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2017
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HIV POSITIVE YOUNG PEOPLE'S EXPERIENCES OF PARTICIPATING IN SUPPORT GROUPS ON WHATSAPP AND FACEBOOK AND PERCEPTIONS OF IMPACT ON HIV-RELATED BEHAVIOUR

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Public Health.

Johannesburg, June 2017

Declaration

I Sandisile Tshuma declare that this Research Report is my own, unaided work. It is being submitted for the Degree of Master of Public Health at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



_____ (Signature of candidate)

On the 22nd day of June 2017 in Johannesburg, South Africa.

Abstract

Introduction

South Africa is grappling with the challenge of providing lifelong treatment, care and support to young people living with HIV (YPLHIV). The 2012 HIV Prevalence, Incidence and Behaviour Survey placed HIV prevalence among young people aged 15-24 at 7.1% (Shisana et al. 2014). Concerns abound around young people, and centre around low testing rates in this age group (Shisana 2014), their propensity for risky behaviours such as unprotected sex, age disparate relationships (Shisana et al. 2014) and high loss to follow up of ART-eligible youth (Cornell et al. 2010, Nglazi et al. 2012; Wang 2011). In the Western Cape province where HIV prevalence is 4.4% (Shisana et al. 2014) Clinic X provides integrated adolescent and youth-friendly health services including HIV counseling and testing, sexual and reproductive health, ART and other services for adolescents and youth aged 12-25 years. Services include facilitator-led support group meetings and private WhatsApp and Facebook groups for HIV-positive youth (van Cutsem et al. 2014). The aim of the study was to explore how social support is experienced by HIV positive young people from Clinic X who participate in support groups at the clinic, on WhatsApp and Facebook and to understand how support group membership is perceived to impact their HIV-related behaviours, if at all, during 2015 and 2016. The specific objectives were to (1) identify dimensions of social support experienced by YPLHIV, aged 18-25, in clinic-based and online support groups at Clinic X; (2) explore perceived social cohesion among YPLHIV aged 18-25 who participate in online support groups compared to those who only participate in clinic-based support groups and (3) explore perceptions of HIV positive young people at Clinic X in Khayelitsha regarding the influence of support groups on their behaviour during 2015 and 2016.

Methods

A cross-sectional exploratory qualitative study was conducted, namely focus group discussions (FGDs) and in-depth interviews (IDIs). Ethical clearance was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand in October 2015. The researcher collected data for the study during December 2015 and November 2016 at Clinic X, which is one of two youth clinics in the Khayelitsha Health District of the Western Cape Metro Region. Participants were purposively sampled for the FGD component of the study from the population of young people aged 18-25 years old who attended support group meetings at Clinic X. The researcher purposively sampled interviewees for the IDIs from participants identified during the FGDs. Male and female individuals aged 18 to 25 years old who had been diagnosed HIV-positive, were enrolled in pre-ART or ART care at Clinic X Youth clinic and were participating in a youth club were included. Two FGDs were held, one for users of the online platforms and another for participants in face-to-face youth clubs meetings only. Twenty participants in total were included in the FGDs. Another nine in depth interviews were held with participants purposively sampled from the FGDs. Thematic analysis was used to analyze all data,

which were recorded electronically, professionally transcribed and coded using MaxQDA. Key themes from data analysis included types of social support experienced, sense of belonging, desire to remain in the support groups and susceptibility to peer influence. Inductive themes included HIV-related behaviours, barriers to use of online platforms and sources of social support.

Results

Exploring the dimensions of social support revealed that peers within the youth clubs experienced emotional and informational support during youth club meetings as well as online. Emotional support was underpinned by the youth's positive affect for each other based on shared experiences and the resultant feelings of being understood by their peers. The youth also received emotional and instrumental support from various other sources: health workers, family, and intimate partners as well as friends. The youth opened up about barriers to their seeking or accepting support from family or online as well as their perceptions about the consequences of the attitudes of individuals in their lives and community members about HIV. Participants' perceptions about various indicators of social cohesion within the group showed that, while there was a sense of belonging, there were also limits in the extent to which youth felt susceptible to influence from peers in the youth clubs. Youth expressed a desire to remain in face-to-face youth clubs but were ambivalent about continued participation in the virtual clubs. Findings on the third objective revealed that the youth felt that the youth clubs had improved their knowledge and they were confident to maintain health-protecting behaviours. Seeing other youth looking healthy and overcoming challenges also motivated the youth. The behavioural intentions of YPLHIV were underpinned by gendered motivations for maintaining health, with young women being especially motivated by the desire for motherhood.

