



**The role of community leaders in the effective
implementation of oral pre-exposure prophylaxis in
Vulindlela, KwaZulu-Natal**

Noluthando Fadane 218083873

Supervisor: Prof Eliza Govender

Dissertation presented in fulfilment of the Degree of Master of Science,
In the Centre for Communication, Media and Society,
School of Applied Human Sciences,
College of Humanities,
University of KwaZulu Natal, Howard College, Durban, South Africa

Ethical Approval Number BE500/17

December 2019

Dedication

To my late mother, Soscelina “Sos” Nobantu Fadane, a UKZN Alumnus.

Sukude!!! Your love and memories have pulled me through.

May this dissertation be an inspiration to all those close to me and that they may know with God all things are possible.

Acknowledgements

To God be the Glory! You keep on doing great things for me. I would not have made it without you. Thanks be to you for all the people you put on my path on this journey.

Prof Eliza Govender, my supportive and very understanding supervisor. You went all out to be a supervisor and more. Thank you very much. To Sima and Sis Gethwana, in you I have found not just colleagues but sisters. We worked well as a team. Sima, you went an extra mile and coached me in the final write up stages.

To family and friends, I cannot thank you enough. Your love, prayers and words of encouragement have carried me through. Lindhy and Pearl, thanks for everything but most importantly, opening your homes for me.

Siabu, my brother, I do not have words to describe my gratitude. Thanks Jolinkomo!!!

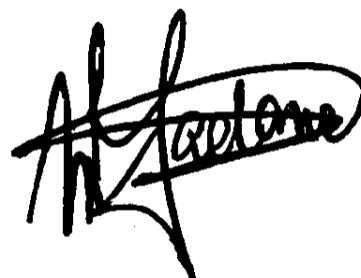
DECLARATION

I know that plagiarism is wrong and that the University of KwaZulu-Natal considers plagiarism a form of Academic Misconduct (Rule 9.28 of the Rules for Students Handbook).

I understand what plagiarism is and I am aware of the University of KwaZulu-Natal's Plagiarism Policy and Procedures (Ref: CO/05/0412/09). I have used a recognised convention for referencing in this work (Harvard) as stipulated by the Discipline. I declare that this submission is my own original work. Where another person's work has been used (either from a printed source, Internet or any other source), this has been specifically acknowledged and referenced.

I have checked this work to ensure that there are no instances of plagiarism contained within.

I understand that disciplinary action may be taken against me if there is a belief that I used someone else's work without their permission and/or did not acknowledge the original source in my work.



Ms. NPN Fadane (Candidate)

Signature:

Date:17 December 2019



Prof E.M Govender (Supervisor)

Signature:

Date:17 December 2019.....

Abstract

Oral pre-exposure prophylaxis (PrEP) is a great stride in the HIV prevention field, particularly for the vulnerable populations including adolescent girls and young women (AGYW) aged 15-24 years who are the hardest hit group with high HIV infection rates due to structural and cultural factors. This study sought to investigate the role that community leaders, as key opinion leaders and gatekeepers, play in the effective implementation of oral PrEP. The SEMCHB was used as the theoretical framework that underpinned the study, further exploring Health Belief Model at individual level of the SEMCHB and CCA at community level of the framework. Purposive sampling was used to select the study participants. A total of 10 participants, 6 councillors and 4 traditional leaders in Vulindlela were sampled and interviewed through the use of in-depth interviews. The data collected through the interviews was analysed thematically, identifying key themes that emerged from the research. The main findings were around the knowledge of oral PrEP in the community, the perceived benefits and barriers of oral PrEP, and the extent to which community leaders were willing to support and promote the implementation of oral PrEP for young women in the community. These findings support the need to empower community leaders with knowledge about oral PrEP so they can play an effective role in the implementation of oral PrEP.

Key words: AGYW, HIV, Oral PrEP, community leaders, Vulindlela

LIST OF ACRONYMS

ABC	Abstain, Be faithful and Condomise
AGYW	Adolescent Girls and Young Women
AIDS	Acquired Immuno Deficiency Syndrome
ARV	Anti Retro Viral
ART	Antiretroviral Therapy
CAPRISA	Centre for the AIDS Programme of Research in South Africa
CCA	Culture Cantered Approach
CPA	Child Physical Abuse
CSA	Childhood Sexual Abuse
CSO	Civil Society Organisation
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
HTS	HIV Testing Services
KZN	KwaZulu-Natal
NGO	Non- governmental Organisation
PrEP	Pre-Exposure Prophylaxis
SEMCHB	Social Ecological Model for Communication and Health Behaviour
STI	Sexually Transmitted Infections
UNAIDS	Joint United Nations Programme on HIV and AIDS
WHO	World Health Organisation

List of figures

Figure 1: Theoretical Approach to Social and Behavioural Communication.....36

Figure 2: The culture-centred approach to health communication.....46

Appendices

Appendix I: Informed consent form.....123.

Appendix II: Interview questions.....128

Appendix III: Ethics Approval Letter.....129

Appendix IV: Turnitin Report.....130

Table of contents

Chapter 1	1
Introduction	1
Location of the study	3
Rationale of the study	3
Objectives of the study	5
Research questions	5
Theoretical framing for this study	5
Structure of the dissertation.....	7
Chapter 2: Literature review	8
Introduction	8
The history of HIV	8
The scourge of HIV in South Africa.....	10
Young women disproportionately affected by HIV	12
The global impact of HIV	14
HIV Prevention options.....	17
Challenges to effective implementation of HIV prevention interventions	21
An introduction to Oral PrEP.....	23
The practical implementation of PrEP	26
The role of community leaders in HIV prevention efforts	27
Conclusion	30
Chapter 3: Theoretical Framework.....	31
Introduction	31
The Social Ecology Model for Communication and Health Behaviour (SEMCHB)	31
The Health Belief Model (HBM)	37
<i>Key constructs of the HBM.....</i>	<i>38</i>
<i>Perceived susceptibility</i>	<i>39</i>
<i>Perceived severity.....</i>	<i>40</i>
<i>Perceived benefits</i>	<i>41</i>
<i>Perceived barriers.....</i>	<i>42</i>
<i>Cues to action</i>	<i>43</i>
<i>Self-efficacy.....</i>	<i>43</i>
The Culture Centred Approach	44
<i>Culture.....</i>	<i>46</i>
<i>Structure</i>	<i>47</i>
<i>Agency.....</i>	<i>48</i>

Conclusion	48
Chapter 4: Research Methodology	50
Introduction	50
The interpretive paradigm.....	50
Research Approach.....	52
Selecting study participants.....	55
Setting and Population Appropriateness.....	57
Data collection method.....	58
Data Analysis.....	60
Ethical considerations	61
Validity and reliability	62
Limitations of the study.....	62
Conclusion	62
Chapter 5: Research Findings and Analysis	64
Introduction	64
Setting the scene	65
Themes that emanated from the research	66
Knowledge about oral PrEP	67
<i>Lack of knowledge among community leaders about oral PrEP</i>	68
<i>Education for oral PrEP for community leaders</i>	69
<i>Awareness of risky sexual behaviour among AGYW</i>	71
Barriers to oral PrEP implementation	74
<i>Stigmatisation of HIV and oral PrEP</i>	75
<i>Long distance for accessibility</i>	77
Promoting the implementation of oral PrEP	78
<i>Resources available in the Vulindlela to support PrEP implementation</i>	79
The implementation of Oral PrEP among AGYW	81
<i>The community's interest in Oral PrEP</i>	81
<i>The unintended consequences of Oral PrEP</i>	82
The role of traditional leaders	84
Interpretation of findings	85
<i>Evident HBM constructs in the data</i>	85
<i>Evident CCA constructs in the data</i>	87
Conclusion	89
Chapter 6: Conclusions	90
Introduction	90

Summary of research findings	90
<i>Research question 1: What is the knowledge and attitude of oral PrEP among community leaders for AGYW in Vulindlela?</i>	90
<i>Research question 2: What are the perceived benefits or barriers from community leaders in Vulindlela that could hinder or promote the uptake of oral PrEP with AGYW?</i>	91
<i>Research question 3: What are the proposed cues to action for community leaders to promote the implementation of oral PrEP with AGYW in Vulindlela?</i>	91
Theoretical relevance to research findings	91
<i>HBM Constructs</i>	92
<i>Culture Centred Approach</i>	93
Conclusion	93
Bibliography	94

Chapter 1

Introduction

South Africa has made progress in reducing the number of new infections and is on “track to eliminate HIV, TB and STIs as public health threats by 2030” (SA’s National Strategic Plan, 2017-2022:3). This is the mission that South Africa has set out to achieve. Amongst the principles that guide this plan are: a people-centred approach; a multi-sectoral approach; commitment to protecting and promoting human rights etc. (SA National Strategic Plan, 2017-2022). The inclusion of social and cultural context in which the HIV epidemic evolves is very important and it allows communities to become involved in the fight of the scourge of HIV. However, HIV and AIDS will continue to rise if social and structural factors such as poverty, gender based violence, inequality, migration, inadequate access to quality education, poor nutrition are not addressed. Efforts to curb the HIV/AIDS epidemic will remain null and void, and gains achieved will not be maintained, if a multi-sectoral approach is not adopted.

Women are most vulnerable to HIV. Adolescent girls and young women (AGYW) are the hardest hit group in South Africa. They are a vulnerable group with the highest HIV incidence of any age or sex cohort, with 2.01% infected in 2015 (SA National Strategic Plan, 2017-2022). Despite all efforts made to curb HIV infections, numbers remain high amongst AGYW. More focus needs to be placed on AGYW especially in high HIV burdened areas. Social and gender norms that support and perpetuate male superiority are amongst factors that drive vulnerability of this key population group (Mabaso, 2017). Gender norms that support sexual entitlement lead to gender based violence causing females not to be able to negotiate safe sex (Mabaso, 2017).

Vulindlela, a largely rural community in the UMgungundlovu District of KwaZulu-Natal, is one of the high HIV burdened communities. The Global Fund Strategy (2017-2022) emphasizes that HIV prevention, testing, treatment and care is one of the approaches to be used in effectively responding to HIV amongst AGYW in high burden settings. This includes HIV knowledge awareness and risk perception. It has to be accompanied by awareness campaigns that are targeted at reaching AGYW and tailor made to reflect their lived experiences. Secondly, male and female condoms play a significant role in reducing HIV and other STI transmission, and unwanted/unplanned pregnancy.

They need to be used consistently and correctly. Voluntary medical male circumcision (VMMC) reduces the risk of HIV transmission by approximately 60% for women to men (Global Fund Strategy, 2017-2022). Pre-exposure prophylaxis (PrEP) is a fairly new HIV prevention method where ARVs are administered to HIV negative people to avoid HIV infections. The availability of oral PrEP is a great stride and a positive step towards bringing HIV/AIDS pandemic under control. Oral PrEP cannot be used in isolation, it complements the existing HIV prevention methods. The World Health Organisation (WHO) recommends PrEP for all population groups who are at substantial risk of contracting HIV. It is required that everybody should play a part in how best to optimize implementation of oral PrEP. Change of communities and their societal norms around the issue of gender inequalities require community mobilisation (Mabaso,2017). Given the benefits of PrEP, it offers hope in reaching young people with an effective prevention method thereby reducing new infection rates. In order to realise its full potential, this study sought to understand the role of communities in implementing oral PrEP by focusing on how community leaders, custodians of culture and tradition, could support the effective implementation of PrEP in their communities.

One of the UNAIDS (2015) priorities regarding PrEP roll –out is to increase public demand by engaging the civil society sector. This study explores the role community leaders play as they are strategically placed in their communities with power of influence. This study is part of a larger study that was aimed at addressing the user implementation gap for oral PrEP introduction in South Africa by exploring the key determinants for user readiness to optimize the demand for oral PrEP. As oral PrEP is a fairly new method in HIV prevention, not everybody knows what it is and how best it can be implemented. For effective PrEP implementation to take place, community readiness for both the user and the community is required. Furthermore, community stakeholders need to be empowered with knowledge about PrEP so as to normalise HIV prevention and thus reducing stigma associated with HIV. This study therefore, focuses on the role that the community leaders play as stakeholders in the implementation of the oral PrEP.

Location of the study

The study will be conducted in the Vulindlela community, a high HIV burden district of UMgungundlovu, KwaZulu-Natal. Vulindlela is a rural community in KwaZulu-Natal with an estimated 400 000 residents (Chirowodza et al., 2009). It has dominantly Zulu speaking people who are well known for embracing and upholding their culture (Kharsany et.al, 2015). Some of the land in Vulindlela belongs to the traditional authority under the Ingonyama Trust. The community leaders are traditional leaders and ward councillors (Kharsany et.al, 2015). The adult males in this community mostly work in urban areas and come back on weekends (Chirowodza et al., 2009). This community has high HIV prevalence and has increased in women of childbearing age (Chirowodza et al., 2009; McKay, 2018).

The unique transmission mode, like other areas of South Africa is different generations that infect each other – young women become sexually involved with older men for financial benefits (McKay, 2018). This phenomenon is referred to as Blesser-Blessie relationships which are common in Vulindlela (Khazan, 2018). It was found that young women in the age range of 15-24 were infected by men who were on average 8.7 years older than them; this was either through consensual sex or rape (McKay, 2018). Of the women aged 25-40 in Vulindlela, 60% were already infected (McKay, 2018). The HIV burden in Vulindlela especially among young women supported the relevance of this study in exploring the community's readiness to adopt, accept and promote oral PrEP with AGYW in Vulindlela from the perspective of the community leaders.

Rationale of the study

According to the UNAIDS 2016-2021 Strategy, the rate of decline in the number of people acquiring HIV is relatively slow (UNAIDS, 2015). The number of people newly infected continues to outpace the number of people initiating HIV treatment. Evidence informed and rights-based prevention frameworks, such as combination prevention (i.e. a strategic combination of behavioural, biomedical, and structural approaches that include the range of primary prevention methods focused on HIV negative people as

well as positive health, dignity and prevention) have several implementation challenges and more needs to be done to increase prevention efforts (UNAIDS, 2015).

In addition to the prevention challenges, nearly half of the estimated two million people acquiring HIV in 2014 lived in eastern and southern Africa with adolescent girls and young women at a disproportionate risk of infection, acquiring HIV five to seven years earlier than men whilst 62% of all adolescents acquiring HIV infection are girls; 71% of these adolescent infections are concentrated in sub-Saharan Africa (UNAIDS, 2015).

The HIV incidence rates remain high in KwaZulu-Natal despite the HIV prevention efforts that have been in existence for long, amongst the population groups at high risk are adolescent girls and young women (AGYW) and sex workers. This is due to vulnerabilities such as power imbalances in relationships, practice of transactional sex due to economic needs and age difference. The above statements justify the importance of the study because women have limited HIV prevention options and South Africa is slowly scaling up oral PrEP only for sex workers yet the AGYW are also a key population that require attention (South African National Strategic Plan of the Department of Health). The study aims at investigating the community leaders' role in strengthening implementation of Oral PrEP. Community leaders are key enablers and stakeholders in bringing the epidemic under control (National Strategic Plan of South Africa, 2017-2022). Community leaders can be referred to as opinion leaders, people who influence the opinions; attitudes and beliefs, motivations and behaviours of others (Valente, 2007). Their functions and responsibilities are critical in the implementation of successful community based health promotion efforts as they act as gatekeepers and provide entry and legitimacy to external change agents; and act as a channel of communication in their communities and therefore convey health messages (Valente, 2007).

Community leaders play a vital role in the success of an HIV/AIDS research or program (Morin et al, 2003) where community advisory board members viewed themselves as advisors and saw their role as legitimizing research in their communities. Community leaders also identify or function as protectors of the research participants. Green et.al (2006) highlight that the commitment of President Yoweri Museveni in the fight against HIV contributed to Uganda's HIV prevention success story, where he called upon all

leaders from the village level to the state house to take the fight against AIDS as a patriotic duty.

Objectives of the study

The study was guided by the following research objectives:

- To explore perceptions and attitudes of community leaders towards oral PrEP use for AGYW in Vulindlela community.
- To explore community leaders' understanding of the benefits of oral PrEP for HIV prevention
- To investigate the role of community leaders in strengthening implementation of oral PrEP

Research questions

In order to gain understanding on the role of community leaders in the effective implementation of oral PrEP, this study was guided by the following research questions which it sought to answer.

1. What is the knowledge and attitude of oral PrEP among community leaders for AGYW in Vulindlela?
2. What are the perceived benefits or barriers from community leaders in Vulindlela that could hinder or promote the uptake of oral PrEP with AGYW?
3. What are the proposed cues to action for community leaders to promote the implementation of oral PrEP with AGYW in Vulindlela?

Theoretical framing for this study

This study was guided by the Health Belief Model (HBM) and Culture Centred Approach (CCA) within the Socio Ecology Model of Communication and Health Behaviour (SEMCHB). Health Belief Model is defined as a psychological health behaviour change model developed to explain and predict health related behaviours, particularly in regard to the uptake of health services (Janz and Marshall, 1984). It

consists of theoretical constructs namely, perceived severity, perceived susceptibility, perceived benefits, perceived barriers, modifying variables, cues to action and self-efficacy (Glanz, Rimer and Viswanath, 2008). Perceived severity refers to the subjective assessment of the severity of a health problem and its potential consequences; perceived susceptibility refers to subjective assessment of risk of developing a health problem; perceived benefits refer to an individual's assessment of the value or efficacy of engaging in a health promoting behaviour to decrease risk of disease; perceived barriers refer to an individual's assessment of the obstacles to behaviour change (Glanz, Rimer and Viswanath, 2008). Cues to action can be internal or external motivation. Self-efficacy refers to an individual's perception of his or her competence to successfully perform a behaviour (Glanz, Rimer and Viswanath, 2008).

The culture centred approach is an approach that promotes the importance of listening and engaging in dialogue with members of a community (Dutta,2008). The culture centred approach is chosen for this study because the community leaders as custodians of culture would be the relevant people with whom cultural myths, ideologies, values can be explored. Community leaders can play a significant role in influencing the users and community positively or negatively towards the implementation of oral PrEP. According to Dutta and Basu (2011:330-331), the culture-centred approach is built upon three key concepts and the interactions amongst these concepts: structure, culture and agency. Structure refers to those aspects of social organization that constrain and enable the capacity of cultural participants to seek out health choices and engage in health related behaviours. Culture refers to the local contexts within which health meanings are constituted and negotiated. Agency refers to the capacity of cultural members to enact their choices and to actively participate in negotiating the structures within which they find themselves. These three concepts are intertwined and of relevance to this study because community leaders as custodians of culture can have a huge influence. The culture-centred approach stresses the need to develop respect for the capability of members of marginalized communities to define their health needs and to seek out solutions that fulfil these needs. In this approach the researcher does not come as an expert imposing on people instead he comes as a listener and a participant and engages with community members in a dialogue. It is for this reason that the socio - ecological model for communication and health behaviour will be used with the culture

centred approach and the health belief model as a framework that will assist in gaining a qualitative understanding of attitudinal and normative beliefs of potential users and the community; and identifying the structural barriers to PrEP implementation in Vulindlela community.

Structure of the dissertation

Chapter one introduces the study by giving a brief idea of what the study is about; the background of the study; the aims of the study; its rationale; the research questions and the structure of the dissertation.

Chapter two reviews literature and presents it in two ways. Firstly, it highlights the HIV scourge in society, reviewing the HIV prevention interventions implemented to reduce the rate of new infections. Secondly, it discusses literature on the role of community leaders on the effective implementation of HIV prevention programmes in communities. Oral PrEP as a prevention method is discussed at greater length.

Chapter three presents the theoretical framework underpinning this study. It begins by presenting the Social Ecological Model of Communication and Behaviour Change as the frame that holds the Health Belief Model and the Culture centred approach.

Chapter four presents the research methodology employed in this study. It details the research paradigm, the research approach, data collection method, selection of the sample and study setting and data analysis method.

Chapter five presents findings and data analysis obtained from in-depth interviews conducted.

Chapter six endeavours to answer the research questions and provide a conclusion for the chapter.

Chapter 2: Literature review

Introduction

This study sought to examine the role of community leaders in the effective implementation of oral pre-exposure prophylaxis among AGYW in Vulindlela in the UMgungundlovu district, KwaZulu-Natal. This chapter presents and reviews literature on the history of HIV, the scourge of HIV globally and in South Africa particularly. In order to understand the severity of HIV among different population groups, this chapter reviews literature on the young women as the most affected population; it further discusses the available HIV prevention options prior to introducing oral PrEP as a prevention option for young women and other populations at high risk of contracting HIV. Lastly, it reviews literature on the role of community leaders in the effective implementation of HIV prevention interventions.

The history of HIV

The Human Immunodeficiency Virus (HIV) has single-handedly tore through every country on earth, leaving no nation unaffected (Weiss and Hawks, 2001). It was identified about forty years ago and has exceeded all estimates with regard to the number of lives affected and the severity of how it has affected people (Piot et al., 2001). HIV, in the initial stages, was found in South Africa, North America and Europe among homosexual men (van Rooyen, 2011). The first two AIDS related deaths occurred in 1982 in Gauteng and the victims were homosexual men (Gilbert and Walker, 2002; van Rooyen, 2011). HIV/AIDS infections were only recorded in the black South African population in 1987, by 1992 new infections among women equalled that of men and thus began the heterosexual transmission of the disease (Gilbert and Walker, 2002; van Rooyen, 2011).

Early on, South Africa lacked the necessary leadership to tackle the disease, even civil society organizations (CSO) were excluded from state mandated implementations (van Rooyen, 2011). The early failures in this regard have snowballed into creating breach between effective policy making and the implementation of these policies (van Rooyen, 2011). The post-apartheid government chose to focus on job security,

housing, post-apartheid freedoms and traditional culture which were more popular than addressing HIV/AIDS (van Rooyen, 2011). Furthermore, the disease was addressed in one scope only, the Department of Health was solely focussed on implementing programmes to curb the spread of HIV. Whereas, it is crucial to involve all departments for the continuous assessment and implementation of procedures that lowers the impact of HIV/AIDS (van Rooyen, 2011).

South Africa is now referred to as hyper endemic since HIV prevalence in adults is greater than 15% due to a number of reasons that put individuals at risk of HIV acquisition. Among these are the risks of having multiple concurrent sexual partners; the low and inconsistent use of condoms (van Huyssteen, 2013). The highest transmission rates of HIV in South Africa predominantly occur in heterosexual relationships and through mother to child transmission (van Huyssteen, 2013). Consequently, every sex act has an even higher exposure to HIV as at least one partner may be HIV positive (van Huyssteen, 2013). In 2016 it was estimated that 7.1 million people in South Africa were infected with HIV (UNAIDS, 2017). The high numbers of people living with HIV is indicative of the many challenges that are faced by government in translating updated knowledge to develop public health that records less HIV infections (Weiss and Hawks, 2001; UNAIDS, 2017).

There are many factors attributed to the spread of HIV dating back to the popularity of quick travel by airplanes, urbanization, promiscuity and drug abuse (Klatt, 2017). At the end of the 21st century, more than 95% of HIV infected individuals lived in developing nations (Klatt, 2017). It is a priority for HIV prevention measures to be extensively implemented in South Africa. The adopted preventative measures should be well investigated also considering the cultural values, traditional customs and religious backgrounds of South Africans that are at the highest risk of infection in order to ensure that the prevention interventions that are implemented responds to the needs of the people in their own contexts. Furthermore, it is important that hyper endemic countries have a broad-based educational approach to understand the root of HIV transmission, such as the socio-cultural and economic drivers that contribute to unsafe sex (van Huyssteen, 2013).

The scourge of HIV in South Africa

South Africa has the highest HIV epidemic in the world with about 7.1 million people living with HIV (UNAIDS, 2017). HIV prevalence among the general population is 18.9% with 270 000 new HIV infections for the year 2016 (UNAIDS, 2017). In that year alone, 110 000 people died due to AIDS related illnesses. A remarkable progress is noticeable in the decrease in HIV/AIDS mortality rate. In 2010, there were 140 000 deaths yet in 2018, 71 000 deaths were reported. This is 50% decrease within a 8 year period (UNAIDS, 2018). Interestingly, with the high TB and HIV co-infection rate (73%) only 46% of TB patients are actually tested for HIV (Pienaar et al., 2017).

The percentage of adults on antiretroviral treatment is 56% while the percentage of children is 55% (UNAIDS, 2017). KwaZulu-Natal and Mpumalanga are listed as provinces with high infection rates of 15.8% and 15.4% respectively, while the Western Cape and Northern Cape are the least affected with 3.8% and 5.9% respectively (van Rooyen, 2011; Kharsany et al., 2015). The same pattern remained true in the later years with KwaZulu-Natal having the highest prevalence sitting at 18%, Mpumalanga 15% and Northern Cape and Western Cape having lowest at 6,8% and 6,6% respectively. These provincial differences, suggest that policymakers should direct their attention to prevention efforts in the highest affected regions (Johnson et al., 2017). This would make efficient use of the already limited HIV prevention budgets and resources.

The variation of infection rates between the countries in Africa is speculated to be attributed to the differences in rates of marriage, male circumcision, migration, concurrency, and other STI's (Johnson et al., 2017). However, the provincial differences in South Africa are attributed to the differences in prevalence of male circumcision and the differences of high-risk group populations (Johnson et al., 2017). The Western Cape and Northern Cape have low rates of non-marital sex and men have reported low levels of multiple sexual partners (Johnson et al., 2017). Men living in Limpopo have high rates of adolescent circumcision (the Pedi and Venda ethnic groups), men in the Eastern Cape also have a high rate of male circumcision which happens on or after adolescence (Xhosa ethnic group), KwaZulu-Natal has the lowest

fraction of male circumcision (the Zulu ethnic group) which puts them at a higher risk of HIV infection (Johnson et al., 2017). Notwithstanding the health benefits of male circumcision but it requires further analysis to decipher whether this does play a role in promoting risky sexual behaviours among men (Johnson et al., 2017). Traditionally circumcised men in Cape Town understand the protective benefits of this procedure and it directly relates to HIV risk behaviour in this area (Johnson et al., 2017). Women who are aware of medical male circumcision for HIV prevention are also of the opinion that this procedure reduces the need for males to worry about contracting HIV (Kalichman and Mathews, 2018). The women also feel that men would not feel the need to use condoms, this enhances the concern for proper education on the subject, for both men and women, in places where medical male circumcision is encouraged (Kalichman and Mathews, 2018).

In accordance with the social responsibility of care giving, the elderly are becoming primary caregivers to their own adult children who have progressed with AIDS and also their grandchildren where they take on the role of the parent (van Rooyen, 2011). This drains the elderly's physical, emotional and monetary resources and reverses the traditional roles (van Rooyen, 2011). Close to half of the South African population live below the poverty line and informal settlements in South Africa have twice as many HIV/AIDS infected individuals when compared with rural and urban areas (van Rooyen, 2011). Many inequalities still exist today in multi-faceted biases of gender, race and wealth. For example, 58% of the total health budget was extended into the private health sector that only serves about 20% of the population, this being mostly white South Africans and those of higher income groups (Gilbert and Walker, 2002). This consequently provides fewer health care resources for lower income groups who already experience inadequate living conditions (Gilbert and Walker, 2002; Nicol and Bradshaw, 2017).

