or facilities to aid the performance of such activities. In many societies, it is the responsibility of government to provide accessible infrastructures for all its citizens, hence the social model’s call for appropriate government action.

It is important to note here that the social model, like all human concepts, is not without its imperfections or criticisms.\(^{160}\) However, for countries like Nigeria,


\(^{159}\) One of the research participants is within this category. The complications of HIV treatment resulted in stroke-induced partial paralysis that left her a woman living with disability and HIV.

\(^{160}\) Tom Shakespeare, Disability Rights and Wrongs (Florence: Taylor and Francis, 2006), 2. Shakespeare rejects the social model and recommends an approach that recognises that “people are disabled by society and by their bodies.” Shakespeare’s rejection of the social model is a sharp
which is yet to take proper responsibility for disability mainstreaming in its policies, I posit that the social model is appropriate to advocate government action. This is also because within the Disability Rights Act, gendered-disability provisions are still lacking in the policies of the Nigerian government. In fact, even recent policy papers pertaining to women’s rights do not mainstream issues of disability for women. Hence, the social model is critical in engaging the Nigerian government agencies to incorporate a gendered disability approach in its systems and structures.

It is estimated that a greater number of any given population of persons with disabilities are women. Women, however, experience the challenges and stigma associated with disability more severely. Writing from her experience with disability in Kenya, Muigai says,

Through physical, attitudinal, or societal barriers, disabled adult women have been treated like children, sterilized, prohibited from engaging in sexual activity and marriage, excluded from mainstream social and leisure activities.

Muigai’s experience mirrors the inadequacy of society to provide an enabling environment for women with disabilities. It also shows the powerlessness of women with disabilities whose identities have been compromised, and their sexuality

departure from his defence of it in 1996. (See Tom Shakespeare and Nicholas Watson, ‘Defending the Social Model’, Disability & Society 12, no.2 (1997): 293-300. Shakespeare’s recommendation is what he calls a ‘bridge between the social and medical models.’ The medical model adopts a medical view of the body and its impairments. It states that it is the impairment that prevents a person from performing normal activities and the model therefore concentrates on finding solution to the medical impairment without regard to the person with the impairment. Ruth Pinder, a Feminist Disability Scholar, proposes a common ground between the medical and social models, in response to Shakespeare and Watson. Drawing from feminist philosophy of “the difference-within-difference,” she imagines a “more holistic version of the social model” that recognises the relationship between the agency (person) and the structures (societal obligations to enablement and medicine). See Ruth Pinder, ‘A reply to Tom Shakespeare and Nicholas Watson, Disability & Society 12, no 2 (April 1, 1997): 301-6. For this thesis, and as explained in the body of this chapter, I adopt the social model, not just with discourse on disability, but with gender and HIV as well.

161 Edwin Etieyibo and Odirin Omiegbe, ‘Religion, Culture, and Discrimination against Persons with Disabilities in Nigeria’, African Journal of Disability 5, no. 1 (31 October 2016). The authors attest that the Nigerian government’s interpretation of disability is informed by the social model. However, the government’s actions seem to make disability the problem of the person with impairment and as such government involvement in disability rights actions is inadequate. Persons with disabilities are therefore, expected to make personal efforts to overcome obstacles that prevent their active inclusion and participant in the society.


controlled by male-dominated societies. It does appear that gender inequalities exist in disability when it (disability) is not regarded as a normal occurrence for both male and female in any given society. Disability therefore means something different for men and women, with women being more marginalised in the process.

Josephine Sinyo highlights some of the ways in which women are more affected by disabilities in the following sentences. Disability drives poverty for women who due to their impairment are unable to engage in economic activities and are thereby dependent on others. Their poor status means that they may be unable to live fulfilling and healthy lives. Many women with disabilities are denied access to health care because they are perceived as people without value or worth. Many women with disabilities suffer various forms of sexual and gender-based violence such as rape, physical assault, emotional abuse, or psychological trauma which are all drivers of HIV. In her words Sinyo says,

> Majority of the women with disabilities are illiterate and untrained. Little investment is made in us and therefore many of us lack confidence and self-esteem. Turning to the issue of power and decision making, the majority of women with disabilities have no credentials, no godfathers, no connections and therefore are the powerless of the powerless in both state and church. Another area of total neglect is marriage. Even the men with disabilities marry able-bodied women. Women with disabilities are always considered of lesser value than the able-bodied women and are often blamed for their disability and are not considered beautiful or admirable and are assumed not able to perform domestic chores efficiently.

Sinyo’s description of the ways in which women with disabilities are treated, though writing from an East African context, is representative of how ‘majority’ of the women with disabilities are treated in Nigerian, and many parts of Africa. However, Sinyo may be guilty of generalising the experience of disability as many women with disabilities are not illiterates and are able to undertake academic trainings. Many women with disabilities, even members of BOLD, are stigmatised even though they are educated and financially viable.

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In 2007, Okafor Cyprian Uzoigwe, carried out a study in Nigeria to investigate whether women with disabilities are more discriminated against than men with disabilities. Uzoigwe observed that,

Women with disabilities in Nigeria, by and large, face all sorts of discrimination. They are not provided access to social facilities. They are not given the opportunity for education and jobs. They are not provided the right social life.¹⁶⁵

Uzoigwe concluded that women with disabilities in Nigeria are still being disproportionately discriminated against. The study further showed that “ethnicity, cultural, and religious beliefs significantly informed negative attitudes towards women with disabilities,” and that these beliefs are passed on from generation to generation.¹⁶⁶ Like Sinyo, however, Uzoigwe’s findings are the realities of many of my research participants where it is assumed that religio-cultural stereotypes influence these negative behaviours. The extent to which this is true will be discussed later in this chapter.

The various forms of exclusion of women with disabilities from religious, cultural, and social spaces, as narrated by Muigai, have not only been by the men. Women without disabilities have often excluded women with disabilities in these spaces. The Circle has declared unacceptable the tendency to silence women and stop them from addressing ‘deadly structural violence against them.’¹⁶⁷ In the same way, Chisale notes how women with disabilities have felt silenced by the Circle’s failure to address their concerns in the Circle’s struggle for gender justice.¹⁶⁸ They have been excluded from women’s spaces as well. This is how Muigai expresses it,

Many disabled women have also experienced exclusion from the women’s movement as women strive to shift from the traditional role of ‘care-givers’. They have also been turned away by the disabled people’s movement because it is still very patriarchal.

¹⁶⁵ Okafor Cyprian Uzoigwe, ‘The Relationship between Culture, Gender, Beliefs, and the Attitudes of Nigerians towards People with Disabilities’ (Dissertation, New York, USA, Teachers College, Columbia University, 2007), 72-3.
¹⁶⁶ Uzoigwe, ‘The Relationship between Culture, Gender, Beliefs’, 75. Nigeria has over 250 ethnic groups and ethnicity plays a role in attitude formations towards women and disability
¹⁶⁸ Sinenhlanhla S. Chisale, “Disabled Motherhood in an African Community”: Towards an African Women Theology of Disability’, In Die Skriflig / In Luce Verbi 52, no. 1 [30 October 2018], Chisale accuses the Circle of neglecting to address the challenges of disability for women and calls this a form of ‘silencing.’
Double exclusion for women with disabilities by men and by women have meant that concerns of disability have not been part of the gender discourse. According to Susan Wendell, ‘disabled women struggle with both the oppression of being women in male-dominated societies and the oppression of being disabled in societies dominated by the abled-bodied.’ As discussed earlier in this chapter, women with disabilities are more disadvantaged whether it is regarding challenges relating to gender or to disability. Sinyo speaks about the ‘life sentence of being alive yet trapped, judged and sentenced for being a woman with disabilities.’ This thesis is not disregarding the challenges that men with disabilities face because of their condition. It notes, however, that primary and secondary data highlight systemic issues that worsen the challenges of women.

It also means that sometimes, the issues confronting women may not be the immediate issues of importance for women with disabilities. One example is in the duty of procreation as an assumed essential gender-specific role for African women. During a focus group discussion, research participants shared how their identities as women had been unceremoniously removed and only being women with disabilities mattered. Some said they were being looked at as incapable of getting married, having sexual intercourse, or bearing children. They expressed a loss of hope for marriage or motherhood because they now live with HIV. As such, the women that I interviewed shared how they carry the triple burden of being women, who suffer marginalisation from men and women; of being defined by their disabilities instead of abilities, and of living with the medical and social effects of HIV. Amid these experiences, was also the determined resilience of the women that I interviewed, as one said, to ‘rise above what people think’ and live to celebrate life.

2.4 HIV within the Context of Women Living with Disabilities

HIV (Human Immunodeficiency Virus) is a biomedical and biological disease. It is a medical condition that requires medical treatment. When people who are living with HIV can access and adhere to treatment, then they can live better and longer lives. Where it is impossible, either due to lack of access to treatment or inability to adhere

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170 Sinyo, Josephine, ‘Gender and Disability Challenges Within the Church’. 209-19.
to treatment, then the virus introduces infections that can degenerate into AIDS (Acquired Immune Deficiency Syndrome) which leads to death. In this thesis, I have used HIV to describe the condition of my research participants because that is the stage of the disease for all that were involved in the study. In adults, HIV is transmitted through blood (transfusion or medical equipment) or bodily fluids (seminal and vaginal).

HIV and the various efforts at HIV interventions have never been only about the medical nature of the disease due to the prevailing religious, cultural, and social misconceptions surrounding the means of transmission of the virus.171 In many cases when people test positive for HIV, it is assumed, especially women, that it is due to sexual relationships not religiously allowed, such as between unmarried people or unfaithful married partners. It is for this reason that this research did not investigate the means of transmission for my research participants. I was careful not to ask the question of how they were infected with HIV, because that question is capable of instigating stigma and judgment. Instead, I asked how they were coping or living with the virus, which is the focus of this thesis.172

To explain causality further, questions about how the infection was transmitted promotes the “personal responsibility model” that blames the infected person’s lifestyle for HIV infection.173 It does not tie with the social model which this thesis adopts. While not minimizing individual responsibility for HIV prevention, the personal responsibility model ignores gender inequalities that rob women of the power to negotiate sex (or safe sex).174 It could be argued that the question of capacity for women with disabilities is a contested issue. Some women are more capable than others. The problem lies in essentialising women’s capacity in the face of inequality. It also tends to fuel stigma that mitigates against efforts towards the elimination of HIV. The personal responsibility model also does not take account of HIV infections through medical interventions such as blood transfusion, use of medical equipment or

172 This knowledge was from part of the HIV Facilitators Training that I attended in South Africa in 2014 organised by Christian AIDS Bureau of South Africa (CABSA), sponsored by the World Council of Church, Ecumenical HIV and AIDS Initiatives and Advocacy.
contact with an infected health professional. Consequently, blaming infected persons for diseases and infections tend to absolve society of its responsibility towards HIV education of HIV risk reduction.

For women with disabilities, they are more likely to contract HIV and AIDS due to abuse, lack of access to information, and treatment when so infected. In tandem with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), UNAIDS reiterates that ‘women and girls with disabilities are at greater risk’ of HIV infection and need specific protection from negligence and violence. Ezra Chitando, who has collaborated with the Circle to address gender inequalities, has highlighted some of the factors that foster the vulnerability of women with disabilities to HIV. According to Chitando,

In some parts of Africa, many women with disabilities are unlikely to marry. There are high chances of them being involved in unstable relationships. Many women with disabilities are also desperately poor, leaving them vulnerable to transactional sex. In addition, women with disabilities are more vulnerable to rape.

As a Theological Consultant for World Council of Churches, Ecumenical HIV and AIDS Initiatives and Advocacy (WCC-EHAIA), Chitando writes from his experience of working on HIV and AIDS intervention in many African countries. His writings are among the few to highlight the connection between disability and HIV as posing a challenge for women due to gender inequalities in largely patriarchal African settings. Another writing about HIV and women with disabilities is Uzoigwe who writes from a Nigerian context and notes that,

AIDS may triple the stigmatization (for women); a person with AIDS who is a woman is first disadvantaged as a woman, stigmatised as a disabled woman, and then stigmatised as a woman with HIV and AIDS.

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175 McGrath, 'The Biological Impact of Social Responses to the AIDS Epidemic'.
176 Michelle Kasongo Kamba, 'Developing a Holistic Educational Programme through Contextual Bible Study with People with Disabilities in Kinshasa, Democratic Republic of Congo: IMAN’ENDA as Case Study' (PhD, Pietermaritburgh, South Africa, College of Humanities, University of KwaZulu-Natal, 2013), 25.
177 'Disability and HIV'.
179 Uzoigwe, 'The Relationship between Culture, Gender, Beliefs', 80-1.
In this observation, we equally observe the presence of the stigma of gender, disability, and HIV for women. This triple level of stigmatisation for women with disabilities who are also living with HIV, according to Uzoigwe, is because of ‘ignorance, negative cultural factors, myths, and misconceptions’ of Nigerians. Uzoigwe also highlights that many Nigerians treat HIV and AIDS as a disability for women because of the misconceived idea that women who are infected cannot have children. Each of these conditions carries the weight of stigma for women in ways that continually affect their relationships in the family, society, and the church. It also makes women with disabilities vulnerable to health crisis.

It has been suggested that men’s negative behaviour in society puts women at an elevated risk of HIV and AIDS. It has been argued, however, that HIV infects both men and women, as men are affected by their behaviour in HIV and AIDS transmission just as women are. As such, men also suffer the effects of the medical and social consequences of HIV. The unintended consequence of this is that whenever women test positive for HIV, they are blamed for voluntarily engaging in illicit sex acts and inequality is ignored as driving this infection. The counter argument is that often, women’s infection is conditioned by gender inequality where women are unable to negotiate safe sex or what happens to their bodies. HIV prevention strategies have not always taken women’s vulnerability or gender inequality into consideration.

One of the earliest attempts to combat HIV was the ABC approach (‘Abstain,’ ‘Be faithful,’ and ‘Condom (use condom).’ ABC approach called for individual behavioural change to eliminate HIV and contained an implied responsibility on

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180 Uzoigwe, ‘The Relationship between Culture, Gender, Beliefs’, 80.
181 Uzoigwe, 'The Relationship between Culture, Gender, Beliefs', 35-6. The women with disabilities and HIV that I interviewed shared that HIV compounded the challenges of disability, but they did not speak of it as an added disability.
184 Kamba, ‘Developing a Holistic Educational Programme through Contextual Bible Study with People with Disabilities in Kinshasa, Democratic Republic of Congo: IMAN’ENDA as Case Study’.
185 Dube Shomanah, The HIV & AIDS Bible, 139. Dube says gender inequalities make ABC bad for women. For example, abstaining does not stop rape, being faithful does not stop unfaithful husbands from having unprotected sex, and many women have no power to insist on condoms making women susceptible to HIV infection.
women to negotiate sexual relations.\textsuperscript{186} In Nigeria, as in much of Africa, many religious leaders rejected the ‘C’ (use of condom) in the ABC approach.\textsuperscript{187} They argued that promoting the use of a condom was akin to promoting sinful sexual habits. This rejection was also informed by the misconception among many church leaders and church fellowships, that HIV infection was punishment for immoral sex.\textsuperscript{188} The church’s stance was counter-productive, and women suffered as a result. Society’s responsibility to ensure appropriate education and control the systemic problems that promote risky sexual behaviour was not tackled.\textsuperscript{189} To address the gaps of implied responsibility in the ABC approach, the International Network of Religious Leaders living with or and personally affected by HIV and AIDS (INERELA+), introduced the SAVE methodology.\textsuperscript{190}

SAVE represents Safer Access, Voluntary Testing, and Empowerment.\textsuperscript{191} SAVE addresses the concerns for HIV prevention, misconceptions about HIV, raises awareness of the negative effects of stigma, and calls for continuous education on HIV and AIDS. Nina O’Farrell of Christian Aid refers to SAVE as challenging all structural drivers of HIV.\textsuperscript{192} However, SAVE has been criticized for being too complex for those without adequate education or exposure to understand or implement. For example, only three women among my research participants knew its details and

\textsuperscript{186} Azetsop, \textit{HIV and AIDS in Africa}, xii.
\textsuperscript{187} Laura S. Grillo, Hassan J. Ndlovu, and A. S. Van Klinken, \textit{Religions in Contemporary Africa: An Introduction} (New York, NY: Routledge, 2019), 217-8. The authors noted that muslim leaders also rejected the use of condom for the same reason that it would ‘allow for sexual promiscuity.’
\textsuperscript{189} Hinga, \textit{African, Christian, Feminist}, 140.
\textsuperscript{190} Grillo, Ndlovu, and Van Klinken, \textit{Religions in Contemporary Africa}, 217.
\textsuperscript{191} For more information, see ‘Save Toolkit’, \textit{Inerela} (blog), accessed 8 February 2019, http://inerela.org/resources/save-toolkit/.
\textsuperscript{192} ‘Save Toolkit’.
only one had attended training on its implementation. Besides, not all religious communities are comfortable with its explicit discussion about sex and the human anatomy.\textsuperscript{193} In my experience facilitating SAVE, it still holds individuals accountable to adhere to the instructions and advice. It also does not adequately acknowledge the role of support systems that are needed to achieve adherence or the positive role that faith plays for religious people. One of the strengths of SAVE, however, is its recognition that HIV is a medical disease but that it is driven by social and religious conceptions. According to Musa Dube,

\begin{quote}
It (HIV) is not just a medical or biological issue. Rather, it is also a social disease, which is very much dependent on poverty, violence, gender inequality, the abuse of human and children’s rights, sexual discrimination, drug and sex trafficking, national corruption, international economic injustice, and globalisation.\textsuperscript{194}
\end{quote}

Until those conceptions are adequately addressed, the goals for the elimination of HIV and AIDS will be difficult to achieve. I could argue that it is for these non-medical reasons, listed in the above quote, that HIV response needs a positive, empowering faith perspective.

These indices that are present in driving HIV also play devastating roles for disability. The social components of gender, disability, or HIV mean that they are communal issues; when one person is affected, the family and the community are affected. On the one hand is the stress of living with disability and HIV, (for my research participants) which makes forming close relationships (in family and society) difficult.\textsuperscript{195} On the other hand, the society is impoverished when a group within it experiences “anger, frustrations and poverty,” because of the way that society is structured.\textsuperscript{196} According to Dube concerning the HIV and AIDS,

\begin{quote}
Its determinants and its magnitude have a far-reaching impact, affecting the economic, political, spiritual, social and cultural aspects of humanity and calling into question all the foundations
\end{quote}

\textsuperscript{194} Dube Shomanah, The HIV & AIDS Bible, 100.
of our relationships, including the vulnerability of occupying our own bodies

The difficulties that the women I interviewed face in navigating personal and communal relationships is discussed in Chapter five of this thesis. These women with disabilities appreciate the medical challenges and medical interventions of living with HIV, but they also demonstrate that faith, believed and practiced, plays a crucial role in helping them to cope better with those challenges. They represent what Njoroge describes as “ordinary women who act with extra-ordinary courage” to overcome oppression and live positively for the good of the community. It is from within these conditions that the women I interviewed shared the place of their faith in helping them to make sense of their realities and of their lives. These women spoke of their faith as an enabler, involving a connection with Jesus Christ through whom other aspects of their lives such as relationship, belongingness, faith resources and social dynamics, all fitting together.

2.5 Faith Response to Gender, Disability and HIV
This thesis seeks to understand the role of Christian faith for women living with disabilities and HIV in South-South Nigeria. This quest hinges on an assumption of the religiosity of African Christians and the premise that the Christian faith influences the lives of its adherents in multiple ways. What this means is that there is an expectation among the Christian community that Christian faith should address the multi-layered consequences of stigma associated with gender, disability, and HIV. It should also address the inequalities of patriarchy and allow for the dignity of all human persons supported by the United Nations human rights provision. This section explores ways in which faith has been used to address these challenges for women.

In the preface to an earlier publication, I had written this about Africa,

We (Africans) are a deeply religious people. Religion is integrated into every aspect of our culture and shapes the very fibre of our being. This in itself is a gift from God, and it forms

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197 Njoroge, “Daughters of Africa Heed the Call for Justice, Peace, and Fullness of Life.” See also Njoroge, Nyambura. “Preach the Gospel of Jesus Christ and tell HER Story.” In Ezra Chitando and Sophia Chirongoma, eds., Justice Not Silence: Churches Facing Sexual and Gender-Based Violence, 17-34. Stellenbosch, UK:EFSA.
our wholeness, binds our interrelatedness to all humanity and to creation, and expresses our belonging to God.  

In Nigeria, and in much of Africa, religion is a core identity shaper, second only to cultural identity. It sets out where we, as Nigerian people, belong and how we express our belonging. However, religion and culture have also been used to justify all forms of oppression. Interpretations of sacred texts in religion or misconceptions of oral tradition in our culture have led to stereotypes that assert that disability is a curse from God or spirits and that HIV is transmitted through immoral sex or ‘risky sexual behaviour.’ The consequence of this is that women who are already marginalised for being women in a patriarchal society, suffer the social consequences of triple stigma – gender, disability, and HIV. Arguably, just as religion is used to promote these negative stereotypes, it can also be used to encourage positive and affirming values.

Circle members have reiterated that “faith plays an important role in individual and community life and that it has the capacity to control social and health conduct.” However, because faith is based on interpretations, it is capable of being utilised for good or for evil. Phumzile Mabizela recognises that just as there are life-giving theologies, there are also theologies that are not life-giving. Mabizela enjoins that because “we are all created in the image of God, we must develop life-giving theologies.” Nyambura Njoroge, echoes the need for life-giving theologies, as those which resist dehumanising systems and seeks transformation towards newness of life. To Njoroge, life-giving theologies that address the HIV and AIDS pandemic must also address the drivers of the virus such as wrong use of Scripture, gender-based violence as well as the conspiracy of silence in Africa.

From the perspective of my research participants however, the culture of silence is two-fold: one that is a personal choice and the other that is a form of abuse.

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198 Fubara-Manuel, Giver of Life, vii.
201 ‘The Challenges of Faith Responses to the AIDS Epidemic’.
203 Njoroge, 'Let's Celebrate the Power of Naming'.
During field work, the women shared how their silence in the face of exclusion is an act of strength. They choose to ignore exclusion or humiliation and find alternative ways of living than challenging the status quo. Whether it is dealing with an abusive marital relationship, coping with exclusion from the church space, coping with fear of family-stigma, these women in this research, make intentional choices not to be intimidated but to flourish. It is the silence from the world towards their stigmatised condition that is the abuse. According to Denise M. Ackermann, not all stories of persons living with HIV are of “silence, stigma, and death,” there are also stories of courage and “endurance under very difficult circumstances.”

Ini Dorcas Dah supports this view by saying that ‘telling women’s stories of marginalisation and pain as well as stories of resilience and … is a form of feminist response that reveals strength in the face of patriarchy.’

Many times, the action of choice for the Circle is inconsistent with the realities of many women, such as women with disabilities and HIV.

Circle members have also called for a critical cultural ‘retrieval and glorification of African religions and cultures,’ as not to do so will ‘continue to erode women’s dignity and wholeness.’ Cultural practices can result in physical and emotional health problems for women. An example is a cultural practice that can enable sexual abuse that could result in sexually transmitted diseases like HIV and AIDS. Furthermore, these negative interpretations hinder the creation of life-giving theologies for marginalised people, because women’s experiences are often shaped by circumstances of culture, gender, class, ethnicity and race.

To Helen Labeodan, the Circle comes from the lens of faith to seek “solidarity with those who suffer marginalisation of every kind, trying to understand, analyse and change the systems of domination and abuse of power”.

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208 Labeodan, ‘Revisiting the Legacy of the Circle of Concerned African Women Theologians Today’. 
greatly enriched by an adequate incorporation of the voices of women with disabilities and HIV for a proper critique of culture.

It has been acknowledged that the Bible has been used to support patriarchy and other forms of discrimination on issues of gender, disability, and HIV. At the Circle’s 2002 conference on ‘Sex, Stigma, and HIV/AIDS,’ it considered ‘the role played by sacred texts, faith communities and African cultures in both the spread and prevention of HIV as it affects African women.’ It noted that Scripture has often been used to justify women’s domestication and oppression, both of which drive inequality. It also affirmed that scripture can be used for the liberation of women, and in this case African women. Musa Dube has written extensively on how reading the Bible with African women “biblical/theologians’ hermeneutics can contribute towards the struggle against HIV and AIDS.” Micheline Kamba used contextual Bible study (CBS) methodology to discuss wholistic healing for persons with disabilities in the African context where healing is fixated on the physical.

Other Circle women such as Musimbi Kanyoro, Ruth O. Oke, and Madipoane Masenya have written on the use of the Bible to address issues such as poverty, patriarchy, social justice, gender-based violence, etc, in the context of HIV and AIDS. WCC-EHAIA has also adopted the CBS methodology in many workshops in Nigeria addressing issues of Sexual and Reproductive Health and Rights, gender-based violence, stigma, and discrimination, etc. The Circle recognises that within Christianity’s Scriptures are verses for women’s empowerment and liberation. In Chapter Six, I discuss the various ways in which research participants use the Bible as resource in creating a sustainable coping strategy for disability and HIV. Such creative

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209 Nadar et al., ‘Roundtable’.
211 Kamba, ‘Developing a Holistic Educational Programme through Contextual Bible Study with People with Disabilities in Kinshasa, Democratic Republic of Congo: IMAN’ENDA as Case Study’.
214 Madipoane Masenya and V. Ndikhokele N. Mtshiselwa, ‘Dangling between Death and Hope: An HIV and AIDS Gender-Sensitive Re-Reading of Psalm 6’, *Verbum et Ecclesia* 37, no. 2 (2016), 1–8. The authors read the Bible HIV and AIDS lens.
ways include Scripture as a constant companion, as resource to address stigma, and as inspiration to assert their personhood.

There have been expositions of biblical teachings from many Christian denominations in Nigeria who have promoted teachings that are not life-giving. In much of Africa, as in Nigeria, there are pastors who claim that persons who exercise faith would never be sick and that Christians who give faithfully would be rewarded with ‘material abundance, wellbeing and perfect health.’ The women who participated in this research talked extensively about healing. Misleading teachings about healing through faith without medical intervention was discussed. Many of the women, based on experiences of deaths of close friends or family members, argued for the use of faith and medicine as they are, according to the women, miraculous gifts from God. J Kwabena Asamoah-Gyadu has written extensively on the new message of Pentecostalism that ‘God is good and powerful to save and prosper his children’ and wonders how this is explained to Christians suffering disease and oppression. That African experience is one of struggle amid diseases, wars and poverty or that life in Africa is hard is no news. For Benebo Fubara-Manuel, the question is how such problems can be handled within the belief that ‘God is sovereignly at work in history’ and in the Christian’s life.

What is commonly agreed upon is that Christianity holds the answers to the complex realities that confront Africans, and the entire world. For the women in this research, it was the simple unambiguous expression of faith in Jesus Christ who is able to help them.

Just as the Circle seeks to reclaim liberating interpretations of sacred texts, so it seeks rediscovering cultural ethics that promote women’s empowerment. Sinenhlanhla S. Chisale, one of the few African women writing on issues of women and disability, attempts to recover the African ethos of community to propose an African women’s theology of disability. Chisale works on the premise of an understanding of *Ubuntu* where there is value for everyone in a relationship of

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interdependence. The idea of difference breeds fear that *Ubuntu* abhors. As cited, van Klinken, Chitando, Moyo, and Dube have considered the idea of the indigenous concept of *Ubuntu* to address the HIV and AIDS dilemma. Chitando’s preference for a “masculinity of solidarity” incorporated in the concept of *Ubuntu*, would, perhaps, address Molly Manyonganise’s concern for the ambivalent nature of *Ubuntu* as both oppressive and liberative for women. A masculinity of solidarity agrees with the suggestion for the creation of “new models” of partnership between women and men to work together towards a less sexist society. The extent to which an African indigenous concept could help deliver an ideology or theology that promotes and facilitates gender equality is yet to be fully explored.

What is also yet to be fully explored is how to respond to the UN call for a resolution of the tension between health and faith values. Faith is not inconsistent with human rights. According to Dube,

> Believers have nothing against the notion of human rights, for our faith holds that every human being was created in God’s image and deserves to live a life of dignity.

Human rights are part and parcel of faith rights and are based on the affirmation of equality of all human beings. Life-giving theologies, fit for incorporation into the United Nations strategies for HIV and AIDS response, honours the dignity of all persons: male and female, with and without disability.

It is a ‘commitment of all of us to life, for all life is sacred to God.’ Equality promotes justice and respect for all. Life-giving theologies must also address an HIV response that integrates the UN health and rights-based strategies with positive faith beliefs and practices.

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223 Musa W. Dube Shomanah, *The HIV & AIDS Bible*, 4. Dube calls on ‘today’s generation of biblical scholars, theologians, church leaders and faith-based organisations,’ to respond to the global AIDS crisis
224 Dube, ‘Culture, Gender and HIV/AIDS’.
2.6 Conclusion for Chapter Two

For my thesis, it is vital to understand gender, disability, HIV and Faith, and the way they are conceptualised. These four elements intersect to provide a comprehensive picture of what my participants contend with amid the complexities and factors of inequality that they have to deal with in their lives. These are socially constructed concepts. These concepts are flexible and learned in terms of behavioural or attitudinal patterns. It could be argued therefore, that the gap between religious values and health responses could be narrowed by an understanding and response to these elements.

Drawing on literatures and field work interviews, this chapter has endeavoured to discuss the complexities of gender, disability, HIV, and faith. It explored the ways and means in which women negotiate these realities within the tensions of religious and cultural beliefs and practices. Embedded in these beliefs and practices is the endemic nature of patriarchy. There is a blame game with patriarchy. Women blame men as perpetrators of negative actions that make women vulnerable to HIV infection. Men blame women for enabling patriarchy through women’s actions or inactions. While there is progress in terms of gender-relations between men and women with some recorded improvement in church leadership, in many cases, inequality still exists.

This chapter demonstrates that women, and especially women with disabilities are disproportionately affected and more impacted by the discrimination because of the stigma of gender, disability, and HIV. I argue that when women without disabilities fail to include women with disabilities in their fight for gender justice, women become oppressors of women indirectly. This demonstrates that the willingness and capacity for women with disabilities to engage with or confront patriarchy may also lie in achieving their solidarity with fellow women.

The chapter further buttresses the place of faith as necessary for a liberating response to the concerns of gender, disability, and HIV. Circle writings presuppose the presence of active faith for women to engage with gender-based challenges. While there may be no deliberate effort to define the term, Christian faith, Christians live out their lives in the understanding that faith in Jesus Christ is critical to their spirituality and response to societal challenges. The next chapter provides details of the
methodology for this research, offering information about the process and the context of data collection and interpretation.
Chapter Three
Research Methodology

3.0 Introduction
In this Chapter, I discuss the research methodology of this study, describing in detail the process of data collection, the research participants, and the research environment. This Chapter further provides the theoretical framework of this research and the extent to which this determined the research boundaries. It highlights the gains of the fluidity in qualitative research, especially when investigating the faith lives of women with disabilities and HIV, who face uncertain challenges daily. I demonstrate as other scholars have done before me, how important is the rigorous and often unpredictable process of research (data collection, interpretation, and analysis) for the findings and usage. In aligning with the social science model to provide such in-depth information of the research process, it takes advantage of the multi-disciplinary nature of World Christianity to use a combination of techniques while staying focused on the way my research participants understood their faith and how that understanding influenced their lives.

3.1 Researcher’s Identity
In May 2018, I carried out a study exploring the extent of disability engagement in a church in Port-Harcourt, Nigeria. This study also served as pilot study for my PhD research investigating the role of Christian faith for women with disabilities, and HIV. As part of the pilot study, I identified Bold Outstanding Ladies with Disabilities Hearts Network (BOLD Network) as the subject for case study for the PhD research and interacted with both the leadership of BOLD Network and some of the members. My proposed PhD research interest was well received by BOLD Network. They appreciated my intention to examine how they understand and practice Christian faith and the impact of this understanding and practice on their daily lives facing sociological challenges. We (BOLD and I) developed a friendship that enabled those also infected with HIV to reach out and indicate their willingness to be part of the study. Two research sites of Port Harcourt, Rivers State and Uyo, Akwa Ibom State in

South-South Nigeria were selected as research sites due to the high prevalence of HIV in these two South-South States of Nigeria.

On arrival for my field work in July 2019, I was familiar with the BOLD Network and to its members. I had also lived in Port-Harcourt and Uyo in the past. I was keenly aware of the dilemma of the insider-outsider dichotomy recognising the fluidity of both positions while acknowledging that knowing the people and places did not mean I knew the experiences of the women. My insider status within BOLD Network, as an ally, opened the doors I needed for my research, but my outsider status, as a researcher, needed to be strong for authentic research to take place. Also, the experiences of disability and HIV were not within my personal sphere of experience and presented another level to my outsider status. These all called for careful listening, learning, and recording. As an African woman, I shared the same gender identity and some common gender-based challenges as the research participants, but I still had to appreciate the distinctiveness of the experience of disability and HIV that they brought to this study. This sense of shifting identities has been likened to a dice with many sides; just as the dice shows one angle at a time without losing its other angles, researchers carry different identities that come to the fore depending on the environment they find themselves. My many identities, embedded within the insider-outsider dichotomy manifested themselves at appropriate times and in appropriate settings.

In my interactions with BOLD Network, a friendship developed that would lace our conversations and our meetings. BOLD Network had started with a few female friends providing safe spaces for mutual support, encouragement, and empowerment. Through their shared experiences, they had become a ‘community of sisters who share similar circumstances and struggles.’ Their friendship has metamorphosed into sisterhood as they felt more akin to each other. It was into this sisterhood that I had been welcomed. Together, we were women, friends, sisters,

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226 Ezra Chitando, ‘The Insider/Outsider Problem in Research on Religion and Migration’, in Religion in the Context of African Migration, ed. A. Adogame and C. Weisskoppel (Bayreuth: Pia Thielmann & Eckhard Breitinger, 2005), 79–94. Ezra Chitando argues that the researcher must acknowledge the complementary nature of both insider and outsider perspectives and optimise the advantages of both.

mothers, wives, and ordinary Christian people seeking opportunities to worship God. Our common faith in Jesus Christ had made us ‘no longer strangers’ and together we were children of God created in God’s image.\textsuperscript{228} This relationship of friendship and sisterhood engendered trust for my person and my research. The freedom to interact and share experiences with my fellow women ensured that my data collection process was engaging. My dressing was casual and comfortable facilitating an easy blend with my research participants. However, I was strongly aware that I was a researcher focusing on the objectives of my research.

Research participants belonged to different denominations and each denomination posed a different challenge for access. I visited 10 churches to which research participants belonged. For each, I had to receive some form of tutorial from the invitee. Such cautions as ‘do not wear trousers,’ ‘do not wear sleeveless or short dress,’ ‘Please cover your hair before you enter the church premises,’ ‘sit on the women’s side of the church,’ etc. I took seriously the admonition of Warren and Rasmussen to alter my ‘dress, demeanour, and conversational style’ to ‘fit the setting even before entry.’\textsuperscript{229} It was prudent to shun actions that might deny me access because they could be interpreted as being inappropriate behaviour for a woman. It is often advisable that things that can facilitate an acceptable impression such as ‘clothing, style, verbalization, traditional or institutional sex-role presentations’ could be managed to achieve access into the field if these are true to the researcher’s person.\textsuperscript{230} In a few cases however, being a woman and researching women’s issues played in my favour. Some people felt as a woman, I could relate with and understand the experiences that are peculiar to women such as issues of sexual and reproductive health and or power dynamics in heterosexual relationships.

In sum, I was intentional about the angle of my identity that was prominent given the requirements of the research environment. I tried my best to comply with the cultural, health, social and religious demands on women to avoid inhibiting the progress of the research, especially given the sensitive nature of the topic.

\textsuperscript{230} Carol A.B. Warren and Paul K. Rasmussen, 21-35.
3.2 Research Participants
The research focused on BOLD Hearts Network (BOLD Network) for its case study. As a network of women with disabilities, those of its members who also live with HIV formed the core research participants for my fieldwork. I interacted extensively with the membership of BOLD Network in which we discussed the research objectives and methodology, in addition to having a Focus Group Discussions (FGD) with the entire membership. However, it was the interactions with those who live with HIV that formed the primary data for this research, and with whom I carried out participant observation in addition to interviews and FGDs.

Unlike previous notions that sampling, and selection were not relevant in qualitative research, it has been posited that every action to identify a research population is an action in research sampling and selection. In the absence of statistical probabilities, this research relied on ‘practical and resource-based issues’ that would enrich the process of generating data to answer the research questions.231 To select a meaningful research sample (core research participations), some key considerations informed the decision to ensure that data collected provided a variety of stories, contexts, and traditions. One was that the State with the higher HIV prevalence would produce more participants. As such, there were seven participants from Uyo and five from Port Harcourt. The second was to highlight the different types of disabilities among the women which meant having women with hearing, sight and physical (mobility) impairments as part of the research. The third was ensuring intergenerational and marital status variety: the twelve core research participants were aged between twenty-five to fifty, three were widows, six married and four were singles. It was also necessary, fourthly, to have women who were willing to take part in the extended rigours of the research with their time and their stories.

In addition to these core research participants, I also interviewed the following categories of persons: 8 health practitioners at the two HIV clinics in Port Harcourt, 2 members each of the International Network of Persons Living with and Affected by HIV and AIDS (INERELA+) in Port Harcourt and Uyo, 7 members of the BOLD Network coordinating team covering Port Harcourt and Uyo, 8 Religious leaders, and 4 leaders of an HIV Support Group in Port Harcourt. I attended one HIV Support

Group meeting each in Port Harcourt and Uyo and conducted random interviews with about 5 members in each location. The number of women at the BOLD Network FGDs in Port Harcourt and Uyo was about 30. The total number of research participants (core and non-core) was about 85 persons. All research participants signed the approved Consent Form and participated in the research freely.