Discussion

To the body of evidence, this study contributes a qualitative understanding of how young people living with HIV experience social support online, showing that the dimensions of social support experienced are the same as those of participants of online health forums for other chronic conditions, namely information and emotional support (Gaysyknsky et al. 2014). Further, the study shows that for YPLHIV, online support groups may act as a barrier to the exchange of instrumental support, which research (Atukunda 2017) identifies as a salient need in this context. In seeking to understand why there may be disjuncture between the intention of pre-ART YPLHIV in the study to remain in care and the actual retention reported in numerous studies, the chapter proposes that social comparison, structural determinants and low risk perception may play a role. The major limitations of the study are the short time of engagement and exclusion of adolescents below 18 years of age who access services at the youth clinic.

Conclusion and recommendations

In conclusion, online peer groups foster peer support among YPLHIV, with implications on their emotional health. Still, more needs to be done to *c*hange perceptions about the use of online

platforms for social support, design community-focused programmes to address gaps in support and reduce the financial burden on young people using mobile phones for health.

Acknowledgments

I thank God whose faithfulness, provision and grace over my life leave me awe-struck and grateful. Bekezela Tshuma, whose voice was the final push I needed to embark on this grueling journey, who encouraged me, kept my eye on the prize and continues to believe in me. Tanganyika Tshuma, who planted the seed and I am sure is proud to have watched it grow from heaven. I am grateful to Pride and Emmanuel Tshuma, who are the smartest people I know and the best brothers ever.

My supervisor, Sara Nieuwoudt: for believing in me, challenging me and demanding the best of me; for encouraging me to find my voice, helping me to puzzle my way out of the darkness into the light and doing the “happy dance” with me when I finally got it. Thanks to the team at MSF: Damian, Ruth, Bella and Pumeza for entrusting me with such important work and providing the financial and logistical resources for me to witness and contribute to documenting how they are helping remarkable young people to empower themselves and live their best lives under tough circumstances.

My heartfelt thanks to all my friends for feeding me a steady diet of laughter, encouragement, hugs, deep conversations and champagne; for helping with logistics, forgiving my lack of a social life for three years of our lives and their unshakable certainty that I could do this and other great things. I am also grateful to my MPH classmates for their partnership in the pursuit of academic growth and excellence and of course the sterling Wits MPH teaching staff who educated me.

Finally, I acknowledge and thank the young people who took the time out of their lives to speak to me and share their lives. It has been a privilege to tell their story. They are brave, strong, resilient and inspiring. I am excited about the future that life holds for them and have the utmost confidence in their abilities to make their greatest dreams come true.

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List of acronyms and nomenclature

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti Retroviral Therapy
ARV	Anti Retroviral
DRC	Democratic Republic of Congo
eHealth	Electronic Health (also referred to as digital health)
FGD	Focus Group Discussion
GSMA	Groupe Spéciale Mobile Association
HCT	HIV Counseling and Testing
HIV	Human Immunodeficiency Virus
ICTs	Information Communication Technology
IDI	In-Depth Interview
mHealth	Mobile Health
MSF	Médecins Sans Frontières
NDoH	National Department of Health
PLHIV	Person/People Living with with HIV
SA	South Africa
TB	Tuberculosis
UN	United Nations
WHO	World Health Organization
YPLHIV	Young Person/People Living with HIV