The gender differences and biases also contribute to the socio-economic challenges. These challenges and inequalities can be seen in many sectors such as employment, reproductive decisions, the law and tradition, education and sexuality (Gilbert and Walker, 2002). Unemployment levels are usually higher for women than men across all races; women still occupy low skilled and low paying jobs and earn 15-25% less than what men with the same qualifications would earn (Gilbert and Walker, 2002). Black women are economically marginalized and the least educated among the

population of South Africa, this places them last on the health care priority list (Gilbert and Walker, 2002; Karim et al., 2011; Kharsany et al., 2015). The other social factors that play a role in the severity of the spread of the disease are the disruptions of family life, migrant labour, increasing poverty levels, increased mobility which increases the movement of the virus to new communities and sites, the resistance to use protection when engaging in sexual activities, the status of women in society, the encouragement of men to have multiple sexual partners and the low integration of sex education in schools, homes and corporate gatherings (Gilbert and Walker, 2002; Karim et al., 2011; Simelela and Venter, 2014).

Young women disproportionately affected by HIV

Globally, women carry the greatest burden of HIV infections as compared to their men counterparts, over half of new HIV infections globally, are recorded among women. In Eastern and Southern Africa, the prevalence of HIV among adolescent girls and young women (AGYW) aged 15-24 years is more than double compared to that of males in the same age range (Brown and Williams, 2018; Price et al., 2018; Schatz and Houle, 2018; Ziraba et al., 2018). Amongst young women in the early 20s, approximately 2000 new HIV infections occur every week, or 100 000 of the 270 000 new infections a year (NSP, 2017-2022). All this illustrates that young women are the most affected group thus requiring more targeted efforts to reduce the rate of new infections. More focus on AGYW will help reduce the number of new infections, premature maternal deaths and unplanned pregnancies.

The main modes of transmission as discussed earlier is heterosexual sex that results in vertical transmission to children (Kharsany and Karim, 2016). In this way, women are more affected with 58% of all HIV infected individuals being women (Kharsany and Karim, 2016). The highest number of AIDS related deaths are also attributed to women (Kharsany and Karim, 2016). Furthermore, pregnant women are also at great risk as they have a higher prevalence rate. In South Africa, the HIV prevalence among pregnant women is around 30% and in some HIV burdened districts it is around 50% (NSP, 2017-2022). This means women carry the greatest burden of HIV infections, and more specifically the adolescent girls and young women (aged between 15 and

24 years) have the highest HIV incidence of any age or sex cohort, at 2,01% in 2015 (NSP, 2017-2022).

The groups who are most at risk of contracting the disease are young females who are part of age-disparate relationships with older men (Brown et al., 2018). Similarly, in a study by Mabaso et al. (2018), HIV prevalence was higher among young women aged 20-24 years compared to adolescent girls and men around the same age. The factors that contribute to this group being at risk is that their male partners have a higher HIV prevalence the older they get, until about 40 years of age (Brown et al., 2018). Another factor is risky sexual behaviour that takes place within these partnerships where safe sex is not practiced, often condoms are not used, the rise of transactional sex and sexual engagements with multiple partners concurrently (Brown et al., 2018). Early age of sexual debut also increases the risk of HIV infection, the use of alcohol and drugs and factors relating to poverty and generally the environment contribute to the increased infections among young women (Malga, 2018).

The average age at which teenagers have had their first sexual experience is 17 years for both males and females in Tanzania, 18 years for males and females in Zimbabwe and 16 years for males in South Africa (Richter et al., 2014). The number of lifetime sexual partners averaged 3 for males from Zimbabwe and Tanzania and 5 for males from South Africa; the women averaged 1 lifetime sexual partner in Zimbabwe and 2 for Tanzania and South Africa (Richter et al., 2014). Close to 50% of participants from South Africa reportedly used condoms always or frequently while Zimbabwean and Tanzanian participants were relatively low, especially among the females (Richter et al., 2014).

According to Richter et al. (2014), the age group with the greatest number of new infections is between 15-24 years. Childhood sexual abuse (CSA) also contributes to HIV transmission among women and men by early sexual activity and even child physical abuse (CPA) (Richter et al., 2014). In Swaziland, 33% of women have reported sexual violence before they turned 18 which translate to a lifetime of STI exposure and unplanned pregnancy (Richter et al., 2014). CPA has been related to a three-fold upsurge in great HIV risk behaviours where 43% of female adolescents and 23% of males were likely to engage in risky behaviour; the other effects of CPA are low self-esteem, short temper, lack of control, mental health issues and anti-social

behaviour (Richter et al., 2014). This shows the vulnerability of the AGYW and as such this study is relevant as oral PrEP would act as prevention for those who are forced to have sex without their consent.

The factors that place AGYW at high risk differ between countries of Sub-Saharan Africa (Mabaso et al., 2018). The vulnerability of this key population is influenced by societal behaviour, where the superiority of men and men's sexual entitlement is supported in some cases, celebrated (Mabaso et al., 2018). The norms of society leads to gender inequality and disparate power dynamics causing females to disregard safe sex negotiations due to fear or respect (Mabaso et al., 2018). This contributes to risky sexual behaviour. This provides understanding of how patriarchy is still valued in Africa along with the obedience demanded from women and children, the traditional notions of men's sexual urges not being in their control, tolerable violence and substance abuse accounts for the abuse of children (Richter et al., 2014). Therefore, this study is relevant as the community leaders who are the custodians of culture can teach the younger generation of males to respect their female partners and not engage in gender based violence.

Poverty is also one of the most concerning socio-economic challenges in South Africa. AGYW are primarily expected to take care of themselves financially and to bear the financial burdens of the family (Mabaso et al., 2018). This interrupts their school life and prevents them from enrolling in secondary or tertiary classes (Mabaso et al., 2018). Poor women are more likely to be dependent on men financially, this limits their power to insist on using protection during sexual intercourses (Mabaso et al., 2018). Educated women are more likely to be aware of HIV and are adequately prepared to protect themselves against the disease (Mabaso et al., 2018). Age also has a bearing on HIV spread. The larger age gap between partners results in higher likelihood of HIV infection (Mabaso et al., 2018).

The global impact of HIV

The most concerning aspect of the HIV and AIDS pandemic is the effect it has on the security of human life. In terms of the future human capacity of a nation, HIV has a detrimental effect on social capital (Piot et al., 2001; Ziraba et al., 2018). The demographic for high likelihood of infection is young adults with widespread across

social and economic sectors – this facilitates high vulnerability socially (Piot et al., 2001; Ziraba et al., 2018). Another social aspect concerned with HIV positive individuals is the stigma that surrounds the disease and infected / affected individuals (van Huyssteen, 2013). Stigma refers to the devaluation of a person or group of people that are infected/affected with certain conditions or diseases (Steward et al., 2008; van Huyssteen, 2013). Stigma infringes on the human rights of people living with HIV/AIDS. The direct effects of stigma can be seen in the complications that arise in the management and treatment of HIV (Steward et al., 2008). Individuals become more reluctant to get tested, more secretive to reveal their status and alter the attitudes of those involved in HIV-related care (Steward et al., 2008). The effect of stigma on an individual's behaviour is seen as a vital component to investigate – in order to facilitate good health (Steward et al., 2008).

The negative reactions associated with stigma can be physical and verbal abuse, forced unemployment and homelessness, rejection from their immediate community and violation of basic human rights (van Huyssteen, 2013). If the challenge of stigma in society is unaddressed it is likely to undermine efforts to reduce the spread of HIV because HIV positive individuals may feel rejected and thus be unable to practice safe measures to protect others without feeling like their HIV status is being exposed. The stigma may contribute to HIV positive individuals avoiding safe sex practices such as abstinence, a limited number of sex partners, revealing their HIV status and practicing correct condom use (van Huyssteen, 2013).

Despite these challenges, the availability of antiretroviral therapy (ART) has offered hope to many living with HIV as they can live longer and healthier lives (Smith and Mbakwen, 2010). This creates a new avenue for those receiving treatment as they are now able to re-imagine their life goals, plans, aims and aspirations (Smith and Mbakwen, 2010). Their most important priorities in tune with their cultural beliefs and social standing usually include sexual relationships, marriage and having children (Smith and Mbakwen, 2010). This produces social, ethical and medical issues in the face of reproduction which conflicts with their life goals and social expectations (Smith and Mbakwen, 2010).

In Nigeria young people, regardless of their HIV status, experience pressure to marry and have children for people who are living with HIV; these pressures are more intense

because of ART and also the social stigma attached to AIDS in that it breaks down filial obligations (Smith and Mbakwen, 2010). In line with this, people on ART feel the need to marry and reproduce to protect their social reputation and hide their HIV status (Smith and Mbakwen, 2010). However, counselling sessions are offered together with ART to inform patients of the serious medical consequences if strict ART regimens are not adhered to and to emphasize the risk they face if they decide to engage in unprotected sex (Smith and Mbakwen, 2010). In South Eastern Nigeria it is a common belief that unprotected sex is a sign of trust between both partners and a possibility that the relationship could result in marriage with children (Smith and Mbakwen, 2010). These contradicting beliefs surrounding HIV and AIDS are evident in many parts of Africa and creates a constant battle between cultural and medical practices.

HIV/AIDS mitigates any efforts placed in the reduction of poverty and elevates the number of people that live in extreme poverty (Luboobi and Mugisha, 2005). The effect poverty has on youth is that poorer households have removed their children from school, especially female children due to the inability to pay school fees and other associated costs (Luboobi and Mugisha, 2005). As parents and older family members advance in the disease, there is pressure on children to provide for their families, when their parents pass they are usually taken in and raised by their grandparents who rely on state grants for their livelihoods (Luboobi and Mugisha, 2005). In addition, poverty also deters some people from accessing and adhering to treatment as prescribed. These factors include the inability to cope with the treatment demands, such as eating healthy food in the context of high poverty rates in society and; the travelling costs to access the nearest clinic for accessing ART (Luboobi and Mugisha, 2005). Moreover, the extended time period for progression of the disease costs the labour market (Dixon et al., 2002). The annual costs of sickness and a decline in productivity reportedly amounted to 17 dollars per employee in a Kenyan car manufacturing plant and 300 dollars in the Ugandan Railway Corporation (Dixon et al., 2002). To minimize the impact of the epidemic on Africa, prevention methods should be implemented along with proper care for those already infected and this will enable people to live longer, healthier and more productive lives (Luboobi and Mugisha, 2005).

Luboobi and Mugisha (2005) identify the problems of fragmentation within each sector as they respond to HIV/AIDS. Different sectors implement separate agendas in isolation from each other in multiple small-scale projects such as governmental

organizations, NGOs, the UN or the private sector (Luboobi and Mugisha, 2005). It is suggested that the government should call on all these sectors to be involved in strategic plans with higher impact rates that combine efforts to result in an innovative and workable approach (Luboobi and Mugisha, 2005). A high-level of political support and planning for behaviour change communication (BCC) that reached an intended target is the Ugandan National AIDS Control Programme (ACP) which launched an intense media campaign in 1996 (Luboobi and Mugisha, 2005). Uganda also launched a Confidential Voluntary Counselling and Testing (VCT) campaign along with the AIDS Information Centre (AIC) and has now since spread into major townships (Luboobi and Mugisha, 2005). The general population followed their leaders' example in the fight against AIDS both in rural and urban areas (Green et.al, 2006). This method of approach is immediate and effective in maintaining the behaviour of HIV negative individuals and those who were found positive were immediately started on ARVs, with the addition of Post Test Clubs, people felt very involved in their community and this acted as a long-term support structure for both infected and non-infected individuals (Luboobi and Mugisha, 2005). The commitment and involvement of high-level political support and multi sectorial response led to the decline in HIV prevalence in Uganda (Green et.al, 2006).

HIV Prevention options

A number of HIV prevention options have been introduced over the years to curb the spread of HIV infections, however, the number of new infections amongst AGYW continue to escalate. There have been a number of experimented therapies developed for the treatment of HIV such as bone marrow transplants, lymphocyte transfusion and therapeutic apheresis which aimed to remove the cells that bore the virus (Klatt, 2017). Since these methods were not successful, pharmacological approaches were developed to reduce HIV replication however none of these methods are able to completely eliminate HIV (Klatt, 2017).

Uganda and Thailand have implemented a multi-sectorial approach that has seen great success in early prevention of HIV (van Huyssteen, 2013). The prevalence of HIV in Uganda declined from 15% in 1991 to 5% in 2001 due to behavioural changes initiated and supported by leadership in political and religious spheres, behaviour

change communication that reached the target group, interventions focused on women, youth, addressed stigma and discrimination, STD control and prevention programmes, condom social marketing and a decrease in multiple sex partners (van Huyssteen, 2013). This questions whether similar results may be evident with the introduction of new HIV prevention strategies.

The key biomedical prevention methods include male circumcision, HIV counselling and testing as well as the use of treatment as prevention. Voluntary medical male circumcision (VMMC) is a minor surgery performed for religious and/or medical reasons (Davis et al., 2018; Lane et al., 2018; Schenker, 2018). It is praised for reducing a man's risk of contracting HIV (Davis et al., 2018). Adolescents are the preferred target group for VMMC since this aligns with the religious and medical context of circumcision (Lane et al., 2018). This age group would also be able to contribute to aspects of the program such as decision making, they would understand the importance of VMMC, are able to take care of the wound by themselves and the wound would heal faster than in adults (Lane et al., 2018). The challenges surrounding this prevention method is the implementation of policy, the clinical setting of performing this procedure, scaling up this prevention method to reach high risk males and creating collaborations with the community, government and joint-nation intervention for the correct implementation of this procedure; all these need to be properly addressed in order to realise the full effectiveness of VMMC (Schenker, 2018).

HIV counselling and testing (HCT) is another biomedical intervention which is an entry point to proper HIV care, prevention and treatment for at risk individuals (Gyasi and Abass, 2018; Mayaphi et al., 2018; Tianyi et al., 2018). HCT is described as a keystone for HIV medical treatment (Gyasi and Abass, 2018; Mayaphi et al., 2018; Tianyi et al., 2018). It is a method of monitoring HIV status in sexually active individuals, it offers support and counselling to those who are unaware of their HIV status and want to get tested and a way for HIV-positive individuals to learn their status and access treatment (Gyasi and Abass, 2018; Mayaphi et al., 2018; Tianyi et al., 2018). The challenges with this key area of HIV intervention is that the personnel providing HCT are not encouraged to attend refresher courses on counselling and updated HIV information, as a result some are outdated and this decreases the quality of the service offered (Gyasi and Abass, 2018; Mayaphi et al., 2018; Tianyi et al., 2018). Another challenge is accessing rural areas and the stigma that surrounds individuals who would access

HCT. The individuals that come in for HCT services may not be screened for their sexual behaviour or HIV risk which hinders tailored and individual treatment. This impacts on the effectiveness of the HCT service (Mayaphi et al., 2018).

Antiretroviral therapy is deemed the most effective preventative treatment available for both HIV and opportunistic infections (International AIDS Society–USA, 2005). In South Africa, young people over the age of 12 are able to access HIV testing and counselling centres (HTC) without an adult present, however there are ongoing concerns with regard to the quality of counselling and care they are receiving at these centres (Pitorak et al., 2013). The number of people on ART in South Africa has increased from less than 200 000 in 2006 to over 1.7 million in 2012; the transmission from mother to child has decreased from 20% to 2.7% (van Huyssteen, 2013). The HIV Prevention Trials Network (HPTN) also contributed to HIV prevention by a study that administered ART immediately after a partner in the relationship study group was found to be HIV positive (Mitchell et al., 2015). This reduced transmission by 96% and showed that there is no need to wait until the CD4 count was at its threshold in order to administer the ART (Mitchell et al., 2015). This is attributed to an increase in political leadership for the AIDS response which is crucial to deal with the hyper endemic (van Huyssteen, 2013).

Behavioural strategies that modify risk behaviours remain central to HIV prevention (Coates et al., 2008). These behaviours aim to delay onset of first sexual activity (intercourse in particular), limit the number of sexual partners, protecting sexual acts at all times, offer testing and counselling, emphasize on the importance of treatment to prevent HIV transmission, reduce sharing of needles and abuse of substances (Coates et al., 2008). It is tempting to have a more simplistic approach to HIV prevention by only choosing one or two prevention methods; however, this may be idealistic and ineffective in its approach (Coates et al., 2008). By taking on a complex grouping of strategies and many risk-reducing choices, an effective HIV transmission reduction strategy would have been developed, if sustained over a long period (Coates et al., 2008).

HIV prevention programmes are mediations that aim to stop the transmission of HIV. One of the popular behavioural prevention methods is ABC method which stands for abstinence from sexual activity, be faithful to one partner (monogamy) and condom

use (USAIDS, 2003). This was intended to prevent or limit the likelihood of sexually contracting HIV. The decline of HIV prevalence in Uganda is an example of the successes of the ABC intervention. The national prevalence for HIV was around 15% in the early 90's and drastically dropped to around 5% in 2001 (USAIDS, 2003). This decline was attributed to positive changes in all three components of ABC prevention methods (USAIDS, 2003). The success of this method was a combination of community involvement, government initiatives and non-government initiatives (USAIDS, 2003).

The ABC prevention method was also effective in countries including Zambia, Cambodia, and the Dominican Republic which have contributed to declines in HIV prevalence (USAIDS, 2003). However, to ensure more effectiveness in more countries, the ABC approach should be appropriately balanced to produce positive results. The high-risk target population should be well-defined so that the appropriate intervention can be implemented, whether it is just one of the approaches or a combination of all three (USAIDS, 2003). Political intervention and community involvement were key factors in effectively implementing these practices (USAIDS, 2003).

The fundamental aim of HIV prevention strategies is to alter the behaviour patterns that expose individuals to HIV risks (Gupta et al., 2008). The individual based HIV prevention strategy is based on sharing knowledge, changing attitudes and behaviours. A practical example of this behavioural change is encouraging the use of condoms, increasing sex education, and highlighting the dangers of sharing needles among people who inject drugs (Gupta et al., 2008). This strategy does produce some results in decreasing risk behaviour, however if HIV prevention addresses structural factors such as poverty and wealth, gender, age and policies, this would produce greater success (Gupta et al., 2008). Structural factors refer to the social, economic, political and environmental factors that contribute to the risk and exposure to HIV (Gupta et al., 2008). These structural issues include gender inequality, income bias and social marginalization among others (Gupta et al., 2008). The influence of these factors in society cannot be denied and it has proven to be difficult to change.

The mechanisms by which the structural factors contribute to HIV risk include examples of gender inequality that manifests as sexual violence that leads to HIV

transmission (Gupta et al., 2008; Karim et al., 2011). Labour migration is another example, taking into consideration mostly mine workers that have been found to succumb to pressures of risky working conditions, sparse social support, geographic separation from family that lead to unprotected sexual behavior with sex workers (Gupta et al., 2008). These challenges can be addressed by adopting a structural based approach to decrease risk and vulnerability through implementing favourable policies as was seen in Thailand and the Dominican Republic to reduce infection rates among sex workers where brothel and bar managers as well as the police effected the 100% condom use policy (Gupta et al., 2008). In another case, the intervention with microfinance for AIDS and gender equity (IMAGE) in South Africa which was developed to minimize gender-based HIV vulnerabilities in terms of sexual violence, women's economic freedom and independence from men, and to address the lack of knowledge on HIV and the modes of transmission (Gupta et al., 2008).

The demographic, social and economic impact of the virus puts developing countries at the greatest risk, producing the greatest rates of infection and greatest loss of life when compared to developed countries. However, developed nations have also seen low beneficial effects of prevention attempts within the poorer minorities (Piot et al., 2001).

Challenges to effective implementation of HIV prevention interventions

Sex education is still seen as taboo in South Africa. Most adults choose not to acknowledge the sexual activity that their children pursue (especially in the case of girl children) and this results in an unsupportive environment to discuss safe sex practices and what a healthy relationship should look like (Campbell et al., 2005; Kharsany et al., 2015). The contributing factor to stigmatization is the connection between HIV/AIDS, sex, sin and immorality; where discussing sex and sin is seen as disrespectful to elders and HIV seen as a punishment for the sins of young people (Campbell et al., 2005). Public schools and clinics often complain about the lack of funding from government to assist patients and learners living with HIV. The head of a school in Durban, KwaZulu-Natal estimated that 50% of the learners in his school were infected with HIV but there is little he could do to help them if he did not receive

the necessary resources such as the help from a clinic, social workers and nurses (Campbell et al., 2005). Similarly, a social worker that visits HIV/AIDS patients to offer emotional support expressed that the individual expects more from the social worker than just conversation, most times they are poor and it is difficult to motivate them to have a positive mind-set if they are hungry (Campbell et al., 2005). The above study was conducted in Ekuthuleni (pseudonym used for ethical reasons), a peri-urban area in Durban, (Campbell et.al, 2005).

Any HIV/AIDS prevention programme should integrate aspects of reducing stigma to have a lasting effect (Campbell et al., 2005). One aspect of attempting to reduce stigma is by conveying factual based information on the spread of the disease in order to make people aware, this method does not automatically result in stigma reduction (Campbell et al., 2005). The second aspect involves punishable offences against people who discriminate HIV/AIDS infected people. Stigma in this area can be very subtle and may be prominent in communities where it is difficult to seek legal action (Campbell et al., 2005). The third aspect community members should be directly involved in any stigma reduction programme. It is suggested that this should involve debates, dialogues and exchange of ideas in meetings where community members discuss the root of their stigma and continuously emphasize the benefits of reducing stigma within their communities and in their own lives (Campbell et al., 2005). Community leaders are people of influence and they can play a significant part in either eliminating or propagating the stigma. It is therefore important to explore their knowledge and attitudes around oral PrEP towards HIV prevention. Also creating spaces for dialogue helps in problem identification and analysis leading to action towards change.

Campbell et al. (2005) emphasize that stigmatization from an HIV infected individual's own family is damaging to the individual and this plays a major role in limiting the HIV prevention attempts. This is also a strong barrier to young people who seek HIV/AIDS counselling (Campbell et al., 2005). The methods of prevention and HIV care should also focus on the role families play in community leadership and the positive networking effects among men living with HIV (Hill and Gottert, 2017).

An introduction to Oral PrEP

Oral PrEP is a fairly new HIV prevention method that is meant for HIV negative people at substantial risk of HIV acquisition. The key populations at high risk of HIV infection include among others men who have sex with men (MSM); sex workers; adolescent girls and young women (AGYW).

Despite the remarkable progress in the treatment of people living with HIV, the new cases of seropositivity remains high in many countries (Pialoux et.al 2016). This indicates the limitations of current prevention strategies and it justifies the need for new approaches to HIV prevention (Pialoux et.al 2016). Burns et.al (2014) also highlight that it is widely documented that even relatively small numbers of undiagnosed cases are capable of not only keeping transmission but also spreading an increase in HIV incidence. Pre-exposure prophylaxis (PrEP) is one of the HIV prevention strategies that must be considered and optimised. It is a prevention option that uses antiretroviral (ARV) drugs to safeguard HIV negative individuals from being infected with HIV (Pebody, 2015). PrEP comes in different forms, including daily oral PrEP with emtricitabine/tenofovir disoproxil fumarate (Truvada) approved by US Food and Drug Administration (FDA) and South African Medicines Control Council (Burns et.al 2014; WHO (2015). The ARV is usually consumed by individuals who are at high risk of contracting HIV through sexual intercourse despite the reason for risk (disregarding the use of condom, sex work, taking concomitant drugs etc. (Pebody, 2015; Pialoux et.al 2016).

PrEP has proved to have significant results in preventing the spread of HIV if consumed as prescribed (Pebody, 2015). This means adherence is of utmost importance in ensuring the effectiveness of PrEP (Pebody 2015; Pialoux et.al 2016). PrEP are ARVs given to HIV negative individuals before exposure to HIV (Pebody, 2015). HIV negative persons would take enough ARVs as to have high doses of the drugs in their blood stream (Pebody, 2015). It is also important to note that vagina and rectum are the main portal of entry of the virus, it is in these genital compartments that the active components of the drugs used to prevent sexual transmission of HIV should diffuse into (Pebody, 2015; Pialoux et.al, 2016). If they do come into contact with the virus, the ARVs prevent the virus from entering the cells and replicating – this prevents HIV transmission and the person remains HIV negative (Pebody, 2015).

What have the clinical trials shown?

The drugs that make up the ARV are tenofovir and emtricitabine and have limited side-effects, low drug resistance, able to reach increased levels in the genital tract and rectum and able to remain in the body for a long period (Pebody, 2015). PrEP has a high significance of reducing HIV transmission in some of the high-risk groups and should be an additional option of HIV prevention (Pebody, 2015). In a study of men who have sex with men (the PROUD study), 9% of gay men who were not exposed to PrEP contracted the disease within a year (Pebody, 2015). In a study of transgendered women and men who have sex with men (The Pre-Exposure Prophylaxis Initiative), there was a 44% decrease of HIV infection when compared to the placebo group (Hurt et al., 2011). Additionally, in another PROUD study of 2015 where participants are men who have sex with men, PrEP was shown to reduce HIV infections by 86% - this has exceeded the real-life effectiveness of constant condom use (Pebody, 2015).

Studies that used participants that were heterosexual have had some positive and some negative results. In the successful studies, men and women who used PrEP had 39-75% fewer HIV infections while the unsuccessful studies showed that women who were using PrEP had just as many HIV infections as women who received a placebo (Pebody, 2015). This was due to individuals that used PrEP regularly remained HIV negative while social factors contributed to the irregular use of PrEP in women (Pebody, 2015). This included the position of women in society and the stigma around HIV since the unfavourable results came from a young group of single women (Pebody, 2015). The biological factors that may have contributed to the results in women may also link with PrEP drugs producing lower concentrations in the cervix and vagina when compared to the rectum (Pebody, 2015).

The assessment, effectiveness and cost of utilizing PrEP in Nairobi were also investigated by modelling. This study suggested that PrEP should be used for target groups of male and female sex workers (Cremin et al., 2017). These groups are high risk for HIV infections since they have documented to have low levels of condom use (Cremin et al., 2017). It also highlighted that improper use and regimen when taking PrEP and ARVs would significantly decrease its effectiveness (Cremin et al., 2017). Cremin et al. (2017) emphasize that all round monitoring on a periodical basis for incidence should be a priority in key populations to effectively administer PrEP. This

is in agreement with a study across sub-Saharan Africa where an optimal prevention outline would prioritize PrEP for high-risk target groups which are female sex workers particularly (McGillan et al., 2016). The study also showed that an optimum strategy for prevention would include PrEP and the choice to use PrEP in a group depends on the likelihood of HIV infection and overall expenditure – this includes the possibilities for impact of other possible intercessions (McGillan et al., 2016). The use of PrEP is also dependent on the modes of transmission in the population and opportunity for development of diverse strategies (McGillan et al., 2016). The marginal loss for implementing PrEP was calculated to be at 7% for the highest expenditure considered, however this is at half the loss that would be attained if PrEP was not executed at all (McGillan et al., 2016).