Due to the sensitive nature of this research, the need to protect the identities of the research participants and to ensure confidentiality, pseudonyms were used in writing up the research findings. Ethical norms require that the identities of research participants be concealed where such revelation could harm their reputation, where such revelation could cause stigma and or where such revelation could cause emotional distress. Although pseudonyms have been used for a long time in research, some scholars have raised objections to its use. They argue that the use of pseudonyms is not scientific, does not facilitate critical evaluation of data and does not allow for fact verification. They worry that disguise of research participants and sites of research could lead to distortion of facts especially in sensitive research. Although these objections are not easily dismissible, it is also fact that pseudonyms are indispensable for cooperation from research participants especially in sensitive research involving sexual behaviour, intimate matters and concerns for personal safety or security. However, to mitigate these objections, the research participants picked their own pseudonym and will check the parts of this work where they appear.

Pseudonyms provided a safe space to tell their stories without the concern that those who are unaware of their status would learn about it in the public realm if the product of the research is made public. Of the twelve core participants, only 6 (1 single, 4 married and 1 widow) had disclosed their positive HIV status to their family members and only 2 out of the 6 (1 widow and 1 married) had disclosed same status to their religious leaders. Family members usually meant just one close sibling or in the case of married couples, just each other. The implication of this was I could not engage directly with some of the family members on the coping mechanisms of the research participants. Visits to such family settings were disguised as I was often

233 Lee, Doing Research on Sensitive Topics, 187.
234 Van Klinken, Kenyan, Christian, Queer, 142. Van Klinken notes the difficulty with disclosure of positive HIV status due to stigma that still surrounds the epidemic.
introduced as a ‘friend from way back’ or a ‘distant relation’ and not a researcher. Whilst I was able to observe their home settings, this disguise portrays the difficulty of their daily lives as they hid their HIV status from their closest people for fear of communal stigma. Non-disclosure to their religious leaders also meant I could not talk with their religious leaders beyond general conversations. I arranged visits to churches but only to observe the extent of their inclusion in the life of the church. It was a privilege that they were willing to share their stories with me even though for many of them, we had been strangers before our first meeting on the field.

3.3 Research Techniques
This research follows a triangulation research design which allows for the use of a blend of complementary research methods so the researcher can cross-check facts and properly critique data.235 In this work, an ethnographic approach incorporated primary data collection techniques of participant-observation, interviews, focus groups and stories of research participants.236 Ethnography offers a research process where through mainly qualitative research techniques, a researcher can study the lives of those being researched over a period. As a written product, ethnography draws on the data collected primarily from the field work to produce a report.237 In view of the fact that my research is on the faith lives of women, it falls within the category of ‘faith-based ethnography’ which involves investigating faith development based on the experiences of faith. Faith-based ethnography has been described as ‘…. a means of being in relationship with God and practising the core values of the faith community.’238 The research conversations I initiated were deliberately inclusive of the faith perspectives of the research participants and respectful of their desire for

235 Diane B. Stinton, Jesus of Africa: Voices of Contemporary African Christology, Faith and Cultures Series (Maryknoll, N.Y: Orbis Books, 2004), 54-55. Stinton draws from Catherine Marshall and Gretchen B. Rossman, Designing Qualitative Research, to make a case for triangulation in research methods. Marshall and Rossman discuss this method as useful to ‘collaborate, elaborate, or illuminate’ facts from research; a resource that I found useful as I navigated the terrain of my research between two cities and twelve different women.
236 I maintained a journal of the field notes and carried about a digital recorder to audio-record interviews and discussions.
privacy in discussing their private lives. Following proper consent, all proceedings in all techniques, were audio recorded in addition to my note taking and all research participants gave written consent. I was able to carry out my research where observations, conversations and multi-levels of interactions could allow for the collection of data without imposition of the researcher’s bias. To do this, I employed different research techniques.

3.3.1 Participant-observation: Participant-observation is a major technique for ethnography and that which distinguishes ethnography from other forms of research. It is the immersion of the researcher within the natural spaces and sites of the research, to learn something of its life and contexts for an extended period. While there is no specific period stipulated for a researcher, it is often assumed that it gives enough time for appropriate knowledge and understanding for the purpose of gathering adequate data. This act of the researcher’s physical presence and interaction with the participants and the community is probably what makes ethnography often referred to as field work or being in the field. The researcher is in the field of study to gather facts and to experience something of the community within which the research is being conducted.

I employed participant-observation within two communities with similar religious affiliations but somewhat differing cultural practices. It allowed me to immerse myself within the spaces normally inhabited by those that I was researching. The research paid attention to the observation of the research participants as well as the cultural, religious, and social rituals of the people. As one conversant with both societies, having a conversational knowledge of the languages spoken and of the gender dynamics in both contexts, I was able to participate while observing the relationships for the research. This act of active participation and observation is what social scientists have called ‘observing participant’ while others have differentiated the terms to just ‘observing and participating.’ Being an observing participant was crucial for contexts where my identity as a researcher was hidden out of respect for the participants’ non-disclosure. This lack of disclosure of their HIV status by the research

participants presented a challenge with the extent of observation of their lived realities that was possible within their homes.

Observations with participation took place in churches, other places of worship, as well as the business places of research participants. I visited ten churches ranging from Pentecostal, Reformed and Catholic congregations in addition to interdenominational fellowship groups. Multiple visits were made to observe the inclusivity of disability in accessibility, life, and liturgy of the church as well as the active/inactive involvement of persons with disabilities. I listened to prayer languages of the research participants and noted the confessions about their relationship with God on one hand, and with the church on the other making the distinctions between faith professed and faith practiced. In participating in the worship activities at the churches and fellowships, I sometimes experienced a ritual of worship different from that of my religious tradition and unwittingly found my faith enriched in the process. I visited other places where research participants spent their days, such as in their homes, offices/business locations and markets. In each of these places, the intent was to know and understand the daily lived realities of research participants and specifically to examine how their faith impacted on the ways in which they handled the challenges of living with disability and HIV.

My programme of participant-observation was adaptive to the circumstance of the research. For example, I visited and observed two HIV treatment centres in Port Harcourt – a state-owned hospital, and a church-owned health centre on the urging of a research participant who said to me, ‘if you want to know about our lives, hospital is an important part of it.’ It is advisable for persons living with HIV to adhere strictly to their antiretroviral therapy (ART) for longer healthier lives. As such, monthly or bi-monthly visits to treatment centres depending on treatment regimen is part of their reality, not only for collection of drugs but also to check viral loads and reaction to ART. I, therefore, wanted to observe the operations at the treatment centres, see the religiosity at these medical centres, and ascertain the extent of its impact on the overall faith experience of my research participants. I observed the treatment protocols from arrival of hospital staff to the close of the offices. It is not uncommon for ethnographic research to introduce new areas for investigation in line with allowing the field work to dictate the flow of the research, if the new dimensions still aid in generating answers.
to the research questions. However, there is always a caution that the researcher’s control of the research be kept in focus to avoid unnecessary distractions especially when confronted with the ‘messiness, twists and turns, dead-ends and unexpected avenues’ that real-life research expectedly presents.\textsuperscript{241} In all activities of this research, I was mindful and respectful that it was about lived realities of human beings.

### 3.3.2 Interview:

One of the pre-field work assignments was the preparation of proposed questions to guide the interview sessions (Appendix 4). The implication is that interview sessions employed throughout the study were not always random unstructured activities but rather in-depth exercises with relevant questions towards achieving the objectives of the research. While there was spontaneity in conversations, these questions served as guide to enable a semi-structural form of ‘qualitative interviewing’ conscious that ethnographic exercise thrives on spontaneity in interactions and conversations.\textsuperscript{242}

Although I interviewed many people during my research, my core research participants, with whom I conducted several interviews, were the twelve women with disabilities and HIV. Interviews were conducted primarily face-to-face with individual research participants and in small focus groups but also on the phone to follow up with earlier conversations or where subsequent physical meetings were not possible. As much as possible, and to facilitate an open free safe space for face-to-face conversations, an informal style was always adopted although each session had a focus to guide the interactions. This is referred to as ‘conversations with a purpose’ where the researcher is mindful of the purpose of the conversations as that to gain relevant data for study.\textsuperscript{243} However, conversations often gave rise to exchange of stories from all research participants including those of the researcher.

The interviews were geared towards gaining clear understanding of the women’s experiences and often included emotionally charged and sensitive topics. Since this was a shared cause, we (researcher and research participants) experienced a

\textsuperscript{242} Mason, \textit{Qualitative Researching}, 110.
cordial collaborative communication process that made the interview sessions very interactive. This process has been referred to as an ‘interactive interview.’²⁴⁴ As our relationship developed during the research, the women often asked me ‘so what do you think,’ or ‘you know how it is with our people.’ This sense of familiarity fostered a safe environment for sharing of intimate details of their lives that sometimes was akin to friendly conversation among friends, except of course, that in this case, my recording device was usually switched on.

Interviews at the hospitals/health care centres took a more formal route. As part of the ethical approval process, I had submitted the proposed questions to the relevant personnel. It was not clear to me whether the staff assigned to me to be interviewed had been given the questions, but I was advised by the approving authority not to depart significantly from those questions. Health care workers interviewed at both the government and church-owned hospitals were two medical doctors, four nurses, one HIV Adherence Officer and one health care clerk. When I interviewed eight faith leaders (church pastors), it was not specific to any research participants due to confidentiality concerns, because many of the women I interviewed had not disclosed their HIV status to their pastors. Within these contexts, I conducted in-depth interviews at different venues (face to face) and online (phone). Interviews were also used at the four Focus Group discussions sessions that was part of the research technique.

3.3.3 Focus Group Discussions

Focus Group Discussions (FGDs), while often used in tandem with interviews played a significant role in the data collection processes for this field work. Focus Group Discussion has been described as involving ‘a focus on specific issues, with a predetermined group of people, participating in an interactive discussion—thereby a focus group discussion.’²⁴⁵ Unlike the one-on-one interviews, FGDs provide space for group participation to facilitate discussions on agreed upon themes or focus. Women became co-researchers as they engaged with the subject of discussion, introducing

varied perspectives and challenging normative practices. The energy of allied interaction and similarities in experiences allowed participants to freely discuss their realities with personal and critical stories. In this group, women discovered the agency of their voices and support for one another as their vulnerability became their strength.

Two FGDs were conducted in collaboration with BOLD Network in Port Harcourt and Uyo respectively for women with disabilities and HIV. Members’ participation was put together by the Network extending invitations to members with HIV positive status willing to share their experiences. Many of those participants, though had not disclosed their HIV status with members of their families, but found the space safe to share their stories without fear of condemnation or judgment. The discussions were moderated by BOLD Network coordinator who is a trained facilitator, and each group’s discussions were preceded by preparatory meetings. One FGD was with women with disabilities without HIV positive status and the another was with women living with HIV but without disability. The last two discussions were informed by the findings on the field of the need to do a comparative study of the faith lives of women with disabilities on one hand and women with disabilities who are living with HIV on the other to explore the extent of extra burden (or not) that HIV and/or disability brings.

It is argued that a single FGD can generate about 70% of the same data as would have been gained from a multitude of one-on-one interviews using the same number of people. This seemed true for my research as the group dynamics helped to stimulate discussions that uncovered a range of individual perspectives. It was akin to a follow-up tool and some of the issues discussed during private or one-on-one meetings were often raised at the FGD platform. Often, I would introduce questions from conversations to tease out how the other women felt about those concerns/issues. I wonder however, if the familiarity and friendship that exist among BOLD Network members and the collective narratives at FGD events, are responsible for what I observed as similarity in many of the responses or interactions: the personal stories.

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were distinct but the response to such experiences was usually not so different. The women would frequently complete one another’s sentences, relate to the same spiritual resources, or provide common understandings for the Christian faith. I found the FGDs an empowering space. In each of these FGDs, a clergymember was always present to provide counselling for women who may need and indeed this proved quite useful. As in the interactive interviews, very emotionally charged and sensitive topics were discussed, and stories shared with little inhibition.

3.3.4 Stories and Testimonies
This study has benefited greatly from the personal stories and narratives of my research participants. Storytelling as a veritable tool for researching human behaviour or experiences was not one of my fieldwork options. However, on listening to the recordings of interviews and focus group discussions, I discovered that even when questions were asked in semi-formal format, women responded with stories of personal experiences to buttress their arguments/points. It became common place to hear such words as ‘let me tell you a story of what happened to me,’ or ‘I remember an experience I had two years ago.’ Because they had created a safe space to share confidential information, these women openly and willingly provided details of their efforts to navigate relationships, make sense of their Christian faith and cope with the challenges of exclusion. Storytelling gives power as their stories often come unfiltered, and uncensored, while providing a compelling research tool to examine their faith experiences.

The details of their age, marital status, careers, or income generating activities mostly came forth in their stories. These women allowed their stories to be interrogated at focus group meetings and listened to advice from fellow women interviewees on alternative courses of action to acts of discrimination. In sharing their stories, they inadvertently offered support and accompaniment for one another while creating a connection that they claimed made their burdens with disability and HIV lighter. Many times, they spoke of their stories as testimonies, particularly on the frequent occasions when they linked their ability to overcome or cope with certain difficulty as a demonstration of the intervention of Jesus Christ, a preference to God which I discuss in Chapter Four. Although it has been assumed that the use of
testimonies is often for churches or religious gatherings, these women used this terminology even though BOLD is not a religious organisation and these research discussion meetings were not categorised as fellowship meeting. It could be argued that these women’s reception of this method may be explained by the common Christian culture of testimony telling which has developed upon a strong oral culture of storytelling within which they [lived. The intermingling of stories and testimonies by research participants provided a huge amount of data for my research.

Whether researching on gender, disability, or HIV, it has been generally noted that personal experiences and the voices of the research participants needs to be prioritised. Even when the contention about the subjectivity of memory is argued, I believe the telling of stories before others with somewhat similar experiences lays a burden of accountability on the storytellers and listeners. It subjects the stories to public scrutiny and allows for communal vulnerability. This is especially so for women of faith, who often find a sense of sisterhood in shared experiences and challenges. Besides, I believe, from field experience that story telling allows research participants to ‘remember rightly’ especially when such act of remembrance is not staged or prodded but is done freely and at the pace of the storyteller. African women theologians have used stories in promoting ‘life history narratives’ as a suitable research methodology for flexible research environments with its semi-structured interviews and casual conversations. Others have referred to it as a ‘narrative theology approach’ when using stories to find meaning and healing for themselves and others. Outside of research, women’s stories have been received as the tool for imagining women’s liberative options, and the ways women cope with gender-based

248 Danielle Clausnitzer, ‘Disability and the Church in Africa: Institutional and Individual Approaches to Disability and Christianity on the Continent’, Religion Compass, 2021. Clausnitzer opines that voices and experiences of persons with disability are capable of bringing to light their oppressions and oppressors.
251 Fulata Lusungu Moyo, ‘Navigating Experiences of Healing: A Narrative Theology of Eschatological Hope as Healing’, in African Women, Religion, and Health: Essays in Honor of Mercy Amba Ewudziwa Oduyoye, ed. Isabel Apawo Phiri and Sarojini Nadar (Maryknoll, New York: Orbis Books, 2006), 243–60. Moyo says stories have fourfold yield: 1) helps to share personal hurt and search for healing; 2) provide other enriching perspectives to one’s story; 3) make storyteller an agent for life and wholeness instead of victims; and 4) it is therapeutic.
Whether it is through the creative use of religious resources such as Scripture, songs, prayers, and of course, testimonies, the women I interviewed expressed their preferences and their engagement with these resources through details of their lived realities.

3.4 Research Reflexivity
The importance of self-reflexivity in research involving intimate personal experiences of women, sexual behaviours and faith practices was crucial, not only to place proper boundaries but only to ensure ethical respectful research. Reflexivity allows the researcher to be conscious of the connections between them and their effects on the research process. This process has been described as ‘self-examination’ and a ‘means of turning back on oneself, a process of self-reference.’ Here I explain my process with self-reflexivity.

As stated earlier in this Chapter, I was researching a group with whom I had become a friend and a sister. I listened to stories that could only be told to someone regarded as ‘friend.’ In one of my journal entries, I wrote: ‘Who was I today? A researcher, a friend, a pastor, a sister?’ In one of my monthly communications with my research supervisor, I mentioned how I felt the lines were getting blurred for me. I reached out to my pastoral mentor, who herself is involved in HIV work, and talked about the emotional distress I was experiencing from listening to personal stories of stigma, discrimination, and abuse. I remembered the caution of one of my professors to be mindful of my researcher’s role on the field when researching within familiar contexts. Reflexivity was helpful in facilitating a reflection of the circumstances of the fieldwork and to focus on what was helpful and what was not.

My research supervisor’s advice to a particularly disturbing turn in my fieldwork was to answer these rephrased questions: ‘How do I make a virtue of this for my doctorate?’ ‘What am I learning as a result?’ ‘How might I use that learning in my thesis?’ Reflecting on these questions enabled me to accept the unpredictability of

\[\text{252} \quad \text{Oduyoye, } \textbf{Introducing African Women’s Theology}, \ 2001. \ \text{Here Oduyoye uses stories liberally in her writings describing it as narrative theology, as the vehicle for bringing personal experiences into academic stories, as well as the tool for women’s theologizing.}\]

\[\text{253} \quad \text{Slee, } \textbf{The Faith Lives of Women and Girls}, \ 9-10.\]

\[\text{254} \quad \text{Davies, } \textbf{Reflexive Ethnography}, \ 4.\]
the field work and to be a researcher that was on the ‘field’ to gather data for a thesis. I wrote in my journal: ‘I am listening Lord, please help me to listen better, listen objectively, listen empathetically.’ While empathy played a huge part in interacting with my research participants, in that I put myself in their shoes to understand what their stories felt like, my research did not have primarily advocacy aims. Advocacy is a motivating factor for me. I was pleased to provide safe conversational spaces for the women that I interviewed. The primary aim of being on the field, however, was to understand and analyse the situation of women for my thesis.

Scholars have argued that it is unethical for the researcher to have therapeutic goals as researchers are not trained therapists. Others have said that to remove the possibility of therapeutic goals or to not anticipate positive change for a research community from the research makes the research ‘suspect.’ While these may be two extreme views, I opine that a respectful approach could allow for therapeutic possibilities to emerge. This research has themes that cut across disability, faith, feminist theology, the relationship between gender, disability, and HIV; all call for ongoing self-examination in line with ethical research practice.

3.5 Ethical Process
Ethical research approvals were sought and received from the University of Edinburgh, School of Divinity Ethics in Research Committee, Rivers State Research Ethics Committee, Port Harcourt, and Our Lady of the Sick Hospital, Nkpogu, Port Harcourt. I was unable to follow through with the approval process at any hospital in Uyo due to time constraints, especially since hospital visitation was an added activity during the research. Each of the approvals received entailed its own processes, but that of the University, though least stressful, was the most instructive.

To obtain ethical approval for the observation and interviews of hospital staff and patients, I had to put up the identity of a researcher from an overseas University. I was more of an outsider to these spaces and had to make a good first impression both during the submission of my applications and the physical interview sessions before the approving personnel/Board. On my visit to the State-owned hospital, what mattered were my academic credentials and my letter of introduction from my

255 Ellis, ‘Interactive Interview’.
university of study which I carried in a smartly dressed English dress. For the faith-based hospital however, my personal integrity and faith were relevant. Here I presented myself primarily as a Nigerian clergy person researching to find answers that would be helpful to the church’s role in engaging with women with disabilities who are living with HIV. I wore a long African dress and emphasised my roles in my local congregation stressing the factors that informed my research interests.

Ethical research approvals enabled access to speak with, interview, and sit in on voluntary counselling sessions with research participants. I interacted with administrative staff, health practitioners and pharmacists involved in HIV treatment at the treatment centres. To maintain some control of the field work and ask focused questions, the use of interviews as part of the research technique was employed where I interviewed research participants as well as other persons relevant to the research. Two issues that resonated from the University Approval process were the use of an approved Consent Form for Participation and Personal Data, as well as the debriefing provisions for research participants and researcher. Each research participant was given the Consent Form after what was sometimes, a detailed discussion about the study. Some women in the study wanted to know what the possible outcomes would be, and whether it would be beneficial to their denominations in addressing exclusion. Others were not just content to tell their stories and urged me to replicate their words in the way they said it.

The research ethical approval process anticipated that because my research participants belong to a vulnerable and stigmatised community, that there should be measures to alleviate any negative impact of the research. Although persons with disabilities, with or without HIV, are often considered vulnerable due to stigma and discrimination, not all members of my research group considered themselves as such. Having some basic education, engaging in some form of income-generating activities, and having the capacity to consent to this study, evidenced their sense of power. However, many of the women noted the many cases where stigma and discriminating are from forces beyond their control and impacting negatively on their well-being. To this end, I arranged for the presence of a female Christian faith leader, versed in pastoral counselling to be present at all group meetings and be available should any women in this study need further private conversations. The Coordinator for BOLD
Network, a trained Trauma Counsellor, brought her experience to bear during the interviews and discussions.

I put these measures in place aware that non-disabled persons writing about disability, bring an increased level of ethical responsibility to the research as one whose lived reality is different from those of her/his research participants.\(^{256}\) As researcher, I have stated earlier my reliance on a personal pastoral counsellor and mentor for whenever I felt emotionally distressed or overwhelmed with the proximity of so much pain, especially in this context, where the bond between researcher and research participants now seemed more like a partnership of co-researchers.

### 3.6 Situating the Study: Approaches, Fields and Theories

The underpinning assumption in this study is that women with disabilities and HIV suffer varied and multi-layered consequences of stigma. The main objective is therefore to investigate how Christian faith helps them to navigate and cope with these socio-cultural inequalities and stigma in order to raise questions and make suggestions for the inclusion of faith-based strategies in gender, disability, and HIV intervention. This study is therefore multi-disciplinary traversing of fields - (studies) such as gender, social science, African Christianity, and while drawing on disability models. The approaches that this thesis adopts allow for a dynamic exploration of the nature of inequalities and the ways in which structural power contexts shape women’s experiences of socio-cultural and religious exclusion and discrimination. During field work for this thesis, transcription, analysis of date, I have been guided by theories and approaches from three major sources; these are African women theologies, social model of disability and the motif of advocacy.

#### 3.6.1 African Women Theologies:

Apawo and Nadar, in their introduction chapter to the book, *African Women, Religion, and Health: Essays in Honor of Mercy Amba Ewudziwa Odoye*, argue for African women’s theologies to be seen as ‘authentic

field of study." Quoting Mercy Oduyoye, they simply describe African women theologies as theology done by African women, particularly those of the Circle of African Women Theologians (Circle). Within the complexity of a consensus for such description, they identify three characteristics that underground the work and writings of African women theologians. These are, recognising the dynamics of race and class as integral to the discourse on gender; a commitment to ‘grassroots activism’, and the narrative approach of storytelling to navigate the tension between culture and religion for women’s liberation. Njoroge describes African women’s theologies as the ‘missing voices’ in African theology that hitherto had been dominated by male theologians. To her, African women do theology by participating and exploring in the activities that produce theology in Africa. This involves addressing existential problems that plague many African communities of women and men. In this thesis, I bring forth the missing voices of women with disabilities and HIV to enrich the voices of African women’s theologies. Recognising the plurality of religions in African, the Circle incorporates women from all religions in Africa while taking cognizance of liberating attributes from all religious and cultural tenets.

Within the orbit of African women theologies as a viable field of study, the thesis draws on the works on Christianity. It recognises that the Circle has rightly been criticised for its reliance on academic writings and not taking seriously its commitment to grassroots activism in hearing the lived experienced of marginalised groups. This study addresses this gap by taking seriously the every-day experiences of women with disabilities in articulating their faith expressions and identities while coping with HIV. Nonetheless, African women theologies allow a critique of patriarchy that approaches male dominance in many spheres of life through different types of engagement such as participation, confrontation, or ‘treading softly but firmly’. Using this theology, I

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can see that the women I interviewed take a different view; that of navigation of patriarchal terrain. Nevertheless, the Circle has been a significant conversation partner in this research, in offering a faith perspective to social scientific research and facilitating a narrative approach to the stories of the faith lives of women. This conversation is nevertheless, critical of the lacunae in Circle literature discussed in Chapter one. Disability theology and theologies of healing driven by African women have also influenced this thesis. Research findings have provided resources for disability theology while offering an innovative understanding to theologies of healing as discussed in Chapter Four. So, while there are theological insinuations, this study focuses on how the women that I interviewed understood their faith experience rather than doctrinal interpretations of those experiences. This stance is necessary seeing that social models also foreground the work of this thesis.

3.6.2 Social Model of Disability: This research is premised on the social model of disability where society and its agents are the disabling factors that isolate and exclude persons with bodily impairments from social spaces. Since the late nineteenth century, the medical and social models of disability have gained prominence and continue to inform response strategies in academic faith and developmental frontiers. The term ‘social model’ was popularised by Mike Oliver to describe “disability as the product of environmental, structural and attitudinal barriers.” This model recognises the ability of society to remove disabling barriers and therefore holds society (and its agencies of church and state) accountable for disabling obstacles that are the result of discrimination, stereotypes and prejudice. For the social model, an impairment (‘an abnormality or loss of physiological form or function.’) is not necessarily a

disability until social barriers make it difficult for a person to function or carry out normal daily activities.\footnote{Barnes, Doing Disability Research, 66-7.}

It is different from the medical model which sees the impairment as a medical condition that prevents a person from performing normal activities. The medical model argues that the emphasis on impairments as medical conditions has brought about research, innovations and “development of new drugs, equipment, treatments and investigative procedures.”\footnote{Colin Barnes and G. Mercer, Doing Disability Research (Leeds: Disability Press, 1997).} It therefore focuses on attempting to fix the medical condition but misses the mark for conditions that may not necessarily need medical intervention.

There has been a lot of debates in the West about the continued relevance of the social model. Tom Shakespeare, in his 2006 book Disability Rights and Wrongs, outrightly rejects the social model and seeks ‘an alternative which neither reduces disability to an individual medical problem, nor neglects the predicament of bodily limitation and difference.’\footnote{Shakespeare, T, Disability Rights and Wrongs (Routledge, 2006),2.} This does not address society’s responsibility and is a sharp departure from the article by Shakespeare and Watson in 1996 ‘Defending the Social Model,’ where the authors argued for the social model as possible and desirable.\footnote{T. Shakespeare and N. Watson, ‘Defending the Social Model’, Disability & Society 12, no. 2 (1997): 293–300.} Perhaps, as Shakespeare himself admits, it could be the ‘British social model version of disability studies’ that has ‘reached a dead end’ and that other countries may not have this problem.\footnote{Shakespeare, T, Disability Rights and Wrongs, 2-4.} A generalisation of the failure of the application of the social model should not include Africa that is still struggling with the conceptualisation and contextualisation of the model.

Other disability scholars have posited other alternatives. John Swinton recommends acknowledgement of the lived experiences of persons with biological impairments and ‘treating’ the wider social dimensions of the persons without losing sight of the medical dimensions.”\footnote{John Swinton, Resurrecting the Person: Friendship and the Care of People with Mental Health Problems (Nashville: Abingdon Press, 2000), 81.}
of both models” but worries if these two disciplines could work together in partnership for the good of persons with disabilities who are disabled both by the impairments and by society.\(^{271}\) Ruth Pinder, a Feminist Disability Scholar, proposes a common ground between the medical and social models that promotes a “more holistic version of the social model” that recognises the relationship between the agency (person) and the structures (societal obligations to enablement and medicine).\(^{272}\)

Disability discourse has not been as robust in Africa, and particularly in Nigeria as it is in Europe and North America where much of these debates are being done. Nigeria, for example, is yet to take disability discourse as a matter of state importance.\(^{273}\) I am therefore, hesitant to imagine a common-ground or a combination of social and medical models in which I would have called a socio-medical model. The social model is what Nigeria, and indeed Africa needs. This model comprehends that political action is required to achieve systematic social change to improve services and infrastructure for persons with disabilities.

This thesis, therefore, aligns with the social model and describes disability as being relative to the social circumstances of each person and includes everything that introduces any kind of restriction ranging from personal attitudes and prejudices to systemic issues of exclusion.\(^ {274}\) It believes an adequate intervention should include all that is necessary for disability inclusion and accessibility. It has been proved that working within the social model of disability framework with its aim of invoking social action, enables researchers to ask questions from the perspectives of the research participants.\(^ {275}\) This model informed the research and fieldwork approach.

\(^{275}\) Maria Berghs, ‘Coming to Terms with Inequality and Exploitation in an African State: Researching Disability in Sierra Leone,’ *Disability & Society* 25, no. 7 (2010), 861–65.
3.6.3 Research and Advocacy: Matthew David and Carole D. Stutton describes advocacy in a research context, as ‘the situation when the researcher role becomes merged with that of supporting the group being studied in a political or other sense.’

In Chapter One, I provided a brief insight into my relationship with members of my case study, BOLD, and how my research was primarily predicated on curiosity to investigate how Christian faith helps them navigate socio-cultural challenges. I hoped that through this academic process, that the voices of the women living with disability and HIV will be heard in places that would enable faith-based responses. This expectation demonstrates that research and advocacy are much more organically integrated rather than distinct and separate as I had initially imagined.

My role as researcher had become merged intricately to my passion as a gender and disability advocate and it is evident in Chapter Seven where I suggest ways in which different groups can engage with my study. So, while the research was not merely focused on changing people’s attitudes as David and Sutton, would imply, this desire manifested as part of the research process and output. Addressing disability or HIV concerns call for advocacy, and that involves being on the side of the marginalised, hearing their stories while critically engaging with their beliefs and concepts.

The focus therefore was on the persons who willingly were partners in the research, enabling what scholars call ‘person-centred research’ while allowing the ‘circumstances of fieldwork’ to inform its progress. As will be obvious, the consequence of this person-centred approach was in the models, theories and theologies employed in this research.

I mentioned in the immediate section above that this research is shaped by the social model of disability which means bringing out unheard voices of women living with both disability and HIV, ‘to be heard in the struggle to inform legislation, policy

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and practice’. This thesis impacts upon global policy change as it calls the attention of international development agencies to action in the light of its findings. The concern for advocacy is apparent in the choice of a qualitative research methodology. Data collection and analysis about ordinary people’s experiences through a focus on the stories of their lives enabled an exploration of the lived realities of women who are often marginalised. African women theologians have called this method of using women’s stories to ‘critique oppressive practices in African religio-culture’ as a form of narrative activism. For persons who are often silenced, this agency of owning and directing their narratives is the result of advocacy.

Maureen C. McHugh highlights three shared concerns of feminist researchers which are giving voice to women’s lives and experiences, overcoming gender inequalities at the personal and social level, and improving women’s opportunities and the quality of women’s lives. This is essentially another way of describing advocacy research which this thesis has endeavoured to accomplish. It draws on feminist liberationist methodology in acknowledging that women’s experiences and realities with life are usually different from those of men, no matter the social and cultural contexts. This was confirmed by a research participant in the following words:

280 Elizabeth Kiwuwa Namukwaya, ‘Understanding the Experience and Multidimensional Needs of Ugandan Patients with Advanced Heart Failure’ (The University of Edinburgh, 2016).
I don’t understand it. It is like once they (men) see my legs, they think, ‘ah this woman cannot do anything so let me treat her anyhow. In the market where I sell, they will come and say to me ‘even you, what are you doing here? Are you competing with us? Sometimes I think it is jealousy, sometimes, I think it is that they want to make me afraid. I don’t know, but I made up my mind to succeed no matter what.

This quote further highlights the inequalities experienced by my research participants. I dialogue with the broader feminist theory of disability where ‘disabled women struggle with both the oppressions of being women in male-dominated societies and the oppressions of being disabled in societies dominated by the abled-bodied’ are discussed. Feminist methodology is also evidenced in the way the relational and immersive research process and, its findings sought to empower women research participants. This empowering motive aligns with the emancipatory disability model that is also enshrined in this research.

With the intention to stimulate change, in collaboration with research participants, this research adopts the transformative disability-friendly approach of emancipatory research. The emancipatory disability research, although not without its controversies, seeks the ‘production of research that has some meaningful practical outcome for disabled people.’ The positive result of the approach for this research is the immediate creation of friendships between research participants, that continue to foster veritable support systems and exposure. One research participant said:

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288 Colin Barnes, ‘What a Difference a Decade Makes: Reflections on Doing ‘emancipatory’ Disability Research,’ Disability & Society 18, no. 1 (2003): 3–17. This study responds to some of the criticisms/controversies of the emancipatory paradigm by ensuring accountable to the identifiable research population and undertaking member-check of data collected and interpreted.
I never knew there were others in the same situation as me. I thought I was alone. I am so happy to know I have sisters that understand what I am going through. Thank you for this your research.

Its focus allows partnership between the researcher and the persons with disability to move the process from discourse to practice. The anticipated difficulty or suspicion of non-disabled persons writing ‘about’ disability is mitigated when persons with disabilities are involved in the process of the research such that the writing is done ‘with’ them and ‘for’ them. The emancipatory research approach is also applicable for researching HIV especially for ‘communities that are marginalised or that experience discrimination’ and therefore in need of transformative change. Advocacy research, even when not the primal motive, is a much needed one when researching for any possibility of change or action for issues of gender, HIV and/or HIV.

Whilst disability studies are still an emerging concept in Religious Studies, the multi/interdisciplinary contexts of this research situate it comfortably in the field of World Christianity. The study of World Christianity is a ‘synthetic and collective approach to studying Christian peoples, practices, thought and environments across the globe… (and) uses a variety of methods and works across disciplines.’ This approach has allowed me the freedom to explore uncharted grounds in the study of global Christianity. It is no wonder that I have been able to successfully carry out research that crosses the boundaries of social and medical science, theology, and disability. With this study, I am proffering faith-based solutions to medical, sociological, and cultural challenges for women with disabilities and HIV, in Nigeria and the global world.

289 Moore, Researching Disability, 6
290 Hans Reinders, Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics (Grand Rapids, Mich.; Cambridge: William B. Eerdmans, 2008), 205. Colin Barnes also makes a case for non-disabled researchers by saying that ‘emancipatory research is not about biology, but it is about commitment.’
3.7 Conclusion for Chapter Three
This Chapter has provided a detailed account of the methodological processes, techniques, and themes as well as the ethical values that guided this study in order to provide evidence for veracity of the research findings and analysis. Employing qualitative research methods of participant observation, interviews, and focus group discussions, I show the extent to which the fluidity of each technique allowed the research to take its course and to answer relevant research questions.

Stories and testimonies discussed here as the means of communication through which women shared their experiences, is discussed further in Chapter Six as a faith resource. Findings from data analysis reveal that women’s ability to cope with the challenges of disability and HIV is drawn primarily from their relationship with Jesus Christ, which enables them to navigate human relationships and employ faith resources that are appropriate to their needs. These emerging themes of relationships with the divine and humans, of belonging and of the use of spiritual resources of Scripture, prayers, songs, storytelling and testimonies, are discussed in the following three Chapters.
Chapter Four

Women’s Personal Relationship with Jesus Christ: A Demonstration of Christian Faith

4.0 Introduction
This is the first of three Chapters discussing the core findings that emerged from the interviews, focus group discussions and observations with research participants in Port Harcourt and Uyo between July and December 2019. My core research participants, share a particular set of circumstances: they are all women living with disability and HIV who have similar Christian beliefs, even as their personal interpretations of Christian faith are unique. The interviews sought to capture how they used their individual knowledge and experience of faith to navigate the challenges of their daily lives as women who are living with disability and HIV.

This chapter aims to understand faith interpretations that influence the ways in which women understand and live with disability and HIV. When I asked my research participants about their understanding of Christian faith and what it means for them, the most common answer concerned their relationship with Jesus Christ. As explained in Chapter Two, this relationship is derived from their belief in Jesus and the various ways that belief is exercised and practised. Many of these women told me about their relationship with Jesus Christ as healer, as best friend, and as One who enables relations with others in the church and society. They described their faith as a journey through life with Jesus Christ who accompanies them as they go through their various challenges. These women often linked their personal experiences of marginalisation, exclusion and sufferings to the sufferings experienced by Jesus Christ in ways that are liberating and empowering for women.293 They explained that they do not have to

293 For similar examples, see Mercy Amba Oduyoye, ‘Jesus Christ’ in S. Parsons ed., The Cambridge Companion to Feminist Theology (Cambridge: Cambridge University Press, 2002, 151-170). Oduyoye is careful to mention that linkage of Christ’s suffering to African women’s suffering is not acceptable to all women who view this as perpetrating patriarchal domestication. Teresia Hinga cites Mary Daly’s extreme position that women imitating Jesus as model would lead women to ‘fulfil the role of victims and scapegoats in their various cultures.’ See Teresia Mbari Hinga, African, Christian, Feminist: The Enduring Search for what Matters (New York: Orbis Books, 2017, 82-3). Also, not all persons with disabilities hold the view of disability as a suffering akin to the suffering of Jesus Christ, a view which Joni Eareckson Tada advocates from her personal experience. See Joni: An Unforgettable Story. W. Graham Monteith, a person with disability and a clergy man argues that because disability is a forced condition as opposed to Jesus’ suffering which was voluntary, the experience of suffering for both cannot be equated as same. See W. Graham Monteith, Disability: Faith and Acceptance (Edinburgh: The Saint Andrew Press, 1987, 67-9)
suffer because Jesus suffered, but that because Jesus suffered, Jesus understands and can relate to their suffering.

In this Chapter, I explore the various relational images that women use for Jesus as that which is central to their faith, how Jesus provides holistic healing for the women with disability and HIV, and how women relate with Jesus as healer within religious and societal spaces. Distinctively, women spoke about healing from Jesus as transformation of identity in a lifelong journey. I interrogate women’s claims against the broader African women’s expressions of faith and relationship with Jesus Christ, grounding it in the emancipatory features of the social model theory of disability. As stated in Chapter Two, and will be demonstrated here, religious motives and responses are not always supportive for women or marginalised groups, hence the need to listen to the stories of the people themselves. The women that I interviewed acknowledge this problem and explained how they navigate religious relationships and spaces.

4.1 Women’s Relationship with Jesus as Healer

I look to Jesus as my hope, and he never disappoints me. He is the Lord of Lords for me. I had stroke and for a long time and could not stand or walk, but Jesus healed me, I can walk even though slowly, and I can lift up my hands like this (lifts up hand). Because Jesus healed me, I know he loves me.

During my fieldwork, it was instructive to observe how conversations about the Christian faith, about women’s complex identities, about the ways in which women coped with the challenges of disability and HIV always tended to include discussions about healing. This explains why I discuss the issue of healing first, and why I do so in such lengthy detail. The women I interviewed spoke of their Christian faith as a personal relationship with Jesus Christ, the healer, who gives hope, and they made personal experiences of health and healing a recurring theme in our conversations. The above quote by Kaka aptly supports this point.