Chapter 1: Introduction

1.0 Overview

To the outside world, it appears like a massive challenge, a crisis of giant proportions: nearly one in ten young people aged 15-24 infected with HIV! To those on the inside who know the resilience and potential of young people in South Africa, this crisis presents an opportunity to change the trajectory of the nation's future. In this vein, South Africa, presently runs the largest (antiretroviral) ART programme in the world for people living with HIV, with over two million people on treatment (Shisana et al., 2014). With a HIV prevalence of approximately seven percent among 15-24 year olds (Shisana et al. 2014) retention in the care continuum is critical. There is evidence of significant levels of attrition along the entire continuum of care in sub-Saharan Africa with less than 50% retention in pre-ART adults (Govindasamy et al. 2014; Lessells et al. 2011; Mugglin et al. 2012). Young people, too, have poor pre-ART retention rates. Recent findings at a clinic in Cape Town found retention rates of 52.9% (95% CI 40.0-64.2) among pre-ART youth compared to 86.0% and 94.0% retention newly initiated and ART stable youth respectively (Wilkinson et al. 2016). Given the numbers of young people living with HIV, health providers are keenly interested in understanding how to initiate young people into the care and treatment continuum and to retain them in care, as this has an impact on reducing transmission of the virus and reducing HIV-related morbidity and mortality (Evans 2013).

1.1 Background

Specific services have been developed in the Western Cape for young people living with HIV (YPLIV). The HIV prevalence among young people in South Africa is around 7.1% and in the Western Cape this proportion is on the rise, with a 4.4% prevalence of HIV among 15-24 year olds in 2012, up from 2.3% in 2005 (Shisana et al. 2014). The Western Cape is the only province in which HIV prevalence has increased in South Africa (Shisana et al. 2014). There is a high HIV burden in Khayelitsha (Médecins Sans Frontières et al. 2010). The City of of Cape Town Health Department (City Health), in partnership with Medecins Sans Frontieres (MSF) provides YPLHIV, aged 12 to 25 years old in Khayelitsha with youth friendly clinical services at Clinic X, a community health centre (Médecins Sans Frontières et al. 2010; van Cutsem et al. 2014).

Youth receiving services at Clinic X are benefitting from differentiated and comprehensive care. In addition to a range of sexual and reproductive health services, Clinic X provides young people with HIV counselling and testing (HCT) and conducts point of care CD4 testing of YPLHIV to determine their ART eligibility (Médecins Sans Frontières et al. 2010; van Cutsem et al. 2014). ART eligible youth are initiated on ART and, as of 2013, there were over 500 YPLHIV in care out at Clinic X, of whom about 60% were on ART with the remainder in pre-ART care (Médecins Sans Frontières et al. 2010). MSF employs a model of care designed to reduce loss to follow up by offering immediate point-of-care CD4 testing to all those who test HIV positive for HIV (van Cutsem et al. 2014). This is followed by counselling for ART preparation and initiation for ART-eligible patients or in the case of ART-ineligible patients, individual or group counselling focused on coping with their diagnosis (van Cutsem et al. 2014).

Clinic X implements an especially crafted programme for continued care and support for youth who test positive for HIV. Pre-ART and ART eligible youth are invited to join support groups called youth clubs (van Cutsem et al. 2014). Groups of 15-20 YPLHIV meet either monthly or every other month at Clinic X (van Cutsem et al. 2014). Those stable on ART receive ART refills, while those who have been on ART for less than a year receive a clinical assessment and ART refills (van Cutsem et al. 2014). A facilitator leads a group counselling session where topics such as disclosure of status in relationships and ART adherance are discussed (van Cutsem et al. 2014). The aim of the youth clubs is for YPLHIV who are on treatment and those not yet on treatment to support each other and reduce the likelihood of loss to follow up (van Cutsem et al. 2014).

Since support groups meet monthly or every two months at the clinic, MSF has introduced supplementary online youth groups using the mobile social networking platforms WhatsApp and FaceBook (can Cutsem et al. 2014; Henwood et al. 2014). The purpose of the online youth groups is to complement the face to face youth club meetings by offering the young people opportunities to interact with each other more regularly, increasing social cohesion and social support amongst group members, which is in turn expected to improve the psychological well being of YPLHIV and increase their positive behaviours, such as remaining in care (can Cutsem et al. 2014; Henwood et al. 2014). Facebook is a free social networking site allowing users with profiles to interact with other users, create and join public and private groups and share information (Ellison 2007). WhatsApp is an instant social messaging software that can be used on smart mobile devices, which also allows the creation of chat groups (WhatsApp Inc. 2017).