For PrEP to be effective, between four and seven daily doses is recommended for gay men and a longer time period for women (Pebody, 2015). It is slightly more expensive than other HIV prevention methods but if used correctly it is cost-effective for target populations that are at high-risk for HIV infection (Pebody, 2015). Hurt et al. (2011) suggest that a profile of patients who are likely to benefit from PrEP should be drawn up and effective care plans should be implemented for the successful intervention of this treatment. A Nigerian study that focused on modelling the effectiveness of prevention used couples in a stable relationship as the centre of focus, considering that this group was seen to have the highest number of new infections (26-46%) (Mitchell et al., 2015). The PrEP trial in this region found that HIV incidence was reduced by 67-75% with constant adherence to treatment regimen (Mitchell et al., 2015). From the model, condom promotion was predicted to be the most cost-effective method with the prevention of HIV transmission (Mitchell et al., 2015). Another cost-effective treatment method was to offer the HIV negative partner PrEP until the HIV positive partner started ART – this method was predicted to prevent HIV infections by 10% (Mitchell et al., 2015).

The practical implementation of PrEP

A South African review expresses concern in terms of resource allocation by implementing PrEP, some may see it as a trade-off between removing drugs from sick patients and allocating them to healthy ones in the form of PrEP (Karim and Karim, 2012). This concern could have been brought about by the issue of cost around implementing PrEP. Pialoux et.al (2016) concluded in their review that the implementation of PrEP should not be done in isolation instead it should be incorporated within programmes for prevention of all STDs. They cited that the cost of implementing oral PrEP is minimal as compared to the cost of giving ARVs to the HIV positive people for the rest of their lives. They further indicated that the cost of PrEP depends mainly on the cost of the ARV combinations used and there is a possibility of generic forms of drugs to be used.

Karim and Karim (2012) also highlight that behavioural inhibition is a concern with PrEP where users may feel safeguarded against HIV and discard other protective measures such as condoms. Burns et.al (2014) cite a study in the United Kingdom that showed an increase in HIV testing and ART uptake occurred in parallel with an increase in condomless sex and HIV incidence amongst MSM. This requires that oral PrEP awareness campaigns should emphasise and clarify that oral PrEP should be seen as an addition to other forms of HIV prevention methods as it does not prevent unwanted pregnancies and other STIs.

Some notable challenges relating to oral PrEP implementation include adherence, risk behaviour, drug resistance, access and cost (Burns et.al, 2014). It is also noted that slow uptake amongst potential users in the United States include, inter alia, a low perceived risk of HIV acquisition, a dislike of taking medication, lack of awareness of oral PrEP, the cost of the drugs, concerns regarding potential adverse effects, the cost and/or inconvenience of required follow-up visits, the requirement to undergo repeat HIV testing prior to each new prescription (Burns et.al, 2014). This list of challenges questions significant questions for this study in a South African context and specifically for AGYW who are at highest risk of infection in Vulindlela. It is cited that some barriers to oral PrEP uptake include limited knowledge of PrEP, inadequate healthcare access for many persons at greatest need of PrEP and social stigma (Burns et.al, 2014). This

study sought to identify any common barriers to oral PrEP implementation that could hinder its uptake by AGYW in the Vulindlela community.

Karim and Karim (2012) emphasize that PrEP has a unique standing among adolescent girls and young women (AGYW), especially in South Africa since they are heavily burdened with the disease. This stems from the social pressure for women to be obedient and have very little contribution to the decisions of their male partners in terms of condom use, relationship limitations or knowing their HIV status (Karim et al., 2011; Karim and Karim, 2012). With PrEP, new delivery technologies are being explored such as PrEP injections that last 2-3 months and implants that may last 6-12 months in an attempt to increase the prevention methods targeted for women (Karim et al., 2017). The Global Fund (2017) further emphasizes the need for HIV prevention and care to be adolescent friendly and according to the guidelines set by UNAIDS and WHO. The lack of knowledge on infection incidence rates per country is something that needs to be addressed since the price of expanding prevention measures cannot be accurately calculated (Horton and Das, 2008). The ideology and implementation of HIV prevention should be redefined in a way that eliminates the causes of HIV infection, and prevents the deeply tragic social consequences (Horton and Das, 2008).

The role of community leaders in HIV prevention efforts

South Africa is seen as a complex nationality with a mix of developed and undeveloped characteristics of a country. This makes it difficult to gain positive responses to the disease (van Huysteen, 2013). Understanding the informal hierarchy in high prevalence areas is vital for the success of treatment and promotion of prevention strategies (Hill and Gottert, 2017). Among the personal networks of men, family remains the fundamental level at which the individual gets socialised and it is the most prominent followed by traditional/ community leaders (Hill and Gottert, 2017).

Community leaders can be defined as key opinion leaders (Valente, 2007), people who influence the opinions, attitudes and beliefs, motivations and behaviours of other people. Opinion leaders act as role models for behaviour change within the community (Valente, 2007). Community leaders have an obligation to look after the interests and well-being of their communities. They can contribute positively in building strong social

systems, including strengthening communities and families, to decrease the risks of transmission and to mitigate the impact of HIV and AIDS (National Strategic Plan of SA, 2017-2022). Given the above definition and responsibilities that community leaders have, this study was positioned to discover and unpack the role that community leaders in Vulindlela can play in supporting the implementation of oral PrEP amongst the AGYW in their community.

In South Africa, leaders have a prominent role in society and have the ability to affect change based on their beliefs. Their opinions are valid, honoured and adhered to. Community leaders have significant influence over their communities (Campbell, 2010). Leaders are role models in their communities, and their behavior is a reference point to others, regardless of whether it is good or bad (Kgatlle, 2018). This makes it all the more necessary that leaders act in a way that is appropriate and lead by example (Kgatlle, 2018). Traditional leadership is a vital part of a nation especially in terms of facilitating transformation, solving challenges and promoting development. As custodians of culture, working with them and having their active support where significant behaviour change is needed is important (Tshitangoni and Francis, 2018). Traditional leaders are a central component of rural communities and have a deep understanding of people in their communities (Tshitangoni and Francis, 2018). People's perceptions of traditional leaders is not that different compared to elected leaders, people hold a positive linkage between these two institutions. They both command respect within their communities (Tshitangoni and Francis, 2018).

Indigenous healthcare systems are seen to be antagonistic when compared to western medicine, however, to tackle the issue of HIV and AIDS, a collaborative approach is required (Nemutandani et al., 2018). Colonization had negative impacts on the two health care systems which resulted in mistrust, miscommunication and the marginalization of those infected with HIV (Nemutandani et al., 2018). Traditional health practitioners (THP) are defined as individuals in the community that are competent to provide health care services by using natural compounds that are socially, culturally and religiously acceptable (Zuma et al., 2016). There are around 25 000 THP's in KwaZulu-Natal and only around 7000 are registered with a professional body (Zuma et al., 2016). Efforts to create accreditation of the THP's as part of the public health system have been futile (Zuma et al., 2016). The researcher will examine

the community leaders' perceptions of barriers or benefits that could hinder or promote the uptake of oral PrEP among AGYW.

The main role of traditional and elected leaders is to serve as base level entities of local government to enhance local economic development (Baloyi, 2016). The traditional leaders should be consulted on any new law or policy that the government plans on introducing (Baloyi, 2016). This ensures that all opinions from the community level are taken into consideration. The community council, of which leaders are a part of, decides on how resources should be used that will benefit the community, accept accountability for their decisions, encourage community members to be involved in local government, ensure service delivery to the community is quality and maintain a safe and healthy environment (Baloyi, 2016). This study sought to explore from the community leaders' viewpoint what resources are there in Vulindlela and how best they think can be utilised to promote the implementation of oral prep with AGYW.

Leaders play a huge role in influencing communities to take up health interventions. This was evident in Uganda's HIV prevention success story where President Yoweri Museveni called upon all leaders from village level to the state house to take the fight against HIV and AIDS as a patriotic duty (Green et.al, 2006). Another study conducted in Nigeria on the role of community leaders in community development programmes in Ideato Local Government Area (LGA) of Imo State showed results that local leaders' role in decision making is of paramount importance (Ozor & Nwankwo, 2008). Leaders' involvement in development issues contributes positively to the wellness of communities. HIV and AIDS is a development issue (Govender, 2014). This justifies the validity of this study and the need to explore the role of community leaders of Vulindlela in implementing oral PrEP in their community, influencing community members to accept oral PrEP as one of the HIV prevention strategies that will curb the epidemic.

Conclusion

The very gaps in knowledge on the scientific basis of HIV infection on the population is what makes this study unique in its approach. The way communities engage and interact about sexual matters ultimately determines the way prevention and treatment is administered with regard to the debilitating disease of HIV and AIDS. By harnessing every aspect of society and sending one clear message to high risk groups, there will be more effective implementation of oral PrEP to AGYW in Vulindlela, leading to reduction of HIV infections.

Chapter 3: Theoretical Framework

Introduction

This study adopts the Social Ecology Model for Communication and Health Behaviour (SEMCHB) as the framing model to be used to investigate the role of community leaders in strengthening the implementation of oral PrEP amongst adolescent girls and young women (AGYW) in Vulindlela. The SEMCHB is a multi-layered model that seeks to understand health communication across different levels of interaction ranging from the individual to the environmental level as these are all crucial in understanding contexts where health decisions are made in communities. However, for the purpose of this study, the researcher focused on two layers of the model, which are, the individual and the community level to understand how community leaders can influence the decision of AGYW to take up oral PrEP as an effective health intervention to prevent HIV infection. To conceptualise the study within the SEMCHB, the study further adopted the Health Belief Model (HBM) which seeks to explore the individual layer of the framework through understanding the perceptions and the role of community leaders as individuals in promoting or enabling the adoption of oral PrEP among AGYW in their communities. The HBM explored the knowledge and perceptions of the community leaders about oral PrEP, the perceived risk and susceptibility of AGYW to HIV infections. Furthermore, the Culture Centred Approach (CCA) was adopted to explore the influence of culture amongst community leaders and the role it played in constituting health meanings and decisions. This chapter begins with a detailed discussion of the SEMCHB and how it relates to the study. It further discusses the HBM, its constructs and their relevance to the study. Lastly, it provides a discussion of the CCA and links it to the overall study.

The Social Ecology Model for Communication and Health Behaviour (SEMCHB)

The SEMCHB originates from the Social Ecology Model (SEM) which was aimed at understanding the dynamic interrelations among various personal and environmental factors (Bronfenbrenner, 1979). Social ecology models view individual health

decisions as part of a collective or a broader social system (Golden et al., 2012). In other words, while the individual has the responsibility to make positive health decisions but the contextual factors and other actors such as the community, government, policy positions also play a significant role in the adoption of positive health behaviours for improved health outcomes. Bronfenbrenner who was among the first to propose a multi-layered framework to health promotion focused on human development. He interrogated how human beings create environments in which they live, exploring how humans are influenced by their immediate environments in the adoption of health interventions that promote positive health behaviour adoption (Bronfenbrenner, 1979). What is key to ecological models is systems thinking, which is the way to understand how things can influence one another within a whole considering that health decisions are not made in isolation from the broader social system (Bronfenbrenner, 1979).

During the earlier years of health communication, more emphasis was on individual-level theories of learning, persuasion and decision making on health behaviour and behaviour change (Storey and Figuerora, 2012). Psychosocial theories such as Reasoned Action/Planned Behaviour and Social Cognitive Theory that were used in most health programs, even though successfully measured communication processes and outcomes reliably, they overemphasized individual-level behaviour change (Storey and Figuerora, 2012). Hence critics of this individualistic approach had concerns about the missing theoretical elements, that is, community level processes and their contribution to health outcomes. Such criticism led to the bridging of gap by challenging theorists and practitioners to move towards a socio-ecological perspective on health communication. Social ecology is defined as “the study of the influence of the social context on behaviour, including institutional and cultural variables” (Sallis and Owen (2002:462).

As a framework, the SEMCHB moves beyond the initial understanding of health communication and decision making as a responsibility of an individual. It is an evolution of theories of behaviour and social change that emphasises a shift from looking at communication as a one-time, one way communicative ‘act’ to a multi-level dialogue which unfolds over a period of time (Storey and Figueroa, 2012). Some authors have argued that theories do not progress as a series of successive rejections of earlier models but resemble biological evolution of a simple organism into a more

complex one (Neuman and Guggenheim, 2011 in Storey and Figueroa, 2012). This applies to the theory of health communication where communication has been seen to strengthen many aspects of human agency and creating change at all levels, be it individual, family, community or societal levels (Storey and Figueroa, 2012).

Furthermore, the SEMCHB illustrates the complexity, interrelatedness and wholeness of the components of a complex adaptive system, rather than just particular components in isolation from the system. Embeddedness and emergence are two main features of this model (Storey and Figueroa, 2012). Embeddedness refers to a state in which one system is nested in a hierarchy of other systems at different levels of analysis, and emergence, in which the system at each level is greater than the sum of its parts (Storey and Figueroa, 2012). It is for these reasons that the SEMCHB was used as a relevant framework to underpin the study because even in the case of Vulindlela, it is important to understand the role of community leaders in influencing the adoption of oral PrEP among AGYW using a holistic approach realising that AGYW cannot make health decisions in isolation from their communities.

The SEMCHB has four levels of interaction that influence health decision making (Bronfenbrenner, 1979; Lindridge et al., 2013). The first layer of the framework is the individual level which recognises the individual's attributes, attitude and perceptions towards a health condition and how these influence health behaviour of an individual (Lindridge et al., 2013). The individual level suggests that the adoption of specific health behaviours can either be repressed or encouraged by personal incentive, intent and demographic profile (Lindridge et al., 2013; O'Donnell, 2005). However, individual health decision making is also dependent on the parents' awareness, educational background and attitude towards the health behaviour (Holme et al., 2009; Lindridge et al., 2013), thereby suggesting that this level alone is not sufficient for the adoption of health interventions. In the context of this study, AGYW in Vulindlela are unable to solely make the decision to adopt oral PrEP as a prevention intervention outside other factors of influence. This means the other levels of the framework are equally important in HIV prevention among AGYW in the community of Vulindlela.

The second layer of the SEMCHB is the social networks level which seeks to understand the social constructs such as family and friends and how they encourage positive health behavior adoption for an individual (Lindridge et al., 2013). This level

recognises the role of families, friends and social networks in health communication and promotion. In other words, the decision by AGYW to adopt oral PrEP could be greatly influenced by their families and friends and that could either be a positive or a negative influence. However, in the main the interpersonal relationships remain key in decision making within the SEMCHB framework.

The community level is the third layer of the SEMCHB framework which focusses on the involvement of the community in encouraging mutual efficacy (Cohen et al., 2006; Green and Tones, 2011; Kauppi, 2015; Lindridge et al., 2013; Ragnarsson et al., 2011). Within this level, there are different influences such as the community structures constituting community leaders, schools, businesses and others who have a role in influencing the adoption of a health intervention. Likewise, community leaders in Vulindlela within this framework are also understood to have a critical role in directing the health behaviour of AGYW. A positive exercise of their influence on the topic of oral PrEP adoption among AGYW could lead to positive outcomes for the young women. Hence, it is important for the purposes of this study to understand the influential role of community leaders in Vulindlela on the adoption of oral PrEP among AGYW. This layer of interaction is likely to contest already established social norms and may result in resistance from the community to the promoted health change (Lindridge et al., 2013).

The fourth and last layer is the societal level which recognises the wider societal factors that influence health decision making these include government, policies, social and cultural factors. The societal level further refers to the cultural components of an individual's life as well as the expectations placed on the individual (Lindridge et al., 2013). In this context, it can be assumed that a positive cultural belief can contend with structures that limit access to that health behaviour (Corcoran, 2013; Dupas, 2011; Kauppi, 2015; Kelly et al., 2005; Lindridge et al., 2013). When the community has the relevant information regarding the health concern and there are relevant and enabling policies in place then individuals and communities become more willing and able to adopt the preventative health behaviour in order to achieve positive health outcomes (Corcoran, 2013; Kickbush et al., 2008; Lindridge et al., 2013; Nutbeam, 2000). However, when individuals and communities are less informed or aware of the health concern then this becomes a challenge to health communication and the ability and willingness of communities to adopt a behavior change (Atkinson et al., 2011;

Babalola et al., 2006; Kauppi, 2015; Lindridge et al., 2013; Nielsen-Bohlman et al., 2004; Riehman et al., 2013).

Understanding how these different layers of the SEMCHB interact allows researchers to address and act on them in a way that leads to a positive behavioural change (Bronfenbrenner, 1979; Lindridge et al., 2013). An example of this interaction within this framework is captured in this illustration: an individual is born into a family, he or she learns through socialisation the norms and values of the society. S/he interacts with peers at school and learn new ways of doing things. Throughout this process, there is communication that takes place and it is what links all the stages of growth of an individual. Communication is of paramount importance in all these stages of growth and in all the relationships formed. There is a dialogue that takes place, and this makes it possible to understand human behaviour. In fact, to understand human behaviour, both the individual and social context need to be understood.

The SEMCHB framework offers a comprehensive approach to understanding health communication and the adoption of changed health behaviours. The interactions between the different levels are key to attaining a positive health outcome and this is also true for this study of exploring the role of community leaders on the adoption of oral PrEP among AGYW in Vulindlela. This study acknowledges the importance of all the layers of interaction of the framework but only focuses on two levels for the purposes of this study. The study explores in detail the individual and the community level of the framework. The individual level is important in understanding the perceptions of community leaders on the issue of HIV prevention for AGYW as understanding this provides insights on their willingness as leaders to support or reject the adoption of oral PrEP. Furthermore, community leaders are placed within the community level of the framework as they have influence in determining behaviour of their communities. Thus, understanding the challenges and opportunities in the community to promote PrEP is important for this study. In order to ensure sustainability, this study adopts the assumption that when individual change is facilitated and supported by social changes at higher levels it is more likely to be self-sustaining. This means the AGYW in Vulindlela would be more successful in taking oral PrEP if they are supported by community leaders who can mobilise resources for them to ensure sustainability and positive outcomes from the intervention.

Theoretical Approach to Social and Behavioural Communication

SOCIAL ECOLOGY MODEL & COMMUNICATION FOR SOCIAL AND BEHAVIORAL CHANGE

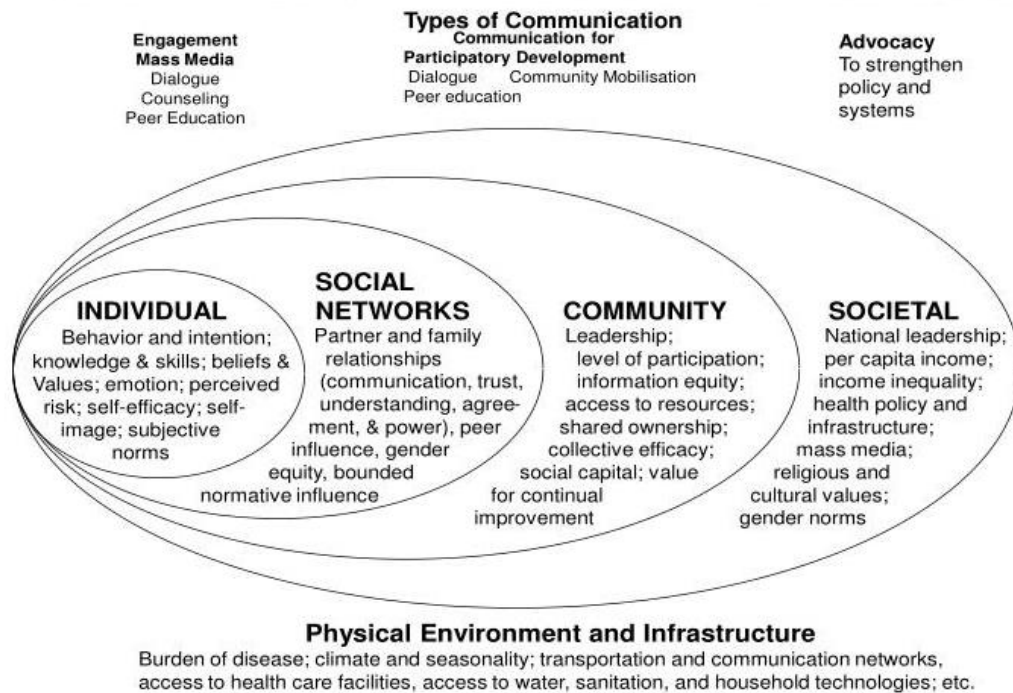


Figure 1. Source: Kincaid et.al (2007)

Panther-Brick et.al (2005) argue that for health interventions to be successful, emphasis should be put on community members who are receptive to change. They further state that interventions should be 'culturally compelling' that is, local communities' engagement is very important (Panther-Brick et.al, 2005). In a study they conducted in malaria prevention in Gambia they examined interactions of people within their social and physical environment using social ecology model of behaviour change (Panther-Brick et.al, 2005).

The Health Belief Model (HBM)

The Health Belief Model is a psychological model that seeks to explain an individual's behaviour through predictions. The HBM focuses on understanding the perceptions of an individual towards a health condition and the proposed interventions and predicts the extent to which an individual will be willing to adopt the health intervention (Tarkang and Zotor, 2015). The assumption that led to the development of this model was that individuals are generally scared of diseases and getting sick, however, their response to preventing the sickness relies on the extent to which the cure will benefit them more and have less harmful effects (Hochbaum, 1958; Rosenstock, 1966).

The Health Belief Model was developed in the 1950s by social psychologists who sought to describe the poor participation of people on diseases prevention programmes (Glanz et.al 2002). In 1952, Hochbaum (1958) conducted a study with a sample of 200 adults with the aim of exploring their readiness to obtain X-rays taken in tuberculosis screening. This study was aimed at understanding their perceptions on their susceptibility to tuberculosis and perceptions on the perceived personal benefits of early detection. The findings showed that 82% of the sample realised their susceptibility to the disease and the benefits of early detection (Glanz et.al 2002). Through this study it was evident that there is strong association between the individual's perceptions of susceptibility to a health condition and the benefits of a health intervention to ease the susceptibility (Glanz et.al 2002). Similarly, another research study found that the frequency of dental visits can be predicted by perceived susceptibility to dental problems (Glanz et.al 2002). In this way, the HBM specifies the beliefs that are responsible for certain health behaviour patterns which can be addressed by educational intervention (Kegeles, 1963).

According to Metta (2016), the Health Belief Model has been valuable in the successful application of many diseases and health issues amongst adults. It has been shown to be effective in increasing voluntary screening for cervical cancer, breast cancer, participation in support groups dealing with cancer, chronic disease controlling, adult physical activity classes, vaccinations and the prevention of HIV and perceptions of risk with this disease (Bailey, 2008; Brewer et al., 2007; Champion and Menon, 1997; Clark et al., 1988; Hay et al., 2003; Juniper et al., 2004; Metta, 2016; Orji et al., 2012; Sherman et al., 2008; Taylor et al., 2007; Winfield and Whaley, 2002). This model

emphasizes the role of an individual and the individuals' choices in terms of their perceived notions to cause a change in their behaviour (Metta, 2016; Tanner-Smith and Brown, 2010). The major drawback of this model is the attempt to isolate the individual and remove other social factors such as culture, tradition and other group behaviours that contribute to the way an individual may think, perceive and behave (MacKian, 2003; Metta, 2016; Roden, 2004).

There is a shift from the HBM being used for screening behaviours to include preventive actions. This supports the relevance of the use of HBM in this study as its focus is on the role of community leaders in effective implementation of oral PrEP amongst the AGYW of Vulindlela. This study was conducted to determine the overall attitude and knowledge of oral PrEP amongst community leaders for AGYW in Vulindlela. The HBM was used to further understand perception of risk and barriers/enablers of community leaders. The researcher also aimed to find out what community leaders envisaged as perceived benefits for AGYW to oral PrEP uptake. The HBM further allowed the researcher to explore what could prompt the community leaders to take positive action towards promoting oral PrEP uptake. Taking into consideration the predictive power that the HBM has, the researcher attempted to use it in finding out how community leaders are likely to influence positively or negatively the AGYW because of their beliefs and perceptions. Here the concept of community efficacy (Dutta 2008) would be examined.

Key constructs of the HBM

According to Metta (2016), seeking to improve one's health is a conditioned behaviour that when viewed from the point of inspiring people to seek out specific health care needs, a thorough understanding of their motivation for this should be achieved. For the successful implementation of any health intervention, it is valuable to gain a profound understanding of the complex factors that make up common behavioural practices (Metta, 2016). Once the understanding of behaviour is achieved, the health promotion can be tailored to ensure that it is introduced into people's lives efficiently and effectively (Metta, 2016). The HBM as a model involves the personal beliefs and insights about a disease by an individual and how this affects their health behaviour (Hochbaum, 1958). It also prods on the approaches that need to be developed in order

to decrease the occurrence of the current health problem (Hochbaum, 1958). The HBM has 6 constructs that seek to predict health behaviour, and these will be discussed in detail below.

Perceived susceptibility

Perceived susceptibility refers to an individual's belief or attitude towards the risk of contracting a health condition (Glanz et.al 2002; DiClemente and Peterson, 1994). This construct suggests that individuals assess their risk levels or extent of their susceptibility to a health condition before adopting a health behavioural change or intervention. If the perceived risk is considered as significant such as having detrimental effects on the physical components of a human being, causes great physical pain, or any other human associated discomfort and displeasure, then the more likely it will be for an individual to adopt the behaviour that will reduce the risk of them contracting the debilitating disease (de Wit et al., 2005; Metta, 2016; Taylor et al., 2007). An example of this would be homosexual men obtaining vaccinations to prevent contraction of Hepatitis B and also adopting the use of condoms during sexual acts to prevent the likelihood of contracting HIV/AIDS (Belcher et al., 2005; de Wit et al., 2005). Another example of perceived susceptibility is in people who choose to obtain vaccinations for the flu virus (Chen et al., 2007). Individuals are motivated to adopt a health behaviour when they strongly believe that they are prone to the infection thereby making them susceptible to the condition.

The opposite is also likely to occur which is a disadvantage of this construct. If a person believes they are not susceptible to a health condition or if they perceive that they have very low susceptibility, they tend not to adopt preventative measures available to them and may even adopt unhealthy behaviours. An example of this is in the case of older adults who choose not to protect themselves against HIV/AIDS during sexual acts since they perceive that they have lower chances of being infected (Maes and Louis, 2003; Metta, 2016; Taylor et al., 2007). Similarly, in another study, Asian American college students opted not to protect themselves during sexual acts since they had the perception that HIV/AIDS was not an Asian epidemic, hence they were at a lower risk for contracting the disease (Yep, 1993). While individual perceptions of susceptibility are important, they are not always correct and sometimes increases the

individual's chances of contracting a health condition. This was evident in the case of Asian American college students who increased their risk to HIV infection as a result of a misplaced belief (Lamanna, 2004; Lewis and Malow, 1997). In the context of this study, it is important to understand the extent to which community leaders perceive the risk or susceptibility of young women in their community to HIV infection as this will influence their response towards this epidemic and further determine their willingness and lack thereof to adopt oral PrEP.