The women in my study expressed their understanding of healing as holistic and encompassing all aspects of well-being. For these women, healing includes all that facilitates human flourishing, including social, mental, physical, economic, and emotional well-being, transforming their identities, improving their physical conditions, and enabling some degree of inclusion. These women claimed they can be
healed of scientifically incurable conditions because of their personal relationship with Jesus. They said their belief in the miraculous gives them the ability to cope with the daily challenges and realities of gender, disability, and HIV. As highlighted in Kaka’s words above, healing is a demonstration of Jesus’s love for them, and this healing could be gradual and specific to ailments.

This section argues for a broader understanding of healing by examining two distinct ways that the women in my research appropriate healing and how this appropriation impacts on their experiences of living with disability and HIV. Firstly, that healing is transformation of identity that is liberating and affirming of their Christian faith; and secondly, that healing involves physical change or curing of a disease or disability. I will interrogate the claims of the women in my research through the lens of theologians but more narrowly with Micheline Kamba’s scholarly and experiential understanding of healing. An African female theologian, Kamba’s views, borne out of her personal experiences of disability, shape her theology of healing, which largely focuses on social, spiritual, and emotional aspects of holistic healing rather than on the physical. This thesis offers an understanding of healing that reflects popular understandings of healing as a physical change in someone’s body. More importantly, it foregrounds an innovative understanding of healing that emerged from participants who construed healing as transformation of identity from one of insignificance to one with dignity and value.

4.1.1 Healing as Transforming Identity
The first experience of healing that women in my study talked about is what I have interpreted as ‘transformed identity’. These women explained how Jesus makes them feel, how Jesus is the friend on their journey with disability and HIV, and how this relationship with Jesus gives them a sense of self-worth. Their stories, when speaking of healing, were often indicative of a changed perspective of themselves following their renewed commitment with Jesus Christ. It enables them to see themselves as.

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294 It is not uncommon in Nigeria to hear some pastors claim to cure HIV and AIDS.
295 Bethany McKinney Fox states that the belief that Jesus heals, which is ‘beyond mere human power and effort’, serves as inspiration for people today (2019, 46–7).
296 All of these women were Christians and regular at church attendance but here, were speaking of an experience of being ‘born again’, a Pentecostal-charismatic expression for Christian converts who
having value and worth when the stigma of society suggests otherwise. Transformed identity for these women means they can engage in affirming human relationships as friend, mother, wife, daughter etc. They speak of relationships as necessary for mutual support and a crucial aspect of healing for women’s flourishing. Transformed identity also means they can engage in economically beneficial ventures for women who live within the context of poverty and oppressive systems.

These points were illustrated with Ula’s narration of her understanding and experience of the Christian faith:

My faith is about Jesus. I was nothing, nothing at all. I used to pray to God. I would say, ‘Lord, please take away these crutches so that I can walk normally.’ I was not born like this. I was walking until I was seven years old and started having problems. I would cry, ‘Lord, please take away this disease (HIV).’ I wanted to kill myself. A neighbour witnessed to me about the love, grace and mercy of God and asked me to give my life to Christ. My life was so rotten, sad and bad. How could I give that to Jesus? But by God’s grace I did, and I received strength. Then, Jesus came into my life and gave me strength, real strength. I started small, I started treatment. Now, I have my own house, even though it is small. I have a business [so I can feed my family] better than those with legs. All because of Jesus.

Ula is a single 34-year-old woman with physical disability. At the time of this interview, she was running her own business and I was able to visit her at her home because she lived alone. She began her narrative by linking her faith relationship directly to Jesus and continued to make him the centre of her struggle, survival and victory over the challenges of disability and HIV. Furthermore, Ula mentioned the ‘strength’ that she received despite living with disability and HIV: she can now do things she could not do before she ‘gave’ her life to Jesus Christ. It is also interesting to note from Ula’s story that while she prayed for her ‘crutches’ and ‘disease’ to be taken away, she felt content that when Jesus came into her life, that was the ‘strength’

confess a renewed commitment of faith in Jesus Christ as Lord and personal saviour. This has been discussed in Chapter Two of this thesis.

297 Kenneth Ross (2002, 53) notes how, in the Gospel narratives, ‘women found Jesus approachable’ as Jesus often ‘spent time with women… showed understanding of the issues that concerned them… and how women engage directly with Jesus’.

298 Diane Stinton (2004, 174–5) quotes John Mbiti as saying that in Africa people affirm that ‘divine healing is an extension of the saving benefits of God and Jesus Christ’.
that she received to start treatment for HIV, get a house and have a business. Ula was not disparaging physical healing. She prayed for her crutches to be taken away. However, there was a contentment in the strength that she received instead; for it was in that strength that she was able to start life afresh, medically, economically and psychologically. It does appear that her identity as a ‘nobody’ has been transformed into that of one who is a ‘friend of Jesus’, ‘a house owner’ and ‘an entrepreneur’.

The way Ula described herself as a ‘nobody’ is common among many Nigerian women whose identities are shaped by patriarchal relationships that can make women feel less than or inferior to men.299 It is a picture of women whose place in church or society is often ignored or overlooked so their self-worth is diminished.300 It is also a picture of women whose identities are defined by the stigma of disability and HIV.301 Psychology literature recognises that trauma that results from rejection and abuse is capable of evoking self-stigma and poor self-esteem.302 This provides further insight into Ula’s description of her feelings of ‘rottenness’ and ‘nothingness’. According to her, it was therefore what Jesus did for her (her transformed identity) that gave her the ‘strength’ to live and cope with the challenges of life, an experience she further described as healing.

It is important to note that, as a researcher, I did not ask questions about healing at the FGDs or interviews. Stories of healing came forth naturally. Ula’s story, which she said was a ‘testimony of God’s goodness about the ‘healing mercies of Jesus’, is somewhat like Maryann’s:

God has done the impossible with me before. People thought with disability, I cannot marry, I cannot give birth. By the grace of God, I have given birth, even though it was through operation, in spite of disability. I thank God my children are negative, even though I am positive. Everything they said I couldn’t do with disability, I have done.

299 Mercy Amba Oduyoye, Hearing and Knowing, 123.
300 Oduyoye, Hearing and Knowing, 125. Oduyoye has acknowledged that ‘women are very much concerned about the church, but the church is not so much concerned about women’.
301 Janet A. Parsons, Virginia A. Bond, and Stephanie A. Nixon, ‘Are We Not Human?’ Stories of Stigma, Disability and HIV from Lusaka, Zambia, and Their Implications for Access to Health Services. (Report’), PLoS ONE 10. Also, in Jessie Fubara-Manuel (2014, 57–60), I discussed how people with disabilities lose their identities, are nameless and are often defined or described by their visible disabilities.
Maryann was referring to limitations that stigma placed on her due to her physical
disability. She claimed her ability to overcome those limitations is by the grace of God
or put differently the help of God. Her testimony was given during the discussion on
healing. In moving attention from healing as primarily physically to healing as God’s
intervention in her life, she presented an alternative understanding to the concept of
healing. At 35, Maryann is not only a wife and mother: she is also a college-trained
teacher working at a government-owned secondary school in Port Harcourt.

Women with disabilities and/or HIV tend to suffer more from paternalism
because of the myth that women are helpless or weak. This notion leads to women’s
oppression through a denial of their intrinsic capacity for or interest in engaging with
and successfully carrying out responsibilities. Consequently, when women with
disabilities perform acts, such as having babies or having a career, they are praised
disproportionately, as they were never considered fit for such achievements. Women
with disabilities and HIV in my study claimed this paternalistic way of viewing them
robs them of their value and dignity. Consequently, they assert that it is in a
relationship with Jesus Christ that they can reclaim a sense of value of their personhood
and identity, which enables them to cope with the stigma associated with disability and
HIV. They spoke of this experience as a healing experience.

At the focus group meeting in Uyo, when it was Daisy’s turn to speak, she
began with a song of praise to God. A married woman of 30, with sight impairment,
Daisy said:

It is because of Jesus that I can love myself. Even when people
want to make me feel bad because I am blind and do not have
children, I think about Jesus, everything he has done for me, I
know that I am somebody.

It was not unusual for women to burst into songs during interviews or discussions, as
I will discuss in chapter six. For Daisy, this was a way of expressing, what she referred
to, as her joy in recounting what Jesus’s love has done for her and how that has changed
her self-esteem and perspective of who she is and what she is able to do. The idea of

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303 James I. Charlton, *Nothing about Us without Us: Disability Oppression and Empowerment*
(Berkeley, Calif.: University of California Press, 2000), 54-5. This is not unrelated to the assumptions
present in many African cultures that people living with disability are ‘inferior and an embodiment of
bad luck’ and also casts women as the epitome of ‘shame and pity’
being ‘somebody,’ which is discussed in chapter 7, resonated greatly with the women that I interviewed, as representing a different and transformed identity.

Micheline Kamba refers to my research participants’ experience of what I term transformed identity as physical healing. To Kamba, physical healing is ‘seeing the person shifted to another level than was expected, because many people with disabilities have been alienated by the culture and tradition of their contexts so that they cannot do anything in their lives because they are disabled.’ Yet, physical healing, which is discussed in the next section, means, for my research participants, healing that results in specific visible physiological change in the body. The comprehensive nature with which my research participants view healing includes Kamba’s view of a shift from one position to another as further illustrated by the stories of Kaka and Eddy.

Kaka says: ‘the person I am today, it is because of Jesus.’ When Kaka said those words at the focus group discussion meeting in Uyo, she was not smiling. It was a statement loaded with a painful past but with a hopeful future. Over conversations, Kaka shared her story.

I am a 42-year-old divorced woman without a child, I am HIV positive and as you can see, I have stroke. I was married for ten years, no child. When I discovered that I was HIV positive, my husband packed my things to my father’s house and asked for a refund of the dowry. As in Ibibio land, he broke a calabash that he does not want me to be his wife again. We were married in church but nothing the church could do.

Kaka suffers from one-sided paralysis (hemiplegia) affecting her face, an arm and a leg impacting on her ability to walk or grasp objects, which she says is the effect of the emotional distress. Kaka says:

My life changed when I asked Jesus to have mercy on me and save me from my sins. God became God for me and lifted me up. He gave me hope and healed me.

Kaka emphasises her encounter with Jesus as the turning point in her life; one which brought a new identity that changed her life, lifted her up with the experience of God. Whilst she still lives with the disabling physical effects of stroke and HIV, she still

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spoke of hope and healing because Jesus changed her life. Kaka did not confront her husband; instead, she focused her energy on the succour that she said, Jesus provided.

For Eddy, her story was like this:

Jesus Christ is my Saviour because he died for me to wash my sins away. He gives me life and everything to protect me, he protects my children and family. I am no longer afraid. When I go out or when I am in my house, I know God protects me.’

Eddy is what is often referred to as an ‘HIV widow.’ She was 26 years old when her husband died of AIDS leaving her with two little children and very little money. She was often afraid but more so when she tested positive months after her husband’s death. She was afraid she would die of the HIV, afraid her sins had brought on the calamities (widowhood, disability, HIV) on her and afraid she may lose her children to HIV. Eddy said while at a Support Group, a woman ‘like her’ (with disability and HIV), told her about Jesus. She continued: ‘I gave my life to Jesus; I am now born again. Now I know it is not my sins and I know Jesus loves me, so my fear is gone.’ In saying that it was not her sins that caused her problems, Eddy was reacting to and challenging the popular teaching among Nigerian pastors that disability and/or HIV could be the result of a person’s sins. In further conversations, it became clear that Eddy’s new perspective was consequent upon her renewed relationship in Jesus whom she believes, loves her. There was always a before and after story with the before being of a woman beaten, shunned and stigmatised while the after is of a woman ‘saved’ and alive.

For Kaka, the person she was before she asked Jesus to have mercy and save her, is not the same person she is today. For Eddy, her fear is replaced by faith. Now, they speak of lives ‘changed,’ ‘protected,’ and ‘lifted up.’ Like other research participants, Kaka and Eddy spoke generously about the transforming role of Jesus Christ, the Son of God, in their lives. Jesus, to them, was the one who died for their sins, as Saviour, not only from sins but also from truncated identities that childlessness, widowhood, HIV, and disability may have imposed on them. Added to their perception of healing as transformed identity, the women in my study maintained a belief in physical healing that is accompanied by physiological change.
4.1.2 Healing as Physical Change

The Bible says, by his stripes we are healed. I believe it. Jesus healed all manner of diseases and infections in the Bible. What is HIV before him? Nothing. What is disability before him? Nothing. The Bible says nothing is impossible with God.

Physical healing has been described as ‘the complete and successful functioning of every part of the human body in harmonious relationship with every other part of that body and with its particular and relevant environment.’

This understanding of physical healing is especially promoted by neo-Pentecostal groups. However, this description by an African woman theologian fits only partly with how the women with disability and HIV in my research talked about the kind of physical healing that they pray for and which they anticipate that Jesus as healer is able to perform for them. Speaking from their lived experiences of praying for healing, many of the women would argue that physical healing can take different forms across varying timeframes, from instantaneous healing to progressive healing. It is interesting that, although these women still live with disabilities and HIV, they cheerfully testify about being healed from illnesses such as stroke, malaria, typhoid, as well as the hope of being completely healed in future of disability and HIV. Maryann, who made the above statement, continued at the focus group meeting in Port Harcourt:

I believe strongly in God. My faith is anchored on the work of Jesus on the cross for me. That is why I believe that one day I will be healed. God has done the impossible with me before. So, nothing is impossible with God. He can heal me of HIV.

Maryann’s defence for her belief in physical healing are the healing stories of Jesus in the Bible, the work of salvation of Jesus on the cross for her, as well as the other ‘impossible’ things that Jesus had done for her previously.

It is noteworthy that the women in this study did not try to minimise the effects of their struggles or underestimate their resilience in coping with the challenges of their daily lives. They shared stories of being emotionally and verbally abused. They talked about feeling shamed by regular visits to the hospital to receive antiretroviral

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305 Moyo, ‘Navigating Experiences of Healing: A Narrative Theology of Eschatological Hope as Healing’.
treatment. Others told of unpleasant experiences with partners, family, and church members. So, when they pray for physical healing, they claim that because nothing is impossible with Jesus, they could be healed physically in addition to the healing of their identities. Far from being an oppressive expectation that Kamba seems to suggest below, the anticipation for physical healing fills them with hope and determination.

Kamba has reservations about praying for physical healing. In her writings, Kamba narrates her experience, ‘as a person with disability who has experienced failed physical healing’ and who found it difficult to accept herself as a creation of God because of her disability and who therefore resorted to attempted suicide. In the midst of her trauma and frustration with her disability and lack of physical healing, Kamba said she ‘prayed, cried, implored God to teach me the meaning of my life.’ Following this encounter with God, which she refers to as a healing time, she never prayed to God to heal her physically but accepted herself as a woman with disability. Consequently, Kamba said she reached her understanding of physical healing (visible change) from a liberation theology of disability perspective as the ‘improvement of the abilities’ which is possible when a ‘person has experienced an emotional and spiritual healing.’ Kamba’s views also seem to derive from what she describes as the focus on physical healing by pastors that ignore the need for inclusion, and the detrimental effects when physical healing fails to occur.

Within Kamba’s Kenyan religious spirituality, as in Nigeria, people with disabilities are often perceived as needing physical healing and therefore often made to submit to being prayed for by pastors and church leaders. Therefore, Kamba warns about the guilt factor when healing does not result in a change in physical condition as expected, especially when one has prayed for such healing. Often, one is accused of lacking faith and this guilt-trip can demoralise a person who is already stigmatised and excluded. Consequently, Kamba advocates that healing for people with disability should start from the soul, to help them negotiate their identities and

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306 Michelle Kasongo Kamba, ‘Developing a Holistic Educational Programme through Contextual Bible Study with People with Disabilities in Kinshasa, Democratic Republic of Congo,’ 274.
307 Kamba, ‘Developing a Holistic Educational Programme through Contextual Bible Study with People with Disabilities in Kinshasa.’ 275.
308 Kamba, ‘Holistic Healing in Acts 3’.
restore relationships with God and humanity, instead of seeking physical healing. She promotes a ‘theology of acceptance’, which is acceptance of a person’s current condition, whatever it may be, despite its limitations.\(^{310}\) This means accepting one’s disability to accept one’s personal value and worth.

Klaus Fiedler and Samuel Kabue share Kamba’s fears about praying for physical healing. For Fiedler, while he is ‘convinced that God can and does heal people’, he fears that this is rare for people living with HIV. This, he says, often leads to ‘God’s name being misused by those who serve him and instead of healing, in too many cases, death has resulted.’\(^{311}\) For Kabue, ‘an emphasis on the physical has at times worked out very negatively on the faith of many persons with disabilities … if no healing takes place, one is presumed to have no faith’\(^{312}\) Many of the women I interviewed seem not to have allowed these fears or guilt to deter them from praying for and expecting physical healing, even though they had experiences to this effect. A few of the statements that came out in this discussion are as following:

Not to pray for healing is to say there is no cure. And to say there is no cure for HIV or that God will not heal me is like doubting God, and I cannot doubt him. One day, I will be healed of this HIV. This cannot be my story. There is nothing God cannot do. God who healed my bones from stroke can heal me of HIV. (Kaka)

We cannot decide how God heals, if we trust God to heal headache, why can’t we trust him for HIV or AIDS or cancer or anything at all. I cannot trust science over God so I will prayerfully hope that one day, God will remove the virus from my body. (Maryann)

\(^{310}\) Kamba’s theology of acceptance follows on from her theology of suffering which she claims would ‘create a sense of happiness and build self-confidence’ because suffering is the life of disability (Kamba 2013, pp. 211–4). Here she refers to Joni Eareckson Tada as saying that among the benefits of suffering is the fact that it ‘heightens quest for Christ and restores a costly beauty in Christ’. The women in my research did not agree that they should suffer much more because of their disability or that they will feel closer to Jesus if they suffer. They felt Jesus has done all the suffering and therefore they should no longer suffer. Besides, they felt the challenges of being disabled and having HIV presented enough suffering in themselves.


Interpreted in English, Emily, in the last quote, was saying that there is a cure for HIV which is being denied to those who are infected. To say that anything is without cure is impossible because there is nothing Jesus cannot do. Emily’s comments, like those of others, demonstrate her utter dependence on God to do the impossible concerning healing and beyond.

However, Emily was quick to address the polemic nature of this position when pastors teach that healing that is dependent on God should be without scientific intervention. She turns to English language and narrates her experience below:

In 2002, my husband fell ill and was sick every time. In 2003, I delivered a child, and the child was sick from day one. I did not know what was happening. My husband did not tell me he went for testing and was positive. He was taking medicine, but I did not know what the medicine was for. His family said it was attack from the village that we should go for prayers. So we went to Mummy K. Mummy K gave us fasting and prayer. Because of the fast, they asked my husband to stop every drug so he stopped. On the day we appeared before mummy K, she screamed at us ‘you have HIV.’ Then she gave us anointing water and anointing oil and said ‘you are healed.’ But after that visit, the child died. I could not ask my husband about the HIV. I told my junior brother who is a doctor about Mummy K and HIV. Quickly my brother travelled from Onitsha to come and see us. He took me for testing. The result was positive. My husband refused to go. He said if he has HIV, then mummy K has cured it. Mummy K said if you have faith, believe and leave the drugs. And my husband said he believed and refused taking his drugs. My husband continued to fast and pray every day for healing. My brother said that from what he is seeing that my husband already has AIDS. I did not understand HIV and AIDS. My brother said my husband must continue his drugs. That was when I knew that the drugs my husband was taking were HIV drugs. I cried and cried. I said, God, please don’t forsake me. My husband did not agree to take medicine and died after some months. His family said I killed him and came and carried everything. I was shocked. I asked God, what did I do wrong?’ Why this man (husband) do this to me? Why? I cried and cried. During my husband’s burial,
the secret went out that my husband died of AIDS and the church people did not come to my house because they said I already have the disease. I buried my husband and stopped going to that church. Now, I go to another church where nobody knows my story. I believe it is God that made me live and not die. Jesus saved my life. So I go to church and I take my drugs.

I have provided this long quote to illustrate the complexities of relationships for my research participants. Embedded in Emily’s in-depth narrative are the nuanced inequalities that facilitated her infection, the stigma she suffered, and the attendant poverty that she endured. It also highlights her reliance on faith while establishing the place of medical intervention. She is saved by Jesus Christ, even though she continues to live with both disability and HIV. Emily, who has sight-disability, considers herself a survivor from the hands of religious leaders who exert influence on their followers with misleading teachings about healing. She strongly believes her husband would have still been alive if the pastor had not asked him to stop his medication in quest for physical healing. Still on the negative impact of a pastor’s influence on physical healing, Enny, another widow with sight-disability, shared her story:

My husband died because of Pastor. Pastor told him to bring Three Hundred Thousand Naira for healing. He begged that he had only half the amount. He took all our savings and gave to pastor. At that time, I didn’t even know that I was positive. Pastor took the money. When my husband was still sick, he went back to pastor, the pastor told him that because my husband gave only half of the money, he was getting half healing. My husband went and sold his land, sold his motorcycle, and gave to pastor. Pastor said to him ‘now you are fully healed.’ Go and testify. He went, testified, and waited to be healed until he died. After his death, I went for testing and discovered that I was positive. By that time, all our savings, our land, everything gone, and nobody can do anything to Pastor. I swore not to tell any pastor. It is me and my God.

With tears in her eyes, Enny said there was nothing wrong with going to the pastor for prayers, what was wrong was pastor’s advice to stop medication while taking all their money.314 The World Council of Churches (WCC) has expressed concerns about the

high mortality rates when persons living with HIV are told by their faith leaders to shun HIV treatment and depend on faith only for a cure (change from positive to negative status).\textsuperscript{315} They have therefore published several books to buttress the point that while healing may not be primarily medical, anti-retroviral therapy (ART) is an ‘integral part of God’s intervention in HIV pandemic’ and should be taken seriously.\textsuperscript{316}

The HIV and AIDS Adherence Counsellor at the Teaching Hospital spoke in defence of WCC’s view:

Faith is good, very good. As Christians, we cannot live without faith, but it would be all round good if accompanied by good correct teaching. Why on earth would a pastor ask someone to stop medication to prove faith? Who gave science knowledge of drugs? Is it not God? It is the bad teaching that is the problem and not faith in itself.

The Adherence Counsellor, a Christian, spoke above about the indispensability of faith for Christians. He also reiterated what the women had said previously that science and faith are both gifts of God. The blame, therefore, is not on faith or the belief that healing is possible, but on the teaching that the exercise of faith for healing should not be accompanied by medical intervention.

Grace, a mother of three children and who lives with physical disability said this about faith and ART:

I dey gidigbam. Since I start to take the medicine, my body don dey better. This medicine na God give us ohh, na miracle the medicine be. Before I bin dey sick well well but no bi so again. I thank God\textsuperscript{317}

With the above quote, Grace testified at the meeting that her health had greatly improved since they started treatment. She mentioned how the virus had made her sickly but that is no longer the case since commencing on ART. For her, ART is not just a gift from God, as the Adherence Counsellor had said, it was a miracle from God.

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\textsuperscript{316} Ezra Chitando and Charles Klagba, eds., \textit{In the Name of Jesus! Healing in the Age of HIV}, EHAIA Series (Geneva, Switzerland: World Council of Churches Publications, 2013), 40-1.  \\
\textsuperscript{317} Translation from Pidgin English: I am very well. Since I started taking my medication, I feel well. The medication is given by God and it is a miracle. Before the medication, I was often sick but not again. For that, I thank God
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When asked how this perspective impacts on her daily living, she answers

Na God dey help me ohhh. I trust in God by myself. I pray God
dey hear me, the medicine dey work for my body. I no dey tire
like before, I strong to do my business. Na Jesus dey help me like
that. Plenty sickness dey kill people, cancer, diabetes, malaria sef
kill pass this one. So I tell myself say this sickness no go kill me
and the thing no go kill me. Everyday Jesus dey keep me
strong.\textsuperscript{318}

Her answer exuded confidence and hope. She felt sure that there were more deadly
diseases such as cancer, diabetes, and malaria; as such she would not die of HIV or
AIDS. Her last sentence is that Jesus keeps her strong daily, indicating what my
research participants considered a journey of faith with Jesus.

During the discussion in Uyo, some women began to call attention to the place
of the miraculous for HIV, which Kaka puts very succinctly as below:

Jesus can heal, full stop. No one else has done what he (Jesus)
has done for me. Every area of my life. Not like the enemy
thought but God is with me and fights my battles against the
enemy because no one else can fight for me. It is all because of
Jesus.

Kaka, and the other women at the meeting, were trying to make room for the
miraculous amid the contested balance between faith and medication. For Kaka,
Jesus’s power reaches both the natural (medical) and the supernatural (the devil). This
may not be unconnected to the belief that the devil or evil spirits can cause troubles
for people including disability and HIV & AIDS.\textsuperscript{319} For Kaka however, the miraculous
power of Jesus exists in all spheres. I asked the HIV and AIDS Adherence Counsellor,
if he knew anyone who had been healed miraculously of HIV or AIDS before. This
was his response:

All I can say is like me, I have seen many people live healthy
normal lives, marry, have children and work with HIV. That is a
miracle. That is a real miracle for a virus that was killing
everywhere. That is another form of healing for me and all I can
say for now about that. There are two issues here about faith and

\textsuperscript{318} Translation from Pidgin English: It is God th
at helps me. I trust in God. I pray to God and God
hears me. The medication is effective for me. I used to be very tired before, but now I am strong
enough to do my business. It is God that helps me to do that. There are lots of sicknesses that kill
people like cancer and diabetes. Malaria kills more than AIDS. So, I tell myself that his sickness will
not kill me, and I am sure it will not kill me. Daily God keeps me strong).

\textsuperscript{319} Fubara-Manuel, ‘Speaking Meaningfully about Disability and Evil Powers’, 275-98.
healing. The first is that faith must go with ARVs no matter the level of viral load. The second is faith alone without ARVs interferes with the treatment process and leads to default and the circle begins again. Many times, defaulters do not survive it, within a year, there is full blown AIDS and sadly death.

While saying that as a Christian, she is not out to doubt anyone testifying on television about the miraculous healing of HIV or AIDS, a Nurse at the Teaching Hospital, explains why she insists that treatment must continue:

Many Pentecostal churches, prayer houses and Prophet and Prophetess will declare healing for HIV and ask the person to go and testify without confirmation test. Others may have test result saying negative. But the tricky aspect is that when viral load is below 20, HIV is undetectable which means the result will be negative and it is therefore untransmittable which is the U=U (Undetectable equals Untransmittable). But the person cannot stop treatment therapy (ARVS and nutrition) because it is the therapy that aided the undetectable status in the first place. They may actually get a negative test result but to stop medication is ruled out because the person still has the virus inside the person. It is tricky that is why we have HIV training and seminars here in the hospital.\footnote{320 The Nigerian public space is filled with testimonies about the miraculous healing of various kinds of diseases that are often scientifically said to be without cure. There have been many cases of persons testifying on television of divine healings from HIV and AIDS, often showing test results from labs that indicate positive to negative HIV status.}

During interactive interviews with research participants including church leaders, many were unable to see that HIV could be undetectable even though the virus is still present in the person and so the person is still positive. Often a negative HIV test is regarded as being cured of the disease.

It is safe to say that it is because of teaching at the HIV Treatment Centre and encouragement from BOLD Network members that Kaka could conclude with these assertive words:

It is God who gave us the medicine. ARVs (antiretroviral drugs) are part of the healing mercies of God, we need it until God perfects the healing. So, while still on treatment, I confess to myself. I will not die with this disease. I will live. It is well with me. I will not allow what happened to others who died with this disease to happen to me, that is why I take my drugs seriously.
Consequently, I observed a consensus among the women at the focus group on two issues relating to their belief to pray for and expect physical healing that comes with physical change. The first was their commitment to continued adherence to HIV antiretroviral treatment because, for them, the medical is part of God’s miraculous healing process. The second reason was that they do not know the source of what they described as ‘their troubles.’ This is not removed from the understanding that the problems of life in Africa are both physical and spiritual; often physical manifestations are said to have spiritual (supernatural) undertones. It could be argued that these women’s determined sense of confidence is part of their self-understanding or faith understanding, flowing from the deep connection they experience through their relationship with and faith in Jesus Christ, indicating that belief and relations are essential components of faith.

Two other African female theologians have commented on the discourse of physical healing. Musa Dube cautions that, while the church may interpret disability ‘metaphorically to include a spiritual’ dimension, ‘we must remember that an integral point of the gospel of Christ was actual physical healing of the sick.’ Dube does not deny the crucial place of a holistic healing that integrates and impacts social, emotional, spiritual and mental well-being, but she is also careful to mention that physical healing is integral to the Gospel narratives. As stated earlier, there is room for all spheres of healing, especially considering that the act of healing is assumed to be within the supernatural realms, which are removed from the natural. According to Fulata Moyo, who inadvertently responds to Kamba, ‘it seems in the disappointment in prayer, that we should remember that God is wiser than any human person’

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321 Obinna, ‘Nigeria’. Obinna observes ‘how many Pentecostal and Charismatic churches devote much time to deliverance from the satanic forces that are believed to oppose Christians and are held to case material and psychic problems in the sphere of health and wealth.’ See also Benebo Fubara-Manuel, ‘Speaking Meaningfully about Disability and Evil Powers,’ for a detailed conversation on causation for disability within the Nigerian context. Kwabena Asamoah-Gyadu notes that in much of Africa, demons are seen as having considerable influence on the lives and endeavours of people’s lives and one sign is disability. See J. Kwabena Asamoah-Gyadu, African Charismatics: Current Developments within Independent Indigenous Pentecostalism in Ghana (Leiden, Netherlands, The: Brill, 2004), 168, 179.
323 This view appears to be a slight shift from Dube’s earlier position (2002, 132) when she spoke of healing in the context of HIV as belonging to the eschatological sphere.
324 Moyo, ‘Navigating Experiences of Healing: A Narrative Theology of Eschatological Hope as Healing’. 
While Kamba’s concerns for praying for physical healing merit consideration, they seem to go against the grain of Nigerian African spirituality where members and pastors pray for and believe in healing from physical and spiritual forces as the norm. Her reluctance or aversion to pray for physical healing, from the perspectives of my research participants, limits the concept of holistic healing, which is all encompassing and all fully dependent on their relationship with Jesus Christ. This thesis acknowledges two major theologies of healing and introduces a third alternative. It recognises the popular Pentecostal theologies of healing that prioritises physical bodily change. It also recognises the dominant Western-influenced biomedical view of the generally incurable nature of HIV. The third, which is the alternative from this research is the position of research participants about their experience of healing. This thesis proffers a theology of holistic healing that emphasises healing as the transformation of one’s identity, and by extension relationships, whilst challenging the notion of incurability for any disease, and upholding the place of the miraculous for physical healing. The transformed identity is enabled by the women’s relationship with Jesus Christ as friend and healer. This relationship heals women’s stigmatised identities and allows them the freedom to live lives in more liberating ways.

4.2 Women’s Relationship to Jesus Christ as Central to their Faith

My Christian faith is a journey with Jesus Christ. I am not saying that is an easy journey, no, no, no. I can tell you it is not. Anywhere I am, today or tomorrow. Even when I am in school. I know Jesus is with me. I can believe that. I call Jesus my friend.

The women living with disabilities and HIV that I interviewed and observed seized every opportunity during the fieldwork to affirm their relationship with Jesus Christ and the various perspectives of that relationship as fundamental to their faith. While the image of Jesus as healer and the many experiences of healing were most prominent, they also spoke about the many ways in which Jesus came through as friend. Interestingly, this friendship not only enabled and empowered them, but it also laid an obligation to show love and friendship to others; an obligation that they felt able to carry out because of a transformed identity.

The women that I interviewed understood Jesus in particular ways. Some of the metaphors they used for him resonate with the writings of African women
theologians. Some are distinct, while others were differently applied or appropriated. In this section, I examine the oral descriptions of Jesus given at the interviews and focus group discussions and interrogate these descriptions with those of written Christology. As part of the overall objective of this study, I investigate how they describe Jesus, what it means for them and how it helps them cope with the challenges of gender, disability, and HIV. In this venture, the women in my study join in answering the question what the language of African Christian women of Jesus is, and how ‘in their own words they speak of the one in which they have believed.’

For my research participants, the way they spoke of Jesus was with relational metaphors that suggest one who fills the gaps of often failed relationships or lack of companionship. As Maryann stated in this section’s opening quote during a visit to the school where she teaches, she can call Jesus the friend on a not-so-easy journey. I demonstrate that because women come to Jesus with and from the way they live, from their spirituality as Christian women, and from their gendered contexts, the women in my research related with Christ as the friend and companion who is always present in all aspects of their lives.

4.2.1 Jesus as Best Friend

I think of Jesus as my best friend. Jesus means a lot to me.

The above quote was Ula’s opening line at a group meeting in Port Harcourt, explaining what her faith meant for her and how it had influenced/impacted her life. After telling her story of societal and self-rejection due to the stigma of disability and HIV, Ula concluded that it was all because of Jesus, whom she had introduced at the beginning as her best friend. While the idea of Jesus as friend is a popular metaphor within African Christology, especially among female scholars, the idea of ‘best friend’ seems not so popular. It was only Ula who used that metaphor to describe a relationship in which Jesus was the one she turned to, cried to in despair, the one with whom she was invited to have a deeper relationship, and the one who saved her and

gave her strength to start life afresh. It was this idea of a friend who is constantly present in their lives that the women I interviewed spoke of Jesus.

Deedee is a 38-year-old single woman with physical disability. While she used the word friend to describe Jesus just a couple of times throughout the fieldwork, her narrative of Jesus was always of fondness, closeness, and companionship. During a private conversation, she said:

The person you talk with most is your friend. And it is Jesus that I talk with all the time. I want to talk with Jesus the way Martha did. The way she ran to Jesus and started telling Jesus about her brother. When you live alone, or when are you alone, the person there with you is your friend. For me, that person in Jesus. I guess I can put it that way.

Deedee used other words and sentences such as ‘my Jesus’ when referring to Jesus, expressing a sense of possessiveness or endearment. She would say things like ‘Jesus knows what is in my heart,’ or ‘Jesus listens to my heart,’ etc, always managing to paint the picture of a person who is not far from her or removed from her lived reality. This picture of Jesus on a journey with women seems to have been made by Teresa Okure when she asked: ‘who Jesus is to the Nigerian women and how does the Nigerian woman relate to Jesus? Her answer is that Jesus is ‘one of us, knows us and therefore can accompany us in our daily joys and struggles’ Okure drew an analogy of Jesus with the Samaritan woman, with Jesus as the one who talks with women and makes them his partners in mission. This partnership relationship, Okure posits, is possible because Jesus can share the experiences of rejection, prejudice, and isolation, with women who undergo these experiences as a daily reality. Ula, Deedee, as well as the other women in my research could identify with rejection, prejudice, and isolation.

There is a rich resource in the African Christological articulations of Jesus Christ. The Christ for African women responds to the common challenges that African women face in the context of patriarchy, poverty, and injustice. African women therefore want, and find in Jesus the liberator from oppressive cultures, the companion,

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328 Okure, 'Jesus and the Samaritan Woman', 401-18.
friend, healer, the Saviour, and the one who upholds the integrity of the woman.\textsuperscript{329} It has been noted however, that the title ‘friend’ is one of the most popular among women, precisely because women need such a personal friend the most. Further, African women theologians have described the Jesus for African women as ‘personal saviour and personal friend – accepting people as they are and meeting their needs at a very personal level – Jesus ‘friend of the lonely’ and ‘healer of those who are sick, whether spiritually or physically.’\textsuperscript{330} These characteristics of being lonely and sick resonated greatly with my research participants and could explain the need for Jesus as friend and companion.

At the focus group discussion in Uyo, I asked the women what it means for them that they regard Jesus as friend? In what followed a chain-answer format, one after the other, the women said such a things like: ‘it means that Jesus is always with me,’ Jesus loves me and I love him too,’ ‘God is with me,’ ‘he (Jesus) never disappoints me,’ ‘he (Jesus) has done the impossible for me,’ ‘I talk with him (Jesus),’ ‘Jesus knows me,’ ‘Jesus gives me strength,’ ‘Jesus means a lot to me,’ ‘without Jesus in my life, life is meaningless.’ Jesus as healer, the one who heals or the one who takes away diseases, featured strongly as well. These relational ‘notions of close and faithful companionship are central to the image of Jesus as friend’ that women have.\textsuperscript{331} It could be argued that the idea of having a friend who never disappoints but always loves, and is always present, provides succour for women as they navigate the tensions of disability and HIV.

African women theologians have written about the unique relationship that women have with Jesus, when compared to men. They argue that African women’s challenges are different from those of men, and these challenges, such as suffering, inform relationships with Jesus.\textsuperscript{332} Another is that women, as carers, can relate with Jesus’s maternal instincts such as care and compassion for the weak and excluded.\textsuperscript{333}

\textsuperscript{331} Stinton, \textit{Jesus of Africa}, 167.
\textsuperscript{333} Oduyoye, ‘Jesus Christ’, 2002.
Jesus was born by a woman, therefore, they argue that Jesus feels much more the ‘heartbeat of a woman.’ Although men have used relational metaphors for Jesus, as loving friend, personal friend, personal companion, not much of men’s lived experiences have demonstrated or documented these relationships. Instead, Christological endeavours by African male theologians have presented masculine metaphors of Jesus, such as Chief, Master, Male ancestors, as discussed in the next paragraph.

In Nigerian Christology, male theologians have presented Jesus as ‘guest’ or ‘stranger.’ Jesus has been conceived as ‘Oga Kpatakata (overall Boss), Bulldozer, Kabiyesi (great one), Oba a yiku (Immortal God), Son of God, Saviour, Lord and Master of Peace, Eternal Second Person of the Trinity, Mediator, Intercessor, and Conqueror.’ Many African women theologians reject the default masculine images of Jesus because of the hierarchical authorities embedded in patriarchal structures that do not support participation and inclusion of all. However, the women I interviewed differed from the popular opinion of African women theologians. They did not express any objection to the masculine metaphors of Jesus as male, king, or ruler, even though they did not necessarily use those metaphors. Instead, they voiced the opinion, already discussed in Chapter two, that Jesus as a positive male figure could bring about positive masculinity into the patriarchal system of Nigeria. In the stories of the women that I interviewed, the more contentious relationships were those of the males in their lives (boyfriends, husbands, brothers) and so they voiced the need for a male relationship (friendship) in Jesus that was affirming and empowering.