Youth choosing to sign up for the Facebook group are added to a private group on Facebook and those choosing WhatsApp are clustered into chat groups on WhatsApp according to their face to face youth club membership (van Cutsem et al. 2014). Youth counselors stimulate discussion, respond to questions and generate content three times a week on both the WhatsApp and the Facebook platforms (van Cutsem et al. 2014). Counselors moderate content, generate new content to stimulate discussion, respond to questions, and make themselves available for private messages. MSF monitors Facebook and WhatsApp activity on a weekly basis (van Cutsem et al. 2014). The introduction of the WhatsApp and Facebook groups was informed by a pilot conducted by MSF in 2012 using the mobile online platform known as mXit (Henwood et al., 2014). The pilot found that while the mXit chatroom called "Khaya Youth," was an acceptable concept to the youth club members as a means to interact with each other and a facilitator between face to face meetings, problems with the mobile platform limited its usability, resulting in its abandonment (Henwood et al., 2014).

1.2. Problem statement

HIV disproportionately affects young people in South Africa (Shisana 2014). Those living with HIV require age-appropriate health services for positive prevention, chronic treatment, and psychosocial and other kinds of support (Li 2009; Mburu et al. 2013). Presently, testing rates among young people in South Africa are low (50% among ages 18 – 24) (Shisana 2014), young people are prone to risk behaviours such as unprotected sex and age disparate relationships (Shisana et al. 2014) and loss to follow up of ART-eligible young people is high (Cornell et al. 2010, Nglazi et al. 2012; Wang 2011). Given that adolescents and young people make up nearly

30% of the population (Statistics South Africa 2015), there is an urgent need to find ways to provide them with appropriate and accessible health services and support.

1.3. Justification for the study

The bulk of the evidence on interventions to increase retention in care programmes is focused on adults while YPLHIV constitute a key population disproportionately affected by HIV (Govindasamy et al. 2014; Shisana et al. 2014; UNAIDS 2014) and among whom there is evidence of high pre-ART attrition and poor treatment outcomes (Bygrave et al. 2012; Govindasamy et al. 2014; Nglazi et al. 2012; Lessells et al. 2011). The introduction of the 'test and treat' strategy by the SA NDoH (2016) also means that young people testing positive for HIV will be on treatment for longer, and it is thus imperative to devise effective ways to retain them in care. It is also known that young people have poor mental health seeking behaviour (Rickwood et al. 2007), which necessitates closer examination and understanding for YPLHIV, given the relationship between mental health and HIV related outcomes (Dageid 2014; Lam 2007; Li 2009).

Furthermore, while peer support has been identified as a promising intervention, the preponderance of evidence available is on interventions that focus on one point in the continuum of care (Dageid 2014; Govindasamy et al. 2014; Lessells et al. 2011). The literature tells us that social relationships have an impact on health (Coursaris et al. 2009; Cohen 2004 ; Diener-Chan 2011 ; Bateganya 2015). There is thus a need for further research to elucidate the role of peer support on young people living with HIV along the care continuum and to identify platforms that make continued peer support accessible to young people in resource constrained settings

accessible. It is thus critical to understand the social mechanisms that are active in face-to-face support groups and evaluate whether online support groups are an interface that is able to provide YPLHIV with the intended dimensions of support.

For MSF, understanding the perceptions and experiences of YPLHIV in the youth clubs provides valuable insights on the strengths and limitations of the online youth club intervention that can assist the organization to improve the programme's effectiveness at keeping these youth in care.

1.4. Research question

How do HIV positive young people participating in clinic-based and WhatsApp and Facebook support groups at Clinic X, Khayelitsha experience social support and what is the perceived impact of support group membership on their HIV-related behaviour, if at all?

1.5. Study aim and objectives

The aim of the study was to explore how social support is experienced by HIV positive young people from Clinic X in Khayelitsha participating in support groups at the clinic, on WhatsApp and Facebook as well as to understand how support group membership is perceived to impact their HIV-related behaviours, if at all during 2015 and 2016.

Specific objectives

The specific objectives of the study were:

1. To identify the dimensions of social support experienced by HIV positive young people, aged 18-25, in clinic-based, WhatsApp and Facebook support groups at Clinic X in Khayelitsha during 2015 and 2016.

2. To explore perceived social cohesion among young HIV positive people aged 18-25 who participate in WhatsApp and Facebook support groups compared to those who only participate in clinic-based support groups at Clinic X in Khayelitsha during 2015 and 2016.