Perceived severity

Perceived severity refers to an individual's belief of the seriousness of the condition and its consequences towards their health and wellbeing. These consequences are not only limited to medical and clinical factors but also includes social and economic factors that could be a result of the health condition. For example, losing a leg as a result of a health condition would not only affect the individual's health but also the social and economic status in society as their ability to do certain jobs may be limited to some extent. Perceived severity assesses an individual's certainty about the seriousness or severity of a health concern, which may be based on factual knowledge or medical data, or else it would be based on the beliefs they hold about the socio-economic challenges it would create and the negative impacts it would have on the individual's life (McCormick-Brown, 1999; Metta, 2016; Taylor et al., 2007). If the perception of severity to a disease is great and could cause intense physical pain or discomfort, threatens one's livelihood or disrupts an individual's social standing, it could motivate an individual to adopt a health behaviour (Metta, 2016; Stretcher and Rosenstock, 1997; Taylor et al., 2007). In the context of this study, if the community leaders perceive severity of the HIV infection among AGYW then they are likely to take action and promote oral PrEP as a HIV prevention intervention with the hope to reduce the new infections among AGYW in the community of Vulindlela.

Perceived benefits

Perceived benefits refers to an individual's belief on the efficacy of the recommended action to reduce risk or seriousness of a health condition or impact thereof. The concept of perceived benefits is based on an individual's opinion of whether the promoted health behaviour is beneficial, valuable or useful in lowering the risk of contracting the disease (Metta, 2016; Taylor et al., 2007). A positive health behaviour is more likely to be adopted by individuals who believe that it will play a role in decreasing their chances of acquiring a particular illness (Metta, 2016; Taylor et al., 2007). An example of this is colon cancer screening in the form of a colonoscopy that involves preparation such as a diet to completely cleanse the colon, a lengthy tube with a camera for insertion into the length of colon and a long recovery time is seen as beneficial for early detection (Metta, 2016; New York-Presbyterian Hospital, 2006; Taylor et al., 2007). In this example, the procedure itself is not painful but a bit uncomfortable, however, if an individual believes it is beneficial, she or he would do it. Similarly, the daily intake of oral PrEP in a tablet form may not be appealing to some individuals but because of its benefits they make take it.

If colon cancer is detected early, it has a 90% cure rate, however just 36% of people who are most at risk (50 years or older) actually get the screening done (Metta, 2016; New York-Presbyterian Hospital, 2006; Taylor et al., 2007). Interestingly, in this example, it was discovered that women who have seen this screening test as beneficial are more likely to choose to be screened (Frank and Swedmark, 2004). The same was found among women who perform breast self-examinations, when this is performed regularly it is key to early detection of breast cancer and women who found value in this method have adopted this into their self-care routine (Graham, 2002). Similarly, establishing and understanding the perceived benefits of oral PrEP for AGYW in Vulindlela will have a positive influence in its implementation among AGYW. It is critical that the perceptions of community leaders on the benefits of PrEP for young women is understood as this will determine the extent to which they will be willing to support the implementation of PrEP for AGYW in their communities in an effort to curb the spread of HIV infections among this population group. Community leaders, by virtue of their status in the community will be able to give direction towards the adoption of PrEP depending on it's perceived as benefits.

Perceived barriers

Perceived barriers refers to one's belief about the lack of tangible and psychological benefits of the recommended health action or aspects that impede undertaking the recommended behaviour or action (Glanz et.al 2002; DiClemente and Peterson, 1994). In other words, perceived barriers, are the individuals' evaluation of what could possibly hinder them from incorporating a new behavior in their personal life (Hayden, 2013; Metta, 2016; Taylor et al., 2007). This construct can determine whether an individual will be willing to adopt a health behaviour or intervention after considering the possible challenges or negative effects that could result from adopting the intervention (Hayden, 2013; Janz and Becker, 1984; Metta, 2016; Taylor et al., 2007). In order for the individual to adopt the behaviour to reduce their susceptibility and severity to a health condition, the benefits of the new promoted behavior should surpass the possible negatives of the condition, if this is not the case, then the individual is more likely to continue with the previous unhealthy behaviours disregarding the new health behavior being promoted (Hayden, 2013; Centres for Disease Control and Prevention, 2004; Metta, 2016; Taylor et al., 2007).

An example of this construct is the health awareness aimed at increasing self-examinations to check for breast cancer; it would seem almost certain that the risk of cancer on its own would be a motivating factor to adopt the new behavior (self-examination), however, the obstacles to executing this new behavior has more benefit than does the risk of cancer (Champion, 1993; Champion and Menon, 1997; Ellingson and Yarber, 1997; Metta, 2016; Umeh and Rogan-Gibson, 2001). Similarly, in the case of Vulindlela, it could be easily assumed that the risk of AGYW to HIV infections would motivate community leaders to promote the adoption of oral PrEP. However, a thorough exploration was necessary to understand the health and social factors that could act as barriers to the uptake of PrEP by AGYW. Nonetheless, when community leaders perceive the benefits of taking oral PrEP to surpass the barriers then they are might encourage the adoption of the intervention.

Cues to action

Cues to action points to the strategies to activate one's readiness to act. The cues to action construct was added to the HBM in later years and is important for its ability to induce health-seeking behaviour and to encourage individuals to consume medication (Glanz et al., 2008; Graham et al., 2001; Metta, 2016). It specifically refers to events, people or things that induce behaviour changing attitudes in an individual (Graham, 2001, Metta, 2016). The examples of cues to action is seeing someone close to the individual suffer with an illness that they themselves are at high risk for, such as the example by Weinrich et al. (1998) that relates the story of a well-known church member suffering from prostate cancer and this acted as a cue to action for African American men to participate in prostate cancer awareness programs. Media reports and advice from others also play a role in cues to action (Metta, 2016). Particularly with regard to foodborne diseases, media reports, advice from others and warning labels on food packaging all induce a cue to action to adopt cautious food preparation behaviors (Ali, 2002; Hanson and Benedict, 2002). This study also sought to identify the community leaders' cues to action, exploring what could prompt or motivate them to promote the adoption of oral for AGYW in their community.

Self-efficacy

Self-efficacy refers to one's confidence in one's ability to take action (Glanz et.al 2002). The construct of self-efficacy was included in this model in 1988 and refers to the belief that an individual has the ability and confidence to undertake a given task or adopt a behaviour (Bandura, 1977; Metta, 2016; Rosenstock et al., 1988; Taylor et al., 2007). It is generally known that people will only choose to do something new once they believe that they can in fact do it (Champion and Skinner, 2008; Metta, 2016; Taylor et al., 2007). When an individual believes that the promoted new behaviour is useful or have a significant health benefit but does not believe that they are able to do it then they are likely not to try it or incorporate it into their lives (Metta, 2016). For example, women who do not attempt weight bearing exercise for the prevention of osteoporosis and due to a low self-efficacy directed towards exercise or have no confidence in being able to perform the exercise results in them not exercising at all (Wallace, 2002). Thus,

for the purposes of this study, it is important to understand the extent to which community leaders believe that they are able to initiate the promotion of oral PrEP for young women in their community. Through this construct of self-efficacy, the community leader was assessed as an individual if they have confidence to influence the adoption oral PrEP in Vulindlela.

The Culture Centred Approach

The CCA is derived from the critical theory which questions how knowledge is created and communicated. (Dutta 2008). The CCA holds that this knowledge creation process needs to be understood and the researcher can only be able to understand it through participation and engaging in dialogue with that particular group of people or community. The CCA questions and investigates knowledge claims made in dominant health communication approaches, as these always adopt a top-down approach. Communicating about health involves the negotiation of shared meanings embedded in socially constructed identities, relationships, social norms and structure (Dutta 2008). The success of health communication is influenced by how people encode and decode messages within their varying cultural contexts (Dutta 2008). The researcher and community relationship in the CCA is of paramount importance as it allows a reflective space for the researcher to locate his/her values in the dialogue. By so doing, it enables co-construction of meaning or dialogue. (Dutta 2008)

The researcher considers the CCA to be appropriate to employ in this study to explore the community level of the SEMCHB framework in order to investigate the role community leaders can play in effective implementation of oral PrEP in Vulindlela. In the introduction chapter, Vulindlela is described as a rural community characterised by high rates of poverty and unemployment. Also, the Zulu speaking people are well known for embracing their culture. The community leaders take pride in upholding their Zulu beliefs and value systems and can act as gatekeepers and custodians of the rich Zulu culture.

The CCA is used as a lens for understanding health communication (Dutta 2008). It is value centred and emphasizes ways of understanding health meanings that are embedded within cultural contexts and values connected with them (Dutta 2008). The

CCA highlights the prominence of dialogues between local communities and the government so that all aspects of current health issues can be co-constructed (Airhihenbuwa and Webster, 2004; Balde, 2016). Additionally, a study of the cultural frameworks provides understanding of the diverse views and beliefs that are apparent in any society (Dutta, 2015). The culture-centred approach to health communication in a society requires open communication within that society which specifically focusses on cultural participants (Basu and Dutta, 2009). For this reason, community participation should be the crux for developing workable frameworks and applying relevant health communications within that community (Basu and Dutta 2009). Govender (2011) argues that participation is key to all contextual factors of the HIV/AIDS pandemic.

Adopting this approach, cultural perspectives are placed at the centre of any process. In this case, cultured centred approaches to health communication will be co-constructed with both the researcher and the cultural participants in Vulindlela to create, maintain and execute communication on oral PrEP for AGYW (Basu and Dutta, 2009). This will ensure an effective outcome for both health promoters and the communities that are facing the current health risk (Balde, 2016).

Participation is one aspect that is of utmost importance and is evident in the culture centred approach in the health communication field. The health communication method should encompass data gathering from the intended audience with the use of decisive research techniques and message broadcasting approaches all with community participation (Dutta, 2016). This inclusion of the community in health communication allows for what is termed “participatory communication” that empowers communities and increases the extent to which they receive health messages (Dutta, 2016). This facilitates the success of health promotion and is likely to cause a behaviour change within that community (Dutta, 2016). It is for this reason that the researcher employs this approach in this study.

Through this participatory method, participants become agents of change within their communities – they are able to respond to the structural constraints that they face and simultaneously seek to radically change these structures (Duraiappah et al., 2005; Basu and Dutta, 2009; Mubuke and Leibowitz, 2013). Ongoing projects and campaigns create a sense of community ownership through entry points for members

of the community to actively, consistently and sacrificially participate in health communication that they individually deal with on a daily basis (Basu and Dutta, 2009; Omedo et al., 2014). The involvement and participation of community leaders in the decision-making process about implementation of oral PrEP would yield positive results.

To understand the culture centred approach to health communication, it is essential to appreciate the constructs upon which it is built as shown in the diagram below. These are structure, culture and agency (Dutta 2008). While the CCA has three constructs, this study will focus mainly on culture and agency to understand the role of community leaders in supporting the implementation of oral PrEP in their communities.

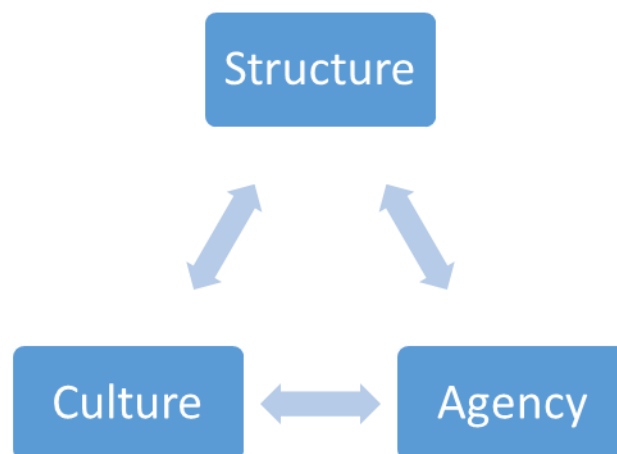


Fig.2 The culture –centred approach to health communication (Source: Dutta 2008)

Culture

“The concept of culture, as embodied in the culture-centred approach, refers to the local contexts within which health meanings are constituted and negotiated” (Dutta, 2008:7). Culture can be defined as an inherited set of inherent and open rules that guide the viewpoints, emotions and the way an individual interacts with their community (Balde, 2016). Culture is something that can be changed over time and has a distinct property of being able to be influenced by people outside that community. In other words, culture is dynamic in its nature (Dutta and Basu, 2011; Balde, 2016).

Within the CCA, the core of the approach is to engage in dialogue with members of the community and come to an understanding of current health issues which involve culture, structure and agency (Basu and Dutta, 2009; Sheik, 2013; Balde, 2016). This inference makes culture a process which is in a state of fabrication and reconfiguration through communication and which leads to a socio-economic and socio-political network branded by values, beliefs, perceptions and communication patterns (Basu and Dutta, 2009; Kandula et al., 2012).

The cultural aspects that an individual adopts play a role in their decision making, influence their thinking and decides their actions in particular ways (Balde, 2016). The perception of risk as well as socially relevant health issues are culturally framed especially in cases where communities still hold on to traditional beliefs and customs (Balde, 2016). Balde (2016) notes the importance of culture with regard to the understanding of health. In order to address any disease crisis, it is suggested that the first step in this process should be to get a firm grasp on the underlying aspects of the population such as their beliefs, opinions and behaviour that determine how they see the current health risk, whether they do acknowledge it as well as whether they are willing to take action for the prevention, treatment and control of the health risk (Balde, 2016). In this study, an exploration of the cultural beliefs and practices of the community of Vulindlela will provide a contextual understanding to the possible role of community leaders in supporting the implementation of oral PrEP. This study recognises that culture is important in influencing and directing behaviour of communities.

Structure

Structure refers to aspects of social organisation that constrain and enable the capacity of cultural participants to seek out health choices and engage in health-related behaviours (Dutta 2008). It is in effect social organization that plays a role with regard to access of resources which determine human behavior in the context of culture and behavior (Hernandex et al., 2006; Basu and Dutta, 2009). Structure also refers to how the healthcare system is organised, and its services delivered (Dutta 2008). Structures are linked with the material resources available to individuals and communities (Dutta 2008). In this study, the researcher examines how community

leaders can effectively use existing structures in enabling oral PrEP implementation in the Vulindlela community.

Agency

Agency is a term that gives indications on an individual or a group's action and how this action gives meaning and co-exists with current structures that are in place (Basu and Dutta, 2009; Stollberg et al., 2015). Dutta (2008) further explains that from a health communication standpoint, agency taps into the ability of individuals and of their communities to be active participants in determining health agendas and in formulating solutions to a variety of health problems, as these are perceived by the community. Participatory spaces are created wherein cultural participants engage with healthcare communicators to finding healthy options and maintaining healthy living (Dutta 2008).

It is also important to note that the three key concepts upon which the CCA is built, are intertwined (Dutta, 2008) and of relevance to this study because community leaders as custodians of culture have a huge influence and their influence could either be positive or negative. This study explored the influential role of community leaders have in getting the community of Vulindlela ready to implement oral PrEP effectively and promote its adoption among AGYW in the community. The researcher adopted the CCA for this study to learn from the stories that the community leaders are sharing about their health experiences; to understand contexts within which these health experiences are realised and enacted and possibly make sense of whether there could be resistance towards the uptake of oral PrEP.

Conclusion

Considering that Vulindlela is a rural community with high rates of poverty and unemployment, it was crucial for this study to consider the role of community leaders in promoting the adoption of oral PrEP among AGYW. This study appreciates that health decisions taken by an individual are dependent on a number of interacting levels as shown through the SEMCHB framework. The study adopted the HBM to further explore the individual level of this framework, realising that community leaders

are first individuals and therefore their individual perceptions are key and important in understanding their role on the adoption of PrEP in the community. Furthermore, the CCA was employed to unpack the community level of the SEMCHB considering that decisions are taken within contexts and these include communities. In other words, the perceptions of community leaders on oral PrEP are likely to influence their willingness to support its adoption among young women.

Chapter 4: Research Methodology

Introduction

The aim of this chapter is to describe the methodology employed on carrying out this research study that examines the role community leaders could play in the effective implementation of oral PrEP amongst AGYW in the community of Vulindlela in KwaZulu- Natal. The research approach that was chosen for this study is clearly stated as well as the justification for choosing it. The data collection method that was used is also explored followed by the description of the sampling technique used.

The interpretive paradigm

This study adopted the interpretive paradigm that is centred on how people construct meaning within their natural environment as the conceptual lens through which the methodological aspects of this research study are examined (Neuman, 2011; Nota, 2015; Kivunja & Kuyini, 2017). The interpretivist paradigm in this study was important in understanding the subjective world of human experience. This study endeavoured to understand the manner in which community leaders interpret their world and make meaning of the issues affecting them. In other words, the social meanings that community leaders attach to the implementation of oral PrEP amongst AGYW in their community were explored as the value of this paradigm lies in these fine interpretations of the world. Oral PrEP gives those at high risk of contracting HIV a chance to protect themselves. This was an important investigation since HIV prevention is a key area of concern in the Vulindlela community.

Through dialogue, the researcher gained access and understanding of the community leaders' interpretation of the world around them. The use of this interpretive paradigm illustrated the importance of understanding the contexts in which individuals formulate their truths and meanings to certain situations. This paradigm further emphasises the importance of understanding the individual rather than universal laws (Kivunja & Kuyini, 2017). In short, the interpretivist paradigm holds that reality is socially constructed. (Kivunja & Kuyini, 2017). In this paradigm, theory follows research so that

it is grounded on the data generated by the research act, theory does not precede research (Kivunja & Kuyini, 2017). The community leaders are gatekeepers and people of influence in their community; therefore this study will show the interconnectedness between the AGYW and community leaders.

The philosophy of interpretivist research involves qualitative methods that do not assume or predict social responses but aim to understand social phenomena (Chiwara, 2017; Snape, 2003). The understanding is pursued in many different ways. In interpretivist research, a social phenomenon is assessed by the meanings assigned to it (Lather, 2006; Stinson and Bullock, 2013). The interpretive paradigm focuses on meaning and the philosophy of what exists or nature of being (ontology) or how people may understand reality (epistemology) (Neuman, 2011; Nota, 2015).

Unlike quantitative methods, in this case, the social world is navigated by meaning and human influence – this is one paradigm of qualitative research (Chiwara, 2017; Snape et al., 2003). The difficulty with this philosophy lies in deciding what aspects of the study should be accepted based on the researcher and respondents' point of view as well as concerns with any part of the study not being generalizable (Eslami, 2013).

The definition of the interpretive paradigm incorporates the idea that the researcher is aware of cultural and historical derivations of the social norms that exist (Crotty, 1998). One of the fundamental aspects of this paradigm is that the researcher is required to take into consideration the reasoning behind why people have a certain perception and what aspect of society influences this perception (Chilisa, 2012; Neuman, 2011; Nota, 2015). The concept of interpretivism stems from the impact the social world and the researcher has on each other and presents it in a way that incorporates both the respondent and researchers' own understanding (Chiwara, 2017; Snape et al., 2003). With regard to this research, the aim was to decipher the perception of leaders in society towards PrEP and what informs their perception. The philosophical foundation then, not only focuses on the perception of community leaders in society but also to identify the cultural and contextual influences that drive these perceptions (Nota, 2015). Thus, by gaining an understanding of the community leaders' preferences, attitudes and overall sincerity with regard to adopting oral PrEP, a greater benefit to society could be reached. As a qualitative method of research, the interpretive paradigm emphasizes the value of investigating a perception in great detail to gain a

more profound understanding and viewpoint (Neuman, 2011). The facts retrieved from this investigation may be context specific and adopt the notion of respondents having subjective viewpoints on reality based on their individual experiences (Chilisa, 2012; Neuman, 2011).

The interpretive paradigm is the framework of qualitative research (Cardey, 2006). The ontological paradigm dictates that reality has limitations of context, space, time and individuals cannot be extrapolated as a general conclusion (Chilisa, 2011; Vukapi, 2015). The interpretive paradigm dictates that participants are interactive and are able to create and define meaning (Vukapi, 2015). In an interpretive study, the aim is to establish an understanding of social life and investigate how people create meaning in a natural environment (Neuman, 2011; Vukapi, 2015). Qualitative research is preferred in this research study considering that the researcher does not come with a preconceived idea that excludes the opinions and perceptions of the target audience (Vukapi, 2015). A participatory inquiry will be created where the researcher and respondent are able to actively engage in gaining knowledge around the topic under study (Vukapi, 2015).

Research Approach

This study adopted the qualitative research approach to explore and understand the role of community leaders in the promotion of oral PrEP among AGYW in Vulindlela. This study sought to explore the perceptions of community leaders on the issue of oral PrEP implementation for AGYW and explore what they could be in ensuring effective implementation of this HIV prevention intervention in their communities. The qualitative approach is useful for this study as it attempts to understand people within their social settings. As such, being able to consider and understand the social setting in Vulindlela that influences the perceptions of community leaders towards PrEP implementation for AGYW was important for this study.

Qualitative research can be described as a social enquiry of how people collate, perceive and make sense of their experiences in everyday life (Chiwara, 2017; Holloway and Wheeler, 2010). Ideally, the research is conducted in a natural, normal environment with a focus on everyday behaviour and provides descriptions of the

norms (Jankowski and Wester, 1990). It can also be defined as a research investigation based on non-numerical information (data). The information may be in the form of images (pictures), words, statements, clothing, written or preserved records, documents and descriptions of situations, norms or behaviour in a particular community, age group, occupation or any related factors (Christensen et al., 2011).

This study examined the influential role of community leaders on the adoption of HIV prevention interventions, PrEP specifically, exploring their willingness to support its implementation for AGYW. It further explored how culture played a role or rather influenced the perceptions of community leaders on the topic of PrEP implementation for young women. Through this research approach, the study endeavoured to answer the research questions on the knowledge and attitude of oral PrEP amongst community leaders for AGYW in Vulindlela; perceived benefits from community leaders that could promote the uptake of oral PrEP with AGYW; perceived barriers that could hinder the uptake of oral PrEP and proposed cues to action. As Berg (2001) puts it the researcher is interested in understanding how these perceptions and truths are formulated within social and cultural settings. He states that “qualitative researchers are interested in how humans arrange themselves and their settings and how inhabitants of these settings make sense of their surroundings through symbols, rituals, social structures, social roles and so forth” (Berg, 2001:6-7). As such, the researcher through the use of qualitative research method also sought to understand how community leaders make meaning of PrEP as a prevention method that could benefit young women in the community considering the influential role of their culture and traditions as well as the social setting.

The research was conducted in a nominalist viewpoint which emphasizes that the way we experience the world, whether physically or socially, is influenced by our cultural backgrounds (Neuman, 2011; Chilisa, 2012; Nota, 2015). Thus, in order to make meaning of the viewpoint, perceptions and attitudes of community leaders on the implementation of oral PrEP, culture had to be recognised as an influencer that could determine or influence how community leaders understand the scourge of HIV in their communities. Furthermore, this study appreciated that AGYW’s health decisions are influenced by the cultural beliefs within their communities and in many communities leaders are perceived as custodians of culture, which made it critical for this study to understand the role of culture while engaging with community leaders.

The research process requires an understanding of the context in which reality is experienced (Rodwell, 1998; Vukapi, 2015). Field-based approaches within the local context are deemed necessary to carry out research investigations (Rodwell, 1998; Vukapi, 2015). With qualitative investigations, an understanding of why things are the way that they are socially, and why people behave the way they do in their daily lives is defined, discussed and analysed (Vukaphi, 2015). This provides a platform where social norms are understood and the change in behaviour is introduced within the confines of societal norms. This would ensure that AGYW are not offended, excluded or placed in a position where they were not informed of an introduced implementation of oral PrEP. It is critical for the researcher to understand the community environment and dynamics from where the respondents live, and take into consideration the factors that play a role in their daily lives (Vukapi, 2015). This is enforced by the core aspects of the qualitative research design where the environment has to be taken into consideration along with the social dynamics and norms – this is due to individuals behaviour which is explicitly tied to their experiences and their immediate community in which they live (Nota, 2015; Shisana et al., 2012; Struwig and Stead, 2013; Vukapi, 2015).

The fundamental purposes of applying qualitative research methods in this study is that they capture the perspectives from the respondent and researcher, where the researcher understands the study topic and experiences from the perspective of the respondent. In some cases, this may be referred to as visualizing the respondents experience from their point of view (Struwig and Stead, 2013; Vukapi, 2015). The concept of contextualism is also critical, where the respondents' behaviour is not understood in isolation from their peers or social influence, but the context is recognised in this learning process. This calls for extensive descriptions and comprehensive analysis of the environment or social norms of the respondent (Struwig and Stead, 2013; Vukapi, 2015). Qualitative research is a process as the respondents' behaviours and interpretation of the world is constantly changing responding to the changes in the world around them (Struwig and Stead, 2013; Vukapi, 2015).

In opting to conduct a qualitative study, the researcher considered various aspects of the study such as what the study will uncover, the level of detail required on the research topic, the manner in which other literature has covered the topic and if any has aligned with this specific research area, if quantitative or qualitative methods are

more appropriate for the study in terms of extracting a great amount of information to provide ground breaking data, and the use of a particular research model (Chiwara, 2017; Silverman, 2013).

Selecting study participants

A purposive sampling strategy, also known as judgemental sampling, was used in selecting the study participants. Purposive sampling is a non-probability sampling that requires sampling of participants based on their knowledge of the topic under study. The purposive sampling technique requires the identification and selection of sample respondents that possess certain characteristics that will assist the researcher to obtain relevant information on the topic studied (Adler and Clark, 2014; Chiwara, 2017). In other words, through this sampling method, the researcher uses his/her judgement to purposively sample individuals that have knowledge and can contribute to the study. Purposive sampling allows the researcher to choose a case or sample because it has some features of interest to the study (Silverman 2000).

In the case of this study, which started with the sampling of the community prior to identifying individuals that would be included in the study, the researcher identified Vulindlela as a research site given the high HIV incidence rate in the community also realising that oral PrEP could be an alternative HIV intervention that could lead to reduced new cases of HIV in this community. Also, the fact that this study forms part of a larger study whose location is Vulindlela affirmed the decision to select these study participants. Once the characteristics of interest were identified in the community, the researcher identified individuals who met the required characteristics (Adler and Clark, 2014; Christenson et al., 2011; Snape et al., 2003) and that is, they had to be community leaders in Vulindlela. For the purposes of this study community leaders referred to traditional leaders and councillors. These community leaders were included in the study if they met the following criteria: the respondent was supposed to have knowledge and experience of the societal and cultural norms within the community; the knowledge of the place and its people; the respondent was supposed to be willing to talk and engage openly, accurately and truthfully about their experiences within the community, and the respondents must be able to represent a

wide range of viewpoints that are present in that community (Rubin and Rubin, 2005; Vukapi, 2015).