Friendship with Jesus for the women that I interviewed was not seen as an abstract relationship. In referring to Jesus as friend, they confessed the embodiment of all other ways in which they relate with or have benefitted from that relationship within their current realities. Eve, a 40-year-old single woman with physical disability said during an interview: ‘Jesus is everything to me. That is why I talk to him about

334 Stinton, Jesus of Africa, 248.
335 Stinton, Jesus of Africa, 165-67.
337 Nkem Emerald Osuigwe, ‘Crude Oil, Conflict and Christian Witness in Nigeria: Baptist and Pentecostal Perspectives’ (The University of Edinburgh, 2010), 199.
338 Stinton, Jesus of Africa, 308.
everything. What will I leave out? Nothing.’ While the metaphor of Jesus as saviour from the penalty of sin was mentioned several times or implied in their stories/testimonies, it was the ways in which Jesus saved from pain, disease, poverty, isolation, and abuse that resonated more in our conversations. It was therefore within these challenging circumstances that the women expressed their appreciation to Jesus as friend, who unlike other human relationships, accompanies them through all the bad stuff. As aptly put:

Jesus Christ is the liberator and saviour of women from all the oppressive contexts … and empowerer of women in their contexts of powerlessness, and their friend and ally in the context of alienation and pain that women may be confronted with.339

I argue that this image of friend was connected to the way in which the women in my study understood Jesus as provider, protector, companion, saviour, and liberator. They talked about it, shared it in stories, and sang songs to embrace it. Furthermore, it was because of the empowered identity that Jesus enabled that they felt the responsibility to break the moulds of exclusion and reach out to others to create safe inclusion spaces for all.

4.2.2 Jesus as the One who enables love for others

Mme yene Mbuot idem ke Eyen Abasi340 Faith in God kept me through my husband’s death, blindness, and HIV. God loves me and gave me his Son Jesus to save me, even me. In this my condition, I give God thanks because I know he still loves me. When this sickness (HIV) started, I did not believe I would live to see this day. I did not believe I would have friends again. But no matter, Jesus loves me that is why I have to love others – so my faith means I must love others no matter what. Many of my friends are in the mortuary but God continues to keep me because he loves me. So, I thank God every day. I know no matter what anybody says that Jesus loves me.

In the above quote, we observe how Enny, a 56-year-old widow with sight disability, attributes her faith identity to Jesus Christ and that which obligates her to love and

340 English translation of Efik: I have faith in the Son of God.
relate with other people. This is a faith experience which connects her to other people facilitating mutually enriching relationships.

She says, ‘because this Jesus, in heaven can love me, then I am somebody.’ In Enny’s story, she notes an implied responsibility in her new identity of being ‘somebody’ who once felt worthless to offer a gift of her worthy self to another and in so doing engender mutual relationship. This new sense of worth has been facilitated by Enny’s acclaimed relationship with Jesus Christ, in a way that enables her to redefine herself. Furthermore, it has been argued that the ‘theology of relationships might contribute to bring us closer to human life as God desires it.’

It is therefore, safe to say that Enny’s perception for a communal faith agrees with African women’s theologians’ approach to collaborative effort towards the liberation of all. For Oduyoye, the distinctiveness of African women’s pursuit for liberation is for a collective liberation that involves both male and female as a community for equality, dignity, and justice. At the heart of this pursuit is relationship of equals where all voices and all concerns are important at the table of intervention.

For Enny, and the other women at the group discussion, faith ceases to be abstract or lived in isolation when looked at through the lens of gratitude with which Enny’s sees her faith journey. Enny’s avowed commitment to love others ‘no matter what’ is framed within her acceptance of God’s love for her, a love that made God to give ‘his Son Jesus to save me.’ She demonstrates that her faith is enabled by trust in and relationship with Jesus Christ, which creates a dignified identity and produces good for personal and communal benefit. Jesus is not just a historical figure and faith is not an addiction for the women I interviewed. For women, whose identities have been normatively shaped by society’s (culture and religion) stereotypes about disability and disease, their Christian identity allows them to counter dominant cultural narratives. They feel they can claim their identities, something that had been impossible previously.

While there was unanimity in accepting that the love of Jesus enables a new identity, not all the women at the group discussion at Uyo felt called to love all others. The women I interviewed had at various times during the fieldwork narrated their

341 Stinton, Jesus of Africa, 39.
342 Oduyoye, ‘Jesus Christ’.

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experiences of being mistreated and disrespected because of their disabilities. Often, dehumanising acts against them have caused self-stigma that hindered full participation and integration. They had been excluded from the community, whether in religious or cultural settings. This sense of conflict was expressed by some of my women during the group discussion, as they struggled to make sense of their exclusion and this call to communal love. Kaka, for example, wondered how to use the word ‘love,’ for her ex-husband who disgraced her and made her homeless. Another agreed with Kaka that love was not the word to use for men who had constantly abused her, verbally and emotionally.

Enny, whose story of being called to communal love ignited this intense conversation, tried to explain that the obligation to love is only possible because of what Jesus had done for them. ‘What would you gain in not loving,’ she asked. The women who agreed with Enny, tried to diffuse the argument. They argued that because love may be a strong word to use, they should just ignore all the men and others who tend to make them feel inferior. This way of ‘ignoring’ the men and those who abused them, was a recurring option that these women explained how they dealt with patriarchy or oppressive practices and texts. The tendency for my research participants was to focus on what was liberating and what enabled their flourishing for an ability to cope with challenges.

Some of the women in my research face the dilemma of love and abuse as a sociological problem that is integral to their lived experience. The question of the possibility of communal engagement in Africa in the face of ‘exploitation, oppression, and domination of women by men’ have been previously asked. The implication of this is that men are often perceived as the oppressors and women the oppressed that need to be saved. While the women I interviewed opted to ignore the men and focus on Jesus Christ, many African women theologians advocate confrontation on one hand, and collaboration on the other. Some, like Njoroge, have argued that because

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344 A. S. Van Klinken, Transforming Masculinities in African Christianity: Gender Controversies in Times of AIDS (Farnham, Surrey, England; Burlington, VT: Ashgate, 2013), 3-4. Men have rejected this rhetoric that they claim puts the blame on men without considering other socio-cultural and economic factors that influence the behaviours of men.
working together involves reconciliation between the oppressor and the oppressed, such reconciliation must be the absence of evil, injustice, and sin.\textsuperscript{345} This means confronting and changing all forms of oppression instead of improving or condoning them, which seems not to be the preference for the women in my study.

There appears to the an insistence for solidarity, based on gender justice and equality, for women to ‘reclaim their moral agency to bear in eradicating the death-dealing realities of our times and in constructing a humane and just future in the global village.’\textsuperscript{346} All women are therefore called upon to be moral agents ‘not only to be recipients of liberation, … but also to be challenged to become subjects by actively undertaking the task of liberating, transforming not only themselves, but also society to ensure a more humane and egalitarian future.’\textsuperscript{347} As discussed in Chapter Five, for the participants, this option comes from a place of power and privilege, which they claim they lack. Instead, what the participants suggested was the mutual accompaniment of women by women, in the first instance. They acknowledged that gender justice driven by women did not always include women with disabilities. The inclusion of women by women, was for the women I interviewed the first point towards gender justice.

The women I interviewed did not discuss in detail what loving others, men included, meant for them, and I did not ask further. There was always a reluctance to stay on the conversation about men and patriarchy. They did not mention what they hoped to gain from this act of loving others, even husbands who mistreated them, or church that excluded them. What I gathered was that this responsibility to love others that my research participants discussed was not about the recipients (others - people) of the affection, but about the enabler of the action (Jesus). It could be argued that it was a demonstration of a transformed identity in their relationship with Jesus as friend that made commitment to community a vital aspect of faith. This is recalling the statement by one of the participants, ‘because Jesus loves me, I must love other.’ Or perhaps, it was a response to the Biblical injunction to love others (Mark 12:31).\textsuperscript{348}

\textsuperscript{345} Njoroge, ‘A Spirituality of Resistance and Transformation’.
\textsuperscript{347} Hinga, \textit{African, Christian, Feminist}, 50.
\textsuperscript{348} Mark 12:31, ‘The second is this: ‘love your neighbor as yourself’. NIV.
What they claimed was that the renewed relationship with Jesus gave them boldness and placed on them an obligation for communal engagement. This agency could in fact be a type of resistance, in which their sense of esteem is improved, and they can add value to the society by offering love instead of hate. In Chapter Five, I discussed further with evidence, that transformed identity enabled the women I interviewed to have empowered navigation of contested relationship with others whether family, the church or among friends.

4.3 Women’s Understanding of Faith: Journeying Through Life with Jesus

It is a journey that affects every aspect of my life, everything I do, because it is my faith that helped me. I will stay in faith forever. That is why I have many testimonies.

Ula’s quote above exemplifies Christian faith as a lifelong journey with Jesus Christ. For these women, it was not a part time relationship or one with a possible terminal date; it was a relationship for life. The first question at the interviews and group discussions was ‘what is your understanding of Christian faith?’ To make it clearer and elicit further conversations, I asked ‘what does faith mean for you as a woman who has a disability and is HIV positive’? The purpose of this second level exploratory question was to create a space whereby each participant would speak freely from personal perspectives and experiences. What resounded from both Port Harcourt and Uyo groups was the idea that the Christian faith is a journey with God, and more specifically with Jesus Christ as companion.

Ula defined faith as a journey. If we attribute to this short definition the earlier claims of Jesus as friend, then what emerges is, Christian faith holistically as a journey with Jesus Christ as friend and healer, who transforms their identity to cope with life’s challenges. The specific of this journey is that it is unending for as long as they are on earth. This was aptly put when Maryann said, ‘Yes, it is like a journey but this journey ends in heaven. It is strong faith.’ Earlier in the chapter, I had quoted Maryann as saying that her Christian faith is a journey with Jesus Christ. Maryann elaborated on

349 Interestingly the women in my research also referred to the Bible a journey companion, which is discussed in Chapter Six. The idea of a journey may need further research as time constraint did not allow for that to happen.
this explaining that having found Jesus as friend with whom there are no impossibilities, that, there was no letting go.

During conversations with Eve in Uyo, she said:

Christian faith for me is life. That is life – if it is good and if it is bad. It is my life. I do not know how to say it. Maybe what I want to say is I don’t have anything apart from this.

Eve painted the picture of the intricate connection of the Christian faith to her overall reality. For her, her life is not separate from her faith, despite the uncertainties. Her faith is about her life for life (as long as she lives). As a single woman, whose parents have passed away, and who is negotiating life in a community in which she lives, often stigmatised due to her HIV status, Eve indicated that she had nothing outside of her faith. Here, again we observe the concept of Christian faith as the essence of life and/or as a lifetime of commitment.

Enny used Ibibio to define or describe faith. She said it is *mbuot idem*. The literal translation for *mbuot idem* is to trust or rely on someone or something. It represents an act in which ‘the body’ is rested in a state of surrender to someone or something. So, when Enny spoke of *mbuot idem* at the focus group meeting, she unconsciously bent towards the next person to her imagining that person as the one to whom she surrenders. This sense of trust as essential to faith, within indigenous understanding, was also expressed by a Kalabari speaking research participant in Port Harcourt. In Kalabari language, faith is *minini*, which when interpreted signifies the surrender of ownership of something to another without reservation. This not only reveals the presence of an active relationship but also one of trust one for the other. This sense of trust in God, is what Enny said enables her, not only to surrender to God, but also to love others making her faith a communal one affecting her life and that of her community.

In all the stories shared, women’s responses during the group discussions were never framed in theological debates or arguments. Women spoke from their lived experiences and the reality of their challenges. The exploration of faith as understood, expressed, and lived out by the women is therefore integral to the interpretation of how women dealt with their identities and articulated the ways in which disability and HIV were assimilated as part of their lived reality. African Christian scholars, agree that an
understanding of faith that is ‘sensitive to the local contexts in which faith is lived and experienced’ is necessary for the study of African Christianity’. But as can be seen in this study through the stories of the research participants, it is also necessary for an insight into the ways in which women’s identities are shaped by their faith knowledge and experience. While the role of faith in lived Christianity of the African continent, have been variously researched, few researchers have carried out an in-depth analysis of what people’s personal understanding of the Christian faith represents and how it informs their personalities and/or actions. This study does not intend to essentialise African’s faith experience, it recognises that faith is never practised in a vacuum but always within a context.

Teresia Mbari Hinga has written of how a meaningful Jesus for African women ‘would need to be a concrete and personal figure’ who gives confidence and courage to women. Hinga dismisses the view that making Jesus personal whether friend or saviour is an ‘unwarranted privatization’ on the grounds that women do indeed need a personal friend as one ‘who helps them to bear their griefs, loneliness and sufferings.’ This need for Jesus resonated with all my research participants from all church traditions, because in the face of society’s often exclusion of those considered vulnerable, this personal aspect is vital. The women that I interviewed therefore spoke about Jesus in very personal terms; as the one who comes into their lives, to whom they live their lives to, the one they connect with, and at the time of despair, gives them strength, and means a lot to them. The imagery that the women paint of Jesus Christ is also that of companion who gives a new identity from the one dented by disability, abuse, and HIV. Relationship moves from the external to the internal in a way that allows for transformation for the women that I interviewed.

For some research participants, it was not all about belief but more about the rituals of faith and worship. When I asked Mary in pidgin English if she was a Christian, this was what she answered:

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Yes, I like church well well. We dey sing, we dey dance, we dey happy. My sister dey carry me go church. Me and my children we dey go church well well.

Mary’s answer was not about belief, which was the essence of my question, but about the ritual and her joyful experience of going to church, singing and dancing. As one with learning disability, Mary’s understanding of the severity of her HIV status or of her disability is limited. She cannot read or write, nor does she understand the meaning of the songs or rituals. Yet, she describes Christian faith only in connection to church rituals of singing and dancing. It has often been said that for persons with learning disability, their mere presence in church is capable of mutual edification, for them and the congregation. It does appear that the often ceremonial and celebratory atmosphere within a church setting is able to conjure feelings of calmness and joy for worshippers. This was even though their involvement in the worship services were often limited to attendance. Many research participants shared that physical presence is an expression of belief irrespective of the level of participation, inclusion, or exclusion.

The women in this study affirm a Christian faith in God through Jesus Christ that is not necessarily based on sensory observation of seeing, touching, hearing, smelling or just feeling because some had hearing and sight impairments. They testify to the outward manifestation of an inward faith in reclaiming their dignity, affirming their identity, enabling relationships, and empowering economically. I demonstrate that faith understanding, like most religious concepts, could be difficult to describe definitively. It might only be possible to express it experientially, which is what my research participants have done, often with similar metaphors or words. Although many of the faith understandings expressed by the women in this study reflected some common ways in which persons without disabilities appropriated their faith, there were

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353 Benjamin T. Conner, *Disabling Mission, Enabling Witness: Exploring Missiology through the Lens of Disability Studies*, Missiological Engagements Series (Downers Grove, Illinois: IVP Academic, 2018). Benjamin’s book analyses the mission contribution of persons with limited intellectual development which could very often be the ‘gift of their presence.’ See also Brian Brock, *Wondrously Wounded: Theology, Disability and the Body of Christ*, (Waco, TX: Baylor University Press, 2019) where he shares his experience as parent of a child with intellectual disability who has watched the child’s joy as being part of the church without reasoning capacity.

some that were unique. Foremost was the direct connection of their faith to relationships, firstly with Jesus Christ as one who accompanies on the journey of life, and subsequently with members of their community and family, through the enabling love of Jesus. Faith therefore provides the agency for women to navigate difficult circumstances associated with disability and HIV, while offering succour in the process.

My enquiries into the support for women living with disability and HIV could have gone no further than an understanding of BOLD Network or the mechanisms of community support, but that would have ignored the opinions of the women themselves. Whilst each of the research participants expressed that they were very grateful for organisations like BOLD Network that provided supportive community, they testify to Jesus Christ as the friend who brings them together in love and supports them on life’s difficult journey. Without considering the faith perspectives of women, studies will be inadequate in addressing the specific concerns and challenges that identified populations face.

4.4 Conclusion for Chapter Four
This Chapter explored the way in which Christian faith provide strength for those who live with a disability and HIV. Specifically, it examined three areas of faith understanding that emerged consistently from fieldwork interviews, discussions, and observations which are belief, social relations, and practice. The chapter focused on women’s response to Jesus as part of their Christian belief system. I have explored these emerging themes and their articulations of faith in dialogue with writings from African women theologians. The chapter argues that the personal faith of many women is centred on a personal relationship with Jesus, as the healer and friend. To these women, Jesus can heal the physical body while giving them transformed identities with which they can live better lives. This changed or transformed identity gives them greater confidence in themselves, improves their self-esteem and provides the tools to live with disability and HIV. They found alternative ways of negotiating patriarchy while creating affirming relationships. They were no longer ‘nobodies’ but persons deserving to be treated with dignity. They viewed Christian faith as a journey
with Christ as their constant companion, in a world which is often lonely for many of them.

The majority of them claimed that their relationship with Jesus helped them to overcome societal stigma that they found in daily life and in the church. Focusing on the centrality of Jesus in their lives, many women professed Jesus as friend who understands, and in whose love, there is an obligation to community. Some women interviewed here expressed their reservations about loving those who mistreated them but opted to ignore the oppressors instead of collaborating or confronting them.

The women interviewed spoke about how they have felt alienated from close relationships, some have been abused, others rejected and many of these women have experienced isolation due to inhuman traditional laws. Overall, however, as this Chapter has demonstrated, women with disabilities and HIV found that their Christian faith was a source of support as they sought their well-being and positive self-worth. The way in which the women I interviewed place their Christian faith at the centre of a positive experience of who they are should be regarded as important to all who are interested in those living with disability and HIV in Nigeria and other places where religion plays a large public role. For it is this positive experience that supports them in navigating the other social relationships in their lives.
Chapter Five

Women’s Relationships with Others: Family, Church, and Friends

5.0 Introduction
This Chapter presents fieldwork findings to examine the support systems and relationships available to women with disabilities and HIV in the church and society. It addresses one of this study’s objectives which seeks to understand the extent to which relationships influence or provide support and succour for Christian women as they navigate the challenges of disability and HIV. By doing so, it illuminates another research objective to understand faith and belief interpretations that influence the ways in which women in this study live with disability and HIV.

In Chapter Four, I discussed how participants described their relationship with Jesus Christ and the way that this relationship enabled a sense of communal belonging and responsibility. This Chapter furthers that discussion by analysing how each of the women engaged with, navigated, and negotiated the different relationships and stereotypes in the family, church, and society, because of their relationship with Jesus. They do this from their desire for community within a positive sense of self to a response to which they are perceived and live with others. Building on African feminists’ concerns and the social model theory, the chapter demonstrates the responsibility of society (and church) to provide enabling spaces for persons with disabilities and challenge social boundaries that are often restrictive for women.

Focusing this chapter on the relationships in the family, the church and with friends, I interrogate the descriptions of these relationships and explore how women are navigating the tensions in each of them. This Chapter argues that participants appeal to their relationship with Jesus Christ to address stigma and to create affirming human relationships suitable for their flourishing.

5.1 Women Navigating Family and Intimate Relationships
The identities of the women I interviewed in south-south Nigeria are formed by their family units whilst at the same time they acknowledged that commonly held notions of the family did not always support them. Basic to this notion is the gender subordination of women to men, in family units, in ways that curb the rights of
women. This section examines briefly how ‘family’ is commonly perceived and why women living with disability and HIV navigate their family relationships. Families are very important to women, but in some cases, families do not give the support that women would expect. Women sometimes create new forms of families in case of rejection from their kin.

For my interviewees, the family was conceived as being the basic unit of relationship and first point of socialisation. The family has been described as ‘group of people related by blood or by law, living together or associating with one another to a common purpose, that purpose being the provision of food, shelter, and the rearing of children.’ Drawing from western scholarship, this description points to families as being the outcome of marriages between men and women who go on to increase in number through procreation of children.

Within the Nigerian context, there are many forms of family relationships. A more comprehensive description of an African family highlights the key features that are common in families in the south-south of Nigeria, namely ‘preference for extended family structure; high degree of male and female roles and responsibilities, integration of reproductive and productive functions, stronger lineage than conjugal solidarity, propensity to polygamy, and dominance of elders.’ During interviews, the women described families in ways that resonated with this description of family as consisting of ‘two or more nuclear families affiliated through an extension of the parent-child relationship rather than the husband-wife relationship.’ The women in my study also introduced what I call ‘alternative family relationships,’ in which

355 Nkiru Uwechia Nzegwu, Family Matters: Feminist Concepts in African Philosophy of Culture, (Ithaca: State University of New York Press, 2006). Writing for the Igbo south context of Nigeria, Nzegwu notes that ‘women’s roles…as the provision of labour, the production of children, and the provision of sexual favours for me’ is a based on post-Christian, European colonial perceptions that are derogative to women. She notes that this has been left unchallenged and therefore continues to be norm for families in Nigeria. Some male theologians have joined African women in challenging the domination of men over women. See Adriaan S. Van Klinken, Transforming Masculinities in African Christianity: Gender Controversies in Times of AIDS (Surrey, England: Ashgate Publishing Limited), 2013, 64-5.


357 See Nzegwu, Family Matters, 1-22, for a full description of the various forms of family relationships, particularly within the south of Nigeria, where my research is also based.


women adopt and belong to new forms of family when their traditional families do not meet the need for mutual support.

In this section, I discuss the various ways in which women with disabilities cope with social relations in the family. I do so by examining their relationships with their mothers, siblings, partners in marriage, and strangers. I show that they use the most supportive relationships within these groups whilst attempting to attain some level of independence. As Christian women, these women share stories of family life where the elements of trust, value and support experienced in their relationship with Jesus are often lacking. This research finding provides that the centrality of these women’s relationship with Jesus provides the strength and courage to navigate difficult human relationships listed above.

5.1.1 Women Engaging with Parents and Siblings

For me, it was only my mother that helped me

Daisy explained the care she received from her mother with those words. In evaluating the extent of support that women in this study claim to have received from their parents and/or siblings, I interrogate the women’s limited access to family support. Two sides of care were noticeable in this context. The first was the responsibility of the immediate family to care for women with disability and HIV; the second was the duty of the women with disability and HIV to care and protect their families. Each aspect of this care equation was wrapped in the extent of trust that allowed or did not allow for disclosure of HIV status. The relationships of women in this research were profoundly shaped by the disclosure and non-disclosure of their HIV status.

Daisy is in her mid-thirties with limited sight vision. This is Daisy’s story:

For me, it was only my mother that helped me. I believe God used my mother as my support. She noticed I was losing weight and she sent me for testing. When it was positive, she encouraged me and accompanied me to the hospital for treatment. When neighbours asked what was wrong with me, she would quickly answer and give different excuses for me. One time, she told them it was painful menses. I was always sad, crying all the time, she told our neighbours that I was sad because I failed my exams. With my mother’s encouragement, I started going to church again, I finished my degree and surprisingly I met my husband. I told him I was positive, but he still agreed to marry me.
Daisy did not disclose her status to her siblings or any other member of her family. Her mother forbade her to do so. Daisy told us at the meeting how difficult it was to live in the same house with such a secret from people she loves and who support her with the challenges of disability. When Daisy said God used her mother to support her, she was alluding to her mother’s role in the agency of God’s provision and support. Through her mother’s support, she returned into society and went to church, which could be a spiritual or social exercise. There is a sense in which she is receiving good support from her husband, who agreed to marry her even though she was HIV positive. Without her mother’s initial support however, getting tested or treated for HIV would have been impossible.

During the interview with the HIV Adherence Counsellor in Port Harcourt, I asked him what difference family support makes to HIV treatment adherence. He exclaimed and said ‘ahhhh big difference.’ He explained that family support is crucial at every stage of HIV detection and treatment. He said:

One problem we see is when people come when the virus has progressed far, which case their lateness causes problems. And this coming late is because they were hiding the infection from their family and friends, they did not tell anyone or come to the clinic – lack of disclosure is a big problem.

While not every case of disclosure was accompanied with support, there were women in this research who received support when they disclosed to their family members. For some women, the support from family was from siblings. Emily shared her experience with her brother’s support, stating, ‘without my brother, maybe I would have died’. Emily said her younger brother helped her all through in her journey with HIV and provided her with funds to start her business to take care of herself and her children:

I told my junior brother who is a doctor. Quickly my brother travelled from Onitsha to come and see us (in Port Harcourt). He took me for testing. The result was positive. I did not understand HIV and AIDS. I cried and cried. My brother said I will not die. My brother carried me up. My brother gave us money for me and my children to get another place and to start small business. Without my brother maybe I would have died.
When Emily lost her husband to AIDS, she also lost a community due to the stigma of HIV for a sight impaired woman. She had to move with her family to another part of Port Harcourt to start life afresh. But what she lost in her relationship with her husband and community, she gained in the support of her brother. Again, as with Daisy above, Emily links her brother’s help to the work of God through the saving experience of Jesus as she said ‘I believe it is God that made me live and not die. Jesus saved my life.’ However, while Emily enjoyed her brother’s support, her HIV status was still shrouded in secrecy as she could not readily share with her children that both their parents were HIV positive. Living within that space of non-disclosure was according to Emily, very hard.

Another story of sibling support was from Mary, who was supported not only by her sister but also her daughter. When I asked Mary, who takes care of her, she replied, ‘my sister or my daughter. I have many children.’ The constant members of that family were Mary, her sister who was the primary carer for Mary and Mary’s 6 children. Due to Mary’s learning disability, one of Mary’s daughters also contributed to the care for the family. Throughout my interactions with Mary, it was her relationship with her sister and her children that she presented as her human support in coping with disability and HIV.

Scholars have noted the far-reaching effects of HIV on the well-being and structures of families. In Nigeria, as with many other parts of the world, there is an implied sense, not only of identity but also of care and protection that is expected of the family. Without regard to religious beliefs or practices, the basic expectation of an average family is the provision of a safe, hospitable, and flourishing environment for all its members. Frequently, children take on care-giving roles when parents have

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360 It is not uncommon for family members to take care and make decisions concerning the sexuality of persons with learning disabilities. For more, see Susan Ledger et al., ‘Contraceptive Decision-Making and Women with Learning Disabilities’, *Sexualities* 19, no. 5–6 (2016), 698–724.
been ill because of HIV or AIDS. At the focus group discussion, women discussed how disability and HIV have adversely impacted on the care system in their homes.

On the other hand, women also spoke of how their responsibility as carers is the motivation for their survival. This was Eddy’s experience:

I think I motivate myself to survive because of my family. So I have to live for my children, my aged mother and my siblings. I don’t want to give them sorrow and if I die, they will be sorrowful. As Jesus protects us, I do my best by God’s grace.

Eddy is an example of the reverse role that families play in the lives of research participants and how because of the strength they get from their relationship with Jesus Christ, they can navigate socially constructed gender roles.

Role reversal for some women with disabilities and HIV meant their reluctance to disclose their HIV status is to protect their family from family-stigma and pain. Ula explains it this way:

I cannot tell my family. It is a very heavy secret. Because I used to hide to take my drugs and it was hard. I had to find a small container that can enter my purse so I can carry my drugs with me all the time. If I tell my family, it will be sadness everywhere. And it may spread in the market place because my mother sells in the market and has all these prayer partners and prayer groups. It will be embarrassing. I will become serious prayer point. So, I had to relocate to Port Harcourt because it was becoming difficult to keep this secret.

Here we see Ula’s desire not to be the cause of sadness for her family, and for her mother specifically, for which reason she feels obliged to carry the ‘very heavy secret’ of HIV infection. Also, we can observe how prayer, from which Christians draw strength as a means of communication with God, is here described in negative terms when one becomes the attention of prayers. Within the Nigerian spirituality, to become a concern for ‘serious prayer point’ often means the person being prayed for is undergoing a rather difficult ordeal, which presumably had become public knowledge. When this ordeal is HIV, there is fear of stigma that could lead to

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exclusion. Ula’s mother may lose her customers and be alienated on the assumption that she may be infected by Ula.

However, her inability to confide in her family may not also be unconnected with the experience of her childhood. Ula shared the story of her rejection by a mother who did not know what to do with a child, who at 7, developed polio and became paralysed in both legs. Her father had died when she was 6 years old and upon her paralysis, her mother sent her to a mission Catholic school for orphans. At 28, Ula was abused, raped, and infected with HIV. Ula said her negative experiences with disability made her unable to speak about HIV indicating that the negative emotions from childhood were still heavy on her mind.

Ula was suffering from self-stigma as she is laden with ‘intense disabling feelings of fear, anguish, shame, dejection, self-doubt, guilt, self-blame and inferiority.’ It has been noted that often, self-stigma is more injurious than the actual experience of stigma because it has the tendency to destroy a person’s self-worth without any substantiated evidence of stigma. Subsequently, persons inflicted with self-stigma are unable to access available support for fear of rejection, condemnation, or outright inability to live positively. Like many women in this study, self-stigma manifests itself in non-disclosure. The women wondered what it would be like to be completely open to every member of their families about their HIV status but agreed it was not a risk they wanted to take.

Grace said,

To tell is difficult. I must ask, is it necessary? What is the good in telling this or that person? How will the person take it? How will it affect that person?

In response to comments like Grace’s, I asked the women if their inability to disclose was putting the strain on family relationships more than the fact of HIV infection. Most of the women expressed the opinion that they would probably be able to disclose their HIV status if they had no disability, implying the double burden of disability and HIV on women in this study.

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Disclosure is a personal decision and there is no way to query a person’s private choice.\textsuperscript{367} But it is difficult to adequately assess the extent of family support if there was no disclosure of HIV status by the women.\textsuperscript{368} For women in this study, the family may not be harmful place, but it is not a place in which they are properly cared for or respected due to the stigma of HIV and disability. HIV made these women live secret lives because for them, family relations are not deemed strong enough to withstand such stigmatising news. This suggests that the fault in these often-contentious relationships may not be with the family members per se, but was imposed by societal expectations of women, with or without disability or HIV.\textsuperscript{369} In what would seem to be the common attitude to such difficulties, women in this study did not try to change their families but rather concentrated on changing their lives to environments and relationships that were affirming. Sometimes, this involved movement to new jobs, new places of residence and new relationships.

5.1.2 Women Embracing Strangers as Families

He saw me on the road and took me in.

Participants demonstrated that the concept of family goes beyond the nuclear or extended family members within one’s community. They acquired new forms of family due to perceived failure or inability of the traditional family unit to provide the needed support. Drawing from the above, some women in this study reveal how they had to embrace strangers and make them families, often in a bid to fill the gaps created by lack of support from their immediate families. These women narrated how the adoption of strangers is a manifestation of the love of Jesus providing protection for them.

In the above sub-section, I discussed the story of Ula who had to relocate to Port Harcourt due to the difficult condition which the non-disclosure of her HIV status placed on her. Ula said, the move was, ‘to be far from my immediate family because

\textsuperscript{367} Kamau, \textit{AIDS, Sexuality, and Gender}, See the accounts in Zambia in Janet Parsons, et al, 'Are We Not Human?' Stories of Stigma, Disability and HIV from Lusaka, Zambia and Their Implications for Access to Health Services.


it was becoming difficult to keep this secret.’ Ula says after she gave her life to Jesus, she knew she could not continue to lie to her family, so she left home and relocated to Port Harcourt. Ula further shared her experience on arriving in Port Harcourt where she had no place to stay and with little money.

I came to Port Harcourt with only N20,000.00 (£45) looking for a place, looking for food. Someone out of nowhere offered me batcher\(^{370}\) and I had to live with the boy and his mother whom I never met or known the boy before. He saw me on the road and took me in. He helped me to get a batcher and the mother started bringing food for me. I could not go home for Christmas because someone that used to take a bag of rice—my mother would disgrace me. My Christmas was with these people (the boy and his mother.)

In Chapter Four, Ula described her faith as a relationship with Jesus as a best friend who gives her ‘real strength’ with which to face the difficulties of living with disability and HIV. Ula here attributes her ability to leave home even though she had nowhere to go as a strength derived from her relationship with Jesus Christ. Although she did not use the word ‘family’ for the people who saw her and took her in, a family relationship is implied as she not only stayed with them but also spent Christmas with this family. In south-south Nigeria, the Christian Christmas holiday is a time of celebrating the birth of Jesus Christ and it is usually expected that many would travel to spend the holidays with family rather than with friends. Where families are absent, women found new models of family to belong to and to access support.

Eno’s story resonates with this new model of family. She told me how she had already lost two relationships due to the stigma of HIV. The first was her traditional family where, due to the pressures from her disability, she did not feel adequately supported or valued. The second was her relationship with her fiancé that was broken when she tested positive to HIV. With her face lit up, Eno shared the story of her new family:

When I moved to my new house, I want to say Jesus is with me and mysteriously sheltered me. He gave me hope again through my neighbours. They started talking with me, invited me in their house. They offered to train me in fashion design. With my problem (hearing impairment), they are patient. I was rejected by

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\(^{370}\) A batcher is Pidgin English referring to a makeshift or temporary accommodation.
my family, so they are my family now. I have a sewing shop and I can take care of myself.

From further interviews and observations, I highlight three elements in the stories of Ula and Eno regarding their new families. The first was that there was no disclosure of their HIV status and they felt neither the need nor the obligation to do so if they were careful to prevent transmission of infection. Secondly, there was no expectation of care or support. Therefore, any support they did receive was greatly appreciated. Thirdly, it appears the women were intentionally creating new relationships to fill the gap created by the families they had left behind. These elements portray the women’s intention to take control of their lives and live within relationships that were affirming, supportive and empowering. If it meant moving away from familiar relationships into creating families with strangers, these women took the chance with a strength they claimed they drew from their relationship with Jesus Christ.

Not all women moved away from home. One woman, Eve, moved back home on learning of her HIV status. This is Eve’s story:

I was surprised when I got my HIV test result that I am positive. If this can happen to me, then no girl is safe. That is why I went back to my village, to tell my people about HIV and AIDS. That is what my Support Group is about, especially for young girls and women.

With a deceased mother and without siblings, Eve refers to the young people involved in her Support Group as her family. In this circumstance therefore, family for Eve is one with the values of togetherness, reciprocal care, and presence. Eve continues: ‘in the Group, we have our meetings, I talk to the young people about HIV, we talk about how we are doing, and we look out for one another.’ Eve found familial values within this Support Group outside of her kin structures. Eve’s new model of family is however transient since many of the young people grow and relocate to urban areas and others drop out of the Support Group due to fear and/or the effects of stigma.

For Eve however, she claims her motivation is that her life has been saved by Jesus Christ to serve others. She claimed having a group of people to relate with and help as family was what gave her purpose. Although women claim a sense of completeness in their relationship with Jesus Christ, there was noticeable longing for
fulfilling human relationships and family support. It is this longing that in fact, makes these women create relationships even when such relationships are fluid or temporal. It seems they did not mind that lack of permanence in these relationships as soon as they found some values that had features of a family as defined by them. These movements or new family bonds did not exempt them from the identity and responsibility to their traditional families.

Ula, for example, sends gifts to her mother at Christmas time although she spends the holidays with her new family. She says, ‘I used to send rice to my mother at Christmas.’ It highlights the fact that no matter what women do, their identities are intricately tied to and informed by her family status. However, the women that I interviewed claim their new families afford them a ‘fresh start’ in their efforts to live well amid their daily challenges.

Speaking from the social model of thought, the family has a responsibility to all its members to create an enabling and safe environment. When that is missing, my research participants indicated a search and adoption of alternative families. One such alternative, as described above, could be what anthropologists call ‘fictive kin’ referring to ‘family-like relations out of individuals to whom someone is not related by the usual practices of blood, marriage and adoption.’ Whatever motive facilitates fictive kin, a prominent one is the longing for women in this study to find safe relationships to cope with the demands of their daily lives, whether such relationships are temporal or permanent. These women claim that, both the provision of new family relationships and the ability to navigate these relationships are part of the outpouring of their relationship with Jesus Christ who enables them to cope with the challenges of the stigma of gender, disability, and HIV.

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371 Patricia Lather and Chris Smithies, *Troubling the Angels: Women Living with HIV/AIDS* (Boulder, Colo: Westview Press, 1997), 65. A similar trait is seen in women in the USA where women talked of the stress of the secrecy of non-disclosure of HIV status and the resulting preference for transient non-kin families. The US study also recognised that the strain of family relationships led women to prefer to live alone.


5.1.3 Women Coping with Supportive Marriages and with Abusive Marriages

Early she is taught, her purpose for being, her reason for living, to be the hand that cleans, the head that carries. She struggles, she propels herself. From point to point, braving the odds, just to be my African Mother.\(^{374}\)

Marriage was one controversial family space that many married women in this study daily navigated. For some, they claimed unquestioning support from their spouses; for others they spoke about abuse and neglect. These women expressed from their experiences, that marriage is not always the safe space that it is expected to be. Here, I examine the place of marriage for African women within patriarchal and societal boundaries that stipulate gender roles for women and how these boundaries affect women living with disability and HIV.

The assumption that marriage could be used to fight HIV has been met with different debates. On the one hand are those who argue that the risk of HIV infection is minimal among married people because people remained faithful to their partners.\(^{375}\) On the other hand are those who argue that married people are more concerned about contracting HIV infection from their spouses, suggesting that marriage may not be a veritable tool for the elimination of HIV.\(^{376}\) Melissa Browning refers to marriage as ‘risky’ in the context of HIV infection and indicates that her research participants in Tanzania felt women were more assertive as single than married in negotiating safe sex or sexual partners.\(^{377}\) Women in my research did not subscribe to the assumption that marriage is an HIV-free zone but that marriage was a negotiated space, with or without spousal support.