3. To explore perceptions of HIV positive young people at Clinic X in Khayelitsha regarding the influence of support groups on their behaviour during 2015 and 2016.

1.6. Literature review

A review of studies in sub-Saharan Africa documented evidence suggesting that programmes that provide peer support may decrease attrition of patients from care, however, the evidence base was of low quality (Govindasamy et al. 2014). The review found strong evidence from randomized control trials in Uganda and the DRC that extended counseling and peer support have positive effects on linkage to HIV care (Govindasamy et al. 2014) and these positive effects have been echoed in other reviews and studies (Holtzman et al. 2015; Mupambireyi et al. 2014; Greifinger & Dick 2011; Lam et al. 2007; Dageid 2014). Support groups facilitate improved wellbeing and treatment outcomes, such as viral load suppression (Dageid 2014; Funck-Brentano et al. 2005), although there is also some evidence of non-causal association between support group membership and mental disorder (Freeman et al. 2007). This review of literature seeks to elucidate the social forces that operate at the individual and interpersonal level within groups of

young people that can help us to understand how support groups could influence young people's experiences of social support and social cohesion as well as their HIV-related behaviour.

1.6.1. Unpacking social support and social cohesion

A useful starting point is to pose the question, "What is social support?" Basic typologies for social support have been characterized as emotional, instrumental, appraisal and informational support (Mo & Coulson 2008; Gaysynsky et al. 2014; Berkman et al. 2000; Cohen 2004). Emotional support encompasses care, affection and sympathy between individuals (Mo & Coulson 2008; Gaysynsky et al. 2014; Berkman et al. 2000). While Berkman (2000) includes esteem as a form of emotional support, it has been distinguished as a separate type of support by other authors such as Mo & Coulson (2008) and Gaysinsky and colleagues (2014) who define it as validating, complimenting or even relieving another from feelings of guilt, blame or responsibility for a situation. Instrumental support is the provision of tangible resources such as money, food or performing tasks for another (Mo & Coulson 2008; Gaysynsky et al. 2014; Berkman et al. 2000). As such, Mo and Coulson (2008) and Gaysinnsky and colleagues (2014) refer to it as tangible support. Appraisal support is the provision of assistance with making decisions, while informational support is the provision of information or advice (Mo & Coulson 2008; Gaysynsky et al. 2014; Berkman et al. 2000).

Social support is one of the mechanisms by which social networks, such as those in support groups, are thought to influence patterns of health and disease. Several observational studies in sub-Saharan Africa have found that support groups have enabled the exchange of social support

which members have found to be valuable for their mental wellbeing and general coping with life (Abrefa-Gyan et al. 2015; Pronyk et al. 2008; Dageid 2014; Lessells et al. 2011). In a USA study on a Facebook support group for HIV positive people, Gaysynsky (2014) found that the most frequently provided support was informational and emotional, followed by esteem support, while not much tangible assistance was offered among support group members (Gaysynsky et al. 2014). In the context of living with HIV, social support has been identified as playing a critical role for people living with HIV. Research has shown that HIV-positive individuals who feel satisfied with their social support have healthy coping strategies, less mental health problems and lower progression of HIV-related symptoms regardless of their baseline medical status (Coursaris, 2009; Ashton et al., 2005, Turner-Cobb et al., 2002).

Attempts at defining social cohesion suggest it to be a reflection of a number of characteristics of a social network. These include the density of interpersonal ties within a group, the strength of those ties and the extent to which there is a desire to remain in the group and to participate in group activities (Friedkin 2004; Berkman et al. 2000). It is also understood to be the extent to which groups are susceptible to influence by members and mechanisms by which such social forces operate to influence the behaviour of group members (Berkman et al. 2000). Social cohesion is important to understand because in the context of support groups, the degree of cohesion may have an influence on the extent to which members can experience the desired social learning from peers leading to positive health behaviours.