The recruitment of the study participants was facilitated by COMOSAT which is a community-based organisation working in Vulindlela. COMOSAT does a lot of community work in the area and have through different platforms engaged with different stakeholders in the community including community leaders on health issues. Thus, in order to ensure that the right participants were recruited for the study, the researcher worked closely with COMOSAT layering on its existing relationships and access to community structures to recruit the study participants.

The process of determining the inclusion and exclusion criteria for the participants was carried out. For the purposes of the study, the study participants did not include all community leaders in the Vulindlela community, but community leaders refer only to the traditional leaders (linduna) and councillors. Other community leaders which include religious leaders from faith-based organisations and churches were excluded from the study. Traditional leaders and councillors were the relevant community leaders for the purposes of this study also considering that in its nature, the qualitative research study does not aim to recruit a sample that is representative of the general population but to select individuals that assist in answering the research questions. As such, it was beyond the scope of this study to include all individuals considered as community leaders to participate in this study. However, those included were sufficient to understand the possible role that could be played by community leaders in supporting the implementation of oral PrEP among AGYW in Vulindlela. The recruited participants met the selection criteria of a sample according to the information and characteristics that the researcher was interested in studying (Struwig and Stead, 2013).

A total of 11 participants were recruited to participate in the study and these included both traditional leaders and counsellors. However, only 10 participants were interviewed for the study as the one participant had pressing commitments and could not find time for the interview. Qualitative studies generally employ a small sample size for the following reasons: there exists a point where no new information is gained with an increasing sample size; the incidence of phenomenon is not of concern; and the knowledge gained is rich in detail to be analysed accurately, the sample size

should not be abundant (Chiwara, 2017; Snape et al., 2003). The characteristic of qualitative sampling is that it uses respondent sampling as representative of a generalized norm in that community or target group (Chiwara, 2017; Eslami, 2013). The practical research aspects of qualitative research are that it is interpretive and is dependent on many types of data that is subjective in nature (Chiwara, 2017; Christenson et al., 2011). This calls for investigating people in specific contexts within the norms of their daily lives (Chiwara, 2017; Christenson et al., 2011). The data is collated and examined before and after the course of the research study, with many attempts on understanding the subjective perspectives of the respondents (Chiwara, 2017; Christenson et al., 2011).

Setting and Population Appropriateness

This research study forms part of a continuing study in the Vulindlela area and the community leaders are stakeholders that needed to be studied. A previous study was conducted in Vulindlela to understand the willingness of AGYW themselves to take up oral PrEP as a suitable prevention option for them. This study is a continuation of this study that was conducted in Vulindlela and aimed to understand the role of community leaders in supporting an effective implementation of oral PrEP for young women in the community. This study is important as young women are also influenced by the views and attitudes on oral PrEP. The assumption is that if community leaders support AGYW to take up oral PrEP then young women are more likely to consider this prevention option, but resistance from community leaders might also lead to AGYW rejecting oral PrEP. Drawing from this previous study, Vulindlela was a preferred research site for two reasons. Firstly, there is already a study that was done in this community that focussed on AGYW as individuals to explore their perceptions and acceptance of oral PrEP, so this study builds on this past study to include an enquiry to the role of community leaders. Secondly, Vulindlela is an HIV burdened community in KwaZulu-Natal and a lot of research is done in the area which has made access to the community easier. The appropriate people (target population) were accessible through the assistance of community organisations such as COMOSAT in this instance.

Data collection method

Multiple data collection methods are used in qualitative studies. This allows the researcher to ascertain the most accurate and suitable method for the phenomena being studied (Chiwara, 2017; Christenson et al., 2011). There are three common data collection methods that are used in qualitative studies. These are in-depth interviews; focus group discussions and observations (Crottell & McKenzie, 2011). All these methods are useful in collecting detailed information but the relevance of employing one method instead of the other depends on the subject studied, the accessibility of individuals and whether one method has the potential of collecting more relevant information. Each method can be used appropriately depending on the different settings or amongst certain subjects and each method has its advantages and disadvantages.

In this study in-depth interviews were used as the preferred data collection method. Most authors agree on defining interviews as a conversation with a purpose (Berg 2001). Specifically, the purpose is to gather or collect information from the participants (Berg 2001). However, they agree less on how an interview is conducted (Berg 2001). An interview is viewed by some authors as not one sided. They refer to this type of interview as active interviewing. Here, the interview is viewed as a “dynamic, meaning-making occasion where the actual circumstance of the meaning construction is important” (Berg 2001:68).

Seidman (2013) places emphasis on in-depth interviews and the value it offers in providing insight into the respondents’ life experience. These interviews can be done using any electronic medium and even face-to-face; with the options of it being asynchronous or synchronous (real time) (Christensen et al., 2011; Seidman, 2013). The questions used in this setting are open-ended and allows the respondent to build on their experience. An understanding of issues surrounding the study topic can also be gained in this manner even if the respondent did not directly refer to it while relaying their information (Christensen et al., 2011; Seidman, 2013). Closed ended and open-ended questions may form part of the interview schedule usually as questions that gather the participant’s demographic information. However, the value of in-depth interviews is that the actual interview on the subject matter should not be limited by

closed questions, but questions asked must allow for a detailed discussion and the researcher should be able to probe for clarity where the need arises.

In-depth interviews were used as a preferred data collection method, it was appropriate and relevant for this study as it uncovered feelings and attitudes of the community leaders in Vulindlela regarding the issue of effective implementation of oral PrEP amongst AGYW. This data collection method was also used because the participants were few therefore, there was sufficient time to unpack in detail the themes studied with the aim of getting a detailed understanding of the perceptions and role of community leaders on PrEP implementation for AGYW. There were ten participants that were interviewed and this small number allowed for in-depth discussions as it was easy for the researcher to glean useful and relevant insights especially on what community leaders perceive as barriers or benefits that could hinder or promote the uptake of oral PrEP by AGYW. Another reason for choosing in-depth interviews for this study is that it was easier to explore each leader's proposed cues to action to promote the implementation of oral PrEP with AGYW in Vulindlela, without fearing other leaders which could have been the case if focus group discussions were chosen as data collection method. One on one engagements gave them an opportunity to express themselves in a free and unintimidating environment.

In-depth interviews were also appropriate in this study in order to understand how the community leaders of Vulindlela make sense of what is happening with the AGYW in their area. (Welman et.al 2005) As influential people their beliefs and convictions play a big role in either positively or negatively influencing the decision taken by the communities around them. This then means they can be of great influence to the AGYWs decision making regarding oral PrEP.

An interview schedule was developed which is a list of questions that the researcher used as a guide when asking questions. The interview schedule serves as a guide and helps to direct the discussions so that the interview doesn't completely deviate from the themes studied, this helped to ensure that as the conversation flows the relevance of the interviews to the subject studied was maintained. These questions were mostly open-ended, and the researcher probed where the issues raised by the participant were not clear in order to gain a detailed understanding. The researcher asked the participants questions around knowledge about oral PrEP, HIV prevention,

benefits and barriers to oral PrEP uptake by AGYW, cues to action and available resources in Vulindlela to promote oral PrEP uptake.

The interviews were recorded using audio-tape recorder, the aim of this was to ensure that all the discussions were well captured, and that the researcher could focus on the participant's interview without having to take detailed notes. The audio recording was also to prove their authenticity and trustworthiness of the interviews. The consent form was signed by all participants for recording the interviews. Silverman (2005) states that it may not be possible to recall all the conversation/interview so audio tapes come in handy in reminding the researcher of the pauses, sighs, in breaths and overlaps made by the respondents. Tapes can be replayed, and transcriptions can be improved.

Once this phase of the research is complete, the idea of being an 'objective outsider' is applied that removes all previous notions on the study topic and respondents and takes on the information at hand which is the interpretative-subjective data (Chiwara, 2017; Christenson et al., 2011). This then relates to the research aims and the research questions that are attempted to be answered (Chiwara, 2017; Christenson et al., 2011). This type of study is more flexible in that it allows the research questions to evolve with the study and possibly change during the course of the investigation (Chiwara, 2017; Christenson et al., 2011). The phenomena should be explored at length and possibly to the point of being able to generate theories (Chiwara, 2017; Christenson et al., 2011).

Data Analysis

The researcher in this study used the thematic analysis approach which is a method for identifying, analysing and reporting patterns (themes) within data (Braun and Clarke 2006). Thematic analysis is a flexible approach to analyse qualitative data (Braun and Clarke 2006). It has six steps according to Braun and Clarke (2006). Firstly, the researcher familiarised herself with data. It was at this stage where the researcher listened to audio recordings and transcribed into a word processing package. This allowed the researcher an opportunity to listen again and again to interviews and start to make notes. Secondly, the researcher assigned preliminary codes to data. Here, the researcher briefly described what was said in the interview using codes or

descriptions. Thirdly, the codes were organised into themes and further broken down into subthemes. The researcher has adopted an inductive way of determining themes. This means she used data as the starting point and themes emerged from data. Themes were reviewed, defined and named. Finally, the stage where the report was produced is the final stage (Braun and Clarke, 2006). As guided by interpretivist paradigm, she did not declare theoretical position. The data was generalised from the themes and interpreted in the light of the available literature. It is also important to note that the researcher did not only analyse what community leaders said in the interviews but also things that were not said.

Ethical considerations

Ethical considerations are of utmost importance when conducting research. An informed consent form must be signed after the respondent has been truthfully informed of the purpose of the study, he/she must consent to take part. This can be done by means of signing an informed consent form on the day the interview was conducted. In this study informed consent was obtained from the study participants. The aims and objectives of the study were explained to the participants, their participation in the study was also unpacked so that participants are fully informed prior to taking the decision to participate. The main issues that were emphasised during this discussion were the issue of confidentiality, no identifying information of the participants is used in this study. Voluntary participation was also explained emphasising that participants had the right to withdraw their participation from the study at any given point and that they would not be penalised in any way for doing so. Once the consent was explained and participants given the opportunity to ask questions, the consent form was signed, and the participants were given a copy of the form. In this study the researcher has considered all the above factors and ethical clearance was obtained from the University of KwaZulu-Natal to conduct the study. Ethics approval number is BE 500/17.

Validity and reliability

Reliability is mostly based on dependability and consistency, while validity refers to trustworthiness (Neuman, 2011). In a research study it is imperative that the reader believes that the research was conducted in a trustworthy manner and incorporates the dependable findings of respondents - in other words, the research would have occurred according to the recorded facts by the researcher (Durrheim and Wassenaar, 1999; Neuman, 2011; Vukapi, 2015). Silverman (2005) also defines validity as another word for truth. He further states that the claims of a research study cannot be said to be valid if the criteria or grounds for including certain instances and not others are not provided; and if the original form of materials is unavailable. In this study, reliability can be found in the consistent findings of the in-depth interviews and validity is proven in the original form of the materials that can be accessed.

Limitations of the study

Time and language were the two limitations of the study. Interviews were conducted in isiZulu, the researcher tried her best in getting the participants understand the questions as isiZulu is not her first language, and for some both English and isiZulu languages were used. Time constraint was another limitation. The community leaders have busy work schedules. Despite the fact that appointments were arranged two weeks in advance and telephonic calls made a day or two prior to the day, there would still be cases where leaders would spend less time for the interview because of other commitments that they had to attend to. However, the researcher mitigated the time constraints by focusing on open-ended and probing questions. This made the researcher to get the most out of the interview.

Conclusion

In conclusion, this chapter detailed the research methodology employed in this study. The study was placed within the interpretive paradigm that sought to understand the socially constructed truths about the world. Drawing from this, the qualitative research

approach was adopted to understand the role of community leaders in the effective implementation of oral PrEP among AGYW. This research approach allowed for a contextual understanding of the perceptions and attitudes of community leaders towards AGYW's adoption of oral PrEP.

Chapter 5: Research Findings and Analysis

Introduction

The main focus of a qualitative investigation is to gather the perceptions, thoughts, attitudes and feelings of individuals towards social change on a particular concept (Holloway and Galvin, 2016; Merriam and Tisdell, 2015). The purpose of this chapter is to present the research findings on the perceptions of community leaders about implementing oral PrEP in their community among AGYW. It further provides an analysis of the research findings. This study further sought to uncover the barriers that may prevent community leaders from accepting and implementing oral PrEP, the factors that contribute toward the acceptance of oral PrEP and their views on resources available to facilitate the implementation of this HIV prevention method.

Through this study, a large amount of rich data was collected through the use of in-depth interviews with the community leaders but in order to make it more understandable, the data was broken down into themes that emanated from the research. The researcher engaged with the data to identify common themes and subthemes that emanated from the research, analyse patterns in the data, and relate the findings to the research questions (Miles et al., 2013; Ritchie et al., 2013). These themes were then used as the main categories for unpacking and analysing the data collected. To recall, this study was guided by three research questions; the first research question was: what is the knowledge and attitude of oral PrEP amongst community leaders for AGYW in Vulindlela? The second was: what are the perceived benefits or barriers from community leaders in Vulindlela that could hinder or promote the uptake of oral PrEP with AGYW? The last research question was: what are the proposed cues to action for community leaders with AGYW in Vulindlela? The findings presented in this chapter sought to answer these questions.

Setting the scene

To provide context to this chapter, it is worth noting that the data was collected from community leaders which included 6 ward councillors and 4 traditional leaders in the community of Vulindlela. The gender composition of these participants was solely males which could have also had an influence whether positive or negative on how they relate to the HIV scourge among young women specifically. While they considered themselves as representatives of the communities they serve, there were concerns about the extent to which they could truly grasp with the challenges facing young women in the community and reflect these in their efforts to reduce new infections from their own (male) perspective. Therefore, in ensuring that the results presented are contextually understood, it is important to know that the findings of this study reflect the perceptions of male community leaders on an intervention that is targeted to benefit young women mainly in the community. Bearing this mind allowed the researcher to reflect on the findings from the study in two ways. Firstly, acknowledge that male participants are speaking on behalf of young women and their attitudes and perceptions on the issue might be experienced from an outside view, as they may not understand it from the perspective of a woman or a young woman. Secondly, community leaders are in charge of the entire population including both women and men, thus their views may reflect the knowledge and understanding of the HIV dynamics experienced in their community. All these views are important in exploring their role in supporting oral PrEP implementation among young women but assist in better contextual understanding of their role.

Furthermore, the participants interviewed for this study were between the ages of 20 and 50 years. In the main, the councillors represented the younger proportion of the participants whereas the traditional leaders were older in age compared to the councillors. The age disparities were also important to understand in this study as they could have influenced the manner in which the young and the old understand HIV issues in the community as they affect young women. As such, it was important for the researcher to also factor in the age differences in unpacking and understanding the perceptions of community leaders on the adoption and implementation of PrEP. Another factor worth noting is length of service in the community, the traditional leaders had been serving communities longer than the councillors. This can be

attributed to the fact that councillors are elected every 5 years and still tend to be changed frequently even before the 5 years expires, whereas traditional leaders serve for very long periods as their leadership does not have set end dates. Thus, in this context the researcher was also interested to understand through observation how the years in office of the community leaders influenced the manner in which they perceive the HIV challenge among young women in the community. As qualitative research holds, the aim was to extract rich data from the councillors that would inform the manner in which health interventions are understood and supported in communities. The study was not meant to be generalized amongst the broader population but to provide a substantial understanding of the community of Vulindlela and the responses of community leaders towards the implementation of prevention methods that have the potential to reduce the spread of HIV in their communities among young women.

Themes that emanated from the research

From a theoretical perspective, the themes focused specifically on identifying the perceived risk, perceived barriers, perceived benefits and cues to action. The SEMCHB was also used to understand the interpersonal workings of social relationships and how it may influence the acceptability of the new HIV prevention method which is oral PrEP. The CCA model emphasizes the importance of amplifying the voices of marginalized communities, in this case, the community leaders who are the gatekeepers for community members including AGYW.

As mentioned above, the data is presented in themes that emanated from the research. There are five themes that were identified from the research that help in understanding the research findings. Through these themes the key issues coming up from the research are discussed unpacked and analyzed. The first theme relates to the knowledge about oral PrEP in the community. This theme sought to unpack the knowledge that community leaders had on oral PrEP as this could have had an influence on the extent to which they will be willing to support its implementation. The second theme looked at the barriers of oral PrEP implementation, this reflected what community leaders perceived as challenges that would hinder the implementation of PrEP in the community. The third theme focused on the promotion of PrEP in the

community. This unlocked the opportunities as identified by the community leaders to support the implementation of PrEP in their community drawing from existing resources in the community. The fourth theme related specifically to the implementation of PrEP among young women noting the opportunities for implementation as well as the possible barriers faced by this population group in the community that could hinder PrEP implementation. The fifth theme was on how community leaders perceived their role in the promotion of PrEP. In this they reflected on the opportunities and resources available in the community that would facilitate the implementation of PrEP in the community. The last part of this study discusses the theoretical relevance of the study drawing from these themes. Each of the themes will be discussed in detail below.

Knowledge about oral PrEP

Given that oral PrEP is a fairly new intervention, the participants were asked about their knowledge of oral PrEP, if they have ever heard about it, what they understood about oral PrEP. Most participants reported that they had never heard about PrEP and the few, who had heard about PrEP, did not have sufficient knowledge about it to comfortably share with others what it was. In order to facilitate the interview and ensure continuity, the researcher explained to each participant what oral PrEP was, its aim, its benefits, some results from the studies done on the effectiveness of PrEP. This brief explanation about PrEP ensured that the community leaders could continue with the interview with that knowledge and provide their perceptions and attitudes towards it. It was observed that community leaders showed interest on learning more about this intervention as they asked numerous questions to understand this method and how it could assist in the fight against HIV in their communities. While this information was shared with the community leaders but for the purposes of this study sub-themes were identified under the theme “knowledge about oral PrEP” and these sub-themes include lack of knowledge about oral PrEP, the need for education on PrEP for community leaders, the awareness of risky sexual behaviour among young women. These sub-themes are unpacked below.

“...the most difficult one is to abstain. That one is difficult. But should you fail to abstain then you can use protection, different types of protection that are available out there” (Traditional Leader 1, Sept 2018).

“...normally what is dominant is the usage of condoms or abstinence to prevent HIV and AIDS” (Councillor 2, Sept 2018).

“... obviously that’s includes things such as the use of condom, abstaining from sex should you foresee any problems” (Councillor 4, Sept 2018).

Another participant opined that circumcision is also a prevention method, while another highlighted the non-sexual precautions with regard to HIV transmission.

“...we often encourage males to get circumcised when they turn 18” (Traditional Leader 3, Sept 2018).

“There are certain precautionary measures that need to be taken when you are assisting someone who is injured” (Traditional Leader 3, Sept 2018).

While PrEP was a new concept to many of the study participants, but they had knowledge of other HIV prevention options which they have been promoting in their communities. All the study participants had a clear understanding of what HIV prevention means and cited the common forms of prevention methods including the use of condoms and abstinence.

Lack of knowledge among community leaders about oral PrEP

Generally, there was lack of knowledge about oral PrEP among community leaders. When the participants were asked if they knew anything about oral PrEP, the following are some of the responses:

“No, I know that a person can use a condom but I haven’t heard of this pill before” (Traditional leader 1, Sept 2018).

“Can you explain what you mean by oral PrEP” (Councillor 1, Sept 2018)?

“Even though it’s not a lot of information.....” (Councillor 2, Sept 2018).

From the above responses, it is evident that amongst community leaders the level of knowledge about PrEP and how it works is limited. This is similar to what Burns et.al (2014) cited in literature review that limited knowledge to oral PrEP is a barrier to oral PrEP uptake. The perceptions that community leaders formulate about oral PrEP are most likely to be influenced by their lack of knowledge of the intervention. Given the influential role of community leaders, it is important that they are well informed about the available interventions that could benefit their communities. Their response towards the implementation of oral PrEP among young women could be limited by the lack of knowledge.

Even though community leaders showed interest in the intervention, the brief education provided during the interviews was not sufficient for them to make well-informed decisions about the benefits of PrEP beyond just the prevention of new infections and also understand the challenges of oral PrEP. Therefore, in order to appreciate the benefits of PrEP, there is need for intensified education to be provided among community leaders so that they can better decide on the extent to which they believe on the efficacy of PrEP or lack thereof. Even though PrEP is known to be a beneficial intervention in the reduction of HIV but community leaders need to also understand this and make their own decisions on the extent to which they wish to support its implementation without feeling coerced into its adoption.

Education for oral PrEP for community leaders

There were differing opinions in Vulindlela on the realities of oral PrEP, how it works, how it could possibly benefit the community specifically young women in the

community. As mentioned above these all stemmed from the lack of knowledge about PrEP. The community leaders had not been properly educated on what oral PrEP is and how it would affect their lives. In a few cases where some have heard about PrEP, they learnt about it from CAPRISA which was running a PrEP study in the community of Vulindlela. However, the information/knowledge they had was not sufficient to make them fully grasp on how it works and how it could reduce new infections among young women which was reported as a serious challenge in the community.

“...we have not been exposed ourselves into hearing how PrEP works, what are the side effects, if there are any, how do you take PrEP, where does it help you, what kind of person should take PrEP and all those things” (Councillor 2, Sept 2018).

“...you know you hear about something on the street and sometimes you think no, only in New York, not now” (Traditional Leader 1, Sept 2018).

“...if I’m not mistaken, (it is) one of the forms of HIV prevention methods that are going to contribute into the prevention of HIV” (Councillor 5, Sept 2018).

“To be honest, even though I’ve never heard of the dangers of PrEP but.....it’s just that I think we can get that kind of information from CAPRISA” (Councillor 1, Sept 2018).

Drawing from these responses, there is clearly a need for community leaders to be educated about oral PrEP in order for the full effectiveness and implementation of this intervention to be realised in the community. Given that community leaders are the key gatekeepers in their communities, their role in the implementation of oral PrEP is important. As such, it should be key that they get the necessary education with the assumption that if they understand the benefits of PrEP in responding to the high rates of HIV infections among young women in their community then they are more likely to support its adoption and implementation. It can be argued that the poor education on oral PrEP among young women is a missed opportunity for the adoption of PrEP

because leaders have access to communities and can influence communities to some extent to adopt a health intervention

“...to get more education for myself so that when I speak, I speak about something that I know” (Councillor 2, Sept 2018).

“That’s why I was saying we need to be educated about it” (Councillor 4, Sept 2018).

The fact that they are willing to be educated and gain more knowledge on PrEP is an opportunity that should be used to ensure that community leaders are able to engage with their communities through different forums to educate about PrEP and also encourage community members to adopt it.

Awareness of risky sexual behaviour among AGYW

The study participants realised the HIV challenge in their communities especially among young women. They raised great concern about the risky sexual behaviours that young women engaged in that increased substantially their risk of HIV infection. This risky sexual conduct could be attributed to a number of socio-economic factors in the community which included mainly poverty and unemployment. The community leaders reflected on the fact that there were high rates of poverty and unemployment in the community and young women ended up engaging in sexual relationships with older men in order to support their families and meet their needs. The type of relationship that is common in the Vulindlela usually involves older men playing the role of ‘blessers’, where financial favours are exchanged for a sexual relationship with multiple young women. As literature have shown, age disparate relationships increase the risk of HIV infection because older men have greater chances of being HIV positive as opposed to young men. Furthermore, in these age disparate relationships young women are unable to negotiate the terms of sex such as the use of condoms because of the power dynamics in such relationships. These older men tend to have power and dictate the terms of sexual engagement with their young partners thereby increasing the HIV risk towards young women.

“There are many people who are not aware, and you find that older people are taking advantage of their vulnerability” (Councillor 4, Sept 2018).

“Even your boyfriend, you don’t know what he does, you don’t know his ways. You might think that I met her when he/she was negative but as you are saying, maybe she has a ‘blesser’ and maybe the young man also has another girlfriend on the side” (Traditional Leader 1, Sept 2018).

“I think that is where it is most important, to take powers back to women as well as control for prevention back to women themselves... if they are in relationships with ‘blessers’, the power is not with them. It is with the ‘blessers’, depending on what they buy for you and what they do for you and all those things. Therefore, they even control the relationship, what happens and what cannot happen in the relationship, even regarding sex. He just brings what he came with, and then he takes what he wants and leaves. Then in that way infection occurs very easily” (Councillor 5, Sept 2018).

The study participants further highlighted many factors that contribute to the spread of HIV and unsafe situations that AGYW are often exposed to. They emphasized the occurrence of rape, accidents, peer pressure and poverty which play a role either directly or indirectly to the spread of HIV.

“So, when you say it prevents in other instances such as when you are involved in a car accident, or in cases of rape, which is something that occurs every day... So in that situation if a person has been using [Oral] PrEP then automatically they will be protected” (Councillor 2, Sept 2018).

“It’s worse now because you may think your children are safe, but you find that they are getting raped by people they live with. So, it’s a good thing” (Councillor 4, Sept 2018).

“I think a lot of people can take it because it would mean that whatever happens I will be protected by this oral PrEP pill. So, I don’t see it as similar to ARVs” (Traditional leader 1, Sept 2018).

“Like you have said, it can be very helpful among adolescents so that whatever pressure they have, it can be of peer pressure, it can be of poverty or whatever, they can be able to keep themselves safe even in those circumstances” (Councillor 5, Sept 2018).

The underlying factors that contribute to ill-health and the spread of HIV play a key role on the emotional well-being of AGYW and leads to them making decisions that may not be in their best interest. The success of oral PrEP also depends on the immediate surroundings of AGYW and their overall perception of life.

“Because what makes us vulnerable as young people mainly its poverty and unemployment. ... If you are educated you take value on yourself but if you are not educated you just want things to come easily because you are hungry, and you are unemployed..... So, we need to deal with the real issues which are unemployment and poverty. Poverty caused by unemployment” - (Traditional Leader 1, Sept 2018).

“We have no job opportunities, and that’s also one of the things that make people not so keen on taking medication because you find that they don’t even have food at home” (Councillor 1, Sept 2018).

“Teenage pregnancy is a problem so there really is a need to engage young girls” (Councillor 1, Sept 2018).

“But not only the young people, even the married people they must take oral PrEP because you find that people are married but they have other things that they are doing on the side. I think the nature of us as Africans, you see our culture and tradition allows other people to have multiple partners so that gives a person leverage for someone to have another relationship so the way our culture is, it allows an open relationship somehow” (Councillor 2, Sept 2018).

Recognising the sexual behaviours that increase the risk of HIV acquisition among young women was important as the adoption and support for PrEP starts with realising the HIV challenge in the community thereby appreciate the implementation of PrEP to respond to this growing scourge. The community leaders believed that PrEP would assist in reducing new infections given that the sexual risks were high in their community among young women. Also given the power dynamics in the “Blesser-Blessie” relationships where sex is not negotiated to allow for safer sex practices, the community leaders believed that PrEP would offer an opportunity for young women to be in control of their prevention options. Unlike condoms that require negotiation with the partner, oral PrEP was viewed as more empowering to young women as they could take it on their own without feeling the need to inform their partners. The user-centred strength of PrEP was more appealing to some community leaders as they believed women need to be empowered to take their health decisions on their own and change the dominant narrative in the community that men have power over women even in issues that relate to women’s health.