A few women spoke of support from their husbands. Here is what Grace said:

\[\text{I tell my husband. My husband know, but him no talk anything.}
\text{The tin surpr} \text{ise me but I thank God because me, I no know how}\]

\(^{374}\) Fubara-Manuel, \textit{Besides the Water Brooks: Poetic Reflections from the Heart}, 203-4.
I get am sef. Since I marry my husband, I never know another man. So I thank God say my Oga help me with this trouble.378

Grace did not disclose whether her husband is positive or not. She only expressed her surprise at his silent but supportive stance for her when she disclosed her status to him. However, it is not uncommon for married women to lack power to demand answers from their husbands on any matter in the home.379 So instead of inquiry as to his HIV status, women like Grace accept their husband’s support as a gift for which they are thankful to God. This situation may buttress the domestication of women with disabilities in marital relations where reciprocal acts of support is received as an unusual gift.

Maryann has a similar story to those of other interviewees:

Since 2013 I became positive. It was during the second pregnancy. Thank God the baby is negative. I don’t know how I got this infection. My husband is negative. My husband has been good to me. My two children are negative and healthy. I pray a lot. Apart from my husband, only my elder sister knows plus the support group that I attend and there is confidentiality there

It does appear that it was not Maryann’s low education or financial capacity that caused her supposed willing domestication. Maryann is a career teacher with a good job as she explained during our conversations. Yet, she said she had never probed if her husband is truly negative or how she herself got infected. Both Maryann and Grace expressed how the fact that they have good and supportive relations with their husbands was helpful and satisfying in the face of the challenges with disability and HIV.

It was important for these women to maintain supportive human relationships with which to cope with their lived experiences. Although Browning’s study on women and HIV did not involve women with disabilities, her work is instructive for understanding women’s disposition in marriage in the face of HIV. Browning notes how ‘relational vulnerability’ can cause ‘loss of health, of prosperity, and even life’

378 English Translation: I told my husband. My husband knows but he did not say anything. I was really surprised that he said nothing, but I thank God because I do not know how I got infected. Since I married my husband, I have known no other man. So, I thank God my husband helps me with this problem.
for women. By ‘relational vulnerability,’ Browning was referring to married women who were in relationships without love, trust, honesty, faithfulness or freedom, a condition that resonated with many of the women in my study.

Unlike some of the women in Browning’s study, the women in this study express their choice to focus on their newfound relationship in Jesus Christ from whom to draw strength to face the difficulties of discrimination. Women like Enny, a widow with children who discovered her HIV positive status after her husband passed, says her marriage had not been that of equals. Her husband often told her he married her ‘out of pity to help her with her bad eye.’ This further demonstrates women’s vulnerability to abuse even within marriage.

Likewise, Eve’s engagement was called off when she told her fiancé about her HIV infection. Eve says she has not tried to have another relationship but is concentrating taking care of herself. Mary’s husband abuses her. He takes advantage of her learning disability which prevents her from understanding the experience of shame or from confronting the abuse. Mary has limited communication and social skills. Mary’s sister, who is her primary carer, had heard about my research and asked if Mary could be part of it. When I asked Mary if she was married, she giggled and said yes, and this is how she described her marriage:

My husband dey come sleep with me every time. I no no where him dey now but him go soon come. After I go get belle, born fine fine pikin, him go come sleep with me then him go go, come again and then go again.

Mary’s sister had a different story. She claims the father of Mary’s children is an abuser and who does not care for Mary or the kids. Women with learning disabilities are at particularly high risk of abuse and HIV infection. Conversely, HIV infection and related health issues represent a serious risk for persons with various forms of

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381 English Translation: My husband comes to sleep with me every time. I do not know where he is now, but he will come soon. After I will get pregnant and have beautiful children he will come and sleep with me and go; he will come again and then go again.

learning disabilities as they are often without adequate help or support.\textsuperscript{383} Although Mary is under the care of her sister and children, she is not protected from unwanted unprotected sex that has given her 6 children and also infected her with HIV.

Over the years, African women have chosen different ways of navigating contentious spaces by creating strategies of survival and self-affirmation. In an earlier poem, portions quoted at the beginning of this section, I wrote about how African women may have been unconsciously conditioned to accept patriarchy unquestioningly in such a way that the preferred way of resistance becomes acceptance of normalised abuse.\textsuperscript{384} The control of men over women in marriage raises several crucial questions for issues of faith. Christianity has been accused of re-enforcing patriarchal power through its traditionally male leadership, and its male language for the divine.\textsuperscript{385} But to exclude religion as a veritable tool to help disadvantaged women runs counter to my research and to most of what the women of the Circle advocate.

The Circle’s argument for resistance or challenge of patriarchal tendencies was not appealing to the women in this study as resistance comes from a place of power, something that the women did not assume to possess. Instead, two popular approaches resonated with this study although, as expected, the women were not acting in any conscious knowledge of African feminist understandings. The first is the understanding that all persons are created equal before God and are deserving of dignity and respect. These women affirmed the transformed identity through their relationship with Jesus. This they confirm enables them to believe that they are created in the image of God and that possess a sense of worth. The second was actively creating safe spaces for them like belonging to support groups and finding ways of belonging to the church. For the women in this study, single, married, divorced, or widow, family relations are negotiated spaces as are relationships in the society and the church.

5.2 Women Negotiating Relationships in Cultural and Religious Contexts

Religious and cultural beliefs often promote stereotypes that result in stigma, discrimination, and exclusion for women with disabilities and HIV in Nigeria. Basic

\textsuperscript{383} 'Disability and HIV Policy Brief', 2009.
\textsuperscript{385} Kamau, \textit{AIDS, Sexuality, and Gender}, 155.
to these stereotypes are statements that disability is a curse from God or spirits and that HIV is transmitted through immoral sex. Yet, these women must navigate these religious and cultural spaces to own their identities and affirm their sense of belonging. This is crucial for Nigerian communities where socialisation and integration are essential to the flourishing of any society.

Religious and cultural beliefs and practices are frequently interconnected and cannot be easily untangled even though they influence society’s shared valued, goals, beliefs, and attitudes as a cultural unit or community. Yet the women in this study attempt to distinguish between their Christian faith that they consider life-giving as appropriated, and cultural practices, including those found in churches, which marginalise and stigmatise them. Since women under study make this distinction, I examine the religio-cultural practices that they identify as problematic and distinguish them from aspects of their faith in Jesus that they regard as affirming of positive self-regard.

Further, I investigate how women in this study negotiate their sense of belonging and membership within these religious and cultural domains. As explained in chapter two, I have used the social disability model which places the onus on society to reform and become more inclusive. Alongside this though, I identified with the call of African feminist writers that women need to address oppression rather than waiting for society to change, as these women consistently maintained. The women that I studied are taking steps through their relationship with Jesus to re-imagine themselves and to overcome the stereotypes that religion and culture placed upon them.

Their position challenges that of Nyokabi Kamau, who suggests an alternative to religious intervention due the perceived ambivalence of religion in increasing AIDS-related stigma, especially for women. I examine how the women that I interviewed perceived and negotiated their religio-cultural positions as well as their determination to continue to relate with the church, as a possible support, no matter what. I do this by interrogating why women continued to go to church even though the church is not always affirming; and how they understood the leadership of the church in addressing their concerns.

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386 Etieyibo and Omiegbe, ‘Religion, Culture, and Discrimination against Persons with Disabilities in Nigeria’.
387 Nyokabi Kamau, AIDS, Sexuality, and Gender, 158.
5.2.1 Why Women Go to Church

Jesus knows I am there and so he (Jesus) is there with me. I return home after worship each Sunday, sad that the church does not recognise me, but I am refreshed that I have worshipped in God’s presence.

For many Nigerian Christians, attending church-related events is part of the religious life of a family. This is especially so because the church is perceived as the place for solution as Jesus Christ is the ‘solution giver.’ Many of the women in this research claim the church does not acknowledge their presence or address their concerns. However, as highlighted in Ula’s words above, these women continue to go to church because they feel it is the Christian thing to do and because they encounter God and not because the church is inclusive.

This stance is contrary to that of Kamau who views women’s reliance on God or interest in church in the context of HIV as a sign of helplessness and not choice. Although the women in Kamau’s study expressed a deep commitment to religion as their main source of support, Kamau opines that ‘religion does not seem to help those adversely disadvantaged in other ways to cope with life’s stress.’ Kamau’s view, from a research on the experiences of women with AIDS in Kenya, is that the church promotes the vices of stigma and silence by its duplicity of compassion and condemnation. Further Kamba says the church in trying to maintain its moral authority has tended towards exclusion of those infected with HIV by ‘getting rid of those infected’ through excommunication on the grounds of its moral judgment. Eve’s narrative would seem to support Kamau’s on the exclusive tendencies of the church when she said:

I want to feel expected. Every week my church will hold preparatory meetings for Sunday service and other church things. But they never mention people like me (people with disability).

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389 Kamau, *AIDS, Sexuality, and Gender*, 158.

390 Kamau, *AIDS, Sexuality, and Gender*, 158.


They say they are doing training, but HIV is like taboo in this place. I go to church even though I know that the church does not expect me. I think the reason they do not prepare for us is because they do not expect us. I want them to expect me, then they will prepare for me.

It was obvious from the stories of the women under study that they are overlooked by the church because of their disability, and they feel excluded because of teachings on HIV. It has been argued that when the church sees persons with disabilities as ‘unexpected guests,’ they have ‘betrayed the very people with whom Christ closely identified during his life ministry.’ However, in the words of Emily, and still contrary to Kamau’s views, they continue to go to church as they link their worship of God to attendance at church.

I cannot leave God. It is not God that made them (the church) treat me like that, it is Satan so I still go to church. I believe in God and God gave me his son, Jesus Christ, to save me.’ In church, I can sing and dance to my God.

As stated earlier, Christians believe that the church should be welcoming to all but even fellow Christians, like the women in this study, do not always find all congregations or denominations to be welcoming places. It has been observed that the reason many churches are not disability inclusive is because of the mindset that persons with disabilities have nothing to offer and no gifts to share with the church. Yet, these people continue to attend church for different reasons.

For Daisy, the obligation to attend church is to avoid accusations of anti-social behaviour that are the basis for nefarious practices. She said:

I have to go to church ooh. A woman like me with disability, if I stay at home on Sunday, they will say I am a witch. So I go to church whether I like it or not. And whether the church likes me or not.

Among the Ibibios, the fear of the activities of witchcraft pervades all religious traditions in Uyo and people respond differently depending on their religious

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Cultural and religious beliefs have not only stereotyped disability to be caused by witchcraft, persons with disabilities are also seen as witches even in other parts of Africa. In this clear intertwining of religion and culture, we see a religious solution adopted by the study in this study. This could be akin to what the Circle describe as creating theologies through women’s lived realities and relationship with God.

Another difficulty that the women experienced was being viewed with the judgemental lens of Christianity and Indigenous culture. Both Christianity and indigenous culture have directly and indirectly informed stigma by its belief that disability is a result of some wrongdoing either by the person with disability or their family. Eve narrates how a member of her community said to her, ‘What did you do wrong? First your leg, now HIV. There must be something wrong somewhere.’

Eve said:

It is hard sometimes in church because it is the same people in the church who are in the village. Anything that happens in the church, the village knows. But I continue to go to church.

Women with disabilities and HIV spoke of experiencing the consequences of stigma by the social exclusive tendencies in the church and society. While some participants go to church to address religio-cultural challenges, some others go to church to participate in religious rituals.

Deedee, a 38-year-old single woman with physical disability says:

I just keep showing up, I go to church on Sundays, I go to Bible Study on Wednesdays, I go to Prayer meeting sometime on

395 In Ibibio, a witch is ‘any person who behaves abnormally; that is, outside the expected patterns of behaviour, considered ‘antisocial behaviour such as ... not greeting people, living alone in an isolated area, walking alone in the night.’ These prescribed abnormal behaviours could be reminiscence of persons who due to disability are excluded from public spaces, forced to live in isolation or impoverished and unable to take care of their parents. The second usage of ifot is for a person that ‘the community suspects to be practising witchcraft, a person who has confessed to practising the art or a person who has been identified... to be a witch.’ In recent years, persons, adult, and children, individuals accused of witchcraft by the communities have been attacked, maimed, ostracized, and even killed.
Friday, but not every Friday. I don’t lead in anything, but I keep going.

Deedee did not state the level of her participation but only that she keeps showing up at church.

It has been noted that, ‘the simple presence of ….members with disabilities silently confronts societal norms.’\textsuperscript{398} Consequently, it is assumed that it may be unnecessary to say anything about disability as the presence of persons with disabilities is capable of changing internalised perceptions that lead to the marginalisation of persons with disability in a given society.\textsuperscript{399} There was no unanimity among the women in the study as to whether their continued presence changed the perceptions or attitudes of their respective churches. For these women however, it does appear that seeking work in the church was an affirmation of their transformed identity because of their relationship with Jesus Christ.

I mentioned earlier in this section that the women’s non-confrontational stance against stigma was not necessarily inaction. It was concentrating on what they felt was more productive and within their circle of influence or in the words Maryann, ‘for what Jesus has done for me, I will sing for him, at least I can sing. That is why I am in the choir.’ Maryann shared what she termed a sad experience with the choir:

I went for choir practice one day and the people were singing upstairs, singing upstairs when they can see my condition. I stayed downstairs and joined the practice. The next time they brought it back downstairs.

Maryann urged the women at the focus group meeting ‘be busy, give yourself work, don’t get angry or change church.’ Other women had a different opinion of what their response should be. Emily said she had to change church because of discrimination due to her HIV status. About her membership and participation at her new church, Emily says

I am only a member on Sundays and nothing else. I go outside to display my gifts. I join the church Prisons Ministry. I also go to a fellowship outside the church.


\textsuperscript{399} McNair, ‘People with Disabilities on Short-Term Mission.’
The fellowship Emily was referring to is an interdenominational Christian group attended by other members of BOLD. However, Emily’s church membership may be under-represented because it does appear that her involvement with the Prisons Ministry means she does something more than just Sunday worship. In finding a place of value within the Church’s ministry, Emily may in fact receive and add value to the church. There was a perception that the women I interviewed displayed, it was one that seemed to excuse the church’s inaction or exclusion. Eve, for example, had said she is not angry with members of her community, who are also members of the church, for their attitudes of pity, disdain, and exclusion. Instead, she suggested that it is the lack of appropriate education that drives misconceptions about disability and HIV or about the role of the woman in the society, which should not stop church attendance.

5.2.2 What Women think about Church Leadership

In addressing the issue of the Church in the time of HIV and AIDS, Beverly Haddad says:

Perhaps the biggest challenge that HIV/AIDS poses to the Christian church is the call to become a true community where acceptance, love, and belonging flourish. The Christian vocation to build community becomes a clarion call, because those who are HIV-positive experience the exact opposite. The church has become for them a place of stigma, discrimination, and rejection.400

Writing within the South African context, Haddad notes the failed role of the church in providing a welcoming and caring space for persons living with HIV. It is often addressed as a communal failure of the church. While the women I interviewed acknowledged that every member of church needs to be more accepting and supportive of concerns of disability and/or HIV, they place the core responsibility on church leaders.

Daisy’s opinion, which agrees with that of Eve, was that,

I don’t think they teach our Pastors about HIV or Disability? Disability that they see they don’t know what to do, how much more HIV? This is my secret, and I will carry it well.

During the group discussion, the women listed many examples that would otherwise be different if their pastors received what they referred to as the ‘proper training,’ hence the conclusion that pastors are not taught about HIV or Disability. HIV-competent church has been linked to ‘knowledge-based approach that takes church leadership and training seriously.’ For the women in my study, lack of relevant training is what makes pastors unable to treat issues of HIV with understanding and confidentiality.

Disclosure is difficult where there are potentially negative consequences such as rejection, stigma and discrimination or abuse. Grace said,

> Make Pastor talk about HIV first then I go tell am my own. If not, how I go tell my Pastor? Me and my pastor never reach like that. I no wan expose myself. Pastor fit shame you, dem fit use you for prayer and tell everybody your secret. For this sickness, nah me and my Jesus.⁴⁰¹

In Grace’s opinion, the condition for disclosure and trust in her Pastor and by extension the church, is that the Pastor talks about HIV and demonstrates that she would not be shamed. This comment was repeated by Maryann as she responded to not telling her Pastor. She screamed and shrugged her shoulder, ‘Nooooo I can never tell my Pastor. How will I start? He is not involved with anything HIV.’ I asked Ula why she did not disclose her HIV status to her Pastor and wondered how the church would provide support if the church is unaware of the struggles with both disability and HIV. She replied: ‘The church should treat me with my disability as a human being first then I can have confidence to tell them about my HIV.’

It seems a contradiction that whereas it has been confirmed that the church has been at the forefront of HIV intervention and response, the women in this study, claim a lack of, or inadequate pastoral care. It does appear that there is a gap where churches build hospitals with HIV clinics but do not seem to have focus on its members who may be HIV positive. Even with churches with HIV programmes, many of the women say they would rather go far to access treatment than use their church’s health centres

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⁴⁰¹ English Translation: When my pastor talks about HIV, then maybe I can tell him my status. How am I to go and tell my Pastor? I fear he may just expose me and shame me. Besides he may use me as prayer point and before long, the entire church will hear of my secret. No, this sickness is between me and God.
This is how Ula stated her frustration,

I don’t understand the hypocrisy of the church. They have treatment centres yet abuse us when we use the services. They see us a church welfare project not people. Once I was very sick (HIV-related) but when they asked me, I told them it was malaria and my Pastor believed because I am not always sick.

Ula continued,

I stopped going to the church treatment centre. I used to go there for drugs. I don’t want people laughing at me like my own is the worst.

To have HIV-competent churches, it has been argued that the church must see itself as a family of God, striving to ‘make God’s considerate, merciful, and compassionate love present in current history.’

Gideon B. Byamugisha, a prominent religious leader and AIDS activist has called on the church to consider as core duty, to ‘enhance life, bring justice, heal creation and end AIDS stigma as an expression of God’s love for creation.’ In doing this, the church, as the family of God, can help its members to achieve their full humanity to flourish which Christians believe was the intention of God at creation. Many of the women I interviewed suggested this may be impossible because, often the pastors are in denial of the problems in the church.

Grace narrates an experience in her church:

Let me tell you a story. One day in my church, an invited preacher started saying, there is a person with HIV, come out and be healed. I looked at myself, come out in that church? No way. I rather die with HIV than come out. So, I did not go out. Then my Pastor took the microphone and shouted Praise the Lord, there is no HIV person in my church. I just kept quiet. Yet we have HIV clinic.

Unpredictably, pastors with denominational-owned HIV centres may act in the assumption that none of their church members access treatment at the HIV centre. At

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one of the church-owned HIV clinics, I asked the Lead staff who is a worker in the church that owns a clinic, if members of her church access the HIV treatment services. She answered abruptly that, the question was confidential, and that the clinic is for the public. I got almost the same response from a Pastor who works at a government owned HIV treatment centre if he attends to members of his own church. He said no member of his church had come to him, but as medical personnel, he attends patients who are members of other denominations. According to Grace, ‘the church is not ready to have people with HIV in their midst. They may have clinics and all, but they want the clinics to serve outsiders.’

Grace also shared a story about her friend as follows:

I have a friend who went to tell her Pastor that she has HIV. The Pastor said to her, ‘oh no, you don’t have real HIV, it is spiritual HIV.’ The Pastor told her to buy his anointing oil, anointing water, anointing hanky and my friend is still positive, but she left that church.

For these women, when the pastor or religious leader denies or trivialises the concerns expressed, then it is difficult for the church to make any reasonable efforts to address those concerns. The consequence of this denial, whether out of fear or ignorance is that it hinders effective prevention and care, which in turn results in economic powerlessness for the women. Hinga notes that the deadly impact of silence and denial has been particularly palpable in the case of global responses to the crisis of AIDS, where denial, myths, and misrepresentation of the facts of AIDS have robbed humanity of crucial time to seek urgently needed and sustainable solutions.\(^\text{405}\) Within the church however, the women under study seemed to stay on the argument that a pastor’s knowledgeable response would make a difference.

Even when there was disclosure of HIV status to a pastor, it did not seem to invoke any communal education. Enny is one of two research participants that had voluntarily disclosed her HIV status to her pastor. She said:

After my husband died, as a widow in this condition, the Pastor was showing serious concern. So, one day I told him, Pastor, I have HIV. He told me please I should not tell anyone. I don’t

have any problem with him. For me, I think my Pastor is trying. Every time I go to see him, he will pray for me.

Enny objected to my intention to interview her Pastor. According to her, it was a one-time conversation between her Pastor and herself, and they had not talked about it again. Instead, conversations are usually about her sight impairment and how she is coping with that. The women concurred that even in the case of disability concerns, the pastor’s focus has been offering financial support and they felt this was inadequate in the face of the need for integration and participation.

Religious leaders are known to exercise immense influence in the lives of their members. Within the global health partners, the use of religious leaders and faith institutions is considered key in reduction of stigma and discrimination which usually affects testing and treatment for HIV. For the women in this study, they did not consider their pastors, and by extension, the church to be understanding or supportive of challenges as women living with disability and HIV. As Grace said above: ‘For this sickness, nah me and my Jesus.’ Women in Kamau’s Kenyan study shared the same sentiments that although ‘there were disappointments with the church, the women still felt that turning to God and to prayer offered them support that they could not get elsewhere.’ This is reminiscent of how women create spaces for themselves in the church, whether out of cultural obligation or religious commitment. As ably stated,

They (women) have created for themselves survival structures and spaces within the patriarchy of the churches, and, because these have had a quality of invisibility, women have survived.

Throughout the research, research participants shared how with, determination and resilience, they commit to finding a place of belonging within the church and to be treated as valuable members of the church. I argue that the need for relationship within the church motivates the women to seek belonging despite the stigma that disability

407 Translation of Pidgin to English, ‘It is between Jesus and me in this sickness.’
and HIV bring on the women in this study. However, they also shared empowering spaces within which they enjoyed mutual friendship and support.

5.3 Women Creating Empowering Relationships
One of the key findings of this study are the creative strategies with which women with disability and HIV reclaim their dignity amid stigma and exclusion. In this section, I explore how women in this study create relationships that are grounded on their shared experiences of Christian faith and common challenges with disability and HIV. Here, I demonstrate the nature of friendship among these women and the ways in which they claim that these friendships and support systems transit into family-like relations.

Peer or support Groups have been described as tools for encouraging and supporting of persons who share similar challenges and struggles in their daily lives. Research on the role of support groups agrees as to the efficacy of support groups when based on ‘shared experiences and/or ideals such as faith.’

Researching the role of support groups for women with post-partum depression, Lakesha N. Anderson notes that

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Effective support is most likely to come from socially similar others who have faced or are facing the same stressors… empathy and sympathy from similar others is a crucial condition for seeking and acceptance of coping assistance
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Members of BOLD identify themselves as facing similar challenges with the social consequences of stigma that result in discrimination and exclusion, within a society in which they struggle to survive. When women with disabilities and HIV befriend one another therefore, the relationship allows for mutual support in the knowledge and experience of disability and HIV. Friendships formed within these support groups have proven to provide support and encouragement for women facing various challenges.

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Working on the understanding of female friendship as ‘an amicable personal relationship between two or more women,’ I argue that when women face similar challenges, the attributes of reciprocity, equality and non-hierarchy in friendship provide soothing safe spaces for such women. This further explains the presence of a smaller unit of support group for women living with Disabilities and HIV within the larger BOLD Network of women living with disabilities. I hold that the idea of homogeneity is evolving especially when issues of personal experiences and the interpretations of those experiences are being explored from relational and faith perspectives. In sharing their stories, their faith, and their feelings, within the spaces in which they feel most comfortable, women attest to finding strength and support needed for the next challenge. I argue that support groups and female friendships often provide safe spaces within which women address the demands of their daily lives and live out their Christian faith, especially where the church space is not so affirming.

5.3.1 Women Adopting Support Groups

During the pilot study for this research, I asked the Chair of the Coordinating team for BOLD Network what BOLD means for them. This is what she said:

Well for me, BOLD is a place when we special ladies can interact and learn. It is also a place where anyone who feels isolated in her dealings with disability can come in and know that she is not alone. It helps to know that disability is not associated all the time with negativity.

As narrated in Chapter Two, BOLD Network was created by women members of a disability support group for persons with disabilities who felt silenced by the male members. Their response was to leave that group and start one that offered a space for the ‘special ladies’ who shared similar concerns.

As indicated in this study, research participants have always tended towards a different kind of practical feminist response by exploring alternative relationships and means of flourishing instead of confronting patriarchal institutions outright. Judith

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412 Wendell, Susan, ‘Towards a Feminist Theory of Disability., 261’ Susan Wendell notes the choice women with disabilities have to make whether to seek full integration and equal power with men ‘as a goal’ or ‘whether to preserve some degree of separate culture, in which the abilities, knowledge and values of women/the disabled are specifically honoured and developed.
E. Pearson agrees that women ‘share the basic experience of what it is to be a woman…and this creates a special depth of understanding’ to create enabling conditions.\textsuperscript{413} For women in this study, support groups provide safe spaces to garner strength, express their faith, and address dehumanising and limiting practices.

The Secretary of BOLD puts it this way:

although we (men and women) are disabled, disability in women poses different if not more challenges, especially when you talk about love and acceptance. The men do not seem to understand what we are facing as ladies.

This perceived lack of understanding of women’s issues by men, or the inadequate attention to the concerns of women has notably led to the rise of many women initiatives, of which BOLD is one.\textsuperscript{414} During a BOLD Support Group meeting, members shared the support they receive. Enny says:

Talking about support, my faith in Jesus Christ helps me, especially in the face of stigma. But also, with my sisters in BOLD, we support each other. We are there for each other.

One of the peculiarities of the support group is the mutuality of support that the women in this study talked about. It is not the receiver-giver dichotomy that persons with disabilities face when they are helped by those without disabilities or organisations that see them as only needing help.\textsuperscript{415} Lakeshare N. Anderson\textsuperscript{416} and Bernadette Pivarunas\textsuperscript{417} speak of the cohesion in relationships that allow for ‘seeking and acceptance of coping assistance’ when persons share similar experiences and ideals or beliefs. For Emily, this was her response to the support in BOLD:

Apart from my family, I belong to BOLD, and I know that I am not alone. All of us have different problems. We have gone through different things so we can help one another.


\textsuperscript{416} Anderson, ‘Functions of Support Group Communication for Women with Postpartum Depression’.

I hold that one of the reasons that the support group is empowering is because it allows the women to experience being valued in a way that affirms their identity as persons and their dignity as women. What BOLD members claim to share is not a one-sided sacrificial friendship which Harold Wilke describes as having ‘ushered in a new period of sympathy towards persons with disabilities.’ At the Support group meetings that I attended, women brought different snacks, and these were put together and served. Others offered help to someone who needed to be accompanied to the hospital and another needed a babysitter.

Every person had a role that was important to the rest of the group. As always during the study I observed a connection between their faith and relationship with Jesus Christ to their sense of belonging and participation at the group. However, women acknowledged that often, women without disabilities are not as supportive, further distinguishing the oddity of their oppression from men as well as their oppression from women without disabilities. For women in this study, their experiences with oppression were not just because of patriarchy but also, they suffer from lack of support from women, a situation I interpret as being akin to oppression.

Ula narrates an experience she regards as ‘embarrassing.’

My first embarrassment was when they asked the women of the church to wait behind. I did. One woman came to me and said oh, the announcement is not for you. I said why? I am a woman. I volunteered to join the women for cooking for harvest, they refused that they cannot cope with me. I wanted to shout. I live alone, at least I can cook. I forced myself and went to the cooking place, but I was just boiling (angry).

These women wondered aloud how they could ‘dream’ of asking the men to include them in other areas in the church if ‘their fellow women’ do not value their presence in the kitchen. Daisy’s experience was not that she experienced an exclusive attitude from members of her choir, but that the women did not support her. This is how Daisy narrated her story:

I was going to choir practice all the time, I never missed any time. Even for that outing, I was rehearsing with them. On that day, they laughed and said who will carry me upstairs, that the church choir seat at the church we were going to sing was upstairs. I was

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418 Harold Wilke, Creating the Caring Congregation (Nashville: Abingdon, 1980), 36.
standing there, and they just drove away, like I did not matter. My fellow women in the choir were not on my side. That was my last day and I have not returned.

Whilst Daisy’s quote would have been discussed in the section of how women navigate the church space, I brought it here instead because Daisy’s emphasis and the point of the story was how her fellow women did not speak up for her. Maryann had shared her experience of singing from downstairs when her church decided to move up, until they came down to join her. Emily’s encounter in this regard was her experience when she wanted to join the women’s group in her church. She said she was asked if she would be able to pay the dues seeing that she was a widow, and one with disability. Emily said she answered the women’s group, ‘I told them I can pay the money before they wrote down my name. Since then, anytime there is contribution, I try to pay.’ Emily explained that her problem was not being asked to pay the dues but how the women hinted on her supposed inability to do so because of her disability and marital status. As Emily told her story, many other women in the group meeting nodded in agreement of receiving similar treatment from women’s groups in church or in the community.

Women in the study said they often felt humiliated when they are not supported by the women, especially in the church. Chisale Sinehlanhla, a Circle member, has faulted the inadequate attention that African women scholars have paid to the concerns of disability, arguing that ‘the pain of one woman is the pain of all women with disability.’ When I asked BOLD members what actions they would take concerning the perceived lack of support from women for women, Maryann answered promptly:  

We need to talk with them, we need to connect with them so that we can find an answer to this problem. It is not ok for our fellow women to treat us like that.

It was interesting that for women who had consistently indicated a preference for silence instead of voicing their grievances, to want to talk was a change in approach. The women must have noticed the look of surprise on my face because what appeared to be a chorus answer ensued with women talking generally about how

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419 It is common practice for church and community groups to levy its members with registration fees and periodic dues. Usually, when one is unable to pay, then that person is declared as a ‘non-financial member’ and denied any form of monetary welfare in the event of loss or celebration.

women with and without disabilities are sisters and need to walk together which means
talking together. Maryann’s suggestion was also indicative of proactive action in
reaching to the women that they felt were unsupportive, thereby confirming that these
women’s seeming inaction in the face of patriarchy was their agency for survival.
However, they discussed the need for collaboration of all women to face the common
challenges with patriarchy.

5.3.2 **Women and the Gifts of Friendship and Sisterhood**

The women in this study referred to themselves as friends and sisters. They used
endearing words like ‘special ladies’ to speak about members of BOLD. They claimed
that their shared experience of faith and common experience with stigma strengthens
their friendship with one another and facilitates a sense of belonging to BOLD that
they may lack in their institutionalised faith communities. In this sub-section, I
examine this claim with a critique of feminist understanding of friendship within and
without the Christian faith. I argue that for the women in this study, their relationship
as friends and sisters mirrors the empowering relationship which they claim to have
with Jesus, and which enables them address society’s-imposed identities to cope with
the challenges of living with disability and HIV.

During the field work, I observed a congenial atmosphere among all the
members of BOLD. To create a friendly atmosphere for meetings, BOLD
Coordinating team held meetings in the homes of members, fast-food outlets, or quiet
parks. It was normal to hear intimate conversations about romantic relationships,
careers and businesses discussed before and after group meetings. It was not unusual
for members to share their personal stories to buttress a point or to encourage another
or to seek help. When I asked how they would describe themselves, this is what
Maryann said,

> these people here (referring to BOLD members seated at the
> meeting), they are my family, my friends, my sisters. When I am
> here, I am myself, my secret is safe here.

I observed that BOLD members found each other and the group meetings a
safe, happy and empowering space in what seemed like a world away from the rest of
the world. When I asked the women how BOLD made them feel, these were some of
the responses from Eve, Deedee, Maryann and Daisy,

I am happy that I came out today. I am encouraged to do whatever
it takes to be happy. We know the Bible does not discriminate
against us.

I was really depressed this week but coming here and hanging
out with my friends like this has helped me. I feel better.

I feel very happy coming out here and we know we will continue
to encourage ourselves in the faith.

I also feel encouraged. I will see how to participate in church
now and not let anything stop me.

Of all the relationships that the women in this study discussed, I believe the one that
makes them feel closest to what they feel with Jesus Christ is this friendship among
BOLD members.

In Chapter Four, women referred to Jesus Christ as ‘best friend.’ By this they
meant he is a companion who transforms their self-identity and enables them to engage
in human relationships. In this chapter, women talked about their group relations.
They were encouraged through membership of BOLD and determined to participate
in church because it connected them to God and society. For these women, the
friendships made in BOLD is perceived as a gift from God. Although BOLD is not
established as a religious group, the spirituality of the members is often evident in all
their meetings as they would often use religious language and resources in their
meetings. They open and close their meetings with prayers, they use testimonies to tell
their stories, and quote portions of the Bible to support their arguments. The
transformation that friendship afforded was expressed in positive dispositions of
happiness, encouragement and being helped.
John Swinton,\textsuperscript{422} Hans S. Reiners,\textsuperscript{423} and Benjamin T. Conner\textsuperscript{424} have written variously about the place of friendship for persons with disabilities. Their focus has been on friendship as the basis of care and inclusion of persons with disabilities within the Christian communities. This study contributes another dimension to friendship in disability and it is that of friendship between persons with disabilities themselves to form a community of love and support in the face of societal and religious exclusion. For it is in friendship among themselves, that women with disabilities and HIV in this study find the encouragement and support to be happy, to face society and to contribute their gifts to the church.

While acknowledging the importance of friendship, the members of the BOLD Network attest to what they perceive as a deeper kinship in considering one another as sisters.

Maryann summarised it thus:

\begin{quote}
BOLD is a community of sisters who share similar experiences, circumstances and struggles yet determined to work together as part of a team to support, build, strengthen, educate, encourage, thrive and reach out to one another and to others in society.
\end{quote}

Maryann was referring to the reason for which BOLD was established in the first place. In view of their shared expressions of faith and experiences with disability and HIV, BOLD members speak of a relationship of ‘sisterhood’ in which they assume a deepened level of friendship. It was common to hear members of BOLD and indeed research participants refer to one another either as friends or as sisters.

They speak in terms of having ‘a family’ in the Network where, in sharing their stories, their experiences and their struggles, they find the strength and support needed for the next challenge. This is akin to the discussion earlier in this Chapter of the creation of fictive kin or new families by women with disabilities and HIV when their biological families are unable to provide the support that they need.

\begin{flushright}
\textsuperscript{422} Swinton, \textit{Resurrecting the Person}.
\end{flushright}
This perceived transition from friendship to sisterhood within BOLD seems to be a globally shared experience among women with common ideologies and or beliefs. In their article titled ‘Weaving Sisterhood,’ the authors highlight the mutual inspiration between African women theologians and African women creative writers acting as sisters in speaking against inequality and oppression. Circle members often refer to one another as ‘sisters.’ The term ‘Africanist Sista-hood’ was coined to reflect the relationship of Deaf/hearing women in Britain because of their shared experiences. There are instances where women in this study used the words ‘friend’ and ‘sister’ interchangeably making the lines between the two concepts blurred and therefore difficult to speak of transition from friendship to sisterhood or vice versa. According to Emily: ‘these women here (pointing at the women in the meeting room), they are my sisters’, are friends, as though buttressing Maryann’s views about the women being her sisters and friends. Daisy was emphatic that they are more sisters now than friends. Daisy says:

When we started, we were friends, but now we are sisters. Now we know ourselves, we talk together, and we help ourselves. We are more than friends.

Research has suggested the dual and complementary roles of friendship and sisterhood among women as patterns of relationships that provide mutual support. Women have also often considered one another as their ‘sisters’ keepers’ in an interdependent condition that allows the quest of justice for all. Undoubtedly, it is this sense of interdependence that is based on a reciprocal relationship of equality and partnership that these women enjoy as members of BOLD.

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427 Obasi, ‘Negotiating the Insider/Outsider Continua’.
I asked the women their thoughts on the criticism that female relationships are often ‘gossipy, competitive, cliquish, and backstabbing.’\textsuperscript{430} They did not join the feminist response that this rhetoric is part of a patriarchal ploy to ‘reinforce gender stereotypes that place greater value on boys.’\textsuperscript{431} Instead they admitted the possibility of that but said it would not happen to them. This is how the Secretary of BOLD said it,

For us, it about respect. We respect one another. We are here to support and encourage one another; to build good relationship with God and strong active relationships with each other. We cannot allow any negative thing here.

She seemed to have spoken the minds of other members as there were smiles and nods of approval from the women at the meeting. During the entire six months of my field work, I was amazed at how these women showed respect for one another. I hold that for these women, respect is not about seniority, but about the recognition of each other’s dignity and humanity. This may be interpreted as the affirmation of their humanity as defined in God’s image and that which enables them to fulfil for one another the ‘basic needs of being liked and accepted, displaying and receiving affection, feeling valued and attractive and sharing thoughts and feelings.’\textsuperscript{432} Consequently, because respect or the feeling of being valued, is not something they enjoy in society, giving it to each other further cements the support group as an empowering space.

When these women speak about what their relationship with Jesus Christ means for them, their descriptions of friendship, identity and empowerment all point to their claim that Jesus loves and values them. In many ways, I see an attempt to model their relationship with Jesus Christ among BOLD members as friends and as sisters whose shared faith and common experiences with disability and HIV allow for a unique empowering identity. Members of BOLD came together as friends. In their shared expressions of faith, their common resistance to patriarchy and their solidarity before societal and relational challenges, they formed a strong bond which they refer

\textsuperscript{431} Brown, Lyn Mikel. ‘Girlfighting’.
to as sisterhood. It is this bond that I find these women use to survive the broader social consequences of stigma often associated with gender, disability, and HIV.

5.4 Conclusion for Chapter Five
In this chapter, I examined how women in this study navigate and negotiate their identities in their relationships in the home, the church and in BOLD. In researching the role of faith for women with disabilities and HIV, it is interesting to note that faith is a critical influence on the way women related with the people in their lives. The experience they claimed to have in their relationship with Jesus Christ as friend and companion who enables a transformed identity serves as the mirror with which these women critique all other relationships. It was also this transformed identity that these women used to face the challenges of stigma associated with gender, disability, and HIV. In this chapter, the understanding of Christian faith as participation in social relations was ably demonstrated.

This chapter reveals the importance that engaging in relationships and having a sense of belonging means for these women. In this way, relationship is a veritable tool for women’s self-affirmation to overcome the difficulties that disability and HIV place on their daily lives. To reclaim their dignity and assert their self-worth, these women adopted, created, or entered into relationships in which they feel welcomed, valued, and supported. Affirming relationships with Jesus and with others therefore provide the support to navigate and negotiate contentious relationships that these women found in the family, the church and among other women.