1.6.2. Behaviour of young people living with HIV

Membership in support groups has been found to influence risk and protective behaviours among young people (Mupambireyi et al. 2014; Dageid 2014; Greifinger & Dick 2011; Lam et al. 2007; Funck-Bretano et al. 2005). Young people in South Africa, including those living with HIV, engage in sexual behaviours that place themselves and their partners at risk of contracting HIV and other STIs. Risk behaviours among young people include unprotected sex or inconsistent and incorrect condom use resulting from low risk perception, and conformity to harmful gender and peer norms (Shisana et al. 2014; Eaton et al. 2003; Harrison et al. 2001; MacPhail & Campbell 2001). The 2012 South African National HIV Prevalence, Incidence and Behaviour Survey found that over one in five young people aged 15–24 years reported having had multiple partners in that last 12 months and that there is low consistent use of condoms among youth (Shisana et al. 2014). Multiple sexual partnerships are also a risk behaviour as they increase the rate of HIV transmission through sexual networks, and these too are on the rise among young people in South Africa (Shisana et al. 2014). Protective behaviours for YPLHIV include treatment adherence and remaining in care (Govindasamy et al. 2014; Lessells et al. 2011; Mugglin et al. 2012) as well as engaging in protected sex correctly and consistently (Shisana et al. 2014).

Given that stress has an effect on the progression of disease in HIV-infected individuals (Menon et al, 2007; Kopnisky et al, 2004) and the clinically significant relationship between psychosocial factors and immune-related outcomes (Menon et al, 2007), understanding how YPLHIV manage their mental health is of great importance. Literature documents young people as having poor

mental health seeking behaviour due to various structural and individual determinants. These include social norms discouraging youth from seeking help for mental health issues, perceived stigma, limited access to mental health referral services, cognitive distortion and minimization of problems (Rickwood et al, 2007). Moreover, the most commonly experienced mental health issues that young people face – depression, anxiety and substance abuse - increase their social withdrawal, thereby making them less likely to seek help (Rickwood et al, 2007; Wilson et al., 2005; Gould et al., 2004). As they get older, young people are also trying to establish their own identities and autonomies (Crosnoe and Johnson 2011; Rickwood et al., 2007; Campbell and MacPhail, 2002) resulting in them tending to rely on themselves to handle problems instead of seeking help (Rickwood et al, 2007; Wilson et al., 2005). This poses a risk for not only their mental health but their HIV-related outcomes as well.

There is research postulating that support groups create opportunities for social comparison in the form of three key domains. The first is self-evaluation, wherein being in contact with others who have similar experiences, have the same fears about living with the condition, et cetera normalizes the condition (Festinger 1954). The second is self-improvement through upward comparison in which an individual compares himself or herself to someone better off who is then viewed as a role model (Festinger 1954). The final domain is self-esteem enhancement through downward comparison in which an individual compares himself to one less fortunate or worse off in order to feel better about his or her situation (Festinger 1954). In the context of YPLHIV participating in support groups and thus remaining in the continuum of care, the significance of the social comparison theory is that people move into groups whose abilities are near their own or which hold opinions that match theirs and will move out if their drive to self-evaluate is not

satisfied (Festinger 1954). In the African context, a (2017) review of sub-Saharan facilities providing HIV treatment and care to adolescents that included 82 facilities from Southern Africa found that peer support was recommended as a vehicle for improved retention in care, although not all the facilities provided services or opportunities for peer support (Mark et al., 2017).

1.6.3. Theoretical frameworks for how social support and social cohesion operate on young people's health behaviour and outcomes

Berkman (2000) has proposed a model of the social influences on health in which factors associated with social cohesion such as the structure of social networks in terms of homogeneity, size, frequency of contact and reciprocity of ties act as upstream factors, which enable psychosocial mechanisms at the micro or individual level. Included among the psychosocial mechanisms are the types of social support described in 1.1.1 as well as two additional dimensions of social cohesion, namely social influence and social engagement. Social influence includes the development of norms around health promoting behaviour and adherence, peer pressure and influences among peers that either constrain or enable health behaviour (Berkman et al. 2000). Also at the micro level, Berkman's (2000) model includes access to resources such as economic opportunity, healthcare, housing and referrals - or what Friedkin (2004) defines as bridging social capital.

The psychosocial mechanisms identified above then impact health through health behavioural pathways, which could be negative, such as smoking and substance abuse or health promoting, such as exercise or adherence to treatment (Berkman et al. 2000). Psychological pathways

include depression, self-efficacy, and sense of wellbeing among others, while physiological pathways include immune system function, cardiovascular activity and cardiopulmonary fitness (Berkman et al. 2000).