Barriers to oral PrEP implementation

The second theme relates to the barriers that may hinder the successful implementation of oral PrEP in the community of Vulindlela. Following the brief education session on oral PrEP, the participants were asked about their perception of PrEP as a prevention intervention that could reduce infections among young women. Among their perceptions they also reflected on what they perceived as possible barriers to the adoption and implementation of oral PrEP. The community leaders understood the need to implement an intervention like PrEP in their community as they were also concerned about the HIV challenge in their community but added to this was the concern about its effective implementation noting the stigma that is attached to HIV and its responses as well as the accessibility of PrEP in their rural community.

“I am not scared of falling pregnant or getting STIs. The main reason we use protection is because of HIV. I am saying this because as

much as it will help to prevent HIV infection, you may see a rise in the other things such as STIs” (Traditional Leader 1, Sept 2018).

“We can even market it in meetings, even in churches and schools, as children as young as 11 years old are now getting pregnant. Even though the pill does not prevent against pregnancy, but they can be protected against HIV infection” (Traditional Leader 1, Sept 2018).

The study participants voiced concerns on the factors that may hinder individuals in the community from taking oral PrEP. Some of these reasons are that individuals may be complacent with their healthcare, feel pressure from their peer groups, people may see those taking pills and assume things about them, and people may feel ashamed to be on treatment and pre-treatment. The similar parallel has been drawn for ARV treatment, where individuals still feel negative emotions when taking their treatment and are afraid for others to find out. One participant expressed that oral PrEP may encourage individuals to be negligent with their sexual behaviour and not use any other type of protection such as condoms. This is an issue that needs to be addressed given that oral PrEP prevents HIV transmission but does not prevent STI transmission or unplanned pregnancies.

Stigmatisation of HIV and oral PrEP

Literature highlights that there is still stigma towards people living with HIV in South Africa and to HIV in general. This stigma continues to be observed even in the presence of intensified education in the community and the integration of HIV services in health facilities to be part of all chronic diseases. Thus, realising that there is a lot done to diffuse stigma in the community but it still persists, the community leaders were concerned that this stigma would discourage young women from accessing facilities to be initiated on PrEP. The study participants were concerned about the persistent stigma associated with HIV and how it hinders people from accessing care. They believed that there is some form of stigma attached to discussing HIV within their communities and social groups due to the predominant nature of HIV being transmitted

through sexual intercourse. They enforce the fact that people are still not aware of HIV, how it is transmitted and what they can do to protect themselves from the disease.

“So, it’s important to support the things that will help to make them live longer. Because there are still people are not educated about HIV, but this thing, maybe it’s going to be easy to talk about it because it’s not an easy subject to talk about” (Councillor 4, Sept 2018).

“I think it’s because people are afraid to talk about it because they think they are now going to die because it even has stages, so they don’t know in what stage on infection you are in....That’s why I was saying we need to be educated about it. I like that you mentioned the other things such as rape or being involved in a car accident and not only through sex. Some are going to say that, because some people like to be negative” (Councillor 4, Sept 2018).

During the interviews, the community leaders revealed that they strongly believe that the oral PrEP will also be stigmatized based on the fact that it is collected from the clinic, it is a tablet, and it is taken orally every day and is meant to prevent HIV. The idea of taking a pill to prevent HIV could be misunderstood by others who do not know about it and assume to be a pill for HIV positive people. Thus, this lack of information about PrEP in the community will be a huge barrier for young women to access PrEP given that PrEP is an ARV for HIV negative people. Campbell (2005) emphasize that stigma plays a big role in limiting HIV prevention attempts and it acts as a barrier for adolescents to seek HIV/AIDS counselling. This indicates that the issue of stigmatization needs to be addressed and communities need to be involved in any stigma reduction programme (Campbell, 2005).

“My worry is the fact that we, most especially in this community. Some people won’t even take ARVs knowing very well that they are HIV positive but a person will refuse or just ignore the fact that they have to take medication” (Traditional Leader 1, Sept 2018).

“No, but as you said that it’s taken daily....people tend to hate taking pills on a daily basis. I think that could be it, but I don’t think there could

be anything else, unless a person is just lazy to take them” (Councillor 1, Sept 2018).

The lack of education about oral PrEP in the community could arguably be the main root of stigma towards oral PrEP in the community. Since PrEP is also an ARV it is likely that people might assume that the people taking it are living with HIV and be stigmatized in the community. This goes back to the need for intensified education on PrEP in the community to try and diffuse the misconceptions about PrEP and allow more young people to access it without being stigmatized.

Long distance for accessibility

Accessibility is a key consideration when it comes to PrEP and other related HIV services particularly in rural communities such as Vulindlela. There are some parts of the community that do not have a fixed facility serving them which means that some people rely on mobile clinics or alternatively need to walk long distances to access a health facility. In other instances, community members incur transport costs as their serving facilities are far from their residential areas. In these instances, access to services is disturbed because the community of Vulindlela is characterized by poverty and unemployment, therefore people do not always have money to travel to health facilities nor do they always have the strength to walk long distances to access health services. Considering all these challenges the picture looks even bleaker for oral PrEP accessibility, given that participants accessing PrEP services are not sick and therefore there is no great motivation to access health facilities given this stress of doing so. As such, the community leaders are likely to be demotivated by these challenges to access health facilities for PrEP.

“They once proposed having centres in the community where people can collect their pills” (Councillor 4, Sept 2018).

“.....we are one of the communities that is poverty stricken...we have no job opportunities, and that’s also one of the things that make people not so keen on taking medication because you find that they don’t even have food at home” (Councillor 1, Sept 2018).

The study participants cited that the majority of the community members are unaware of oral PrEP and how it works in HIV prevention. With regard to access to oral PrEP, a Councillor mentioned that the infrastructure is in place to start distribution of oral PrEP.

“As you’ve said that it’s only open to some people, so maybe it’s also an issue of access because if they did know about it, they would be talking about it. So no, the people in the ground have no knowledge of it” (Councillor 4, Sept 2018).

“I think those who are in health institutions or those who are working in or on health-related issues [know about Oral PrEP] but the majority, I would say about 90% don’t know about it” (Traditional Leader 1, Sept 2018).

Literature also highlights that poverty plays a major role in making people not to adhere to prescribed regimens and this is also possible in Vulindlela which is a rural area with the majority of people living in poverty. Struggling to access facilities and also not having food to take the pills would disturb their daily administering of PrEP. The fact that they are taking a pill when they are not sick added with these challenges, young women are likely to be deterred from using oral PrEP.

Promoting the implementation of oral PrEP

The community leaders reflected on their role in promoting the adoption of oral PrEP in the community. They realised that it is also their responsibility to assist in the reduction of new HIV infections in their community therefore they had to have an active role in the promotion of PrEP for adoption in the community. In this reflection, they noted the opportunities in the community that could facilitate the implementation of PrEP also noting the useful resources in the community that will assist in the successful implementation of PrEP among young women.

Resources available in the Vulindlela to support PrEP implementation

There are a number of community forums that the study participants used to engage with their communities on issues of HIV prevention and treatment also touching on issues of behaviour and empowerment. The community leaders reflected on the community engagement meetings they hold where they discuss issues of responsible living, self-confidence, self-esteem, and HIV prevention. The study participants deemed community engagements, awareness programs and education a vital aspect of implementing oral PrEP in the community.

“We do have CCGs, we do have Red Cross volunteers, we do have nurses and staff, we have ward committees and also general volunteers who are available to assist at any time and NGOs that we have inside the ward” (Councillor 2, Sept 2018).

“But we also have meetings, where we call the community and tell them that they have to live responsibly, and do things with respect and in a manner that they were taught. But we have planned that before the year ends, we need to have that meeting where we call all the children in Vulindlela and tell them about this oral PrEP so that they can all understand it... I even said that we should make it an official thing, talk to their parents and the guardians who have little girls a certain age to have them take this pill, even if they are not in a relationship with anyone. Just to ensure that they are safe all the time” (Traditional Leader 3, Sept 2018).

“But it will also depend on how well we are educated on this pill. It must not be a case of someone taking it at face value, just as something that will prevent HIV. They must go deep, to understand that even though it will prevent you from getting HIV and AIDS, but it doesn’t protect you from getting pregnant, it doesn’t protect you from getting STIs” (Traditional Leader 1, Sept 2018).

“As a result, you need to have awareness campaigns to make sure that those people know what is happening and how they can prevent themselves from getting those sorts of things that are not good.

Equally so, you make awareness about the good things too. And say this is what will assist going forward as a community. you can even go to the places where they drink alcohol... where the youth gathers together..... strategic places where young people often go to because they are the main target on this one” (Traditional Leader 1, Sept 2018).

“...that we can get volunteers, especially the people who can go door-to-door. Maybe that can be helpful toward the community. Maybe that person can come every second day to check whether they are taking their pills accordingly” (Councillor 1, Sept 2018).

“...community engagement forums and public meetings that can help us because that’s where we get information. That’s where we are able to get people and disseminate information” (Councillor 2, Sept 2018).

The community leaders reflected on a wide range of resources in the community that could assist in ensuring that education programmes on PrEP are done, awareness campaigns to inform the public about the benefits of PrEP and also the community care givers who could provide more support in ensuring that the relevant people are able to access their PrEP to overcome the accessibility challenges noted above. The willingness of community leaders to engage with different structures in the community including community-based health organisations, the local health facilities and its community outreach teams signalled the great appreciation of PrEP among community leaders. This further showed their willingness to draw from external knowledge to engage communities and promote the implementation of PrEP. The fact that they were willing to exercise their powers to mobilise these resources that are available in the community to educate and promote PrEP signalled the opportunity for an effective implementation of PrEP in Vulindlela that is supported by its leaders.

The implementation of Oral PrEP among AGYW

The majority of respondents felt that oral PrEP should be embraced by communities albeit with proper educational programs to facilitate understanding of this new prevention method. They however mentioned that they were not aware of the side effects of oral PrEP. They believed that depending on what the side effects were they would determine to some extent the adherence of young women to PrEP. The assumption is that if the side effects are severe then people are more likely to withdraw from taking the pill. Another noted challenge with PrEP is that since it is in pill form and meant to be administered daily, some may forget to take it as prescribed due to competing daily schedules. The period of twenty days before it works in the blood stream is also a concerning factor with the community leaders. The delayed effect of it was not appreciated by the community leaders as they believed that an effective intervention must not require so many days to protect and that its effectiveness may not be fully realised among young women given this long period before it works. Nonetheless, all the community leaders were enthusiastic about a new prevention method that would curb the spread of infection among young women particularly.

“It’s appreciated because it will (increase) the lifespan of our people. Because like you have said, sometimes you get HIV through rape” (Traditional Leader 3, Sept 2018).

“Yes, it can be a great help to them because it can help to protect them against getting infected by HIV if they are still HIV negative. So they must use it to protect themselves” (Traditional Leader 1, Sept 2018).

“...they do have knowledge of it. Even though it may not be widespread across the community however, they do have an idea of what PrEP is” (Councillor 5, Sept 2018).

The community’s interest in Oral PrEP

The study participants had similar concerns with regard to oral PrEP among AGYW, they expressed concerns about the lack of education and oral PrEP awareness campaigns in their community. However, they do feel that it is worth implementing

since it is a prevention method and safeguards against HIV infection in the case of unprotected sex. The study participants reflected on some cultural beliefs that could have hindered the implementation of education awareness and these include the belief held in their community that discussing sexual matters with young people leads to promiscuity, in the same vein, promoting education about PrEP could be misinterpreted as encouraging sexual engagements among young women. While these reservations are real in their cultural context, community leaders still believed that it is essential to have discussions around sexual health matters to prevent HIV transmission and to protect AGYW. This meant that some study participants were willing to challenge the dominant cultural beliefs in their communities in favour of increasing the adoption and implementation of PrEP for young women. Since this is a vulnerable group, community leaders held that prevention methods should be implemented with the help of NGO's, government and private research institutes such as CAPRISA who have more experience and knowledge on the topic.

“...when it comes to sexual matters, we as Zulu people often think of such things as promoting promiscuity, like its encouraging people to engage in sexual intercourse. So maybe if we were to be educated about it, honestly it would be a good thing because innocent people get infected” (Councillor 4, Sept 2018).

“Condoms they are there but it looks like they are failing. And why they are failing, they are failing because the power remains with the male. And condoms have been stigmatized a lot, so there are myths around them. So, if there can be something else that can help us, I think it will help a lot in the community moving forward” (Councillor 5, Sept 2018).

The unintended consequences of Oral PrEP

Although oral PrEP is an exciting new prevention method, respondents also highlight a few key points with regard to the unintended consequences that may arise with implementing oral PrEP. Some of the respondents mentioned lack of abstinence, lack of condom use, an increase in STI infections and unplanned pregnancies.

“Because now some people are abstaining, and the reason why they are abstaining is because they are scared of getting HIV. As a result, they end up not having unplanned babies because they are abstaining... but this one may expose people to say, no I will have flesh-to-flesh because I know I have oral PrEP.” – (Traditional Leader 1)

“It could help in terms of preventing HIV for those who are HIV negative, but it may also have a bad impact which you may see a rise in terms of people with STIs, and people falling pregnant..... If we were not scared of HIV in our societies, you would see less usage of condoms” (Traditional Leader 1, Sept 2018).

“So, when you speak about this oral PrEP. I heard about it and thought it’s something that can be used easily. Because some things are not user friendly then people end up coming across as failures because they can’t be used easily” (Traditional Leader 3, Sept 2018).

Oral PrEP was argued to have a negative effect on the adoption of other HIV prevention options. Through the adoption of PrEP there was fear that young women could disregard the use of condoms which are part of a comprehensive HIV prevention package. Given that PrEP is not a standalone intervention, it has been tested to be effective if used in conjunction with other prevention methods, it is therefore a valid concern if there are indications that young women could offset the risk of engaging in unprotected sex as a result of using PrEP. This behaviour can be referred to as risk compensation, and occurs when an individual underestimates their risk to a disease/infection on the assumption that they are fully protected with the prevention method they are using. As part of the education programmes on PrEP there is also great need to education on the conditions for PrEP effectiveness ensuring that misconceptions about the effectiveness of PrEP are controlled.

The role of traditional leaders

The community leaders have taken on the role of health stewards in their communities. They have become more open about HIV, communicating this to young people and more vocal about prevention methods. They share a deep concern for their communities, especially AGYW as they are the most vulnerable group. Their main focus is the well-being of the community in all aspects.

“We as leaders are not happy to see our people being destroyed by this disease called HIV” (Traditional Leader 3, Sept 2018).

“Well, as leaders we have an obligation to make our communities to be aware, not only of HIV, of anything. It could be crime related, it could be anything that affects our society, our community. Social ills on the main, we deal with those on a daily basis” (Traditional Leader 3, Sept 2018).

“We are in the right position where we lead the masses. Then we have various sectors and meetings, so I think if we are agreeing that in every meeting that we are holding we must have this item as a stand-alone item and talk about it, then we can do that. Secondly, there is a team of community caregivers that we work with, who visit households and come across these things, you see. Who should be teaching about this but you find that they also lack knowledge. So, I can subject my team to education about PrEP so that they can also move forward” (Councillor 5, Sept 2018).

“...as people who work with the community, as leaders of this community, these are the things we like to see happen in terms of helping people especially in terms of things pertaining to HIV” (Councillor 1, Sept 2018).

“But what I’ve discovered or what I can see is that the response, even from traditional leaders, even from traditional healers, they are adapting to a system of government and they are working with the government to make sure that we decrease the level of infection. Because we all, I think all of us we are concerned about infection.

That's what we are concerned about, that people must no longer get infected. We must minimize the level of infection so that you can be able to deal with the issue of HIV" (Councillor 2, Sept 2018).

The influential role of community leaders offers them an opportunity to engage with key stakeholders in the field of PrEP implementation to ensure that education programmes are implemented, and communities are made aware of this prevention option so that they make informed decisions about its adoption. Added to this is the power of community leaders to endorse the implementation of PrEP through engagement with communities. The forums of engagements with communities were noted as another opportunity for communities to promote and support the implementation of PrEP for young women. The community leaders also showed the need to understand the cultural contexts and consider these in the implementation of PrEP, this was noted by some participants who mentioned that engagements to promote PrEP among young women should also include parents and this is to respect parents who are deemed as the custodians of young women in the community. Understanding the cultural contexts offers greater opportunities for the successful implementation of oral PrEP.

Interpretation of findings

This study focused on the individual and community level of the SEMCHB framework and is informed by the theoretical frameworks of the Health Belief Model (HBM) and the Culture Centered Approach (CCA) respectively. This study is centred on the theoretical notion that communication is the key to implement any change in society (Dutta, 2015).

Evident HBM constructs in the data

The HBM emphasizes the perception of personal risk to health threats, the perception of susceptibility to a health-related concern and the ability of a person to reduce their risk to the health concern (Rimer, 2008). If a person perceives that they are a low risk

to contracting HIV, it is possible that they would forego treatment, in this case, oral PrEP (Hochbaum, 1958). They would not take the necessary precautions in protecting themselves from something they believe would not contract, they would have little to no motivation of seeking preventative measures (Hochbaum, 1958). In this study, community leaders are aware that HIV prevention is a priority for AGYW (it does have a high perception of risk), however they have had little to no education or awareness programs to fully explain the concept of oral PrEP and how it would be effective for AGYW.

A key construct of the HBM is that if an individual adopts a health behaviour, it is most likely due to their perception (Metta, 2016). In this study, perceived susceptibility refers to the community leaders' perceptions of the AGYW vulnerability to HIV infection while perceived severity refers to their assessment of how likely AGYW are to be exposed to HIV infection. Perception of risk is a vital factor that plays a role in the adoption of oral PrEP (Frankis et al., 2016; Young et al., 2014). On the other hand, perceived self-efficacy is also an essential component in the uptake of oral PrEP. This refers to a person's confidence in their own ability to adopt the preventative behavior (Bandura, 1997). In this study, the community leaders acted as representatives of AGYW and brought forth the challenges that would be encountered if oral PrEP were to be implemented.

The results of this study revealed that the relationship between perceived susceptibility and perceived self-efficacy was subjective amongst the community and traditional leaders. They all have stated that there is a high level of risk among AGYW and mentioned various socio-economic factors that contribute to the risk-level in AGYW. The perceived susceptibility was high for AGYW; however the perceived self-efficacy presents a challenge considering the lack of knowledge of oral PrEP, the requirements of use since there is a waiting period, the community perception of AGYW if they were to start consuming it as well as partner dynamics within their spousal relationships.

Furthermore, the community leaders expressed concern for this prevention method and explained that AGYW may feel that they are protected at all costs and endeavour on to promiscuous behaviour. A contributing factor to this argument could be that AGYW may increase their sexual engagements with 'blessers' to rid themselves of their poverty situations. Alternatively, AGYW could be exposed to unhealthy

relationship dynamics that result in STDs or STIs that oral PrEP may not protect them from. Unplanned pregnancies are also an area of priority for AGYW and community leaders.

According to the HBM, high perceived risk and high perceived susceptibility will lead to the adoption of preventative behaviour (Bandura, 1997). Additionally, the benefits of the introduced health behaviour should outweigh the barriers (Bandura, 1997). Community leaders may consider the benefits and barriers as guided by the HBM and will make a decision based on the balance of these two components (Rimer, 2008). The benefits seem to outweigh the barriers according to the perception of the study group (de Wit et al., 2005; Metta, 2016; Taylor et al., 2007). While this is a positive indication for the introduction of oral PrEP among AGYW in Vulindlela, there are still valid barriers that should be overcome before implementing this preventative treatment.

A key factor to consider as well is access to oral PrEP and eligibility to receive this prevention treatment. In this study, perceived susceptibility is high thus there is a need to raise perceived risk, perceived susceptibility, perceived self-efficacy and perceived benefits of oral PrEP to promote, educate and create acceptance of this new preventative method. This includes uptake by AGYW in the form of encouragement from community leaders, elders, councillors and health care workers.

Evident CCA constructs in the data

The CCA emphasizes the value of dialogues between the community and the government so that a joint goal with regard to a current health concern can be achieved within that community (Balde, 2016). The results of this study indicate that there are community leaders who are unaware of oral PrEP and how it works. This calls for more engagement with communities in the Vulindlela district as well as proper educational programmes and facilitations within this group. The community leaders should be adequately prepared to provide understanding to AGYW on this new prevention method.

Some aspects of culture continue to appear in the findings. The shared space within which they live, provides a platform to reach out to community members in big

numbers. As such, they see it as the perfect platform to share and educate about oral PrEP. Community leaders of Vulindlela have shared identities. They view themselves as patriots with the responsibility of protecting their communities against HIV and AIDS, as such willing to play a positive role in implementing oral PrEP.

The HIV epidemic is an area of priority for both councillors and traditional leaders, especially for AGYW. Culture binds them together, irrespective of their differences. It is shared experiences such as seeing people die of HIV and AIDS that make them to value life and thus take a leading role in HIV prevention. With the CCA, a multi-faceted approach is encouraged along with addressing the other negative factors the community may be facing. This will lead to holistically well-being of AGYW in their communities (Basu and Dutta, 2009). The socio-economic considerations of poverty, lack of education and gender inequality are all prominent factors for AGYW in Vulindlela.

By introducing structural changes and creating agents of change within the community, the oral PrEP prevention method would likely be successful for AGYW (Karim et al., 2010). This would create a sense of co-responsibility between the community and the government where AGYW would feel collectively involved in the health communication program (Basu and Dutta, 2009). Within this theoretical framework, a behavior change in terms of oral PrEP within AGYW in the community would be initiated and possibly accepted.

The findings suggest that health communication will be essential in revealing the positive perceptions and possible uptake of oral PrEP among AGYW. Respondents stated that awareness and education is needed for AGYW and other community members with regard to oral PrEP. They acknowledge the need for them to be knowledgeable about oral PrEP. They understand that they are a community and have a culture which serves as a vehicle in the knowledge creation process (Dutta, 2008). They request for educational programmes, training programmes and facilitators to engage with them on this new prevention method.

In summary, it is important to recall that the study is underpinned by the SEMCHB and uses the HBM to explore the individual level and the CCA to examine the community level. The HBM highlights the understanding of individual perceptions, susceptibility,

understanding of risks in relation to oral PrEP use. The CCA draws on the relevance of culture, agency and voice and dialogue. It examines the significant role that the community leaders play in enabling the individuals to make decisions around oral PrEP. This study illustrates the importance of understanding the individual within the broader community. The data presented shows that based on SEMCHB these different kinds of levels, the individual and the community work together to advance oral PrEP.

Conclusion

This chapter presented and discussed the research findings under the identified themes. The discussion revealed an understanding on the perceptions of risk among adolescent girls and young women (AGYW) from the perspective of the community leaders in Vulindlela. This chapter further explored the attitudes, perceptions and beliefs of community leaders on the topics of HIV, HIV prevention and oral PrEP as a prevention method among AGYW. The discussion was centred on the study's research questions and objectives as well as the conceptual framework based on theoretical constructs. Additionally, the chapter presented data in relation to relevant information that would guide the policies and implementation of oral PrEP in high prevalence areas.

Chapter 6: Conclusions

Introduction

This chapter aims to give summary of the research findings and conclusion. The researcher endeavours to illustrate if the research questions have been answered and to examine the theoretical relevance in answering the research questions.

Summary of research findings

Research question 1: What is the knowledge and attitude of oral PrEP among community leaders for AGYW in Vulindlela?

Knowledge is the main finding. It was evident that community leaders lack knowledge about oral PrEP and they state that there is a great need for them to be educated on oral PrEP so that they could be able to share with others and educate both young and old people from their communities about oral PrEP. They acknowledge that they are always involved in community mobilisation and are exposed in addressing bigger numbers of people in different platforms. Therefore, when they are knowledgeable about oral PrEP, they would address people confidently and be able to tackle any concerns around oral PrEP.

Community leaders cite the fact that they know AGYW engage in risky sexual activities due to many reasons. They state that if oral PrEP is intensified in the Vulindlela community, there is an opportunity for it to work because they believe it could be an answer to many of the challenges faced by AGYW.

They emphasized the great need for education of oral PrEP for everyone. Community leaders have a responsibility to support and uphold programmes that are beneficial to the community, therefore there is a great need for them to be empowered on what oral PrEP is and how it works.

The community leaders' attitude towards oral PrEP is that they have a positive attitude towards oral PrEP. Some mentioned that the scourge of HIV in Vulindlela has ravaged their community in a big way that led to many people getting sick and subsequently dying of AIDS. This makes them to be receptive to oral PrEP despite the little knowledge they have as long as it has been proven to be working. They have a positive attitude towards oral PrEP and willing to support its implementation.

Research question 2: What are the perceived benefits or barriers from community leaders in Vulindlela that could hinder or promote the uptake of oral PrEP with AGYW?

The community leaders mentioned both benefits and barriers that they envisage to be promoting or hindering oral PrEP uptake. They acknowledge that there is a high HIV infection rate amongst AGYW in their community. They see oral PrEP as an answer to reducing the rate of HIV infections among AGYW and to be empowering AGYW on taking control of their sexuality, even though for some it could lead to engaging in unprotected sex and thus lead to a high number of other STIs and unplanned pregnancies. The community leaders cited more benefits than barriers, this leads to the researcher concluding that they would support oral PrEP implementation. Also the fact that some see barriers could be that oral PrEP is a new method and a great need for more education and knowledge on oral PrEP is required.

Research question 3: What are the proposed cues to action for community leaders to promote the implementation of oral PrEP with AGYW in Vulindlela?

The community leaders see themselves as agents for change and also having an advantage of being strategically positioned. They draw from structures and resources that are in existence in their community. They mentioned community caregivers, volunteers, imbizo, Umhlanga reed dance as platforms that could assist and support the implementation of oral PrEP. In war rooms, different stakeholders gather together tackling various issues.

Theoretical relevance to research findings

This study adopted the SEMCHB as the theoretical framework and focused on two levels namely, the individual and community level. The HBM is used at the individual level and the CCA at community level. This section aims at illustrating if the theory supported this study.

HBM Constructs

Perceived susceptibility refers to a person believing that there is a likelihood of contracting a health condition. Here, the researcher examined if the community leaders see the AGYW as being susceptible to HIV infection. It transpired that community leaders did believe AGYW to be at risk of HIV infection because they acknowledged the fact that AGYW engaged in risky sexual behaviours. These included low condom usage, transactional sex, alcohol and drug abuse, high teenage pregnancy. According to HBM, if they are susceptible to HIV infection, they are likely to take action to prevent HIV infection.

Perceived severity refers to one's belief that a condition is serious and that its consequences are severe. In this study, it is clear that the community leaders believe that HIV amongst AGYW in their community is a serious issue and has severe consequences for the AGYW in the Vulindlela community.

Perceived benefits refer to the belief that taking action will help reduce the chances of a problem to occur. In this study, the second research question looked at the benefits at greater length. The researcher concludes that community leaders see oral PrEP as a potential intervention to curb the HIV scourge. The benefits outweigh barriers.

Perceived barriers refer to reasons that could hinder a person from taking a certain action. In this study, the researcher concludes that even though the community leaders cited a few barriers as compared to benefits, they still believe benefits of oral PrEP outweigh barriers. This means more efforts and opportunities need to be created for them to get more knowledge on oral PrEP.