This research is informed by the social model of disability to call society and the church to account for disenabling attitudes and systems towards women with disabilities. It was also the intention of applying African feminists’ ideas of resistance to see how women in this study fare in their actions to resist patriarchy and other discriminatory actions. It is noteworthy, therefore that women in this study are not necessarily waiting for society or church to remove social, religious or cultural obstructions. They are not using African feminists’ methods of resisting or challenging patriarchy or the forces of oppression.

Instead, these women continue to devise creative support systems among themselves, establishing empowering friendships and upholding sisterhood, to cope
with the challenges of their daily lives. Besides coping, women in this study, continue to show resilience in adding value in their homes and church to reflect the enabled identity they receive from their relationship with Jesus Christ.

I argue that a transformed identity that upholds a positive self-image driven by a relationship with Jesus Christ can help women of faith, locally and globally, to confront and overcome the stigma of gender, disability, and HIV. It moves women with disabilities and HIV from mere survival to lives that flourish and add value to others in their many relational roles.
Chapter Six

Faith Resources and Practices for Women with Disabilities and HIV

6.0 Introduction
This Chapter provides the findings of this study’s third research objective ‘to understand the ways in which resources and practices of Christian faith influence how women deal with their complex responses to gender, disability and HIV.’ To reach this understanding, I asked three opening interview questions: what are the resources and practices available to you; how and when are you using these resources and practices; and what effects/impacts do the use of these resources and practices have on you? This Chapter focuses on the identified resources and practices of Scripture, songs, prayers, storytelling, and testimonies. I investigate the role of these resources and the specific ways in which these women deploy them as tools.

Drawing primarily on African Christian feminists’ perspectives on the use of Scripture, songs, prayers, storytelling, and testimonies, I examine the extent to which the women that I interviewed used these resources as tools to respond to the social and religious challenges of gender, disability and HIV in ways that impact or shape their lives. Faith resources become the tools that are used not only to make sense of their situation, but also to allow for ‘human flourishing and survival.’ I demonstrate that the engagement of the women with these resources and practices provide narratives into their spiritualities that is constructed on lived experiences.

The resources and practices discussed here are not peculiar to the women in this study. They are part of the spiritual life of the Christian experience in Nigeria. However, beyond the primary general religious intentions of these resources and practices, the women I interviewed show ways in which they distinctively appropriate the same methods to address social stigma. In this way, they find creative ways to respond to the challenges of societal and religious exclusion, either individually or collectively. Findings in this Chapter demonstrate the interface between spirituality and health illustrating how women use their religious resources to combat social challenges.

I argue that for the women that I interviewed, these resources become tools to counter socio-cultural and religious stigma and to affirm and reclaim their dignity as women. These women appropriated faith resources and practices in their communities in broadly similar ways, with some small variations. Scripture, songs, prayers, storytelling, and testimonies are ways in which women further their friendship with Jesus, affirm their positive identities and claim their right not to be stigmatised or discriminated against by the society or the church.

6.1 Scripture as Faith Resource
I read my Bible all the time. It gives me comfort because there is nothing missing in the Bible. When you read it, you see yourself! There is nothing new under the sun. The Bible stories, they help me to understand myself and what is happening to me. It is not like reading novels, I like reading novels. It is not like watching movies. The Bible is the Word of God, the stories are true for me to learn from.

Eve made the above comments as we took a walk discussing faith resources and how they impact on her spirituality. She spoke about the Bible as something personal and through which she can make sense of her identity and experience. These sentiments resonated with many of the women that I interviewed. On my field work, visiting with my research participants, attending meetings of BOLD or an HIV Support Group, I observed how the Bible is an integral part of the spirituality of these women. They regard it as a sacred text that further their relationship with Christ and provides resources with which to address their individual and collective challenges.

Three major themes that emerged were the Bible as a constant companion, the Bible as a resource to address stigmatising stereotypes, and the Bible as repository of wisdom to assert their personhood. This section provides a broader conversation around these themes. Although each woman had a different verse with experience-based interpretation, there were also verses that had a common appeal. Whether read individually, discussed in group Bible study, or memorised, these women claim an empowering feel from the use of Scripture as well as connectedness with Jesus Christ.

During a focus group discussion, I asked the women with disabilities and HIV, what the Bible meant for them. The immediate response from a few women was to quickly bring out different shapes and sizes of Bibles from their bags. Most of the
Bibles were the Gideons New Testament, usually given out free, and easy to carry. When I asked why they had their Bibles even though the meeting was not a religious gathering, one woman started a song, which the others joined in: ‘I have a wonderful treasure, the gift of God without measure. We will travel together, my Bible and I.’434 In singing the song, those with Bibles held them high, and then at the last words ‘my Bible and I,’ they pressed the Bibles to the position of their hearts.

Those without Bibles joined the song and using both palms, pressed them against the position of their hearts. A hearing-impaired woman joined in by signing the song. The sign for Bible is a combination of two signs which are the sign for Jesus and then for book, to indicate that the Bible is the Book of Jesus. The sign for Jesus is done by pointing the index finger to the other palms on both hands signifying the nails on the palms of Jesus at his death. In singing this Bible song, the hearing impaired in this graphic signing, are reminded of the death of Jesus and the Bible as gifts from God for their life journey. The spontaneity and conviction of song and singing show the primary place of the Bible in the lives of these women.

Oduyoye recognises that the Bible has a special place ‘in the hearts and homes of African Christians.’435 She wonders how often it is read? She says the Bible is often used as a talisman. It is carried everywhere or kept at strategic places like a baby’s cot to keep away evil influences or buried at foundation laying ceremonies or put inside cars. Its ‘presence proves comforting, a sort of Immanuel, or places.’436 African Christians also read them and so feel a connection to God. It was not clear whether my interviewees used the Bible as a talisman, as illustrated by Oduyoye, but Kaka’s response seems to indicate otherwise:

Since I gave my life to Jesus, I started reading the Bible to know more about God. That is why I carry it with me all the time. It is not heavy so I can carry it inside my bag. I like the stories of Jesus and it makes me feel closer to him. When I read the Bible, it is as if God is talking to me, just me. Sometimes, I see myself praying or singing after reading, I see myself worshipping God.

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434 Philip Jenkins, *The New Faces of Christianity: Believing the Bible in the Global South* (Oxford: University Press, 2008), 35–8. Surprisingly, Jenkins uses this phase ‘My Bible and I’ to describe the absolute belief and dependency of Africans in the Bible and how it is used to ‘address their daily needs, problems, and concerns.’


It was obvious that unlike those who may use the Bible as talisman, many of the women in my study read the Bible, and through it, get a sense of connection to God. It is also evident that many of these women carry their Bible wherever they are. They read or listen to the Bible as they navigate their relationships in the family, church or among friends.

Many of the women also indicated their preference for the Gospels because of the many narratives concerning Jesus and how Jesus treated women with respect and dignity.\footnote{Elsa Tamez, ‘Women’s Rereading of the Bible’, in \textit{With Passion and Compassion: Third World Women Doing Theology}, ed. Virginia Fabella and Mercy Amba Oduyoye (Maryknoll, N.Y: Orbis Books, 1988), 173–80. Elsa Tamez, like other feminist theologians, opine that women’s preference for the gospels could be because of the ‘spirit of justice, freedom that neutralizes anti-female texts.’} Eno said at the meeting:

\begin{quote}
I like the story of the woman that was bent. This woman still carried her bent body to the church. She did not talk to Jesus, but Jesus saw her and healed her. But the part I really like too, is when the Pharisees came to talk, Jesus told them to keep quiet. Then Jesus called this woman that was bent daughter of Abraham. It is like it is me that Jesus was calling Eno, you are daughter of Abraham.
\end{quote}

Explicating on this story found in Luke 13:10-17, one after the other, the women talked about how this story is an encouragement that neither disability nor disease should be enough reason to self-isolate. They highlighted the role Jesus played in the story in asking the Pharisees to be quiet, explaining that Jesus was like an angel for that woman and that Jesus could still send angels to be on their side in the midst of all kinds of evil.

My interviewees live within a reality of evil, both systemic evil and evil as belonging to the supernatural.

The African worldview ‘sees spirits, demons, spiritual powers at play in all areas of life, and responsible for illness, misery, poverty, hunger, and misfortune…. including spirits causing AIDS.’\footnote{Paul Gifford, \textit{Christianity, Development and Modernity in Africa} (London: Hurst, 2015), 4.} This is true for Nigeria, and among the cities of my research where there is prevalence of fear of witchcraft in Uyo, and of water spirits or marine spirits in Port Harcourt.\footnote{Gifford, \textit{Christianity, Development}, 20-21. Gifford lists different kinds of spirits operating in Nigeria as mentioned by one of the Pentecostal Pastors, Dr Olukoya} It is, therefore, no wonder that in many churches in Nigeria, much time is devoted to ‘deliverance from the Satanic forces that are believed...
to oppose Christians and are held to cause material and psychic problems in the sphere of health and wealth." Some of the women in my research discussed how they find in Scriptures, verses that they use as defence against the supposed works of evil spirits.

One such Scripture in the Old Testament, Isaiah 54:17 KJV,

No weapon that is formed against thee (me) shall prosper; any every tongue that shall rise against thee in judgment thou shalt condemn. This is the heritage of the servants of the Lord, and their righteousness is of me, saith the Lord.

When Eve gave this verse, she did not quote the entire verse, neither did she quote it verbatim as in the Bible. She personalised the first sentence replacing ‘thee’ with ‘me’ and going on to contextualise the verse for her reality. She explained how she lives in a small community ridden with fear of the unknown, of the spirits and of witchcraft. She said,

I used to be always afraid. I used to think maybe it is true that maybe it is wicked people that did this to me. But since I gave my life to Christ, as I read the Bible, I saw this passage, I know that it is for me. I see myself in the Bible. Nothing can touch me.

Here we see a shift from fear to hope by merely accepting a portion of a verse of Scripture without regard to its historical or cultural origins. While acknowledging the popular stereotype that disability or HIV could be caused by evil spirits, she negates its potency by use of Scripture. She engages in a reader-centred approach and makes her fear the motif for this passage while being careful to link its efficacy to her relationship with Jesus. Just like the women appropriate healing because of their relationship with Jesus Christ, they appropriate protection from evil forces which they say is confirmed by the Bible.

During a focus group meeting, some women explained stigma by recourse to Luke 8:43-48. In their retelling of the story, they interpreted its meaning for their own lives, they also shared its telling, recounting it in a chain with different women filling the gaps to complete the story. In this corporate telling of a familiar story, we find what I could call, a form of community hermeneutics in action. The story is about a

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440 Obinna, ‘Nigeria’.
441 Esther Mombo, ‘Doing Theology from the Perspective of the Circle of Concerned African Women Theologians’, *Journal of Anglican Studies* 1, no. 1 (August 2003), 91–103, Esther Mombo refers to this as ‘reader-centred’ where the Bible has to be understood and interpreted in terms of the readers’ specific situations – their problems, their needs, and their anxieties.
woman who was haemorrhaging for twelve years and had spent all she had searching for a cure. She came behind Jesus and touched the border of his garment. She did this hoping to be healed. Jesus healed her and referred to her as daughter. The women at the meeting said they could relate to this woman’s exclusion from social or religious spaces and being unable to come before Jesus. They opined the stigma of constant bleeding would have kept the woman away and the religious community would have said her sins caused her disease.

One interviewee said the part that appealed to her was Jesus saying to the woman, ‘Daughter, go in peace,’ establishing a relationship with the woman, giving her ease from her pains through healing. Another interviewee said she liked the part where Jesus stopped and said, ‘somebody has touched me,’ recognising that this woman who hitherto could not stand in the crowd because of her stigmatised disease was ‘somebody’ before Jesus. At several times during my fieldwork, women told stories of how disability and HIV has made many of them feel isolated from the public, untouchable, and searching for relationships. If Jesus touched the bleeding woman, it is no wonder that Jesus do touch them and would continue to touch them, they claimed.442

In weaving out the relational aspects of Jesus’ encounter with the bleeding woman, my interviewees highlighted the social element of healing that transforms and enables inclusion into the society. Scripture, is an integral aspect of their lived Christianity realities, encompassing all their lives and used to respond to the challenges from the society. Although these are familiar verses that are generally and variously used in church, these women used this story to affirm a positive view of themselves.

One of the popular arguments for inequality within African cultural and religious spaces is that God did not make human beings equal at creation.443 This view has fuelled patriarchal domination as women are perceived as inferior and therefore in

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442 Ruth O. Oke, ‘Healing of the Haemorrhaging Woman as a Model for Checkmating Stigma of People Living with HIV’, *Verbum et Ecclesia* 38, no. 1 (2017), 1–12. Ruth Oke used the story of the bleeding woman to illustrate the ‘revolutionary stance in the Gospels’ that Jesus took in relating and identifying with the woman stigmatised and excluded from the community.

443 Michelle Kasongo Kamba, ‘Developing a Holistic Educational Programme through Contextual Bible Study with People with Disabilities in Kinshasa, Democratic Republic of Congo: IMAN’ENDA as Case Study’ (PhD, Pietermaritzburgh, South Africa, College of Humanities, University of KwaZulu-Natal, 2013), 203.
subordination to men. Consequently, women who live with disability or are HIV-positive generally suffer greater discrimination than men. During my observations and interviews, the women in my research discussed the many ways in which gender inequality further dehumanises them compounded by society’s apprehension for disability and or HIV. From exclusion in church and societal spaces, to inability to engage in romantic relationships as well as being treated with disrespect, these women share stories of the different forms of exclusion that they experience.

To counter this narrative of inequality, my interviewees adopt the Bible as that which provides hope with its ‘stories of wisdom, strength, knowledge and courageous action.’ The Christian creation story in Genesis 1:26-27 becomes the weapon of popular choice at the focus group meeting.

And God said, let us make man in our image, after our likeness:….So God created man in his own image, in the image of God created he him, male and female created he them.

The women referenced the verse from the King James Version, and repeated the last sentence several times for emphasis, hence my presenting it in italics. The passage provides the basis of their argument for equality. Only two women recited the verse correctly and others left out portions of what they felt was not necessary for their purpose. All the women knew the story of creation well even if many could not quote it verbatim and did not know its chapter or verse in Genesis. For these women, the interpretation of being created in the image and likeness of God affirms their essential worth and enables a sense of self that provides confidence to concentrate on living their lives.

I pointed out to the women at a meeting that I had heard Pastors in Nigeria use this creation story to promote inequality, especially when read from the same King James Version. These Pastors refer to the Genesis 2:21-22 creation story that the woman was made with one of the ribs of the man and brought to the man. When I pointed this out to the women, they readdressed my attention to the earlier read verses

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444 Dube Shomanah and Kanyoro, Grant Me Justice!, 4.
445 Dube Shomanah and Kanyoro, Grant Me Justice!, 4.
446 Asamoah-Gyadu, Sighs and Signs of the Spirit, 49-50. Asamoah-Gyadu, writing within the Ghanaian context, notes how Pentecostal readings and interpretations of Scripture by Pastors are often done to reflect specific contemporary messages or address social issues without due regard to the original meaning of the texts.
of Chapter 1:26-27, and explained that, the story in which God created male and female in God’s image is what matters to them. And although these women did not know it at the time, they were in fact engaging with what African women theologians have advised, which is to ignore Biblical interpretations that are discriminatory to women and focus on liberative interpretations.447

During further discussions, Maryann attempted an explanation of her understanding of this Genesis passage:

It is in the Bible that I am created image of God, just like the man. It means, I have something in common with God. God has something in me. If God is in me, I cannot be inferior. It is like the Psalm Passage that says God made everyone wonderfully. And remember even Genesis said everything that God made was good. If what God made is wonderful and good, it means I am wonderful and good. I believe it.448

The surprising element in Maryann’s response was that she, like most other women in the group, did not focus on the aspects of inequality or the gender debate of who is superior or inferior. Instead, they concentrate on affirming their position with God, as women made in the image of God and therefore worthy of their personhood.

Writing about disability and the image of God, Jane D. Deland notes how ‘the idea of being made in God’s image is the fundamental paradox of the creation story – its most mysterious and empowering assertion.’449 She calls the Genesis creation story ‘revolutionary’ when interpreted to mean a ‘direct spiritual connection to God and to God’s creation’ which does not focus on physical appearances but relationships that help to ‘overcome negative stereotypes.’450 Micheline Kamba agrees with Deland in stating that a ‘person who had a disability needs to be recognised as God’s creation, as a person created to connect to all life in perfect harmony.’451 Both Deland and Kamba describe the way of thinking as ‘liberatory theology of disability … which is founded

448 Psalms 139:14 ‘I will praise thee, for I am fearfully and wonderfully made: marvellous are thy works; and that my soul knoweth right well.’ This is the passage that Maryann refers to above.
451 Kamba, ‘Developing a Holistic Educational Programme through Contextual Bible Study with People with Disabilities in Kinshasa, Democratic Republic of Congo: IMAN’ENDA as Case Study’, 23.
upon the biblical image of God,’ in relation with persons with disabilities.\textsuperscript{452} Broadly speaking, Oduyoye confirms that ‘just and loving human relations can survive only when the equal value of all persons is upheld’, and where the ‘Christian principle of \textit{imago Dei} is operative.’\textsuperscript{453} For the women that I interviewed, the narrative in the Scriptures that all are created in the image of God is used to assert their personhood, affirm their dignity and empowers them despite the inequalities present in the society.

To the women in my study, as with most African Christians, the Bible is inspirational and ‘remains both central and normative for the way people live their lives.’\textsuperscript{454} It is the ‘central resource for theologizing’ or formulating biblical principles that can liberate society.\textsuperscript{455} As women told me their favourite passages or verses, it became apparent that, in the immediacy of their engagement with Biblical texts, they found a way of responding to gender insensitivity and dehumanising interpretations. These women use the Bible as a tool against social oppression by picking Scriptural verses/passages that speak to their lived realities or experiences with gender, disability, and HIV.

It is important to note that the way many Christians use the Scripture to construct theologies for their good have been frowned at by some African theologians.\textsuperscript{456} It is not uncommon to find pastors use the Scripture to buttress a point, or address an issue, often without critical engagement or interpretation of text. Many Nigerian Pastors, for example, ‘simply lump together texts which happen to contain the words’ that they are dealing with or looking for, especially when dealing with ‘spiritual warfare’ or ‘stubborn spirits.’\textsuperscript{457} Kwabena Asamoah-Gyadu describes this as a selective hermeneutical method or ‘proof-texting’, where the tendency is to wrench Biblical texts out of context to support predetermined arguments.\textsuperscript{458} Ogbu Kalu

\textsuperscript{452} Deland, ‘Images of God Through the Lens of Disability’, 47-81.
\textsuperscript{456} Obinna, ‘Nigeria’, 189-200.
described such an approach to the Bible as ‘bumper sticker’ hermeneutics where personal and corporate experiences are woven into the task of Biblical interpretation.\textsuperscript{459} Asamoah-Gyadu and Kalu presupposes a critical hermeneutical task which the women in my study do not engage in.

What my research participants do appears to be how people ‘as conflicted and complex individuals interact with the Bible’ in ways in which they find ‘meaning, comfort, inspiration, council, strength, and conviction.’\textsuperscript{460} In some ways, it agrees with the Circle’s call for women to seek out liberating texts from Scripture for women’s empowerment.\textsuperscript{461} I argue that the women I interviewed recognise the contentious cultural contexts of their lived experiences but adopt a person-centred approach in the creative use of Scripture to reclaim their dignity.

\textit{6.2 Songs as Faith Resource}

I like to sing. Singing helps me a lot. I sing when I am happy. I sing whenever I am sad. Singing helps me to forget. But maybe I cannot forget. But as I sing, I will not be thinking about the problem. I sing to praise my Jesus. Sometimes, when I want to pray, I sing.

This attitude to songs expressed in the quote above by Deedee, one of my research participants in Uyo, portrays the place of songs in the lived spirituality of the women with disabilities and HIV that I interviewed. I observed that many of the women in my study sang songs naturally during our conversations, outings or during a drive to a meeting or church event. I observed how songs were representative of the stories they shared and were in many ways a means of communication for them, with humans and with God.\textsuperscript{462} These women sang as they worked or walked, alone, or collectively. They hummed songs as they went about shopping, with facial expressions that indicated to some extent the theme of the songs being hummed. Many of the songs

\textsuperscript{459} Asamoah-Gyadu, African Charismatics, 215.


\textsuperscript{461} Kanyoro, ‘Engendered Communal Theology’.

\textsuperscript{462} Emma Wild-Wood and Peter Wood, ""One Day We Will Sing in God’s Home": Hymns and Songs Sung in the Anglican Church in North-East Congo (Drc)", \textit{Journal of Religion in Africa} 34, no. 1–2 (2004): 145–80, has an expression that ‘what Christians sing is also what they believe/experience.’
centred on Jesus Christ explicating what Jesus means to them and what Jesus has done or is able to do for them.

Some of the themes that came through from the songs were of praise and worship, thanksgiving, affirmation of faith and of mutual solidarity. Whatever the theme, these women found ways of expressing their feelings, belief, and faith using songs as the tool or means of such expressions. Through songs they offer praise and thanks to God; but also, through songs, they reaffirm the reasons for renewed hope, for strength to face another day; and for support for one another. In Chapter Four, I discussed how when my research participants tried to explain the understanding of their Christian faith, it was often in terms of their relationship with Jesus Christ. In singing, this understanding came through more broadly.

There was a great volume of songs that the women that I interviewed sang throughout my field work which make it difficult to choose which songs to analyse for this thesis. This was more so because songs came forth in the regular course of observations as well as in response the interview questions on what resources are available within Christianity with which to address the issues of stigma. Ultimately, I chose songs which were most popular among the research participants and as such were repeatedly sung, individually and collectively. Except for one song composed by a research participant, all the other songs are found within many churches in Nigeria and are regularly heard on social media, the radio and TV stations. No traditional Western Hymns were sung but this may relate to the popular notion among my research participants that hymns are meant for church settings and not the semi-formal settings that we were in.

During the focus group meeting in Uyo, the research participants arranged the seats in a circle form, making space for the placement of crutches and callipers. The Sign Language Interpreter was strategically seated to face the two ladies with hearing impairment. The Moderator of the meeting, who was also the Co-ordinator for BOLD, wheeled herself into the centre of the circle to begin the proceedings. The first item on the Agenda was Opening Prayers, and so she began ‘Welcome Sisters, it is time to praise the Lord. This is the time for praise and worship, be prepared to give to the Lord high praise.’
The first song was, ‘My Jesus today, my Jesus tomorrow, my Jesus forever more, you are a wonderful God.’ As the high pitch singing went on, the conductor changed the descriptive word for God from ‘wonderful’ to ‘miraculous,’ ‘faithful,’ excellent,’ and many other words of praise. Gradually, the rhythm changed into slow pace, and she started a second song, ‘You are Yahweh eehhhh, You are Yahweh, Alpha and Omega, You are Yahweh, Alpha and Omega.’ During this second song, instead of clapping of hands, the hands are raised up toward heaven as the women wave or demonstrate a sign of victory with the fist. With the intensity of the ‘praise and worship’ session, any passer-by would assume that was a church service or fellowship meeting, yet this was an academic research meeting with a full-scale worship on the agenda.

At the hospitals and HIV Clinics, whether government owned or faith-based, the first order of business is opening prayers which is always preceded by songs of praise and worship. Often these worship songs portray God or Jesus Christ as creator, redeemer, almighty, wonderful and such endearing names that express supremacy over evil powers or earthly problems. Each place, people and purpose of meeting determine both the songs and the duration of the praise and worship session. At the HIV health centre that I visited, most of the praise songs focus on Jesus as healer or on what Jesus has done or is able to do for them. Three different songs from the clinics are as below:

What a healing Jesus I’ve found in you
What a healing Jesus
Who restores, refreshes, and renews
What a healing Jesus I’ve found in you

Thank you, Jesus, Thank you my Lord
Whatever I am now, it is by your grace
Many are dying, many are perishing
Whatever I am now, it is by your grace.

What manner of man is Jesus
Hallelujah

He makes the blind to see, Hallelujah
He makes the lame to walk, Hallelujah
Hallelujah, hallelujah, Amen.

Although the above songs were sung during the praise and worship session, the lyrics are of Jesus as healer, and of thanksgiving to Jesus for sustenance. There is an expectation inherent in these songs. So, whereas the context is that of praise and worship, the lyrics do much more than that. They do not only speak of praise, but also act as reminder to the singers of who and what Jesus means for them; as well as what Jesus does and is able to do for them.

Sometimes, the women sang in their native language, in what they claim better expresses their feelings of praise and/or thanksgiving. Songs are therefore also used as tools for thanksgiving during praise and worship sessions. This song below, in Efik, is an example of a thanksgiving song during the praise and worship session sung during the focus group meeting at Uyo.

Sosong o Jesus, Sosong o Immanuel,
Sosong o Andiyanga, ofri ederimbot.  

This one is in Kalabari language, sung in Port Harcourt:

Tamuno eh oribim eh
Ibalafaa ehhh
Tamuno eh oribim eh
Ibalafaa ehhh
Ibalafaa, Ibalafaa, Ibalafaa ehhh

Often, the dichotomy between praise and thanksgiving songs are blurred. The commonality is that it is addressed to God, expressing who God is and/or what God has done. This practice is a fall-out of what occurs in a regular church or fellowship services in Nigeria, and which worshippers replicate in other worship scenarios. It is this fluidity and non-ritualistic nature of worship that Nimi Wariboko has described as the ‘playfulness in Pentecostal-charismatic worship services.’ According to Wariboko, ‘worship services in Pentecostal-charismatic churches are more a series of events, marked more by openness to the realization of potentialities of God’s plan …
in which miracles can be experienced.\footnote{Nimi Wariboko, \textit{The Pentecostal Principle: Ethical Methodology in New Spirit}, Pentecostal Manifestos (Grand Rapids, Mich: Eerdmans, 2012), 99. Let me add that Nigerian Christianity has been greatly influenced by the Pentecostal-Charismatic flavour that tend to emphasise the freedom of the Spirit of God to work in the lives of Christians. For more on Pentecostals/Charismatics, see Michael Adeleke Oguenwu and Isaac Deji Ayegboyin, ‘Pentecostals/Charismatics’, in \textit{Christianity in Sub-Saharan Africa}, ed. Kenneth R Ross, J. Kwabena Asamoah-Gyadu, and Todd M. Johnson (Edinburgh: Edinburgh University Press, 2017), 314–26.} While Wariboko’s view may be considered too generalised, it holds some truth as many of the women in my study who engage in this fluid approach are members of many Pentecostal-charismatic churches. They are also quick to express the possibilities of God’s blessings during the process of singing songs in praise and worship.

When the women I interviewed discussed the use of songs in offering praise and worship to God, they are careful to mention how the act of singing makes them feel. They speak of having a feeling of joy, and an assurance of what Jesus means for them in their lived experiences with the challenges of gender, disability, and HIV. During the focus group meetings, these women shared how praise and worship are regular aspects of their daily prayers and, with and through songs, they feel a closeness with Jesus Christ. This way of feeling is not the preserve of women with disabilities and HIV. Also, all the songs mentioned above are popular songs sung in most churches in Nigeria. Yet, the women I interviewed spoke of how they chose songs that they feel speak to their peculiar challenges and needs; songs that they say also express how they feel about Jesus. In so doing, they claim the affirmation of their faith as well as the strengthening of their relationship with Jesus Christ through Christian songs.

Ula and I met up at a Fast Food outlet in Port Harcourt for lunch and a space to continue our conversations. I went up to the food stand to place our orders and returned to the table to find Ula humming a well-known song. At my smile, she decided to sing the lyrics of the song and beckoned on me to join her in singing.

\begin{quote}
I know he’s my friend,
I know he’s my friend.
Whatsoever it may be tomorrow, I know he’s friend.
\end{quote}

As though for emphasis, she changed the pronoun to who it represents and sang again slowly:
I know Jesus is my friend,
I know Jesus is my friend.
Whatsoever it may be tomorrow, I know Jesus is my friend.

This song was informative as I listened and sang along, that Ula was using a song to buttress the ways in which she has consistently referred to Jesus as the friend who is always with her. Through this song, she affirms her relationship with Jesus as friend but also of the assurance that Jesus would be a friend through all the uncertainties of the future. It has been argued that African Christians prefer the use of ‘Jesus’ instead of ‘God’, because ‘specifying the name of Jesus, properly claims Christian particularity’ in a multi-religious context. This seems far from the intention of my research participants as most consistently preferred Jesus due to the relational component they ascribe to Jesus.

When women with hearing impairment at the focus group discussion sang the above song about Jesus as friend, their facial expression was that of joy and smiles. Their faces would light up with happiness as their hands make the sign for friend after the word Jesus. Using the American Sign language, the sign for friend is made with the two index fingers linked together, like in a hug, in a back and forward movement. To sign Jesus as friend in a song, therefore, provides the opportunity to reassert the connection between the signer and Jesus as two people connected in a mutual relationship. The act of singing songs, therefore, is a means of happiness for the women that I interviewed. For women in my study, making song, whether through vocal singing or signing, privately or communally, provides for them spaces to express and affirm their faith while gaining a sense of happiness, self-confidence, and solidarity.

In Chapter Two, I discussed how Bold Outstanding Ladies with Disabilities Network was established by women with disabilities who needed a space to mutually ‘support, develop and mentor women with disabilities and disability-related issues.’

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467 Oduyoye, ‘Jesus Christ’.
468 Christian Dobel et al., ‘Deaf Signers Outperform Hearing Non-Signers in Recognizing Happy Facial Expressions’, Psychological Research 84, no. 6 (2019), 1485–94. This reference is to show the importance and usefulness of facial expressions for the Deaf, but it also demonstrates how easy it is to recognise happy facial expressions for the Deaf.
469 See BOLD Hearts Profile, 2017
It was not surprising therefore, that at the focus group discussion meetings or HIV Support Group, for the women I interviewed, Christian songs were used to declare their solidarity for one another. Every meeting began with an opening prayer and ended with a closing prayer; both of which are usually preceded with songs. These closing solidarity songs are sung to reinforce their sense of friendship and belonging to one another as well as belonging to the family of God as people of the same faith. One song that the women sang was, ‘hold somebody, tell her that you love her, I love you, lift your hands to heaven, and praise the Lord.’ This song is usually sung with excitement and demonstration where hands are held within the circle and lifted together as the two last verses are sung. There is also usually loud laughter as ‘I love you’ is told to the person to the right and to the left, multiple times, if the song continues. Here also, I notice how a song of worship, with its facial expressions and gesticulations, is also a tool for expressing friendship and solidarity amongst the singers. I argue that beyond the lyrics of the song, the act of collective singing engenders a sense of community and bonding among the women in my research.

Another song that exemplifies this thought is one that was sung at the close of a Support Group meeting in Port Harcourt, ‘We are heirs of the father, we are joint heirs with the son, we are children of the kingdom, we are family, we are one.’ Here also, women hold hands swinging to the rhythm of the song, and as the last verse, ‘we are one’ is being sung, all hands are lifted up in a shout. This song is often used to affirm their belonging to the family of God. Through it, women declare their unity and oneness expressing mutual solidarity as members of one family. I argue that although these songs are not peculiar to the women in my study, their intentional use of the songs to address their core values of shared experiences and faith is worthy of note.

Wild-Wood and Wood have ‘acknowledged that praise singing is a communal exercise of the highest value in realising that supernatural unity which is a distinguishing mark of the church.’ Consequently, they assert that both the act of singing and the knowledge of the hymns sung, helps ‘engender a strong sense of community and a shared spiritual experience.’ Although the above quotations refer

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to singing of hymns within a church context, the women in my research express a sense of unity, community and common Christian experience as they sing together; which explains why they often refer to one another as friends and sisters.

BOLD is not a religious organisation. Yet, the lived Christian spirituality of its members impacts significantly in the conduct of its activities. They give credence to the thought that ‘religion is an expression of commonality, cohesion, and equality among people who share the same faith.’

It should be argued however, that such expression must be done within affirming spaces, especially for people like the women in my study, who do not find positive spaces in their churches or within other religious institutional bodies. The women I interviewed had to creatively use songs to express their solidarity, one for the other, thereby affirming the reason for their establishment, which was to avail themselves of mutual support. BOLD members’ creative ingenuity in using familiar Christian resources to address their social challenges specific to gender, disability, and HIV is significant for actors seeking appropriate response to these challenges.

In a 2013 survey of women’s songs from West Africa, the editors noted in the introduction, that whilst ‘songs as a verbal form is not limited to women,’ it is an effective tool for women as they have ‘a powerful voice in their songs’ especially within Africa’s patriarchal society in which women do not seem to have a voice.

My study has worked on the assumption, which was confirmed by my research participants, that women in Africa are about the ‘most exploited, marginalised, oppressed and poor’ groups for whom liberating alternatives are crucial to enable positive livelihood. As such, songs become liberating tools, not only to voice their worship of God, but also to address problematic issues in their lived realities and in some ways ‘preserve and sustain women’s values and their collective identity.’

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474 Mombo, ‘Doing Theology from the Perspective of the Circle of Concerned African Women Theologians’.
475 Hale and Sidikou, Women’s Songs from West Africa, 1-8.
What the women in this study do has been observed in other parts of Africa.\(^{476}\) Within the Anglican hymns sung in Congo, there is the prominence of the name of Jesus as ‘the most frequent titles used for Jesus …portray him in … salvific and pastoral roles as all powerful: Saviour, Lord, King, Christ, and Redeemer.’\(^{477}\) In the Kenyan study, worship songs in a Pentecostal-charismatic church reveal the ‘most common expressions’ for God are ‘Jesus’ and ‘Lord.’\(^{478}\) However, Amoah and Oduyoye note that in Africa, men and women have different experiences and interpretations of their lived Christianity. They opine that the Christological position of many women is drawn directly from ‘their very spirituality, the witness to what Christ means for their lives’ in their peculiar struggles with oppression.\(^{479}\) As such, Jesus for the African woman is the one in whom ‘the integrity of the woman (a person) as a body/soul is ensured, recognised, and promoted by the way Jesus of Nazareth lived and interacted with women.’\(^{480}\)

It can therefore be argued that the act of singing provides confidence and strength, especially for persons with disabilities, or those facing health challenges or learning disability.\(^{481}\) Music is central to much of human expressions and reflections of the divine providing a bridge to gaps that might be created by doctrinal inclinations.\(^{482}\) This section therefore brings a distinctive contribution to the role of songs for African Christians in discussing how women with disabilities and HIV in Nigeria use songs not only to express their Christian faith and practice, but also to address personal and collective challenges.

\(^{478}\) Prosén, ‘Pentecostal Praise and Worship as a Mode of Theology’, 156-79.
\(^{479}\) Amoah and Oduyoye, ‘The Christ for African Women’.
\(^{480}\) Amoah and Oduyoye, 35-46.
\(^{481}\) Alison R. Ward and Jacqueline Parkes, ‘An Evaluation of a Singing for the Brain Pilot with People with a Learning Disability and Memory Problems or a Dementia’, Dementia 16, no. 3 (1 April 2017): 360–74. Singing for the Brain uses singing as a way to ‘create a stimulating, fun activity within social contexts.’ This was a 2017, Alzheimer’s Society Northamptonshire, UK carried out a project to introduce ‘Singing for the Brain’ for persons with learning disability.
6.3 Prayers as Faith Resource
In the session on Songs above, I mentioned how every activity during my fieldwork with my research participants was preceded by and concluded with prayers. On a typical journey, accompanying any one of the women to a research activity or to their own events, we prayed as we set out from the house, before the vehicle moved and on arrival at the venue of events. In answer to the question as to why this is so, Maryann said,

Without prayers you feel empty. Prayers help you connect with God, you just know that he is not far from you,

Maryann’s view on prayers resonates with many of the women with disabilities and HIV in my study. These women speak of prayer as a means of connection with God because of and through the work of salvation of Jesus Christ. Often these women shared how they may not pray long prayers but that they pray all the time, emphasising that, as another interviewee said, ‘prayer for me, is like talking with a friend, who already knows all in your heart and yet is listening to you.’ It could be argued therefore, that for my research participants, prayer has two broad roles; first is the conversation-like communication with God through Jesus Christ, and second, is the provision of solace and support.

These roles of prayer are crucial for women who face isolation due to the social consequences of gender, disability, and HIV and who need creative strategies with which to cope daily. This section discusses the two far-reaching themes of prayer, as conversation and as support, that emerged from my findings and what difference it makes for the health and faith of my research participants.

Explaining prayer as a means of conversation with Jesus, Eve said ‘when you live alone, you learn to make Jesus your conversation partner.’ Eve is single and lives alone. Like most other women with disabilities and HIV, loneliness due to isolation is a known experience. When BOLD was established, it made certain to include elimination of isolation for its members as one of its objectives, but this is not always possible due to distance. Many of the women who may be living with family members still feel this sense of loneliness because of non-disclosure of their HIV status, which may hinder open conversations.

For these women therefore, Jesus becomes the one with whom they converse through prayers. Eve added, ‘prayer is like having a conversation with your best
friend, and you know, in this life, Jesus is your best friend.’ Eve says she talks to and with Jesus about everything in her life, nothing is removed as she continued ‘I pray about everything, everything, anything God wants to do with the prayers, let him do, I trust him.’ This way of speaking may not be removed from Eve’s declaration in Chapter Four about the relationship she has with Jesus in which she feels Jesus is with her all the time.

Eno seems to reinforce Eve’s point when she said,

You know, sometimes your heart is so heavy, maybe somebody has done something bad to you, or you are feeling bad about the whole situation, and you know, many people do not understand, you just talk with Jesus. That helps.

Eno shared at the focus group meeting how, due to her inability to hear sound and the absence of sign language interpreters, she is often left to herself in many religious and social gatherings. At such times, she says, ‘it is only you and Jesus, you know.’ These women argue that because every conversation with Jesus is prayer, they are in fact, always praying.

As the discussion on prayers progressed, I noticed Maryann did not seem entirely convinced about the classification of prayer as conversation. She said,

I think conversation is about two people talking. One person talks and the other person responds. Well, Jesus does not always respond at the same time when I speak. He responds but you never know the time exactly. For me, I think it is just knowing that I am talking to him (Jesus) and that he (Jesus) hears me. For me, it is the connection that is important. That connection that makes me feel that I am not alone. I think that is what I was talking about.