A construct that is linked to social cohesion and which builds off the early work espoused by Durkheim (1951) on social cohesion and mental health, is social integration (Durkheim, 1951). Social integration is comprised of two components: active participation in relationships and activities of a social nature and feeling a sense of belonging within a community or identifying with one's role in a social group (Brisette et al., 2000, Cohen 2004). Cohen's (2004) examination of social integration posits that social integration operates on individuals' health through the influence of social controls and peer pressure on normative health behaviours such as exercise, smoking, alcohol consumption, et cetera (Cohen, 2004). According to Cohen, being integrated within a social group also engenders a sense of responsibility for peers within the group, which increases an individual's motivation to take care of one's health (Cohen, 2004). Furthermore, Cohen (2004) theorizes that social integration affects sense of self and emotional regulation, limiting negative affective states and increasing positive affect (Cohen, 2004; Cohen, 1988).

More recently, Uchino (2009) proposed a conceptual framework linking social support and health using a life-span perspective where the early family environment of an individual, which includes parental support and affection or conflict, create the individual psychosocial profiles (Uchino 2009). Psychosocial profiles are comprised of individual perceptions of social support, self-esteem as well as a sense of personal control (Uchino 2009). These profiles may, depending on the early family environment, be either positive or negative and act on physical health through

mechanisms such as effective coping with stress and health behaviours. Uchino (2009) proposes that positive profiles are associated with positive behaviours, including adherence to medical treatment in the case of chronic illness.

Taking a different approach to social support from Uchino's (2009) life-span approach, Cohen (2004) identifies stress buffering as a means through which social support can influence physical health (Cohen, 2004). In this model, social support attenuates the individual's experience of stress by providing emotional support in the face of a variety of stressful events and event-specific types of support (instrumental or informational) in response to needs elicited by those events (Cohen, 2004). This emotional support reduces the negative impact of stress by providing solutions to stressors, facilitating health-promoting behaviour and lessening the individual's perception of the importance of the stressor (Cohen, 2004). Swedish research on men found that the perception of availability of social support was significant in reducing risk of mortality among those who had experienced stressful events (Rosengren et al. 1993).

1.6.4. Young People Living with HIV and digital health

Digital technology has offered promise in the elimination or reduction of traditional barriers to health, such as geography (Lewis et al. 2012). Two terms are important to understand in the context of the use of digital technology for the provision of health care. The first is eHealth, which is defined by the World Health Organization (WHO) as using information and communication technologies (ICTs) for health, for example in the diagnosis and treatment of patients, disease surveillance, monitoring and evaluation, training and management of staff and

other functions within a health system (World Health Organization 2016). The second term is mHealth, a subset of eHealth that is broadly understood to mean the use of mobile devices to support the practice of medicine and public health and the delivery of health services (Crul 2014; Lewis et al. 2012; World Health Organization 2011).

South Africa enjoys high mobile phone penetration among young people with up to 70% of 14-18 year olds and 90% of 19-25 year olds owning cell phones (Hampshire et al. 2015; de Lanerolle 2015). A Groupe Spéciale Mobile Association (GSMA) (2014) report on 15 – 49 year old pregnant women and mothers of infants found 94% cell phone ownership among women classified as "bottom of the pyramid" in terms of socioeconomic status, while the remaining 6% had access to a mobile phone within their families (GSMA 2014). Many mHealth services have been piloted in South Africa over the last decade, so many in fact, that the South African government issued a moratorium on new mHealth projects, with the aim to rationalize and regulate the sector through a national strategy that was then developed for the period 2012-2017 (Leon et al. 2012; van Dyk et al. 2012; South Africa National Department of Health 2012). While rigorous evaluations of the impact of mHealth services on young people's health behaviour and outcomes on health status of users are not many (Muessig et al. 2015; Crul 2014), there is evidence of success among SMS-based services in the areas of HIV counseling and testing , treatment adherence and psychosocial support (Simpson et al. 2017; SHM Foundation 2015; Muessig et al. 2015; de Tolly et al. 2011).