Cues to action refers to what motivates the person to take action. The researcher concludes that community leaders see themselves as agents who already have structures and resources in place to be used as tools and platforms to promote oral PrEP implementation. The high number of deaths in their community amongst family members and community members is a motivation to seek out whatever intervention that would help.

Self-efficacy refers to the confidence that they have in making oral PrEP work in their community. Community leaders see themselves as agents. They believe they have the capability of driving this programme.

Culture Centred Approach

The CCA is adopted to address the community level. CCA is based on three tenets, namely, culture, structure and agency. For the purposes of this study, the focus is on culture and agency. Community leaders saw culture as having impact in implementing oral PrEP. Beliefs and norms are transferred from one generation to the next. They made mention of virginity tests that are conducted by older women in young girls. The community leaders promote the Umhlanga or Reed dance, which is one way of promoting culture.

Agency in relation to the study is illustrated in the capability of community leaders seeing themselves as having resources to implement the uptake of oral PrEP. Community caregivers, volunteers, Imbizos, war rooms etc are examples they cited.

Conclusion

In conclusion the community leaders are willing to play a positive role in the implementation of oral PrEP in Vulindlela community as long as it will help curb the epidemic in their area. The willingness and positive attitude shown by the community leaders is a great start for other research studies to be conducted. The ground for future research has been prepared and future research is recommended.

Bibliography

Adler, E. and Clark, R. (2014) An invitation to social research: How it's done: Cengage Learning.

Airhihenbuwa, C.O. and Webster, J.D. (2004) Culture and African contexts of HIV/AIDS prevention, care and support, SAHARA-J: Journal of Social Aspects of HIV/AIDS, 1:1, pp. 4-13.

Albarracin, D., McNatt, P.S., Klein, C.T.F., Ho, R.M., Mitchell, A.L., and Kumkale, G.T. (2003) Persuasive communication to change actions: An analysis of behavioural and cognitive impact in HIV prevention. Health Psychology, 22, pp. 166 – 177.

Ali, N.S. (2002) Prediction of coronary heart disease preventative behaviors in women: A test of the Health Belief Model. Women and Health, 35(1), pp. 83-96.

Atkinson, J., Vallely, A., Fitzgerald, L. Whittaker, M. and Tanner, M. (2011). The architecture and effect of participation: a systematic review of community participation for communicable disease control and elimination. Implications for malaria elimination. Malaria Journal, 10(1), pp. 225–257.

Babalola, S., Brasington, A., Agbasimalo, A., Helland, A., Nwanguma, E. and Onah, N. (2006). Impact of a communication programme on female genital cutting in eastern Nigeria.

Bailey, A. (2008) Culture, risk and HIV/AIDS among migrant and mobile men in Goa, India. Rozenberg Publishers.

Balde, A. (2016) How elements of culture have contributed to the construction of health meanings in regard to the 2014 Ebola outbreak. Master of Arts in the Department of Communication Studies, Indiana University.

Baloyi, T.B. (2016) The role of traditional leadership in local government. Masters Dissertation. University of Witwatersrand.

Bandura, A. 1997. Self-efficacy: The exercise of control, Macmillan.

Bandura, A. (1977) Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review*, 84, pp. 191.

Basu, A. and Dutta, M.J. (2009) Sex Workers and HIV/AIDS: Analyzing Participatory Culture-Centered Health Communication Strategies. *Human Communication Research*, 35, pp. 86-114.

Basu, J. (2010) Development of the Indian Gender Role Identity Scale. *Journal of the Indian Academy of Applied Psychology*, 36(1), pp. 25-34.

Belcher, L., Sternberg, M.R., Wolotski, R.J., Halkitis, P. and Hoff, C. (2005) Condom use and perceived risk of HIV transmission among sexually active HIV positive men who have sex with men. *AIDS Education and Prevention*, 17(1), pp. 79-89.

Bellamy, R. (2004) An introduction to patient education: theory and practice. *Medical Teacher*, 26, pp. 359-365.

Berg, B.L (2001) *Qualitative Research Methods for the Social Sciences* 4th ed California State University, Long Beach

Bharat, S., Ramakrishna, J., Heylen, E., & Ekstrand, M. L. (2014) Gender-based attitudes, HIV misconceptions and feelings towards marginalized groups are

associated with stigmatization in Mumbai, India. *Journal of Biosocial Science*, 46(6), pp. 717-32.

Bingham, B., Leo, D., Zhang, R., Montaner, J., & Shannon, K. (2014) Generational sex work and HIV risk among Indigenous women in a street-based urban Canadian setting. *Culture, health & sexuality*, 16(4), 440-452.

Blankenship, K.M., Bray, S.J., Merson, M.H. (2000) Structural interventions in public health. *AIDS*, 14(1), pp. 11–21.

Blankenship, K. M., Friedman, S. R., Dworkin, S., & Mantell, J. E. (2006) Structural interventions: concepts, challenges and opportunities for research. *Journal of urban health bulletin of the New York Academy of Medicine*, 83(1), pp. 59-72.

Bouma, D.H. and Atkinson, M. (1987) *A Handbook of Social Science Research*, United States: Oxford.

Braun, V. & Clarke, V. (2013) *Successful qualitative research: A practical guide for beginners*, Sage.

Brent, R.J. (2016) The value of reducing HIV stigma. *Social Science and Medicine*, 151, pp. 233-240.

Brewer, N.T., Chapman, G.B., Gibbons, F.X., Gerrard, M., McCaul, K.D., Weinstein, N.D. (2007) Meta-analysis of the relationship between risk perception and health behavior: the example of vaccination. *Health Psychology*, 26, pp. 136.

Bronfenbrenner, U. (1979) *The Ecology of Human Development*, Harvard University Press, Cambridge, MA.

- Brown, B.M., George, G., Beckett, S., Evans, M., Lewis, L., Cawood, C., Khanyile, D. and Kharsany, A.B.M. (2018) HIV Risk Among Adolescent Girls and Young Women in Age-Disparate Partnerships: Evidence from KwaZulu-Natal, South Africa. *Journal of Acquired Immune Deficiency Syndrome*, 78(2), pp. 155-162.
- Brown, K. and Williams, D.B. (2018) Status of HIV epidemic control among adolescent girls and young women aged 15-24 years – seven African countries, 2015-2017. *MMWR Morb Mortal Weekly Report*, 67(1), pp. 29-32.
- Campbell, C., Foulis, C.A., Maimane, S. and Sibiya, Z. (2005) “I Have an Evil Child at My House”: Stigma and HIV/AIDS Management in a South African Community. *American Journal of Public Health*, 95(5), pp. 808-815.
- Campbell, C. (2010) Political will, traditional leaders and the fight against HIV/AIDS: a South African case study. *AIDS Care*, 22(2), pp. 1637-1643.
- Cardey, S. (2006) From Behaviour Change to Social Change: Planning communication strategies for HIV/AIDS. International Association for Mass Communication Research, The American University in Cairo, Egypt.
- Center for Disease Control and Prevention. (2004) Program operations guidelines: Community and individual behavior change interventions.
- Champion, V. (1993) Instrument for breast cancer screening behaviors. *Nursing Research*, 42, pp. 139-143.
- Champion, V. and Menon, U. (1997) Predicting mammography and breast self-examination in African American women. *Cancer Nursing*, 20, pp. 315-322.

Champion, V.L. and Skinner, C.S. (2008) The health belief model. *Health behavior and health education: Theory, Research, and Practice*, 4, pp. 45-65.

Chen, J.K., Fox, S.A., Cantrell, C.H., Stockdale, S.E. and Kagawa-Singer, M. (2007) Health disparities and prevention: Racial/ethnic barriers to flu vaccinations. *Journal of Community Health*, 32(1), pp. 5-20.

Chilisa, B. (2012) *Indigenous Research Methodologies*, California: Sage.

Chiwara, T.B. (2017) Guidelines for improving HIV/AIDS communication for women in Zimbabwe. Doctor of Literature and Philosophy in Health Studies Thesis. University of South Africa.

Chirowodza, A., van Rooyen, H., Joseph, P., Sikotoyi, S., Richter, L., and Coates, T. (2009) Using participatory methods and geographic information systems (GIS) to prepare for an HIV community-based trial in Vulindlela, South Africa (Project accept-hptn 043). *Journal of Community Psychology*, 37(1), pp. 41–57.

Christensen, L.B., Johnson, R.B. & Turner, L.A. (2011) *Research Methods, Design, and Analysis*. 11th edition. Boston: Pearson.

Ciledag, A. and Karnak, D. (2011) AIDS and Opportunistic Infections. *Microbes, Viruses and Parasites in AIDS Process*, 6, pp. 87-112.

Clark, N.M., Rosenstock, I.M., Hassan, H., Evans, D., Wasilewski, Y., Feldman, C., Mellins, R.B. (1988) The effect of health beliefs and feelings of self-efficacy on self-management behavior of children with a chronic disease. *Patient Education and Counseling*, 11, pp. 131-139.

Coates, T.J., Richter, L. and Caceres, C. (2008) Behavioural strategies to reduce HIV transmission: how to make them work better. *Lancet*, 372, pp. 669–684.

Coetzee, J. and Hunt, G. (2017) HIV-I viraemia and drug resistance amongst female sex workers in Soweto, South Africa: A cross sectional study. *PLoS ONE*, 12(12).

Cohen, D., Finch, B., Bower, A. and Sastry, N. (2006) Collective efficacy and obesity: the potential influence of social factors on health. *Social Science and Medicine*, 62(3), pp.769-778.

Corcoran, N. (2013). *Communicating health strategies for health promotion*. London: SAGE Publication.

Cornish, F., Priego Hernandez, J., Campbell, C. (2014) Impact of community mobilisation on HIV prevention in middle- and low-income countries: a systematic review and critique. *AIDS Behaviour*.

Cremin, I., McKinnon, L., Kimani, J., Cherutich, P., Gakii, G., Muriuki, F., Kripke, K.,

Daftary, A. (2012) HIV and Tuberculosis: the construction and management of double stigma. *Social Science and Medicine*, 74, pp. 1512-1519.

Creswell, J.W. (1994) *Research Design: Qualitative & Quantitative Approaches*, California: Sage.

Crotty, M. (1998) *The foundations of social research*, London: Sage Publications.

Dandona, L., Kumar, S. P., Ramesh, Y., Rao, M. C., Kumar, A. A., Marseille, E., Kahn, J. G. and Dandona, R. (2008) Changing cost of HIV interventions in the context of scaling-up in India. *AIDS (London, England)*, 22(1).

Davis, S.M., Hines, J.Z., Habel, M., Grund, J.M., Ridzon, R., Baack, B., Davitte, J., Thomas, A., Kiggundu, V., Bock, N., Pordell, P., Cooney, C., Zaidi, I. and Toledo, C. (2018) Progress in voluntary medical male circumcision for HIV prevention supported by the US President's Emergency Plan for AIDS Relief through 2017: longitudinal and recent cross-sectional programme data. *BMJ Open*.

de Wet, J.B.F., Vet, R., Schutten, M. and van Steenberghe, J. (2005) Social-cognitive determinants of vaccination behavior against Hepatitis B: An assessment among men who have sex with men. *Preventive Medicine*, 40(6), pp. 795-802.

Dixon, S., McDonald, S., and Roberts, J. (2002) The impact of HIV and AIDS on Africa's economic development. *BMJ*, 324, pp.232-234.

Dupas, P. (2011). *Health Behavior in Developing Countries*.

Duraiappah, A.K. & Roddy, P. and Parry, J. (2005) *Have Participatory Approaches Increased Capabilities?* International Institute for Sustainable Development (IISD).

Durrheim, K. and Wassenaar, D. (1999) Putting design into practice: writing and evaluating research proposal. In: Terre B M and Durrheim K (eds) *Research in Practice: Applied methods for the social sciences*. Cape Town: UCT Press, 54-70.

Dutta, M (2008) *Communicating health : A culture-centred approach*. Cambridge, England : Polity

Dutta, M.J & Basu, A (2011). *Culture, Communication, and Health : Guiding Framework*. In Thompson, TL., Parrot, R., Nussbaum, J.F (eds). *The Routledge Handbook of Health Communication*, 2nd Edition. Routledge, Taylor & Francis, 320-333

Dutta, M.J. (2015) Decolonizing Communication for Social Change: A Culture-Centered Approach. *Communication Theory*, 25, pp. 123-143.

Dutta, M.J. (2016) Cultural Context, Structural Determinants, and Global Health Inequities: The Role of Communication. *Frontiers in Communication*, 1:5.

Dworkin, S. L., & Ehrhardt, A. A. (2007) Going beyond "ABC" to include "GEM": critical reflections on progress in the HIV/AIDS epidemic. *American journal of public health*, 97(1), pp. 13-18.

Ellingson, L.A. and Youber, W.L. (1997) Breast self-examination, the Health Belief Model, and sexual orientation in women. *Journal of Sex Education and Therapy*, 22, pp. 19-24.

Eslami, N.R. (2013) At the Crossroads of Research Paradigm. *Confluence February*: 190-196.

Fonner, V.A. (2015) It takes two: The dyadic and gendered context of HIV testing, risk assessment, and partner communication in Kisarawe, Tanzania. Johns Hopkins University.

Frank, D., Swedmark, J., Grubbs, L. (2004) Colon cancer screening in African American women. *ABNF Journal*, 15(4), pp. 67-70.

Frankis, J., Young, I., Flowers, P. and Mcdaid, L. (2016) Who will use pre-exposure prophylaxis (PrEP) and why? : understanding prep awareness and acceptability amongst men who have sex with men in the UK—a mixed methods study. *PloS one*, 11.

Fylkesnes, K., Sandøy, I.F., Jürgensen, M., Chipimo, P.J., Mwangala, S., Michelo, C. (2013) Strong effects of home-based voluntary HIV counselling and testing on acceptance and equity: A cluster randomised trial in Zambia. *Social Science & Medicine*, 86, pp. 9-16.

Gage, A.J. and Ali, D. (2005) Factors associated with self-reported HIV testing among men in Uganda. *AIDS Care*, 17(2), pp. 153-165.

GBD 2015 HIV Collaborators (2016) Estimates of global, regional, and national incidence, prevalence, and mortality of HIV, 1980–2015: the Global Burden of Disease Study 2015. *Lancet HIV*, 3, pp. 361–87.

Gilbert, L. and Walker, L. (2002) HIV/AIDS in South Africa: an overview. *Cad. Saúde Pública*, Rio de Janeiro, 18(3), pp. 651-660.

Glanz, K., Rimer, B.K. and Lewis, F.M. (2002) *Health Behavior and Health Education* (3rd Ed.). San Francisco: Jossey-Bass.

Glanz, K., Rimer, B.K., Viswanath, K. (2008) *Health behavior and health education: theory, research, and practice*. John Wiley & Sons

Glanz K, Rimer B.K and Viswanath K (2008). *Health Behaviour and Health Education : Theory, Research and Practice* (4th ed). San Francisco, CA: Jossey-Bass, pp 45-51. ISBN 978-078 7996147

Govender, E (2011). Chapter 2. Development and health communication for HIV/AIDS prevention. In Tomaseli, K.G., & Chasi, C (eds) *Development and Public Health Communication*. South Africa : Pearson

Graham, M.E. (2002) Health beliefs and self breast examination in black women. *Journal of Cultural Diversity*, 9(2), pp. 49-54.

Graham, M., Liggons, Y., Hypolite, M. (2001) Health beliefs and self breast examination in black women. *Journal of Cultural Diversity*, 9, pp. 49-54.

Green, E.C, Halperin, D.T., Nantulya, V. et.al *AIDS Behav* (2006) 10: 335.
<https://doi.org/10.1007/s10461-006-9073-y>

Green, J. and Tones, K. (2011) *Health Promotion, planning and strategies*. Second Edition. London: Sage.

Gupta, G.R., Parkhurst, J.O., Ogden, J.A., Aggleton, P. and Mahal, A. (2008) Structural approaches to HIV prevention. *Lancet*, 372, pp. 764–775.

Gyasi, R.M. and Abass, K. (2018) Sexual risk behavior and uptake of HIV counseling and testing among youth in Metropolitan Kumasi, Ghana. *Journal of HIV/ AIDS & Social Services*, 17:2, pp. 127-145.

Hansen, J.A. and Benedict, J.A. (2002) Use of Health Belief Model to examine older adults' food-handling behaviors. *Journal of Nutritional Education*, 34, pp. 25-30.

Hassan, N.R. and Swartz, L. (2017) "There is not a safe space where they can find themselves to be free": (Un)safe spaces and the promotion of queer visibilities among township males who have sex with males (MSM) in Cape Town, South Africa. *Health Place*, 49: 93-100.

Hausmann-Muela, S., Ribera, J.M., Nyamongo, I. (2003) Health-seeking behaviour and the health system response. In Disease Control Priorities Project (DCPP) working paper No14.

Hawley, A.H. (1950) *Human Ecology: A Theory of Community Structure*, Ronald Press, New York, NY.

Hay, J.L., Ford, J.S., Klein, D., Primavera, L.H., Buckley, T.R., Stein, T.R., Shike, M., Ostroff, J.S. (2003) Adherence to colorectal cancer screening in mammography-adherent older women. *Journal of Behavioral Medicine*, 26, pp. 553-576.

Hayden, J.A. (2013) *Introduction to health behavior theory*. Jones & Bartlett Publishers.

Hecht, R., Kiragu, M., Smith, J., Hinsley, W., Gelmon, L. and Hallett, T.B. (2017) PrEP for key populations in combination HIV prevention in Nairobi: a mathematical modelling study. *Lancet*, 4, pp. 214-222.

Hendriksen, E.S., Hlubinka, D., Chariyalertsak, S. (2009) Keep talking about it: HIV/AIDS-related communication and prior HIV testing in Tanzania, Zimbabwe, South Africa, and Thailand. *AIDS Behaviour*, 13(6), pp. 1213-1221.

Hernandez, L.M. and Blazer, D.G. (2006) *Genes, Behavior, and the Social Environment: Moving Beyond the Nature/Nurture Debate*. Washington (DC): National Academies Press (US) 2, *The Impact of Social and Cultural Environment on Health*.

Hill, L.M. and Gottert, A. (2017) Understanding men's networks and perceptions of leadership to promote HIV testing and treatment in Agincourt, South Africa. *Global Public Health*, 1-11.

Hochbaum, G.M. (1958) *Public participation in medical screening programs: A Socio-psychological study* (Public Health Service Publication No. 572). Washington, DC: Government Printing Office.

Holloway, I. & Galvin, K. (2016) *Qualitative Research in Nursing and Healthcare*, John Wiley & Sons.

Holloway, I. & Wheeler, S. (2010) *Qualitative Research in Nursing and Healthcare*. 3rd Edition. Chichester: Wiley-Blackwell.

Holme, I., MacAskill, S. and Eadie, D. (2009) *Research to Develop a Communications Campaign to Promote Childsmile within Local Communities – Stage 1: Literature Review*, NHS Health Scotland, Edinburgh.

Hor, L.B., Detels, R., Heng, S. and Mun, P. (2005) The role of sex worker clients in transmission of HIV in Cambodia. *International Journal of STD & AIDS*, 16: pp. 170–174.

Horton, R. and Das, P. (2008) Putting prevention at the forefront of HIV/AIDS. *Lancet*, 372, pp. 421-422.

HSRC and EPC (2005) *Emerging Voices: A Report on Education in South African rural communities*. Nelson Mandela Foundation.

Hurt, C.B., Eron, J.J. and Cohen, M.S. (2011) Pre-Exposure Prophylaxis and Antiretroviral Resistance: HIV Prevention at a Cost? *Clinical Infectious Diseases*, 53(12), pp. 1265–1270.

Hutchinson, P.L., Mahlalela, X., Yukich, J. (2007) Mass media, stigma, and disclosure of HIV test results: multilevel analysis in the eastern Cape, South Africa. *AIDS Education & Prevention*, 19(6), pp. 489-510.

Jankowski, N.W. and Wester, F. (1990) The Qualitative tradition in social science inquiry: contributions to mass communications research. In: Jensen KB and Jankowski

NW (eds) A Handbook of Qualitative Methodologies for Mass Communication Research. New York: Routledge.

Janz, N.K. and Becker, M.H. (1984) The Health Belief model: A decade later. *Health Education Quarterly*, 11(1), pp. 1-47.

Johnson, L.F., Dorrington, R.E. and Moolla, H. (2017) HIV epidemic drivers in South Africa: A model-based evaluation of factors accounting for inter-provincial differences in HIV prevalence and incidence trends. *Southern African Journal of HIV Medicine*, 18(1).

Jones, C.L., Jensen, J.D., Scher, C.L., Brown, N.R., Christy, K. and Weaver, J. (2015) The Health Belief Model as an Explanatory Framework in Communication Research: Exploring Parallel, Serial, and Moderated Mediation. *Health Communication*, 30:6, pp. 566-576.

Juniper, K.C., Oman, R.F., Hamm, R.M., Kerby, D.S. (2004) The relationships among constructs in the health belief model and the transtheoretical model among African-American college women for physical activity. *American Journal of Health Promotion*, 18, pp. 354-357.

Kalichman, S. and Mathews, C. (2018) Male circumcision for HIV prevention: Awareness, risk compensation and risk perceptions among South African women. *Global Public Health*, 1(9).

Kandula, N. R., Khurana, N. R., Makoul, G., Glass, S., & Baker, D. W. (2012) A community and culture-centered approach to developing effective cardiovascular health messages. *Journal of general internal medicine*, 27(10), pp. 1308-1316.

Karim, Q.A., Kharsany, A.B.M., Frohlich, J.A., Werner, L., Mashego, M., Mlotshwa, M., Madlala, B.T., Ntombela, F. and Karim, S.S.A. (2011) Stabilizing HIV prevalence masks high HIV incidence rates amongst rural and urban women in KwaZulu-Natal, South Africa. *International Journal of Epidemiology*, 40, pp. 922–930.

Karim, Q. A., Karim, S. S. A., Frohlich, J. A., Grobler, A. C., Baxter, C., Mansoor, L. E., Kharsany, A. B., Sibeko, S., Mlisana, K. P. and Omar, Z. (2010). Effectiveness and safety of tenofovir gel, an antiretroviral microbicide, for the prevention of HIV infection in women. *Science*, 329.

Karim, Q.A., Kharsany, A.B.M., Frohlich, J.A., Werner, L., Mashego, M., Mlotshwa, M., Madlala, B.T., Ntombela, F. and Karim, S.S.A. (2011) Stabilizing HIV prevalence masks high HIV incidence rates amongst rural and urban women in KwaZulu-Natal, South Africa. *International Journal of Epidemiology*, 40, pp. 922–930.

Karim, Q.A., Baxter, C. and Birx, D. (2017) Prevention of HIV in Adolescent Girls and Young Women: Key to an AIDS-Free Generation. *Journal of Acquired Immune Deficiency Syndrome*, 75, pp. 17-26.

Karim, S.S.A. and Karim, Q.A. (2012) Antiretroviral prophylaxis for HIV prevention reaches a key milestone.

Kaufman, M.R., Cornish, F., Zimmerman, R.S. and Johnson, B.T. (2014) Health Behavior Change Models for HIV Prevention and AIDS Care: Practical Recommendations for a Multi-Level Approach. *Journal of Acquired Immune Deficiency Syndrome*, 66(3), pp. 250-258.

Kauppi, S. (2015) Behaviour change and communication - a descriptive literature review of behavior change and communication in Sub-Saharan countries. Diaconia University of Applied Sciences.

Kegeles, S.S. (1963) Why people seek dental care: a test of a conceptual formulation. *Journal of Health and Human Behaviour*, 4, pp. 166–173.

Kelly, S.E., Binkley, C.J., Neace, W.P. and Gale, B.S. (2005) Barriers to care-seeking for children's oral health among low-income caregivers. *American Journal of Public Health*, 95(8), pp. 1345-1351.

Kgatlhe, M.S. (2018) 'Servant leadership: An urgent style for the current political leadership in South Africa'. *Verbum et Ecclesia* 39(1).

Khamisa, N., and Mokgobi, M. (2018) Risky sexual behaviour and human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) among healthcare workers. *Southern African Journal of HIV Medicine*, 19(1),

Kharsany, A.B.M. Cawood, C., Khanyile, D., Grobler, A., Mckinnon, L.R., Samsunder, N., Frohlich, J.A., Karim, Q.A., Puren, A., Welte, A., George, G., Govender, K., Toledo, C., Chipeta, Z., Zembe, L., Glenshaw, M.T., Madurai, L., Deyde, V.M. and Bere, A. (2015) Strengthening HIV surveillance in the antiretroviral therapy era: rationale and design of a longitudinal study to monitor HIV prevalence and incidence in the uMgungundlovu District, KwaZulu-Natal, South Africa. *BMC Public Health*, 15.

Kharsany, A.B.M. and Karim, Q.A. (2016) HIV infection and AIDS in sub-saharan Africa: current status, challenges and opportunities. *The Open AIDS Journal*, 10, pp. 34-48.

Kharsany, A. B., & Karim, Q. A. (2016) HIV Infection and AIDS in Sub-Saharan Africa: Current Status, Challenges and Opportunities. *The Open AIDS Journal*, 10, pp. 34-48.

Kickbusch, I., Wait, S. and Maag, D. (2008) *Navigating Health: The Role of Health Literacy*, Alliance for Health and the Future, London.

Kirby, D., Laris, B.A. and Roller, L. (2007). Sex and HIV education programs: their impact on sexual behaviors of young people throughout the world. *Journal of Adolescent Health*, 40, pp. 206–217.

Klatt, E.C. (2017) *Pathology of HIV/AIDS*. Mercer University School of Medicine Savannah (28).

Krueger, R. (1998) *Developing questions for focus groups*, Thousand Oaks: SAGE.

Lamanna, L.M. (2004) College students' knowledge and attitudes about cancer and perceived risks of developing skin cancer. *Dermatology Nursing*, 16(2), pp. 161-176.

Lane, C., Bailey, R.C., Luo, C. and Parks, N. (2018) Adolescent Male Circumcision for HIV Prevention in High Priority Countries: Opportunities for Improvement. *Clinical Infectious Diseases*, 66(3), pp. 161-165.

Lewis, J.E. and Malow, R.M. (1997) HIV/AIDS risks in heterosexual college students. *Journal of American College Health*, 45(4), pp. 147-155.

Lindridge, A., MacAskill, S., Gnich, W., Eadie, D. and Holme, I. (2013) Applying an ecological model to social marketing communications. *European Journal of Marketing*, 47(90), pp. 1399-1420.

Luboobi, L.S. and Mugisha, J.Y.T. (2005) HIV/AIDS Pandemic in Africa: Trends and Challenges. *Nota Di Lavoro*, 103.

Mabaso, M., Sokhela, Z., Mohlabane, N., Chibi, B., Zuma, K. and Simbayi, L. (2018) Determinants of HIV infection among adolescent girls and young women aged 15-24 years in South Africa: a 2012 population-based national household survey. *BMC Public Health*, 18(1), pp. 183.