It could be argued, in defence of Maryann, that what she is describing are conversation-like prayers that are broadly referred to as private prayers. But many of the women at the meeting felt the act of conversing best described the ongoing continuous talking that they do with Jesus; claiming that they hear Jesus respond in their hearts. Eve maintained that,

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I really feel it, when I am talking with Jesus, I hear it inside my heart, and I answer and Jesus answers. I do not know how to explain it, but we converse. It is easy.

Spiritual experiences are personal and are often expressed in ways that cannot be proved by another. However, whatever the descriptions of feelings, what was obvious was how prayer enables intimacy between Jesus and the women in my study, in a way what that they themselves are unable to explain. The women in my study have shared several times, their efforts to cope with the difficulties associated with disability as well as managing the health and social demands of HIV. They live within unjust systems that discriminate and exclude them from human socialisation. Living with HIV also means regular visits to the hospital for check-ups and medication, sometimes without human support. For these women therefore, conversational prayers become central to their spirituality as is their personal relationship with Jesus to provide the needed support for their lived realities.

An interesting qualitative study more relevant to this section was conducted in the USA to explore, ‘which type of prayer was associated with positive, emotional and physical health outcomes’ among African American women at advanced stage of cancer. It identified ‘conversational prayer’ described as ‘talking to God throughout the day,’ or ‘when you talk, he (God) listens,’ as being used more regularly for the women with advanced stage of cancer. It further suggests that the prayers that have positive effects on psychological well-being are those which focused on establishing or maintaining close relationship with God. If conversational prayer is, ‘internal running conversation that went on over time throughout the day while the participant was awake,’ then my research participants were also praying all through the day. It is this divine energising communication that enables them to go through each day.

Prayer is primarily communication with the divine, yet my research findings suggests that prayer is also at means through which women with disabilities and HIV find solace and support.

In a private conversation with Grace in Port Harcourt, she said:

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Prayer good well well. Any time wey I pray, e dey as God dey take carry me. This life no easy ohh my sister. Prayer dey give me strong mind.  

The fact that Grace claims to be in a stable home, married with children, has not removed from her the difficulties associated with living with disability and HIV in a context of exclusion and discrimination. However, Grace asserts that when she prays, she feels ‘carried’ by God in a way that offers inner strength and courage to deal with a life that is difficult due to disability and HIV. During conversations and interviews with my research participants, they often explained the various ways in which ‘life is not easy.’ Added to the stigma of gender and disability, they speak of the sufferings brought about by HIV. This, as I discussed in Chapter Two, has attracted multiple levels of difficulties for these women, within the church and society. The women I interviewed shared how they often feel rejected, exploited, and unappreciated. They speak about their responsibilities as daughters, wives, and mothers within the context in which patriarchy determines and often defines their functionality.

Their lives are not easy as tensions between culture and religion continue to impact on their spirituality as Christians, as the stereotypes that stigmatise them are promoted by the institutions that ought to protect them. Within these complicated contexts, women like Grace, affirm that they find inner strength and support from the act of praying to Jesus to cope and to flourish. Prayer becomes a tool of healing for people in circumstances that may be confusing. Prayer, though a common activity for people of faith, becomes for these women, essential in providing a much-needed solace.

Below is an excerpt from prayer said at one of the HIV clinics. The nurse used both English and pidgin:

Our God is faithful to heal, faithful to deliver. Even this sickness wey you dey sick sef, God dey to take am commot. God don deliver you from plenty tings before. Your case worse pass others but those people don die you still dey. Thank God say him fit heal you. Let us continue to serve this our God. God granted you journey mercies. God provides for you. May God

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486 English translation: ‘Prayer is very good. Whenever I pray, God carries me in a special way. My sister, my life is not easy. It is prayer that gives me inner strength. Interview with Grace, Port Harcourt, 5 December 2019.

cover all the doctors and nurses with his blood. This sickness will not kill you in Jesus name, Amen.488

All sentences were punctuated with shouts of Amen by the patients. A cursory look at the words of the prayers will discern a secondary, maybe unconscious, purpose of offering solace and confidence in the patients. Through this prayer, there is an affirmation of God’s ability and willingness to heal, God’s previous acts of good, as well as declaration that HIV will not cause the death of anyone participating in the prayer. It appears that when the women in my study speak of accessing support and strength in and from prayers, they are referring to the liberative elements that prayer provides.

A scientific study examining the role of spirituality and religion, with reference to prayer, for people living in the UK, suggests that, ‘Africans and other individuals’ religious affiliations can have positive effects in terms of coping mechanisms and providing a sense of inner strength to deal with HIV.’489 They observe that, although prayer could be misused as a replacement for HIV medication, that prayer is a useful tool with which people deal with complex emotions. The scientific UK study did not consider the types or words of prayer but rather the act of praying, as what provided support for all kinds of problems that Christians face.

This is also true for the poetic prayers of Madam Afua Kuma of Ghana. Often the emphasis has been on the spiritual contribution that Kuma’s prayers makes to African Christianity and African Christological discourse.490 Others have described her prayers as ‘oral theology’ that furthers the African understanding of Jesus as Kuma is said to express ‘the presence and power of Jesus in her everyday life and that of her community.’491 In my opinion, Kuma’s prayers offer a more direct response to the spiritual needs of the African Christian, in her day and now. It is not similar in words

488 Full English Translation: Our God is faithful to heal, faithful to deliver. God can take away your sickness. God has delivered you from lots of things before. Your situation may have been worse than others who are dead, but you are still alive. Thank God that he can heal you. Let us continue to serve our God. God granted you journey mercies. God provides for you. May God cover all the doctors and nurses with his blood. This sickness will not kill you in Jesus name, Amen.


to my research participants, but its words offer solace and support that Christians need. An example of Kuma’s prayers, provided by Stinton reads,

If Satan troubles us, Jesus Christ, you who are the Lion of the grasslands, you whose claws are sharp, will tear out his entrails and leave them on the ground for the flies to eat.\(^{492}\)

Kuma encourages Christians in this prayer, by conjuring an arresting image of Jesus as a powerful lion, and Satan as the lion’s prey. In a context where Satan (or evil spirits) are sometimes seen as ‘causing AIDS’ and capable of putting ‘HIV blood in the veins’\(^{493}\) of humans, prayers, addressed to God, that Jesus can destroy Satan could be comforting.

Prayer is said to be the ‘very soul and essence of religion.’\(^{494}\) It has been broadly described as ‘deliberative communication between a person and a supreme being, God, or something outside oneself.’\(^{495}\) Within the Nigerian African Christian space, prayer is ‘privileged’ among other spiritual practices, though this did not seem to be the case with my women that I observed.\(^{496}\) For these women, it was just one of the resources used distinctively in which they find succour for life’s challenges. The average Nigerian Christian considers prayers as the ‘key’ to unlocking all anticipated blessings, and as a ‘means of human response to untoward physical circumstances.’\(^{497}\) Amy Smith gives three ways in which people understand prayers. These are, ‘inward prayers (self-examination), outward prayers (strengthening human-to-human connections), and upward prayers (focusing on the human-divine relationship).’\(^{498}\)

While all three aspects of prayer are usually present in any one person’s prayer, the one most highlighted in the prayers of my research participants was the third understanding which is that focusing on human-divine relationship. The women that I interviewed appreciate the place of human-to-human connections, as explained in

\(^{492}\) Stinton, *Jesus of Africa*, 5.
\(^{495}\) Smith et al., ‘How Women with Advanced Cancer Pray’, 310.
Chapter Four, but it is primarily from the human-divine connection that they find healing and succour to engage with their lived Christianity. Prayer, whether private or communal, therefore is a spiritual resource with which these women draw strength and offer mutual support to one another.

Within the themes of conversational prayers and prayers as means of support, I observed different types of prayers when the women in my research prayed. Some of these prayer types were prayers of adoration, supplication, thanksgiving, intercession, warfare, and the Lord’s Prayer. In many cases, the boundaries between these prayers were fluid in terms of their usage, but usually, the transition if obvious, was either in the tone of voice, the facial expressions, or the body movements (where possible). Elijah Obinna identified three types of prayers within an interdenominational African Christian fellowship in Edinburgh such as thanksgiving, intercessory, and ‘warfare’ prayers which are expected ‘not only to give voice to particular intentions … but also to achieve specific ends.’

Brandon Whittington and Steven Scher’s study of the relationship of prayer types and psychological wellbeing in America identified six types of prayers for a multi-religious target. These are adoration, confession, thanksgiving, supplication, reception and obligatory. Within my local Presbyterian Church in Nigeria, we technically observe different prayer types such as adoration, confession, supplication, intercession, and thanksgiving. These show the similarities of prayer types, especially, among Christian denominations across the globe. Like many other Christians, my research participants did not always name these prayer types as they prayed. I observed a shift in content and intent as they prayed.

Another significant observation with the use of prayer was the experience of positive anticipation that many of these women expressed. They claim a sense of certainty that God to whom they pray through Jesus hears them and would do something about their requests. According to one research participant, ‘I know that

500 Whittington and Scher, ‘Prayer and Subjective Well-Being’, 59-68. Brief description of the prayer types are: adoration(worship of God, without any reference to circumstances, needs, or desires), thanksgiving( gratitude towards God), Supplication( requests for God’s intervention), confession(admission of negative behaviours, and a request for forgiveness), reception(passive expectation of divine wisdom, understanding, or guidance), and obligatory prayers(an important component of some religions, such as Orthodox Judaism and Islam, where followers are required to pray three and five times a day, respectively).
anytime I open my mouth to pray, I know that Jesus is hearing me because he is with me, I know he will answer me. I just know it.’ I would argue that this state of constant anticipation enables the women that I interviewed to look forward to possibilities in a way that changes their perspectives for good. Wariboko rightly says that ‘every prayer is a protest against the ambiguities, distortions, and poverty of the present….in prayer, we are saying, there is a better alternative.’\textsuperscript{501} I believe this anticipation for a better alternative that prayer offers helps women with disabilities and HIV to look positively to the future with hope.

Women in my study claim that having hope in Jesus provides them with the confidence to face the challenges of their lives, knowing that their prayerful conversations are not in vain. Isabel Apawo Phiri notes how hope in Jesus as healer gives motivation for persons living with HIV to face another day, ‘even up to the deathbed.’\textsuperscript{502} Having hope that solutions will be found for HIV is a major contribution that the Christian faith makes to the Christian world.

A couple of women at the focus group meeting expressed that neither prayer nor hope comes easy. According to Deedee,

\begin{quote}
But sometimes prayer is hard, like I don’t know what to say. Like I don’t know how to say it. So, I put my hand on my chest, then I feel Jesus knows what is there. Jesus listens to my heart.
\end{quote}

Deedee explains that putting her hand to her chest is a form of prayer for her, because she is asking Jesus to look into her heart and see all the challenges that she is passing through. But it could be said that even in that form of prayer, the expectation of being heard makes prayer a veritable spiritual tool for these women.

Many have argued that prayer expectations that are not met could lead to depression or frustration.\textsuperscript{503} In Chapter Four, I discussed how prayer for physical healing may be discouraged to avoid the pain of disappointment when healing does not take place.\textsuperscript{504} This discouragement is perceived as a possibility for women living

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\textsuperscript{503} Smith et al., ‘How Women with Advanced Cancer Pray’, 310.
\end{flushright}
with HIV as well.\textsuperscript{505} The response to these by Moyo,\textsuperscript{506} Phiri,\textsuperscript{507} Wariboko,\textsuperscript{508} as well as the women in my study, is that because humans do not know how and when answers to prayers would come, it is expedient to believe that, ‘in the end, God would be victorious’ over human conditions.\textsuperscript{509} It is within this context that Benebo Fubara-Manuel encourages Christians with these words,

We must pray instead as people who recognise that God is eager to listen and respond to our prayers and that God is sovereignly leading history to God’s designed end.\textsuperscript{510}

In the above quotation, we can glean prayer as conversation with God and offering hope that gives a sense of comfort for Christians. The women in my study conceived of prayer not just about receiving but primarily about communicating with God through Jesus.

I argue that the centrality of Jesus, ably represented in prayers, in action or words, can provide succour, solace, and comfort for women going through the difficulties of gender, disability and HIV within oppressive circumstances. Consequently, the women I interviewed shared stories and gave testimonies of the various ways in which, they have been strengthened to overcome various challenges.

\textbf{6.4 Storytelling and Testimonies as Faith Resource}

I have many testimonies to show that Jesus is always by my side. One day, I got into accident here in Port Harcourt, around Trans Amadi area. I was trying to cross the road but because of my condition, I was not fast enough and one okada\textsuperscript{511} man hit me and I fell. Immediately, all the other cars stood still. As I was on the ground, I was shouting, ‘Jesus, Jesus, help me, Jesus’. Somehow, I felt Jesus around me that day. Two men came of their cars and carried up. They took me to the hospital. I was treated and they paid the bills. God saved me from being crushed and I thank God.

\begin{itemize}
\item \textsuperscript{505} Kamau, \textit{AIDS, Sexuality, and Gender}. 152-5
\item \textsuperscript{506} Moyo, ‘Navigating Experiences of Healing: A Narrative Theology of Eschatological Hope as Healing’.
\item \textsuperscript{507} Phiri, ‘HIV/AIDS’, 422-31.
\item \textsuperscript{508} Wariboko, \textit{The Pentecostal Principle}, 155.
\item \textsuperscript{509} Phiri, ‘HIV/AIDS’, 422-31. This has been extensively discussed in Chapter Four of this work.
\item \textsuperscript{510} B. F Fubara-Manuel, \textit{In the Missio Dei: Reflections on the Being and Calling of the Church in the Sovereign Mission of God} (Calabar, Nigeria: Presby Press, 2007), 228.
\item \textsuperscript{511} Pidgin word for motorbike
\end{itemize}
The above quote from Ula illustrates a typical testimony expressed in a story of a personal experience about divine intervention. The women I interviewed revelled in telling stories about their lives, either to drive home a point, to share an experience or simply to affirm the experience of another member of BOLD. Drawing from above, Ula expressly mentioned the purpose of her testimony as to ‘show that God is always by my side,’ and that ‘God saved me.’ It highlights her individuality as someone who can call on Jesus in time of need and one who feels the presence of Jesus when she needs it.

Although there were human agents in the two men who cared for Ula, her primary recognition is that God saved her from being crushed. Whilst not in a church setting, the women in my study consciously and repeatedly referred to their stories as testimonies. In many of these stories, these women referred to their relationship with Jesus and would often call on the listeners to learn something or to be encouraged. I argue that women in my study used stories and testimonies to share their personal experiences and to provide mutual encouragement for one another in their common challenges with gender, disability, and HIV. These two major themes emerged from the findings on the use of stories and testimonies as spiritual tools to combat stigma and cope with the challenges of exclusion.

It was the end of a focus group meeting, and the women were commenting appreciatively about the discussions when Grace said,

*When I come here, whether nah for prayer or for talk talk, I be myself, I dey free. I no dey hide anything, because nah my sisters dey for here. Like when my medicine dey confuse me, I come here and dem tell me wetin to do. No be so for outside. Outside nah hide hide, make person no know wetin dey do you.*

Much of the conversations that Grace referred to here were stories shared by the women at the meeting. These stories reflected their daily lived realities dealing with HIV treatment especially when coping with issues of disclosure of their HIV status. Grace said she could freely share her stories because she regarded her listeners as her

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512 English Translation: When I come here (to the meeting), whether it is for prayers or just conversations, I feel free. I do have hide anything because the people here are my sisters. When I was confused about my medication (HIV medication), I came here, and they told me what to do. It is not like outside. Outside is full of secrets because you do not want people to know what is wrong with you.
sisters among whom she did not need to carry the burden of secrecy. Personal stories provided the means of expressing struggles and identifying with others having similar struggles, which in another sense could be considered liberating for women who are often silenced by society. While there were often differences in the details of experiences as no two situations are quite alike, the commonality of the broad issues enabled a safe space for personal storytelling and testimony. Deedee agreed with Grace with these words,

“It is true. When we come here, we can tell ourselves what has been happening with us. I usually keep to myself and don’t have people to talk with. I am not married, I don’t have a boyfriend, so it could be lonely. Talking with people who understand you helps to overcome loneliness.”

I observe that for Deedee, it was not only the sharing of her stories (or talking with people) that was important but also the enabling environment that made it possible for her to do so. Sharing of personal stories was more likely where there is mutual trust and respect. It could be argued that for stories to be a veritable means of sharing lived experiences, the listeners or the environment should be safe and affirming, as these women experienced themselves. Within this safe space, the women expressed how telling their stories made them feel accompanied. This was captured in Eddy’s comments,

“I don’t normally testify in church. When I testify here, about the goodness of my Jesus, I remember that not all in my life is bad, that Jesus is faithful. I hear other people’s testimonies, I feel happy. I feel good.”

Testimony for Eddy, is a means of remembering the goodness of Jesus in what results in praise ‘that Jesus is faithful.’ So here we see testimony as a tool for praise in drawing attention to what Jesus has done for the person giving the testimony. Contrary to the view that testimony within Nigerian African spirituality, is an activity within the church, the women in my study use the word ‘testimony’ whenever there is a reference to God in their stories during BOLD meetings and even during the focus group meetings. Testimonies (and stories), therefore, highlight the relationship of these women with Jesus and how happy the works of Jesus make them feel. It further confirms the point that stories provide a ‘particular understanding of God as
understood by the people telling the story. Testimonies often provide a broader picture of a narrative and listening to it can give information about the narrator as well as his or her present circumstances and relationships, private and public. It is within these relationships that women find mutual support in sharing details of their lives.

I have discussed earlier in this Chapter how the act of singing and the words of selected songs provide solidarity for the women that I interviewed. In much the same way, the women told me how sharing their stories and testimonies offer opportunities for mutual support and encouragement. In regarding one another as friends and sisters, these women spoke of the extent to which their stories and testimonies provided inspiration and reassurance. During conversations, I heard the journeys that these women took to the place of trust that enabled them to openly share their struggles, fears, and hopes for a better life while living with disability and HIV. For these women, one significant tool that broke the biases that had been piled by years of stigmatised living was stories of the women at the meetings. This is what Maryann said to this effect,

As she (a member of BOLD) was talking, it was as though it was my life she was talking about. I felt that I am not the only one feeling like this, I am not the only one having these problems. I was very encouraged to share my experiences as well. There is a connection here, and it helps me to remember the good things that God has done for me as well.

Maryann alluded to a feeling of kinship through the stories that the women told that in many ways mirrored her own experiences. The similarities helped her to reclaim her life and to share her experiences, while making the connection to God, qualifying the narrative as testimony. Telling stories, especially for women with disabilities and HIV, who are often perceived as victims, helped them to make sense of their experiences in often discriminatory contexts.

It helped to reclaim their identity and ‘in the process, finding impulses for hope’. Stories and testimonies also remove isolation, not only because one is talking

to another person from the lived experience of faith, but also because the narrator often receives feedback from the listener. Women in the study spoke of being spurred on to trust God more and being willing to be vulnerable within the community of sisters and friends in BOLD. This is what Eve said,

I know that I can ask for help whenever and from whomever that is in my condition. I am not ashamed or embarrassed because I know we are passing through the same stuff.

Unlike situations where women in this study lived in fear of recrimination, and where inability to ask for help due to stigma often led to suffering, these women expressed delight that they can ask each other for help. Eve’s knowledge of the fact that others in the group are ‘passing through the same ‘stuff’’ draws from the sharing of stories and testimonies by many of the women in BOLD. The beauty of stories and testimonies is that, though they are ‘unquestionably personal and thus primarily an individual story, they are also accessible to others in the community of faith ….to strengthen an individual’s faith but also to build a faith of the community.’516 This reinforces the point made above that a person’s private experience with God can be a source of support and encouragement for others when shared within a community.

At one of the HIV Support Groups, Eno shared a testimony,

Praise the Lord, my testimony today is about how God helps me, it is about my faith in Jesus Christ especially in the face of stigma. There is stigma everywhere. I did not know I was positive. I was losing weight and people were looking at me anyhow. I want to hospital for something else and the nurse asked if I wanted to do HIV test, I agreed, and the result came out positive. I asked myself, if just losing weight and people are behaving somehow, how much more HIV, plus disability? I kept it to myself and prayed to God for help. I prayed, Jesus, please don’t let me die from this sickness. He (Jesus) brought me to this support group. I go for treatment; I take my drugs and make up my mind to live well. Praise the Lord.

Eno’s testimony provides a synopsis of her journey with HIV from the time of diagnosis to the present state of strict adherence to treatment, as well as the role of faith as enabling her to cope with stigma. After Eno’s testimony, the women clapped

and responded with ‘Amen’ to Eno’s shouts of ‘Praise the Lord.’ Many women could relate to the fear of stigma and with the reluctance to disclose their HIV status with family members, echoing Eve’s thoughts that there is no shame or embarrassment among the women as they are all going through similar experiences. Testimonies therefore provide the tool of identification with the experiences and challenges of others. Knowing how others cope or are coping provides creative ways for others to adopt, especially as all share the same faith beliefs. This aligns with the description that:

> Personal testimony is a tool to both stretch the faith in the person giving the testimony, as well as build the faith and community of the people who hear testimony.\(^{517}\)

I argue that stories and testimonies offer women with disabilities and HIV the power not only to own and share their experiences but also to provide mutual support and encouragement for women in similar situations. As the women I interviewed linked their stories and testimonies to Jesus, they confirmed again the centrality of Jesus in the strategies employed to cope with the challenges of gender, disability, and HIV in Nigeria. Interestingly, the agency of fellow women or men to offer succour and support is perceived as part of the intervention or provision of Jesus through life.

Stories provide agency for women’s lived experiences and struggles within a patriarchal African setting, implying that women’s experiences need to be taken seriously in articulating any societal response.\(^{518}\) Referring to Christian women’s voices, Denise M. Ackermann remarks that women’s stories should be heard in churches and outside, because they help in ‘shaping (women’s) identities … and making sense of situations’ that are peculiar to women.\(^{519}\) She describes story as ‘the articulation of one’s experience in verbal narrative … in song, poetry, fiction, (auto)biography, liturgy and sacred texts’ affirming that the inclusion of women’s stories authenticates feminist theology.\(^{520}\) Some of the characteristics of storytelling are that it provides hope, enhances a sense of bonding among humanity, and restores

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\(^{517}\) Lyle L. Zumdahl, ‘Inspiring a Congregation into New Ministry: Examining the Effect Personal Testimony Has in the Transition into a Multi-Site Church Ministry’ (ProQuest Dissertations Publishing, 2010).


\(^{519}\) Ackermann, ‘From Mere Existence to Tenacious Endurance’, 221-42.

\(^{520}\) Ackermann, ‘From Mere Existence to Tenacious Endurance’, 221-42.
the power of the word.\textsuperscript{521} Nadar notes that women’s voices are often silenced whether as victims of abuse or agents of their liberation and that story-telling can give back power to women as their narratives are not filtered through the voice of the (male) narrator.\textsuperscript{522} This use of story as a liberating tool was obvious as the women in my study shared freely whether in personal interviews or in focus group meetings. They claimed to have a safe space within which to reflect and make meaning of what they had been through living as women with disabilities and HIV.

Storytelling is not the preserve of women, or of women with disabilities and HIV. Storytelling is part of the Nigerian-African oral tradition. It is common to have traditional Nigerian families gather to hear stories of the historical experiences within the community. It could be argued that storytelling in Africa is a continuity of the storytelling practices within indigenous communities. Usually, such stories carry moral lessons which the narrators want the listeners, often younger people, to learn from.\textsuperscript{523} These story telling events are however, often about past or imaginary events with multiple possible interpretations depending on the audience. It is no wonder that it has been argued that African storytelling requires ‘years of focused and carefully guided training’ where ‘artistic intelligence’ is required in the telling of the stories as well as in the engagement with the stories.\textsuperscript{524} When women in my study tell stories, they are stories of their personal experiences, interpreted from their perspective and told without prior preparations or artistic intelligence. These stories are described as testimonies when they are focused on God’s actions in personal experiences. Without any conscious intention or training, these women use stories, though a common place activity, as a tool to testify about what they consider as ‘supernatural’ interventions in their lives.

Stories and testimonies therefore play an inter-related role in providing the avenue for the women I interviewed to tell stories of their lived realities, in the church.


and society, with special reference to their relationship with Jesus Christ. It was through this medium that I got much of my ethnographic data as women talked about their experiences of the past, how it impacted on the present and what possibilities it held for the future. As a researcher, therefore, I find the stories and testimonies of the ordinary women in my research as useful in writing my PhD thesis, signifying the mutual benefit of stories and testimonies to the narrator and the listener. It is possible to have familiar resources within Christianity used for multiple purposes depending on the scenario of usage.

Testimonies were such an important part of the spirituality of the East African Revival, that scholars needed to attend to their ‘content, form, and function in order to understand the movement.’ It is no wonder that contributors to the East African Revival history often referred to their testimony as personal stories, although their narratives captured the private and public spaces of their experiences. This is because the personal stories are inherently linked to the work of God in their midst or put succinctly, the stories are a manifestation of the working of God. Like the women in my study, these stories and testimonies often included highlights of their Christian faith, their relationships (with God and with human beings), their struggles as well as their victories.

As stated earlier in this section, telling stories and testimonies involves memory, the act of remembering past events and relating such events to the present with a focus on the future. It is personal and unique to the narrator and emerges from life experience to which only the narrator may be privy. This makes ‘memory a tricky thing’ in that the narrative could be reflective of what the narrator intends the listeners to hear. As such, what is revealed in the stories may be a piece of a life of the narrator. However partial these stories may be, African Christian feminists suggest that

525 Mombo, ‘Doing Theology’, 91-103. Mombo notes that for Circle writings, the stories of ordinary African women, literates and non-literates form the ‘raw data to write qualitative academic papers.’
529 Wyble, ‘Telling Stories’.
telling and listening to the stories of those who are suffering, discriminated against, or oppressed is an essential starting point for counteracting silence, denial, and stigma.\textsuperscript{530} I agree with this feminist position.

One of the objectives of my research is to bring to the fore the stories of the lived realities of women with disabilities and HIV who also face the challenges of gender in Nigeria. Through these stories and testimonies, we discover how women share their private and personal experiences with gender, disability, and HIV, as well as how these narratives provide mutual support within BOLD network.

\textbf{6.5 Conclusion for Chapter Six}

In this Chapter, I have examined the religious resources that women in my study use to respond to the social and religious consequences of gender, disability, and HIV. Without prioritising any one resource, they use Scripture, songs, prayers, storytelling, and testimonies to address their peculiar challenges. They deployed them privately and collectively in navigating their daily lives. The way in which they practised them was drawn from their different church backgrounds. Their practice was also informed by the experiences of oppression, exclusion, and voicelessness. Religious practices or the spirituality of the women, as an essential aspect of understanding and engaging with the Christian faith was the focus in this chapter.

The women understood that their use of Scripture, songs, prayers, storytelling, and testimonies strengthened their relationship with God. They also demonstrated that these Christian resources and the practices that surround them have relevance to every aspect of life. For persons who are religious, the interface between faith and health must be acknowledged to adequately respond to the social challenges associated with diseases and infections. I argue that when properly articulated within safe spaces, religious or sacred practices could effectively address social, religious, cultural, and medical concerns to enable women live and flourish despite their challenges with gender, disability, and HIV.

I have endeavoured to demonstrate how these women use these resources to disprove discriminatory stereotypes and affirm their faith in Jesus Christ. These

\textsuperscript{530} Ackermann, ‘From Mere Existence to Tenacious Endurance: Stigma, HIV/AIDS and a Feminist Theology of Praxis’. 

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resources also provided the means for mutual support and encouragement as they shared personal stories and testimonies, prayed, and sang together as well as read and studied the Scriptures. These women found creative ways to draw strength in their conversations with Jesus Christ and thereby continue to make Jesus central to their survival mechanisms.

This Chapter reveals that popular religious resources and practices in Nigeria can be adopted to address social issues in ways that ultimately enable women to cope with life’s challenges and difficulties. It therefore further highlights the extent to which women intentionally seek faith-based strategies, without engaging in rigorous theological interpretations, to affirm and empower themselves to overcome beliefs and practices that make life harder for them due to their disability and HIV. It demonstrates that the use of religious/spiritual tools is a veritable means of challenging all forms of stereotypes that engender stigma while promoting positive messages of inclusion.
Chapter Seven
Conclusion: Towards Faith-based Strategies in Gender, Disability, and HIV Intervention

7.0 Introduction
The findings of my research show that faith makes a major contribution to well-being in society and needs to be a part of sociological and health care discourses. The women in my research who live with disabilities and HIV in Port Harcourt and Uyo find life-giving hope through their faith in Jesus Christ. This faith enables them to cope with multiple challenges and within structures that often do not promote equality. Their relationship with Jesus facilitates a healing experience that can be described as the transformation of identity. They can imagine themselves and their abilities in a more positive light. In this transformed identity, they assert their personhood and negotiate contentious relationships in the family, church, and society. They exercise their faith in personal ways and in communal spaces. Their faith is central to their understanding of healing and well-being. This thesis demonstrates the importance of life-changing faith experience, affirming relationships, and use of resources of faith for Christian women living with disabilities and HIV. It acknowledges the positive role of stories in offering strategies for consideration to parties, such as church leaders, theologians, medical practitioners, and international organisations, who engage with issues of women, disability, and HIV.

In this concluding chapter, I provide a summary of the stories and themes that emerge, from the members of the case-study organisation, Bold Outstanding Ladies with Disabilities Hearts Network (BOLD), to show the contribution of Christian faith in the lives of women with disabilities and HIV in Nigeria. These themes include faith as relationship with Jesus, relationship with others who may be families, church members or friends, and faith resources of Scripture, songs, prayers, stories and testimonies. From this summary, and as a form of advocacy, I show how my research raises questions for faith communities, theologians and international medical and humanitarian groups. I suggest ways in which faith discourses can contribute to improved health and sociological understanding of people living with the challenges of gender, disability, and HIV.
7.1 Women’s Stories of Positive Intervention

Maryann is a 35-year-old woman, who is married with two children. She is a High School teacher in Port Harcourt. Due to a spinal cord injury, she uses a wheelchair. Maryann was pregnant with her second child when she was diagnosed with HIV. She experienced stigma that led to discrimination and exclusion from what she perceives as the stereotypes regarding the causes of disability. She could not go to church. She felt people looked down on her and thought it would be impossible for her to be or do anything. She believed the limitations placed on her and that affected her self-esteem and happiness. Then she gave her life to Jesus Christ, and everything changed. Maryann says her ‘faith is anchored on the work of Jesus’ whom she refers to as a friend, one who is on a journey with her and with whom there are no impossibilities. Maryann is a member of BOLD and attends an HIV treatment centre in town. She says because God has done the impossible for her (living with disability and HIV, getting married, giving birth, having a career), that there is nothing impossible with God. She believes that in Jesus Christ as healer, she will be healed of disability and HIV. Maryann asserted her right to personhood by saying ‘if God is in me, I cannot be inferior…if what God made is wonderful and good, it means I am wonderful and good.’ She had a positive attitude throughout the fieldwork. She hummed tunes and songs came easily to her. At the group meetings, she encouraged the women not to change church because of the unwelcoming environment but to be busy and not be angry. She herself had experienced exclusion as a member of her Church Choir but she was undeterred. She urged them to find ways of connecting with women without disabilities in the church so that they would work together. She spoke of BOLD as her family, friends, and sisters. She talked a lot about how grateful she is that Jesus saved her, gave her a new life and how she feels connected to Jesus in prayers.

Maryann’s story, interspersed in Chapters Four to Six, offers an example of the lived experience of the remarkable women in my research. Seeing how these women lived ignited my curiosity to examine the extent that faith, as belief, practice, and relations, help them to strive despite the challenges of disability and HIV. As explained in Chapter Three, these women freely and willingly shared their stories during interviews, informal conversations, focus group discussions and observations. Stories and storytelling were essential to this research. Stories were the means through which
the women shared their experiences about gender, disability, and HIV. These women’s stories were complex: they included suffering and resilience and the agency of Christian faith in their lives.

During six months of field work, I heard different but similar versions of stories about the lives of my research participants. They told stories in which they were victims, but also stories as survivors. They used stories to share testimonies of God’s help and intervention in times of difficulties. Within what they regarded as empowering spaces of support group meetings such as with BOLD, they talked about the mutual encouragement that sharing their personal stories offered to them. They demonstrate that stories, shared within safe spaces, can provide support for women who are often alienated and isolated. Stories need to be taken seriously as a means through which women can reclaim their voices and their identities.

The women that I interviewed were clear on the point that they want their stories to be heard, not just by me, but by those who would read this thesis. They want their stories to be told for understanding of their situations but also, for possibilities of effective engagement with issues of gender, disability, and HIV. At a meeting in Port Harcourt, one of the women said, to the nodding of others present, that they were happy to share sensitive details of their lives because they hope the world would get to know what they are going through. The same sentiment was raised at a meeting in Uyo. There the women expressed appreciation that the research provides opportunities to further share their stories, to learn from one another, and have an input in an academic activity. Listening to these stories, mostly verbal and a few by Sign Language, I observed the incredible strength that these women showed in navigating their identities and negotiating relationships within the family, the society, and the church. They wanted their stories to reflect that strength, to be comprehensive and include the ways they deal with the challenges of their realities.

This thesis makes a case for dedicated research on the stories of the faith lives of women with disabilities and HIV in Nigeria to be carried out. Using the words of William J. Bausch, the women in this research have owned their individual and collective stories. According to Bausch,

to own one’s story means to accept the whole of it, the whole of our lives, the light side and the dark … in short, owning the story
is to give ourselves the total acceptance that God gives us. There is no room for self-hatred in our story.531

Stories of the women in this research reflect narratives owned by the storytellers. Just as they ask to be accepted as persons, they ask to be listened to, to be heard, and to be responded to, from the knowledge of their stories. Women’s stories are referred to as ‘faith journeys … told in a way that includes analysis, reflection and a call to action.’532 These stories must, therefore, reflect all sides, as much as is possible, the lives of those concerned, irrespective of who is telling or retelling the stories.

Chimamanda Ngozi Adichie, a Nigerian author and storyteller, speaks about the ‘danger of a single story.’ Adichie describes ‘a single story’ as a ‘one-sided point of view of something or someone… originating from one’s lack of knowledge of others.’533 The single story, Adichie warns, ‘creates stereotypes, and the problem with stereotypes is not that they are untrue, but that they are incomplete. They make one story become the only story.’534 This appears to be the problem with many of the stories about women with disabilities, and/or HIV. Frequently, because the women themselves are not actively involved in the stories, the stories become single stories with the danger of misinterpretation. Often the single stories do not reflect the totality of the story. On one hand, when actions and assumptions are made based on an incomplete story, they fail to address the concerns adequately. On the other hand, popular stereotypes generated from incomplete stories are believed and may inform people’s actions. Adriaan van Klinken, et al, highlight the need for comprehensive stories and the various ways in which storytelling benefit marginalised people. They assert that telling personal stories both empower and provide agency to individuals and the community, offer ‘counter narratives to popular representations in society,’ and

534 Adichie, *The Danger of a Single Story*. 

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‘insert new critical and alternative forms of knowledge’ about the lives of those concerned.535

When the women that I interviewed asked that I endeavour to provide a complete version of their stories, they were asking that the description, shared during the fieldwork, be retold. They were also asking for a change in popular narratives, from a predominantly negative to a balanced reality that represents the totality of their experiences. It is not uncommon to find narratives about gender, disability and HIV being presented with negative experiences. Sometimes, in trying to draw attention to the problems associated with these circumstances, everything is painted in dark lines and the light lines are dimmed. It is a fact that women are disproportionately affected with disability and HIV. It is a fact that women with disabilities are more vulnerable to HIV infection due to inequalities and abuse. It is a fact that stereotypes concerning causes of disability and HIV place women at a disadvantage. These are facts which this thesis has also used to make a case for inclusion.

These facts have led to HIV being given a female face and being made a woman’s burden.536 Stories of infection have been centred on these facts and the brokenness of women in these circumstances played out repeatedly.537 While these facts are not untrue, accompanying stories have not always included the resilience of women to overcome these challenges. Stories about the crucial role of faith for women and women’s belief in a God who enables them to face the challenges of each new day with hope have been side-lined in an attempt to focus on their suffering and exclusion. Negative narratives pervade the public space and often fail to recognise women as active partners in response strategies. This makes most of the stories about women with disabilities and HIV, where such stories exist, single or incomplete stories.

This thesis opines that the stories of faith empower the women who tell them, showing how their relationship with Jesus allows them to overcome adversity and live with difficulty, therefore possessing agency in their situation. Stories of faith also inform the listener who cannot ignore the perspectives of the women in their

536 Masenya and Mtshiselwa, ‘Dangling between Death and Hope’.
circumstances, and who might work for the improvement of women’s conditions or simply be encouraged by the stories. Storytelling, therefore, in uncovering hidden voices of many marginalised groups, become ‘legitimate forms of knowledge in social and academic’ endeavours, of which this thesis serves as evidence.\textsuperscript{538} There are several groups for whom stories require reflection and change. I discuss below the way my findings might influence faith communities, African theologians, International (Humanitarian) Organisations and the medical establishment. The first group I discuss is faith communities and church leaders because it is the group that has the greatest immediate impact on the sociality and spirituality of women living with disability and HIV in Nigeria.

7.2 Engaging with Faith Communities and Churches in Nigeria

A theme that emerged from women’s stories was a disconnect between their expectations of churches as inclusive, faith communities and the reality of stigma and ignorance in many churches. The women’s understanding of Christ’s salvation informed their thinking that churches should be inclusive of all persons. As highlighted in Chapter five, many churches fall short of these expectations and effectively deny the personhood of women living with disabilities and HIV. My research suggests that churches need to critically address how women with disabilities and HIV are treated in the church, and by extension in the community. If they are treated with the dignity and respect accorded to everyone, then perhaps, issues of stigma would be reduced. In this light, I propose that the attention to effective inclusion requires the training of church leaders, appropriate use of faith resources, general accessibility needs of disability, as well as the involvement and participation of women with disabilities and HIV for effective action.