MacKian, S. (2003) A review of health seeking behaviour: problems and prospects. Health Systems Development University of Manchester, Manchester, UK.

Maes, C.A. and Loius, M. (2003) Knowledge of AIDS, perceived risk of AIDS, and at-risk sexual behaviors of older adults. *The Journal of the American Academy of Nurse Practitioners*, 5(11), pp. 509-516.

Malga, P., Setlalentoa, B.M., Oduaran, C. and Maforah, N. (2018) Factors influencing HIV/AIDS and risky behavior among learners in South Africa. *Global Journal of Health Sciences*, 10(5), pp. 197-208.

Maman, S., Abler, L., Parker, L., Lane, T., Chirowodza, A., Ntogwisangu, J., Srirak, N., Modiba, P., Murima, O. and Fritz, K. (2009) A comparison of HIV stigma and discrimination in five international sites: The influence of care and treatment resources in high prevalence settings. *Social Science and Medicine*, 68, pp. 2271-2278.

Mamulwar, M., Godbole, S., Bembalkar, S., Kamble, P., Dulhani, N., Yadav, R., Kadu, C., Kumar, P., Lalikar, S., Acharya, S., Gangakhedkar, R., Risbud, A. and Venkatesh, S. (2018) Differing HIV vulnerability among female sex workers in a high HIV burden Indian state. *PloS one*, 13(2).

Manopaiboon, C., Kilmarx, P.H., Supawitkul, S. (2007) HIV communication between husbands and wives: Effects on husband HIV testing in northern Thailand. *The Southeast Asian Journal of Tropical Medicine and Public Health*, 38(2), pp. 313-324.

Mattson, M. (1999) Toward a reconceptualisation of communication cues to action in the Health Belief Model: HIV test counseling. *Communication Monographs*, 66, pp. 240-265.

Mayaphi, S.H., Martin, D.J., Olorunju, S.A.S., Williams, B.G., Quinn, T.C., Stoltz, A.C. (2018) High risk exposure to HIV among sexually active individuals who tested negative on rapid HIV Tests in the Tshwane District of South Africa—The importance of behavioural prevention measures. *PLoS ONE*, 13(2).

Mbuagbaw, L. and Shurik, E. (2011) Community Participation in HIV/AIDS Programs. *HIV-Infection – Impact, Awareness and Social Implications of Living with HIV/AIDS*.

McCormick-Brown, K. (1999) Health Belief Model Overview.

McGillen, J.B., Anderson, S. and Hallett, T.B. (2016) PrEP as a feature in the optimal landscape of combination HIV prevention in sub-Saharan Africa. *Journal of the International AIDS Society*, 19(6).

McKay, B. (2018) Slowdown in HIV/AIDS progress puts focus on young women. *The Wall Street Journal*.

Merriam, S. B. and Tisdell, E. J. (2015) *Qualitative research: A guide to design and implementation*, John Wiley & Sons.

Metta, E.O. (2016) Health-seeking behaviour among adults in the context of the epidemiological transition in Southeastern Tanzania: A focus on malaria and diabetes [Groningen]: University of Groningen.

Miles, M. B., Huberman, A. M. and Saldana, J. (2013) Qualitative data analysis, Sage.

Mitchell, K.M., Lepine, A., Terris-Prestholt, F., Torpey, K., Khamofu, H., Folayan, M.O., Musa, J., Anenih, J., Sagay, A.S., Alhassen, E., Idoko, J. and Vickerman, P. (2015) Modelling the impact and cost-effectiveness of combination prevention amongst HIV serodiscordant couples in Nigeria. *AIDS*, 29, pp. 2035-2044.

Moore, L., Chersich, M. F., Steen, R., Reza-Paul, S., Dhana, A., Vuylsteke, B., Lafort, Y. and Scorgie, F. (2014) Community empowerment and involvement of female sex workers in targeted sexual and reproductive health interventions in Africa: a systematic review. *Globalization and health*, 10(47).

Morin, S.F.; Majorana, A; Koester, K.A; Sheon, N.M and Richards, T.A (2003) Community consultation in HIV Prevention Research : A Study of Community Advisory Boards at 6 Research sites JAIDS Lippincott Williams & Wilkins, Inc, Philadelphia

Morrow, R., Rodriguez, A. & King, N. (2015) Colaizzi's descriptive phenomenological method. *The Psychologist*, 28(8), pp. 7-10.

Mthembu, J.C. and Mabaso, M.L.H. (2017) Prevalence of psychological distress and its association with socio-demographic and HIV-risk factors in South Africa: Findings of the 2012 HIV prevalence, incidence and behavior survey. *SSM Popular Health*, 3, pp. 658-662.

Mubuuke, A. G. & Leibowitz, B. (2013) Participatory action research: The key to successful implementation of innovations in health professions education. *African Journal of Health Professions Education*, 5(1), pp. 30-33.

Mukumbang, F.C. (2017) Actions of female sex workers who experience male condom failure during penetrative sexual encounters with clients in Cape Town: Implications for HIV prevention strategies. *South African Journal of HIV Medicine*, 18(1).

National Strategic Plan of South Africa 2017-2022

Nemutandani, S.M., Hendricks, S.J. and Mulaudzi, M.F. (2018) Decolonising the mindsets, attitudes and practices of the allopathic and indigenous health practitioners in postcolonial society: An exploratory approach in the management of patients.

Neuman, W.L. (2011) *Social Research Methods: Qualitative and Quantitative Approaches*: Pearson.

New York- Presbyterian Hospital. (2006) Colonoscopy promoted during colorectal cancer awareness month.

Nicol, E. and Bradshaw, D. (2017) Perceptions about data-informed decisions: an assessment of information use in high HIV prevalence settings in South Africa. *BMC Health Service Res*, 17(2), pp. 765.

Nielsen-Bohlman, L., Panzer, A.M. and Kindig, D.A. (2004) *Health Literacy: A Prescription to End Confusion*, Institute of Medicine of the National Academies of Sciences, Washington, DC, National Academies PressSallis.

Noar, S.M., Carlyle, K. and Cole, C. (2006) Why Communication Is Crucial: Meta-Analysis of the Relationship Between Safer Sexual Communication and Condom Use. *Journal of Health Communication*, 11(4), pp. 365-390.

Nota, P.B. (2015) A comparative study of students' attitudes, preferences and acceptance levels towards microbicide products; the tenofovir gel and the dapivirine ring at UKZN. Master of Social Science, In The Centre for Communication, Media & Society Dissertation. University of KwaZulu-Natal.

Nutbeam, D. (2000) Health literacy as a public health goal: a challenge for contemporary health education and communication strategies in the twenty-first century. *Health Promotion International*, 15(3), pp. 259-267.

O'Donnell, M.P. (2005) A simple framework to describe what works best: improving awareness, enhancing motivation, building skills, and providing opportunity. *American Journal of Health Promotion*, 20(1), pp. 1-7.

Omedo, M., Ogutu, M., Awiti, A., Musuva, R., Muchiri, G., Montgomery, S. P., Secor, W. E. & Mwinzi, P. (2014) The effect of a health communication campaign on compliance with mass drug administration for schistosomiasis control in western Kenya--the SCORE project. *The American journal of tropical medicine and hygiene*, 91(5), pp. 982-8.

Orji, R., Vassileva, J., Mandryk, R. (2012) Towards an effective health interventions design: an extension of the health belief model. *Online Journal of Public Health Informatics*, 4.

Panel on Opportunistic Infections in HIV-Infected Adults and Adolescents. (2018) Guidelines for the prevention and treatment of opportunistic infections in HIV-infected

adults and adolescents: recommendations from the Centers for Disease Control and Prevention, the National Institutes of Health, and the HIV Medicine Association of the Infectious Diseases Society of America.

Pebody, R. (2015) PrEP. Nam AIDS Map.

Pienaar, M., van Rooyen, F.C. and Walsh, C.M. (2017) Reported health, lifestyle and clinical manifestations associated with HIV status in people from rural and urban communities in the Free State Province, South Africa. *South African Journal of HIV Medicine*, 18(1).

Pilgrim, N., Jani, N., Mathur, S., Kahabuka, C., Saria, V., Makyao, N., Apicella, L., Pulerwitz, J. (2018) Provider perspectives on PrEP for adolescent girls and young women in Tanzania: The role of provider biases and quality of care. *PloS one*, 13(4).

Piot, P., Bartos, M., Ghys, P.D., Walker, N. and Schwartlander, B. (2001) The global impact of HIV/AIDS. *Nature*, 410, pp. 968-973.

Price, J.T., Rosenberg, N.E., Vansia, D., Phanga, T., Bhushan, N., Maseko, B., Brar, S., Hosseinipow, M.C., Tang, J., Bekker, L., Pettifor, A. (2018) Predictors of HIV, HIV risk perception and HIV worry among adolescent girls and young women in Lilongwe, Malawi. *Journal of Acquired Immune Deficiency Syndromes*, 77(1), pp. 53-63.

Ragnarsson, A., Thorson, A., Dover, P., Carter, J., Ilako, Fe., Indalo, D. and Ekström, A. (2011) Sexual risk-reduction strategies among HIVinfected men receiving ART in Kibera, Nairobi. *AIDS Care*, 23(3), pp. 315 –321.

Richter , L., Koma, A., Desmond, C., Celentano, D., Morin, S., Sweat, M., Chariyalertsak, S., Chingono, A., Gray, G., Mbwambo, J. and Coates, T. (2014) Reported Physical and Sexual Abuse in Childhood and Adult HIV Risk Behaviour in

Three African Countries: Findings from Project Accept (HPTN-043). *AIDS Behavior*, 18, pp. 381-389.

Riehman, K., Kakietek, J., Manteuffel, B., Rodriguez-Garcia, R., Bonnel, R., N’Jie, N., Godoy-Garraza, L., Orago, A., Murithi, P. and Fruh, J. (2013) Evaluating the effects of community-based organization engagement on HIV and AIDS-related risk behavior in Kenya. *AIDS Care*, 25(1), pp. 67–77.

Rimer, B. K. (2008) Models of individual health behavior. *Health Behavior*, 41.

Ritchie, J., Lewis, J., Nicholls, C. M. and Ormston, R. (2013) *Qualitative research practice: A guide for social science students and researchers*, Sage.

Roden, J. (2004) Revisiting the Health Belief Model: nurses applying it to young families and their health promotion needs. *Nursing & Health Sciences*, 6, pp. 1-10.

Rodwell, M.K. (1998) *Social work, constructivist research*: Taylor & Francis.

Rosenstock, I.M. (1966) Why people use health services. *Milbank Memorial Fund Quarterly*, 44, pp. 94–124.

Rosenstock, I.M. (1974) Historical origins of the health belief model. *Health Education Monographs*, 2, pp. 328–335.

Rosenstock, I.M., Strecher, V.J., Becker, M.H. (1988) Social learning theory and the health belief model. *Health Education & Behavior*, 15, pp. 175-183.

Rubin, H.J. and Rubin, I.S. (2005) *Qualitative interviewing: The art of hearing data*: Sage Publications.

Schatz, E. and Houle, B. (2018) How to ‘Live a Good Life’: Aging and HIV testing in rural South Africa. *Journal of Aging Health*.

Schenker, I. (2018) Cutting-edge success in preventing heterosexual HIV transmission in Africa: voluntary medical male circumcision has reached 15 million men. *AIDS Education Preview*, 30(3), pp. 232-242.

Scott-Sheldon, L.A.J., Carey, M.P., Carey, K.B. (2011) Impact of HIV testing on sexual health communication in South Africa. *Sexually Transmitted Infections*, 87(3), pp. 242-247.

Sheeran, P., Abraham, C. and Orbell, S. (1999) Psychosocial correlates of heterosexual condom use: a meta-analysis. *Psychological Bulletin*, 125(1).

Seidman, I. (2013) Interviewing as qualitative research: A guide for researchers in education and social sciences. 4th Edition. New York: SAGE.

Sheik, Z.B. (2013) Reviving 'White Elephants': A culture-centered approach to the African Ivory Route Tourism Partnership. Master of Social Science Degree, University of KwaZulu-Natal.

Sherman, A.C., Pennington, J., Simonton, S., Latif, U., Arent, L., Farley, H. (2008) Determinants of participation in cancer support groups: The role of health beliefs. *International Journal of Behavioral Medicine*, 15, pp. 92-100.

Shisana, O., Rehle, T., Simbayi, L.C., Zuma, K., Jooste, S., Zungu, N., Labadarios, D. and Onoya, D. (2012) South African National HIV Prevalence, Incidence and Behaviour Survey, Cape Town: HSRC Press.

Shisana, O., Rehle, T., Simbayi, L.C., Zuma, K., Jooste, S., Zungu, N., Labadarios, D., Onoya, D. et al. (2014) South African National HIV Prevalence, Incidence and Behaviour Survey, 2012. Cape Town: HSRC Press.

Sinha, S. (2014) Reasons for Women's Entry into Sex Work: A Case Study of Kolkata, India. The Society for Social Work and Research 2014 Annual Conference.

Silverman, D (2005) Doing Qualitative Research : A practical Handbook 2nd Ed SAGE : London

Silverman, D. (2013) Doing qualitative research: a practical handbook. Los Angeles: SAGE.

Simelela, N.P. and Venter, W.D.F. (2014) A brief history of South Africa's response to AIDS. *South African Medicinal Journal*, 104(3), pp. 249-251.

Smith, D.J. and Mbakwem, B.C. (2010) Antiretroviral therapy and reproductive life projects: Mitigating the stigma of AIDS in Nigeria. *Social Science and Medicine*, 71, pp. 345-352.

Snape, D., Spencer, L., Ritchie, J., Lewis, J., Elam, G., Arthur, S., Nazroo, J., Legard, R., Keegan, J., Ward, K., Finch, H., O'Connor, W., White, C. & Woodfield, K. (2003) Qualitative research practice: A guide for social science students and researchers, edited by J Ritchie & L Lewis. London: SAGE.

Sood, S., Shefner-Rogers, C. and Skinner, J. (2014). Health Communication Campaigns in Developing Countries. *Journal of Creative Communication*, 9(1), pp. 67-84.

Struwig, F. and Stead, G. (2013) Research: Planning, Designing and Reporting, Cape Town: Pearson.

Steward, W.T., Herek, G.M., Ramakrishna, J., Bharat, S., Chandy, S., Wrubel, J. and Ekstrand, M.L. (2008) HIV-related stigma: Adapting a theoretical framework for use in India. *Social Science and Medicine*, 67, pp. 1225-1235.

Storey, D., & Figueroa, M.E., (2012) Towards a Global Theory of health Behaviour and social change. In: Obregon, R., & Waisbord, S. (eds) *The Handbook of Global Health Communication*. UK : John Wiley & Sons INC., 70-94

Suthar, A.B., Ford, N., Bachanas, P.J. (2013) Towards universal voluntary HIV testing and counselling: a systematic review and meta-analysis of community-based approaches. *PLoS Med*, 10(8).

Talbott, J. R. (2007) Size matters: the number of prostitutes and the global HIV/AIDS pandemic. *PloS one*, 2(6).

Tanner-Smith, E.E., Brown, T.N. (2010) Evaluating the Health Belief Model: A critical review of studies predicting mammographic and pap screening. *Social Theory & Health*, 8, pp. 95-125.

Tanser, F. and Vandormael, A. (2017) Effect of population viral load on prospective HIV incidence in a hyper endemic rural African community. *Science Translational Medicine*, 9(420).

Taylor, D., Bury, M., Campling, N., Carter, S., Garfield, S., Newbould, J. and Rennie, T. (2007) A Review of the use of the Health Belief Model (HBM), the Theory of Reasoned Action (TRA), the Theory of Planned Behaviour (TPB) and the Trans-Theoretical Model (TTM) to study and predict health related behaviour change. The National Institute for Health and Clinical Excellence (NICE).

The Global Fund (2017) Technical Brief Adolescent Girls and Young Women in High-HIV Burden Settings. Adolescent Information Note.

Tianyi, F., Tochie, J.N., Agbor, V.N. and Kadia, B.M. (2018) Audit of HIV counselling and testing services among primary healthcare facilities in Cameroon: a protocol for a multicentre national crosssectional study. *BMJ Open*.

Tindana, P., Rozmovits, L., Boulanger, R., Bandewar, S., Aborigo, R., Hodgson, A., Kolopack, P. and Lavery, J. (2011). Aligning Community Engagement With Traditional Authority Structures in Global Health Research: A Case Study From Northern Ghana. *American Journal of Public Health*, 101(10), pp. 1857-1867.

Tlou, E.R. (2005) The effectiveness of a HIV/AIDS health promotion approach derived from the Health Belief Model. Master of Philosophy (HIV/AIDS Management) at Stellenbosch University.

Tshitangoni, M. and Francis, J. (2018) Relevance of Traditional Leadership in Rural Community Development amidst Democratic Institutions in Southern Africa: A Critical Review. *Stud Tribes Tribals*, 15(2), pp. 70-83.

Umeh, K. and Rogan-Gibson, J. (2001) Perceptions of threat, benefits and barriers in breast self-examination amongst young asymptomatic women. *British Journal of Health Psychology*, 6(4), pp. 361-673.

UNAIDS (2017) UNAIDS Data 2017. Joint United Nations Programme on HIV/AIDS.

USAIDS (2013) The ABCs of HIV Prevention. U.S. Agency for International Development. Bureau for Global Health.

Valente T.W 2007 Identifying Opinion Leaders to promote Behaviour Change
<https://doi.org/10.1177/1090198106297855>

Vamos, S., Cook, R., Chitalu, N., Mumbi, M., Weiss, S.M. and Jones, D. (2013) Quality of relationship and sexual risk behaviors among HIV couples in Lusaka, Zambia. *AIDS Care*, 1-7.

van Dyk, A. C. (2001) Traditional African beliefs and customs: Implications for AIDS education and prevention in Africa. *South African Journal of Psychology*, 31, pp. 60-68.

van Huyssteen, C.C. (2013). The nature and extent of HIV/AIDS related stigma reported by aspiring faith-based leaders. University of Pretoria.

Vukapi, Y. (2015) "ZAZI-Know Your Strength"- A reception Analysis of contraceptive utilisation in correlation to unplanned and unwanted pregnancies among young female learners' in Umnini, KwaZulu-Natal. Master of Social Sciences, in The Centre for Communication, Media and Society Dissertation. University of KwaZulu-Natal.

Weinrich, A., Hodlford, D., Boyd, M., Creanga, D., Covern, K., Johson, A., Frank-Strouborg, M., Weinrich, M. (1998) Prostate cancer education in African American churches. *Public Health Nursing*, 15(3), pp. 188-195.

Weiss, H.A and Hawks, S. (2001) An overview of the global epidemiology of HIV/AIDS. *Leprosy Review*, 72, pp. 92-98.

Wilson, D., Lavelle, S., Greenspan, R., and Wilson, C. (1991) Psychological predictors of HIV-preventive behaviour among Zimbabwean students. *Journal of Social Psychology*, 131, pp. 293 – 295.

Wilson, D., Manual, A., and Lavelle, S. (1991) Psychological predictors of condom use to prevent HIV transmission among Zimbabwean students. *International Journal of Psychology*, 26, pp. 705 - 721.

Winfield, E.B. and Whaley, A.L. (2002) A comprehensive test of the Health Belief Model in the prediction of condom use among African American college students. *Journal of Black Psychology*, 28, pp. 330-346.

Young, I. and Mcdaid, L. (2014) How acceptable are antiretroviral for the prevention of sexually transmitted HIV? : A review of research on the acceptability of oral pre-exposure prophylaxis and treatment as prevention. *AIDS and Behavior*, 18, pp. 195-216.

Yep, G.A. (1993) HIV prevention among Asian American college students: Does the Health Belief Model work? *Journal of American College Health*, 41(5), pp. 199-205.

Zamanzadeh, V., Jasemi, M., Valizadeh, L., Keogh, B., & Taleghani, F. (2015) Effective factors in providing holistic care: a qualitative study. *Indian journal of palliative care*, 21(2), pp. 214-224.

Ziraba, A., Orindi, B., Muuo, S., Floyd, S., Birdthistle, I.J., Mumah, J., Osindo, J., Njoroge, P. and Kabiru, C.W. (2018) Understanding HIV risks among adolescent girls and young women in informal settlements of Nairobi, Kenya: lessons for DREAMS. *PLoS ONE*, 13(5).

Zuma, T., Wight, D., RoCHAT, T. and Moshabela, M. (2016) The role of traditional health practitioners in Rural KwaZulu-Natal, South Africa: generic or mode specific? *BMC Complementary and Alternative Medicine*, 16, pp. 304.

Appendix I

Informed Consent Form: interviews

Community leaders- adults

Project title: The role of community leaders in the effective implementation of oral Pre-exposure prophylaxis in Vulindlela, KwaZulu-Natal.

Dear Participant,

My name is Noluthando Fadane, a student at the Center for Communications media and Society (CCMS) department at University of KwaZulu-Natal in Durban.

Contact details

Centre for Communication, Media and Society

Memorial Tower Building |Howard College Campus

University of Kwa-Zulu Natal

4041|South Africa

Phone: +27 072 136 3072

Email: ndozaf@gmail.com |Website: <http://ccms.ukzn.ac.za>

Project Details

You are invited to participate in my project. This project seeks to understand if adolescent girls and young women are ready to use oral pre-exposure prophylaxis, known as PrEP. Oral PrEP is a pill which can help reduce your risk of getting HIV. The main reason for this project is to investigate the role of community leaders in supporting the implementation of oral PrEP among adolescent girls and young women in order to reduce new HIV infections. This research will be conducted under the supervision of Prof Eliza Govender. This research aims to understand the role of

community leaders in preparing adolescent girls and young women for oral PrEP uptake.

Participation is Voluntary

You can choose whether or not you want to participate, you do not have to decide immediately. Even if you agree now, you can change your mind at any point. This decision can be difficult because sexuality and sexual health is a sensitive topic, so you are free to ask as many questions as you like. Participation is voluntary and the participant is free to withdraw from the study at any stage, for any reason. The participant has the right to decide to stop participating in the discussion at any time that you wish.

If you agree to take part in the interview, you will be asked questions surrounding oral PrEP and your opinions, thoughts, and knowledge about oral PrEP. You will not be asked to share any personal stories that you are not comfortable to share.

If you do not wish to answer any of the questions, you may say so. You do not have to give any reason for not responding to any questions, or for refusing to take part in the interview.

Data storage and confidentiality

The interview will be electronically recorded and kept confidential. The recording will be kept securely for 5 years at UKZN. Your information will not be shared outside of the research team. Any information about you will have a number on it and your name will not be recorded or mentioned in the research.

Reimbursement

You will be reimbursed R100 for your participation in this project, this is to show appreciation for your time spared for the interview.

Problems/Questions

In the event of any problems or concerns/questions you may contact the student at (072 136 3072) or the study supervisor Prof Eliza Govender at govendere1@ukzn.ac.za. This study has been ethically reviewed and approved by the UKZN **BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**, ethical number **BE500/17**.

CONSENT (Edit as required)

- I _____ have been informed about the study entitled “The role of community leaders in the effective implementation of oral Pre-exposure prophylaxis in Vulindlela, KZN by Noluthando Fadane.
- I understand the purpose and procedures of the study.
- I have been given an opportunity to ask questions about the study and have had answers to my satisfaction.
- I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.
- I have been informed about any available reimbursement of R100.
- If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher at ndozaf@gmail.com or on 072 136 3072.
- If I have any questions or concerns about my rights as a participant, or if I am concerned about an aspect of the project or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Email: BREC@ukzn.ac.za

Signature of Participant

Date

Signature of Witness

Date

(Where applicable)

Signature of person obtaining consent

Date

Appendix II

INTERVIEW QUESTIONS

1. What do you know about HIV prevention?
2. Have you heard about oral PrEP?
3. What have you heard about oral PrEP?
4. Where do you get this information from?
5. Do you believe that oral PrEP can work? If yes, why? If no, Why?
6. Do you think your community knows about PrEP? (If yes, what have you heard from the community about PrEP?, If not, why do you think the community has not heard about oral PrEP yet?)
7. Do you think oral PrEP can reduce HIV transmission amongst AGYW in your community? (Yes or No If yes, how so?, If not, please elaborate)
8. What do you think will be the community leaders' responses to oral PrEP if the product was available?
9. How would you describe the attitude of the community leaders towards HIV prevention, and oral PrEP specifically?
10. Are there any factors that may contribute to PrEP resistance and give examples?
11. Are there any benefits to oral PrEP that you believe can help AGYW?
12. What positive contribution do you, as a community leader, think you can make towards making the community ready for oral PrEP?
13. As a community leader do you believe you have a contribution to make in helping fight the HIV transmission? (If yes, how would you then influence your community towards using oral PrEP? if not, who do you think is responsible to make the community aware and ready to use oral PrEP?)
14. Do you think your community has the resources needed to implement oral PrEP effectively? (If yes, what are they and how do they need to be maximised? If not, what resources are needed and how would they be effectively utilised?)

Appendix III

Ethics Approval letter



01 June 2018

Dr Eliza Govender
School of Applied Human Sciences
Faculty of Human Sciences
Eliza.govender@caprisa.org

Dear Dr Govender

PROTOCOL: User Readiness for oral Pre-exposure Prophylaxis: Strengthening HIV prevention efforts in the high HIV burden district of UMgungundlovu, KwaZulu-Natal. Non-Degree
BREC reference number: BE500/17

Your Application for Amendments received on 14 May 2018 to add the students listed below to the above study has been noted and approved by a sub-committee of the Biomedical Research Ethics Committee.

Name of student	Title of masters study
Gethwana Mashase	Exploring readiness of the Primary Health care clinics for the provision of pre-exposure prophylaxis to Adolescent Girls and Young Women (AGYW): A case study in Vulindlela
Noluthando Precious Nomalungisa Fadane	The role of community leaders in effective implementation of oral pre-exposure prophylaxis in the Vulindlela community in Kwa-Zulu-Natal.
Simamkele Bokolo	Exploring adolescent girls and young women's oral PrEP readiness from a school based perspective in Vulindlela , KZN

This approval will be ratified at the next BREC meeting to be held on 10 July 2018.

Yours sincerely


Mrs A. Marimuthu
Senior Administrator: Biomedical Research Ethics

Appendix IV

Turnitin Report

Document Viewer

Turnitin Originality Report

Processed on: 12-Dec-2019 4:04 PM CAT
ID: 1233094591
Word Count: 32220
Submitted: 1

Dissertation 2 By Noluthando Fadane

Similarity Index	Similarity by Source
9%	Internet Sources: 4% Publications: 3% Student Papers: 9%

[include quoted](#) [include bibliography](#) [excluding matches < 15 words](#) mode:
quickview (classic) report ▼ Change mode [print](#) [download](#)

1% match (student papers from 06-Dec-2018)
[Submitted to University of KwaZulu-Natal on 2018-12-06](#)

1% match (student papers from 23-Dec-2015)
[Submitted to University of KwaZulu-Natal on 2015-12-23](#)