My research participants asserted their right to be treated as persons because, in their acclaimed relationship with Jesus Christ, their identities have been transformed. One participant said that if Jesus could forgive her sins, come into her life and be her friend, then there is nothing she could not do, and so should not be treated otherwise. These were women who had been defined by others by their disabilities and disease. By societal discrimination and exclusion, they had been made

\textsuperscript{538} Klinken et al., Sacred Queer Stories: Ugandan LGBTQ+ Refugee Lives & the Bible, 124.
to feel uncomfortable in places of socialisation and worship. Their faith, expressed in their relationship with Jesus Christ was now the difference between a state of hope and that of hopelessness; this faith became the enabler for new possibilities, new relationships, and new opportunities. In Chapters Four and Five of this thesis, some narratives of women’s stories were told. Although they still lived with the struggles of gender, disability, and HIV, they were making choices from a place of faith-informed concept. These choices were the difference between surviving and striving, from continuing to stay in church instead of leaving.

It is the distinction that Denise M. Ackermann makes between mere existence and tenacious endurance. Ackermann describes those in mere existence as those with HIV who live in fear and loneliness and are unable to disclose the status of their infection. Mere existence, according to Ackermann, does not ‘describe life that is lived fully and truthfully or life that affirms our human dignity and worth.’ Ackermann may be right in that non-disclosure may cause some loneliness for persons living with disabilities, but from the stories of my research participants, it does not impact on their dignity and worth. Some of my research participants made deliberate choices at disclosure and non-disclosure. For some, it was to protect their families from stigma, and for others, it was to protect themselves from further stigma and discrimination. In either case, they claimed that strength from their relationship with Jesus enabled them to negotiate various relationships and engage in what was affirming of their persons.

Tenacious endurance, on the other hand, while the term endurance may be problematic, best describes my research participants. It represents the, cultivation of hope in situations that offer scant grounds for hope…. It means bearing suffering with fortitude, courage, and tenacity without giving way to it…. It affords dignity and meaning to a life despite the fact that it might be infected with the HIV virus.

540 Ackermann, 'From Mere Existence,' 224-5.
The women living with disabilities and HIV in my research, show from their stories, how this tenacity is perceived as part of the healing mercies of Jesus. It is this improved self-esteem that they offer to the society and church, asking to be treated as persons who deserve to be recognised and included. The assumption is that if churches worked towards dismantling the stereotypes that women with disabilities and/or HIV are not useful to church or society, and instead emphasising their value, that there would be better acceptance of their dignity. Churches need to see Jesus’ healing ministry with regards to women with disability and HIV in the alternative and innovative way that these people see it: a transforming power that can change every aspect of their lives positively.

Churches can also draw on African philosophies that uphold human dignity and a communal sense of belonging to promote inclusion. Dube notes that the African philosophy of community,

should be integral to the promotion of gender equality and liberation in general, for unless all members are respected and equally empowered, then we cannot be community.541

An African concept of community is embedded in the equality and dignity of all persons and allows for a sense of belonging that woman in my research seek. There are many indigenous African cultures embedded with positive life affirming beliefs and practices, often expressed in proverbs or idioms that promote the dignity of persons, and by extension, persons with disabilities.542 An appreciation of the cultural aspects that are affirming and life-giving would aid the church in its efforts towards acceptance of the personhood of all, because of the linkages and influences between the church and society.543

Among the Ibibios of south south Nigeria, the concept of dignity can be expressed in two popular proverbs. The first is, ‘owo di owo,’ which literally means ‘a person is a person.’ Anyone in the community is described as a person, a human being, whether female or male, with or without disability. The second proverb is owo

541 Musa W. Dube, ‘Gender and the Bible in African Christianity’, Anthology of African Christianity, accessed 12 November 2020, https://www.academia.edu/36127048/. This signals the Ubuntu concept has been discussed in Chapter Two.
542 While the role of indigenous beliefs was not discussed in this thesis, it is worth considering how the concepts of personhood and gender justice can be addressed from positive African concepts.
543 Oduyoye, Daughters of Anowa, 15.
edi inyene, meaning a person is wealth. It means that one who has human relations is indeed a rich person, and that person, does not necessarily need anything else. On one hand, it speaks to the dignity of humanity. On the other hand, it promotes the interdependence of one to another, or put differently, the indispensability of one without another.\textsuperscript{544} A person is a person, whether female or male, with or without disability.

Personhood is acknowledging the dignity of each individual and appreciating that individual as valuable within and to the community. Judging from the narratives of how they were treated, the women in this research opined that the focus on the visible disability instead of their innate quality of being human beings first and therefore persons, is what causes discrimination and exclusion in the church and society. As discussed in Chapter Two, often this focus on disability instead of the person could be due to misconceptions about disability or disease. While there were no overt attempts by the women to challenge these misconceptions, this urgency for the acknowledgement of personhood is both an affirmation and a call. It is an affirmation of their self-acceptance as human beings and a call for the church and society to do likewise. There was a deliberate emphasis by the women, on the church’s duty to recognise and treat women with disabilities and HIV with dignity and respect. They regarded this call to the church as foundational to positive attitudinal change and hence shared many stories around this theme.

Oduyoye makes a similar call to the church, to utilise ‘women’s creative energies,’ to ‘empower women to be fully present in decisions and operations …and to make the church home.’\textsuperscript{545} These views resonate with those of women in my study. For while they did not find the church any different, as enumerated earlier, they wanted to remain members of their respective churches. They were not looking for nor did they express a desire to change church or denomination.

The reason for this state of ambivalence was because they had unconsciously created a church-like environment in BOLD, that filled the gaps occasioned by the

\textsuperscript{544} Teresia M. Hinga, \textit{African, Christian, Feminist: The Enduring Search for What Matters} (Maryknoll, NY: Orbis Books, 2017), 23. The concept of \textit{Ubuntu} is already discussed in Chapter Two. Hinga here differentiates \textit{Ubuntu} from the often-perceived individualistic tendencies of the West that does not acknowledge the interdependency of persons.

\textsuperscript{545} Oduyoye, \textit{Daughters of Anowa}, 177-81.
lack of inclusion in traditional church settings. BOLD provided a space for fellowship, friendship, a sense of belonging that they called family, where their church-like life was satisfactorily displayed. Whilst they categorically said that BOLD is not a church, I could see many ‘churchly’ elements that raises the question about what a church is. Oduyoye says that a church is an organisation that should offer an empowering home for all, including women. This definition fits BOLD very well. I argue that women in my research found in BOLD what they lacked in the church, such as inclusivity, acceptance and belonging. It raises another question as to the extent to which BOLD models something churchly or perhaps, represents some form of church for its members.

Nevertheless, the above argument about BOLD as church did not come up on the field. My impression is that the women view BOLD as a social organisation that met their spiritual needs for fellowship and a place for communal exercise of their religious rituals, without the categorisation of it as a church in the institutional sense. The general feeling was that faith leaders need appropriate theological and sociological training on issues of gender, disability, or HIV for adequate engagement with those issues. They envisaged that such a training could facilitate a typology of what a church that fully incorporates the concerns of gender, disability and HIV would look like. They wanted active membership opportunities for involvement and participation in the life and worship of the church. They alluded to active membership as being enabled to create affirming spaces as what they experience in BOLD, and to form friendships with those with and without disabilities. The church would also have an intentional disability and HIV-sensitive liturgy where sermons and Bible Studies about disability or disease are not stigmatising but affirming. Such a church would have visible efforts towards making it accessible to concerns of disability such as ramps, sign

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546 Oduyoye, Daughters of Anowa, 177-81.
547 A. S. van Klinken, “The Body of Christ Has AIDS.” A Study on the Notion of the Body of Christ in African Theologies Responding to HIV and AIDS, Missionalia. Journal of the Southern African Missiological Society 36, no. 2/3 (2009): 319-. In this article, Klinken discusses the metaphor of the church as the body of Christ in the context of HIV and AIDS as well as the church’s missional response to this disease. Particularly important at this point, is Klinken’s offer of Agbonkhianmegbe Oroborator’s argument that the ‘church of Christ is to be found where we encounter Christ ... in the faces of people living with HIV and AIDS...— in the least of Christ’s brethren.’ The extent to which the church as an institution sees itself as infected with HIV because some of her members are infected is still debatable and needs further work by African Ecclesiologist.

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interpretations, guides for the blind, as well as projectors and large print materials. Especially for churches with HIV programmes and/or clinics, appropriate accessible HIV-related information and support would be available for its members. In Nigeria, only a few churches that are involved in health care provision have departments specifically catering for HIV and AIDS intervention. Only a handful of churches have ramps, sign language interpreters, and projector boards for persons with disabilities, but these are mostly found in the city churches.

My research confirms that, certainly, there is insufficient training of church leaders in the areas of gender, disability and long-term disease, as such, this affects their competence in engaging with these issues. The assumption that faith leaders may know what to do and are willing to do it or are able to interpret life-giving theologies could mean the continuance of ignorant pulpits and inadequate care. It therefore calls for the training and education of Christian leaders as an ongoing endeavour to include both the lay and the ordained, female and male, as well as the young and the old, with and without disability. During the fieldwork, many pastors reinforced their lack of training by mentioning that courses on gender, disability, or HIV were not part of their theological education. One pastor denied that members of his church could be living with HIV. Others felt the proper response to disability and diseases was by prayers for them to be taken away. These, I argue could all be due to the inadequacy of practical theological education for church leaders.

In the last two decades, the World Council of Churches has responded to this gap by publishing books and manuals on theological education, advocating curriculum reform and the introduction of courses on disability and HIV. During my fieldwork, I noticed that some of these books seem to end up in the office shelves of theological schools and never in the classrooms. Other times, these books do not get to the pastors in the churches who need them for practical application. Perhaps, there needs to be some way of investigating how theological books published in Africa are distributed and utilised by the relevant bodies. Online versions are not easily accessible due to internet connectivity issues in Nigeria. Churches and their leaders

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require good and accessible theological bases to embed positive changes into their faith practice. With this in mind, I now suggest how the theologians with whom I have engaged productively in this thesis may include the marginality of those living with disability and HIV in their reflections.

7.3 Engaging with Theologians
This thesis benefited from the works of some African theologians, especially the writings of African women theologians. Prioritising their work has ensured my research is informed by an attention to context and faith-based response to contextual problems. My thesis challenges theologians who attempt to understand African women without adequately considering the voices of women who live with disability and HIV, and without intentionally including this group of women in its gender advocacy strategies. The implication is that gendered intervention strategies fail to address the issues related to these disability and HIV. As discussed in Chapter Two, women in this research spoke about the systems that deny their dignity, such as gender inequality often driven by patriarchy. These women showed creative and pragmatic ways to problem solving and to addressing conflict in their lives. They demonstrate that conflict is not always resolved by conflict; that dialogue or roundtable discussions are not always possible but that subtle approaches to rejection of oppression could sometimes prove effective.

Patriarchy drives gender inequality and indirectly conditions women’s behaviour as agents of oppression. The bigger issue for my research participants was the oppression of women by women. Women with disabilities in my research felt silenced by men, and by women without disabilities. In Chapter Two, I noted the many efforts by the Circle of African Women Theologians to speak against patriarchy, describing it as a major factor in HIV transmission and violence against women which could result in disability. From the stories of my research participants, without excusing patriarchy however, the most painful experiences of inequality are not at the hands of men, but that meted on them by women without disabilities. Hence, this thesis calls on the Circle to primarily revisit positive femininities in which women are champions of women, and thereafter, work together (women with and without disabilities) to promote gender justice. The question before the Circle is how it should
conceptualise theological strategies with which women with disabilities and HIV are adequately incorporated in its gender justice advocacies.

This thesis also proposes some considerations to the Circle for the collaboration of men and women for justice on the issues of gender, disability, and HIV, acknowledging that such a collaboration is important for both parties. One possible consideration is exploring the complex realities of how HIV and disability affect men and women, as well as the extent to which women’s infection affect men negatively. This consideration is drawn from the fact that often, the emphasis or negative impact is concentrated on women and less on men. The effects of HIV and disability on men and women alike aligns with the argument that ‘patriarchy hurts all because it falls to mobilise all available resources for the building of the whole.’ My particular emphasis is that it hurts all because a larger number of the whole are hurt. As theologians engage in discussions and consultations on gender and HIV from a Christian perspective, this needs to be done more objectively to engender a more congenial response towards the pitfalls of patriarchy. African male and female theologians must seek ways of working together for the good of all, drawing here also, on the African ethics of community and communal well-being. This would address the concerns of the women in this research where a common pattern of power dynamics tended to silence the women, and where women negotiated safe spaces without any active engagement with men. In Chapter One, I discussed how BOLD was formed after the women disassociated themselves from men with disabilities because the women felt misunderstood and oppressed. It is worth exploring what a conversation about creating a mutually beneficial and empowering Christian space would have been like for BOLD.

Another possible consideration that could be used to promote gender justice is an alternative understanding of the concept that all are created in God’s image or the *imago Dei*. In the context of HIV and AIDS, Isabel Apawo Phiri notes that the Genesis


creation story shows ‘… God’s image is found in both men and women … there is an interdependence and goodness of creation.’ This is a reimaging of Genesis creation story that is more popularly interpreted in defence of equality, and which tends to ignore the aspect of goodness. This emphasis, not just on equality, but on goodness resonates with my research participants. They quoted the verse, ‘God saw everything that he had made, and indeed, it was very good.’ (Genesis 1:31), and supported their interpretation from Psalms 139:14, ‘I am fearfully and wonderfully made.’ With these verses, they affirmed that even with their disabilities, they were wonderfully made, because whatever God made was good and should be so appreciated. This argument of the mutuality of goodness in all of God’s creation could prove a rather helpful reflection for the conversation between men and women and one that needs further exploring by African theologians.

It is worthy of mention that the concept of imago Dei has attracted differing interpretations to address stigma associated with disability and HIV. Like Phiri mentioned above, Jane S. Deland, and Chisale support the emphasis of goodness in creation. For Phiri, Deland and Chisale, imago Dei is not just about equality, it is more about the fact that everything God made was adjudged good and therefore nothing should be considered otherwise. Whilst this debate was not a concern for the women in my research, it is becoming an emerging issue in Africa’s discourse on disability and HIV. Theologians, particularly those writing on Christianity in Africa, need to address the tension around the language of imago Dei, how it might be used to challenge stigma, and whether it is limited or problematic where disability is perceived as part of God’s design or the result of sin. Further work in this area must include theological reflection on the relationship between inclusion and the Christian doctrine of the imago Dei.

553 Deland, ‘Images of God Through the Lens of Disability’.
Another aspect that needs further consideration by theologians is the concept of the ‘disabled God’ promoted by Nancy Eiesland. Eiesland has attracted a lot of attention with her primary work of the ‘disabled God’, but this research has concerns about her analysis of God as disabled, especially as observed from my research participants. It is doubtful that the women I interviewed, who view God as the epitome of perfection in all respects, would want a Christ or a God who is disabled. It is doubtful that women who pray for healing from disability and HIV would refer to God as one with the disability from which they seek to be free of. Christ for the participants is the one in whose greatness is healing and power. It is this belief that gives them hope for the miraculous and the capacity to live better lives. This thesis calls attention for an African theological engagement with Eiesland’s position from the perspective of healing as understood by my research participants.

Another suggestion that theologians should consider promoting about inclusion is the fact that the Christian salvation is offered to all without regard to gender, disability, disease, or class. From my observation, it does appear that many faith leaders pay lip service to the equality of all in accessing God’s grace without reflecting on what it means in practice. They often give the impression that those with disabilities or disenabling diseases need other ways of accessing salvation, and by extension inclusion in the church because of their sinfulness or lack of faith. This is not far removed from the stereotype that disability and diseases including HIV could be the result of sin committed by the person involved or by his/her family. David J. Bosch speaks about salvation as including ‘the total transformation of human life, forgiveness of sin, healing from infirmities, and release from any kind of bondage.’ He continues that everyone needs salvation, because ‘each persons has his or her specific sinfulness or enslavement,’ from which there is forgiveness in Jesus Christ. This thesis therefore, raises the following questions for theologians: How can African theologians address the rhetoric that disability and HIV are the result of sin from this understanding that salvation is the same for all Christians? What would a theological

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discourse that addresses gender equality for the empowerment of women, and the collaboration between women and men look like? Put more directly, how can the Circle engage with these questions in ways that address their concerns for gender justice for all? I further ask that theologians, male and female, reflect on what faith means for those marginalised and stigmatised because of their gender, disability, and HIV status, seeking ways of inclusion for all. Qualitative research could identify how far Nigerians equate sinfulness with disability.

My thesis has demonstrated that those involved in theological training of church leaders should consider the inclusion of women with disabilities and HIV in the life of the church and society as part of its Christian mission and practice. To do this, they should learn from the lived experiences of women with disabilities and HIV as a practical reference. Circle theologians have already highlighted the importance of curriculum change to incorporate studies on disability, HIV, and gender. Dube’s edited volume on *HIV/AIDS and the curriculum: methods of integrating HIV/AIDS in theological programmes*, provides a useful resource for theological schools in Nigeria. It offers practical ways of teaching HIV and AIDS in Christian schools with gender lens. Often there is a sense of complacency in teaching about HIV because it is assumed that many people know the basics. My experience in the field is contrary to that because many faith leaders claim ignorance even of the basics on HIV and/or disability, and therefore needs to be taught from the seminaries and theological schools.

These trainings are not limited to those for ministerial training, it is also necessary for the lay people who are presently taking on major roles in the church. The 2016 book by the Ecumenical Disability Advocates Network of the World Council of Churches maintains that to make disability concerns sustainable in the church, theological education must form the means of discourse. Although the book does not indicate how the essays could be adopted for curriculum purposes, it provides a broad spectrum on the basic understandings of approaches and concepts of theological engagement with disability. My thesis provides good compliment with stories of women with disabilities and HIV. I now turn to organisations which have often been at the forefront of medical and humanitarian interventions yet fail to understand BOLD

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558 Kabue, Ishola-Esan, and Ayegboyin, *Perspectives on Disability*. 
women and others like them, because they do not sufficiently understand the central role of faith.

### 7.4 Medical and Humanitarian Organisations

Medical and humanitarian organisations operating in Nigeria often fail to fully integrate faith into their planning. They are often influenced by international organisations which ignore the role of faith or consider it to be an added extra. They consider that a secular approach to medicine, aid and development is the best way forward. This is to disregard the place which faith has in the lives of many people they intend to help. Many of the women that I interviewed were categorical in their views concerning healing. Healing, for them, comprised of physical, emotional, spiritual, psychological, and mental well-being, and could be received when one prayed to Jesus Christ. When they received healing, with or without medical intervention, it was perceived as healing from God. The women claimed that everything, every resource, every means to healing were gifts from God, and received as part of one’s relationship with Jesus Christ. The findings of this thesis question an undermining of the place of faith to emphasise the importance of medical treatment. The thesis challenges institutions concerned with health and healing, whether secular or religious, who often fail to fully recognise and act upon the centrality of faith in people’s lives.

BOLD women argued that there is cure for every kind of disease or condition. According to them, to say that there is no cure for HIV or disability, is to doubt God or to put limits on what God can or cannot do. For them, the decision to heal or not to heal ultimately belongs to God because God is all powerful. Human beings do not have any insight or pre-knowledge of when or how God would heal. The responsibility for Christians is therefore to trust God that eventually but hopefully that healing would come, in the manner (progression) or extent (physical) that God so desires. They concluded therefore, that, with God, there is nothing without cure in this world. For these women, belief in the miraculous, was part of their faith existence and reality. It is what gave them hope that tomorrow could be better, and therefore, hope to live well in the present. These women listed the following as belonging to the miraculous: the availability of antiretroviral treatment which allowed HIV infected persons to live longer and better lives; transformed identities in Jesus Christ from persons who
considered themselves as ‘nobodies’ to self-assured persons; as well as the ability to have families, jobs, and friends. This thesis argues that people of faith with this mindset are more likely to accept medical interventions framed within the acknowledgement that all things are gifts from God, and nothing is impossible with God. To dismiss this aspect of their spirituality would be to belittle the prayers they make or belittle the significance of faith in the response to life’s challenges whether medical, sociological, or economic.\textsuperscript{559} Most African Christians live in the expectation that God would answer their prayers and that things would be better. The implication of this for responders is to recognise and acknowledge different perspectives of healing for many religious people.

The women in my research promote continuance with medical treatment and prayers to God for healing of the removal of the virus and/or disability. The experiences of women like these, who believe in miraculous healing as encompassing of natural (medicine) and supernatural (faith), would make more impact on people who struggle with conflicting teachings on health and faith. This thesis proposes a study that provides detailed narratives of Christian women who believe in faith healing, and who navigate the terrain of what holistic healing means for those with disability and HIV. Perhaps such a study would address the assumed polemics and issues that surround the concept of faith healing in the face of struggles with adherence to treatment for any disease, especially HIV and AIDS. Such issues include the various understandings and descriptions of healing and faith healing.

To provide clarity, healing for my research participants, extends to the transformation of their identities, the improvement of their physical conditions, and should allow for some degree of inclusion within social and religious spaces. As explained in Chapter Six, when women in my study pray for healing, the prayers cover every aspect of their lives. To them, all aspects of healing are gifts from God, and all are received as part of their faith experience. Whilst many people adopt this comprehensive view of healing, it appears to be the tendency for some to speak of healing as pertaining essentially to physical healing. This view of healing therefore perceives that healing has not taken place unless there is some physical change. An

\textsuperscript{559} Bernard Boyo et al., ‘African Christianity and the Intersection of Faith, Traditional, and Biomedical Healing’, \textit{International Bulletin of Mission Research} 45, no. 2 (1 April 2021): 133–44.
example of this position is with Marcellin Setondji Dossou’s descriptions of healing. According to Dossou, ‘to be complete, health must be a state of an individual’s dynamic well-being … altogether physical, social, and spiritual; living in harmony with God.’\textsuperscript{560} This description gives a comprehensive view of healing as encompassing all aspects of a person’s life, including the relational aspects of harmony. However, Dossou, in the same chapter states as follows about healing for HIV infection,

when speaking about healing, we mean a durable and complete annihilation or disappearance of the virus and of all its symptoms, and the physical, psychological, and even spiritual restoration of the person affected by the virus.\textsuperscript{561}

Dossou’s statement seems to indicate that healing has not taken place until there is a complete removal of the virus from the body of the infected person. This widely held understanding of healing is different to that of BOLD. It undermines the holistic nature of healing that my research participants claim, even though they still live with disabilities and HIV. The audacity of my research participants to claim healing as intricate to their faith experience, with possibilities of healing having visible or invisible change, with its relational aspects should serve as guide in articulating a faith-based description of healing.

Another concept that makes the idea of healing problematic for many Christians is the description for faith healing. In 2019, the World Council of Churches, Ecumenical HIV and AIDS Initiatives and Advocacy (WCC-EHAIA) published a manual for religious leaders on \textit{Treatment Adherence and Faith Healing in the Context of HIV and AIDS in Africa}. In the manual, it describes faith healing as

the ability of faith to help restore balance to human beings by addressing psychological, biological, social, economic and spiritual issues that bring about the lack of such balance. Faith healing is holistic and compliments treatments prescribed by medical and psychiatric professionals.\textsuperscript{562}


\textsuperscript{561} Dossou, ‘Healing and HIV: A Theological Proposal’, 175.

This understanding of faith healing could be seen as appropriate because it considers the multi-layered conditions that HIV brings upon those infected. It also considers the complimentary role of medical intervention as part of holistic healing measures. What WCC-EHAIA frowns at, is the belief and claims to ‘faith curing’ by many pastors. The manual describes faith curing as the

Exclusive claims to the ability of faith to eliminate the physical, biological, and mental sickness and sickness-causing agents from the body of a person who is sick. Faith curing presents itself as an alternative to psychiatric and medical responses to sickness.\footnote{Gunda et al, \textit{Treatment Adherence and Faith Healing}, 29.}

This differentiation between faith healing and faith curing in the WCC manual emerged from a particular context in which some religious leaders, by claiming healing by faith only or that miraculous healing is acceptable, have discouraged HIV patients from taking their medication. The result of this action is often fatal for persons living with HIV. Consequently, WCC, through this Manual, seeks to ‘develop life-giving theologies that promote adherence in the context of HIV and AIDS’ because ‘ART is God’s miraculous provision.’\footnote{Gunda et al, \textit{Treatment Adherence and Faith Healing}, 3, 35.}

As one who has been involved in HIV intervention, working with religious leaders and persons infected/affected with HIV, promotion of treatment adherence has been crucial to our work. Like my research participants, many people of faith have struggled to hold the balance of faith and medical intervention, without losing sight of the power of faith in all the processes. For example, a faith-based organisation, which states that ‘there is currently no known cure for HIV,’ could say, there is currently no known \textit{scientific} cure for HIV.\footnote{Gunda et al, \textit{Treatment Adherence and Faith Healing}, 35.} The idea in the manual that faith healing should focus on ‘helping people living with HIV to access all the services they need in order to lead normal lives’ could be misleading and most probably, unacceptable to the women in my research.\footnote{Gunda et al, \textit{Treatment Adherence and Faith Healing}, 47.} This advice is not faulty on its own, although being so categorical denies it of having any nuanced application. However, it might be seen as depriving women of hope especially where hope for a better future is what strengthens many
African people to live well today. Perhaps, the language of speaking about cure needs to be revisited, because, for most African Christians, healing as recovery from illness is reality that they pray for.

The assumed dichotomy between faith healing and faith curing could also leave many Christians who pray for healing to be confused, as to what to pray for and what not to pray for. As one of my research participants said, ‘if we trust God to heal headache, why can’t we trust him to heal HIV or cancer or anything at all?’ A study in Botswana on faith healers and Christian mission showed that faith leaders believe in faith healing, that ‘God can heal all diseases…’ but that there are diseases such as HIV and AIDS that ‘God has decided not to heal.’ For these faith healers therefore, what is needed is a collaboration with medical doctors for ‘illnesses such as HIV/AIDS, cancer, diabetes, high blood pressure.’ The faith leaders in this Botswana study appear to put limitations on what God can and cannot do.

Stories from many of my research participants demonstrate their belief that all forms of healings operate from the realm of the miraculous. They speak of this experience as a journey, in which they speak of being healed when still living with the physical evidence of disability or the invisible challenge of HIV. Musa Dube would describe this as ‘healing here and now, healing where there is no healing.’ This further calls for a recognition that the miraculous is acceptable for those who chose to so believe. It is not a matter of countering medicine as nonsense but to confess in all circumstances that God is in command. This notion is basic to most of African Christians’ belief in God. It is part of the prayer language, in the Bible studies, and in the songs of the spirituality of the average Nigerian African Christian. I gathered from my research participants, that taking away any kind of healing from God’s ability, is a

567 Isabel Apawo Phiri, ‘HIV/AIDS: An African Theological Response in Mission’, The Ecumenical Review 56, no. 4 (2004): 422–31. Phiri agrees that for many African Christians, ‘hope in Jesus the healer is what gives them motivation to face another day, even up to the deathbed.’ She further acknowledges that ‘Jesus is the healer, even though the medical world has not yet found a cure for HIV/AIDS.’ This is the language that my research participants want to be used, to place the limitation on the medical world and not on Jesus, consciously or unconsciously.


569 Togarasei et al., ’Christian Medical Mission’.

contradiction to their faith. Like one research participant said, ‘there is nothing God cannot do. God who healed my bones from stroke can heal me from HIV.’ This unapologetic position of my research participants needs to be respected in response strategies by all parties, medical and faith-based, involved in health and healing interventions.

In Chapter Two, I highlighted the United Nation’s acknowledgement of the role of faith in HIV and disability response. Like other international organisations that organise global humanitarian work, the UN recognises the importance of faith and the work of religious organisations in health and development work. This thesis argues that a mere acknowledgement is inadequate. The UN requires a faith-based approach in its strategies and policies. All the United Nations conventions are based on its Universal Declaration of Human Rights (UDHR). The preamble to the UDHR reaffirms ‘their faith in fundamental human rights, in the dignity and worth of the human persons and in the equal rights of men and women.’ Furthermore, the Convention for the Rights of Persons with Disability (CRPD) advocates the promotion, protection and assurance of human rights and respect for all persons with disabilities. The Sustainable Development Goals restates the UN’s commitment to leave no one behind in all sectors of national and international response. It recognises that it is in the treatment of all persons as equal, and in the inclusion of all, that the world would be better. Under the Joint United Nations Programmes on HIV and AIDS, (UNAIDS), the UN recognises that women and girls with disabilities, who are more vulnerable to HIV infection should be included in all intervention strategies. These arguments demonstrate that UN’s fundamental human rights are consistent with Christian faith rights. Both are based on the ethos of equality and equity, that all are equal and so should be considered. The UN however falls short in its commitment to faith-based approaches because of its caution about religious faith or its misunderstanding of the crucial role of faith for religious people.

573 For more information on the Sustainable Development Goals, see, https://www.un.org/sustainabledevelopment/. There are 17 goals proposed and implemented by the UN to seek to transform the world. Goals 4, 8, 10, 11 and 17 have provisions for health and disability inclusion while Goal 5 is specific to gender equality.
Members of BOLD told me stories that demonstrate the centrality of their relationship with Jesus Christ and their Christian churches to their ability to live positively with disability and HIV. It is the centrality of faith to lives of people that the UN and other international organisations overlook. The women I interviewed expressed their Christian faith as vital for their empowerment and positive sense of self. Their faith allows them to address the problems of disability and HIV and seek ways of overcoming them. Although medical treatments and counselling services are available in Nigeria and appreciated by BOLD women, they attested to the primacy of their faith in overcoming stigma and exclusion. This view has been expressed by others like Micheline Kamba, discussed in Chapter Four. Kamba, a theologian who lived with disability said, ‘I am God’s creation and am loved by him (God). God cannot forget me. Understanding this was my liberation.’ Kamba’s realisation changed her from wanting to commit suicide because of stigma, to accepting herself as unique and valuable.

BOLD women found creative ways of being part of the church’s life, sometimes for cultural reasons, but other times, to appreciate the ambience of Christian worship. They use faith resources, Scripture, songs, prayers, storytelling or testimonies – to handle complex situations. These resources were integral to women’s lives. Their faith, expressed personally or communally, is not secondary. It is fundamental to everything else and provided the impetus for the women to cope with challenging circumstances and relationships. Their faith is not like a bus that one hops in and out of without much obligation. It is a life-long journey, the basis upon which every other thing rest, as discussed in Chapters Four and Five. Their relationship in the families, church and society are enabled and sustained because of their Christian faith, even while they stressed that most days still presented peculiar challenges. The centrality of faith for many people around the globe should propel the integration of faith-based concerns in the formulation and implementation of response strategies to gender, disability and/or HIV in Africa. This thesis challenges the tendency of

575 Kamba, ‘Interview: I Am Not Sick’.
international medical, humanitarian and development organisations to downplay the central role of faith for many people in Africa.

**7.5 Conclusion to the Thesis**

This thesis has endeavoured to discuss the ways in which my research participants understand and live their Christian faith and how this understanding plays a role in their dealings with the challenges of gender, disability, and HIV. It has concentrated mostly on their practice of faith as individuals and within the support groups such as BOLD. This thesis demonstrates that Christian faith is fundamental for how women in Nigeria cope with the stigma and challenges associated with gender, disability, and HIV, even when they feel excluded from mainstream Christian institutions. It gives them a new identity, a hopeful future and makes them able to claim all things as possible, even for things that are scientifically said to be impossible. Through the belief and practice of faith, women addressed sociological, economic, cultural, and religious concerns that hitherto mitigated against the expressions of their personhood. The thesis proposes the telling of women’s stories that take seriously their faith experiences with gender, disability, and HIV.

The connection between gender, disability, and HIV is an emerging discourse in the study of World Christianity. This thesis offers a contribution to that debate and enables the voices of Christian women living with disabilities and HIV in Nigeria to be heard. It challenges churches and faith-based organisations to own the complexity of the many dimensions of healing as belonging to the supernatural. My findings suggest that churches need continuing education to be inclusive, to eliminate patriarchy and to develop forms of worship that are gender, disability and HIV sensitive. The tenets of faith with regards to equality are consistent with fundamental human rights. It accepts that gender inequality drives much of the issues that promote infections, abuse, poverty, and marginalisation for women, especially women with disabilities and HIV. This thesis recognises the inter-connection of faith and women’s human rights and argue for its inclusion in policy and implementation documents of international development agencies.

This thesis emboldens the voices of women who hold that faith is the essence of life as they live with disabilities and HIV and the enabler for them to cope with daily
challenges, whether social, medical, cultural, religious, or economical. It challenges the biomedical view that faith is marginal or a ‘nice extra.’ Women in this study bring the unique gifts of their personal stories covering gender, disability, and HIV from Africa to enrich the interdisciplinary studies of World Christianity.
Bibliography

**Primary Sources**

The table below represents details of core research participants observed and interviewed for this thesis.

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<td>28</td>
<td>Widow</td>
<td>Trader</td>
<td>Physical</td>
<td>18-20/11/19; 8/12/19</td>
</tr>
<tr>
<td>9.</td>
<td>Enny</td>
<td>56</td>
<td>Widow</td>
<td>Trader</td>
<td>Sight impairment</td>
<td>21-23/11/19; 7/12/19</td>
</tr>
<tr>
<td>10.</td>
<td>Eno</td>
<td>35</td>
<td>Single</td>
<td>Fashion Designer</td>
<td>Deaf</td>
<td>25/11/19; 1-2/12/19</td>
</tr>
<tr>
<td>11.</td>
<td>Eve</td>
<td>40</td>
<td>Single</td>
<td>NGO</td>
<td>Physical</td>
<td>27-28/10/19; 6/12/19</td>
</tr>
<tr>
<td>12.</td>
<td>Kaka</td>
<td>42</td>
<td>Divorced</td>
<td>Unemployed</td>
<td>Stroked-induced paralysis</td>
<td>9-11/9/19</td>
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Secondary Sources


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Appendixes

Appendix 1

School of Divinity, University of Edinburgh

Consent Form

for participation and personal data to be used for research

Thank you for agreeing to participate in the research project, the details of which are:

<table>
<thead>
<tr>
<th>Research Project name:</th>
<th>The Role of Christian Faith for Women with Disabilities and HIV in South-South Nigeria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of researcher:</td>
<td>Jessie Fubara-Manuel</td>
</tr>
<tr>
<td>Researcher’s Contact details:</td>
<td>School of Divinity, New College, University of Edinburgh, UK.</td>
</tr>
<tr>
<td>Scope of the project:</td>
<td>This research investigates the influence of Christian faith for women who are living with disabilities and HIV in Nigeria, examining how faith is a tool as they cope with the challenges of their status. The research is for a PhD degree in World Christianity. The following are possible data sources:</td>
</tr>
<tr>
<td></td>
<td>Participant-Observation: Notes from observing involvement at BOLD activities</td>
</tr>
<tr>
<td></td>
<td>Interview: Answers to loosely-structured interview questions and comments.</td>
</tr>
<tr>
<td></td>
<td>Stories: Details of personal stories relating to dealing with issues of gender, disability and HIV.</td>
</tr>
<tr>
<td></td>
<td>Visual: Photos and music of involvement in BOLD activities and faith-based spaces.</td>
</tr>
<tr>
<td></td>
<td>Focus Group Discussion: Notes from FGD among BOLD members</td>
</tr>
</tbody>
</table>
| Confidentiality and Anonymity                                      | All transcripts will be anonymised. Confidentiality of data will be limited to spaces and persons involved:  
- Personal interviews and stories confidential between researcher and informants.  
- Observations and FGD discussions confidential to persons participating. |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Handling of Data</td>
<td>All data will be accessible to researcher and Supervisors. Data will be used for purpose of research and destroyed on submission and approval of dissertation. Published research findings during and after dissertation will be anonymised.</td>
</tr>
</tbody>
</table>

**Please complete the following:**

I consent to participating in this research project and understand that I may withdraw at any time.  
YES  ❑  NO  ❑  

I consent to my personal data, as outlined below, being held for use in the research project detailed above YES  ❑  NO  ❑  

*Researcher to specify personal data to be used for research*

Name:  
Signature:  
Date:
Appendix 2

Emma Wild-Wood, BD, MTh, PhD, FRHS, SFHEA, Senior Lecturer, African Christianity and African Indigenous Religions, School of Divinity.

New College, University of Edinburgh, Mound Place, Edinburgh, EH1 2LX

16th July 2019

Research by Mrs Jessie Fubara-Manuel

To whom it may concern,

Mrs Jessie Fubara-Manuel is a PhD student at the University of Edinburgh examining the role of Christian Faith for Women with Disabilities and HIV in South-South Nigeria. She has carried out appropriate training for her ethnographic research and has fulfilled the ethical requirements of the university. I cordially request that Mrs Fubara-Manuel be permitted to carry out her research without impediment.

Any questions or concerns about the research programme may be directed to me as her primary supervisor at the address above.

With thanks for your co-operation.

Yours faithfully,

Emma Wild-Wood
Appendix 3

Guiding Interview Questions

What do you understand by the Christian faith? (Faith understanding and experience)
   a. What does it mean for you personally? (Personal Salvation)
   b. What is your personal experience of the Christian Faith? (Faith journey).

2. What things within your Christian faith expression help you cope with the challenges of living with disability and HIV? (Role of faith)
   a. What are your specific faith-coping mechanisms? (faith as enabler)
      i. Scripture? To what extent?
      ii. Songs and Poems? To what extent?
   b. Are there other things that assist you cope with Disability and HIV?
   c. Which is the greater burden: Disability or HIV?

3. Within your denomination, what are the programmes/rituals/activities that are available? (Inclusion)
   a. To what extent are you involved, or do you participate in these events?
   b. What factors determine your involvement and/or participation?

4. To what extent is your denomination aware/conscious of disability and/or HIV? (Denominational awareness)

5. Do you feel supported by BOLD? friends? Family? To what extent?

6. What is the understanding of Christian faith for women with disabilities and HIV, and how is their identity shaped by this understanding of faith?

7. How do women with disabilities and HIV cope with the socio-cultural and religious challenges of living with the stigma of gender, disability, and HIV?

8. What are the support systems available for women with disabilities and HIV in church and society?

9. To what extent do resources of faith impact or shape the lives of women with disabilities and HIV, and how are these resources used?