The cost of using mobile phones remains burdensome for young people (Hampshire et al. 2015), particularly given the socio economic challenges, including poverty and lack of employment that

they face (Campbell & MacPhail 2002, World Economic Forum 2016). Fifty-five percent of young people aged 14-25 years in a 2014 survey of young people in South Africa reported having airtime with those who had purchased airtime in the previous week having had to forego basic needs such as medicine, food, school-books or clothes in order to buy airtime, with similar results in Ghana and Malawi (Hampshire et al., 2015). Social networking sites accessible via mobile phone are of interest to designers of programmes aimed at supporting YPLHIV due to their high acceptability as a communication channel (Patten et al. 2014) and widespread general use for seeking health information by adults (Thackeray et al. 2013; Atkinson et al. 2009). However, the prohibitive cost of airtime and data services has been identified as a barrier to YPLHIV's uptake of mHealth services such as the virtual support groups created by MSF on the mXit platform (Patten et al. 2014). Finding ways to reduce the cost burden on young people living with HIV is thus an important consideration in use of mHealth solutions to support treatment, care and support to this population in South Africa.

1.7 Chapter summary

The introductory chapter has provided the background to the problem of providing effective treatment and care for young people living with HIV in South Africa. The chapter identified reasons why research is necessary on the use of support groups as a means to retain YPLHIV in the continuum of care and thus presents a research question aimed at better understanding YPLHIV's experiences in support groups. Three specific objectives were articulated aimed at responding to the research question on social support experiences in virtual and face-to-face support groups and influences of such experiences on HIV-related behavior of YPLHIV. The

review of literature substantiates the need identified by the researcher for better understanding of the mechanisms of social support and social cohesion in influencing health behaviour and the phenomenon of mobile phones services as a means of providing health services is addressed. This is further substantiated by the scarcity of research on these issues as they pertain to the sub-Saharan Africa. A gap in relevant literature from the African continent was revealed during the course and scope of reviewing literature on this topic and highlights a need for more research in this area. It is important to note that having drawn from literature from the global North, it is possible that some of the constructs described in this literature review operate differently or may not apply in the South African context. Finally, the review of literature briefly highlights important issues related to conducting research on YPLHIV, including theoretical constructs, which have informed the methodology employed in this study. The following chapter details the methods used to conduct the study.

Chapter 2: Study Methods

2.0. Overview

The methodology chapter documents the processes followed in conducting the study to answer the research question: *How do HIV positive young people participating in clinic-based and WhatsApp and Facebook support groups at Clinic X, Khayelitsha, experience social support and what is the perceived impact of support group membership on their HIV-related behaviour, if at all?*

2.1. Study design

A cross-sectional exploratory qualitative study was conducted, namely focus group discussions (FGDs) and in-depth interviews (IDIs). This design produces rich data that allows the researcher to understand the experiences of the participants and how they perceive social cohesion within the support groups, in addition to allowing the researcher to probe into how they perceive peer support to influence their behavior (Grund & Hennink 2012) making it the most appropriate for the research objectives.

2.2. Study site and setting

The researcher collected data for the study in December 2015 and a programme manager from MSF collected additional data in November 2016 with youth from Clinic X, which is one of two youth clinics in the Khayelitsha Health District of the Western Cape Metro Region. Established in 1983, Khayelitsha is a mixed settlement township on the outskirts of Cape Town in South

Africa with a population of approximately half a million inhabitants making it the second largest township in South Africa after Soweto. Site C is one of the newer areas of the township with a higher proportion of informal homes compared to older areas of the settlement (Affordable Land and Housing Data Centre 2017). Khayelitsha has a predominantly black African population (90.5%) with small numbers of Coloured (8.5%) and White (0.5%) demographic groups within the community (City of Cape Town 2005). According to the Affordable Land and Housing Data Centre (2017) residents of Khayelitsha experience overcrowding, poor access to services, high unemployment and poverty with as many as 72% of households living below the household subsistence level. Furthermore, Khayelitsha carries a high HIV burden coupled with TB (Médecins Sans Frontières et al. 2010).

2.3. Study Population

The study population was comprised of HIV-positive young people aged 18-25 years who received clinical care and attended support groups known as "youth clubs" at the Clinic X youth clinic in Khayelitsha, Cape Town in 2015 and 2016. The population included individuals who were not yet eligible for ART, those who were newly initiated on ART and those who were ART-stable. According to MSF, all the youth club participants were horizontally infected, that is, they contracted HIV through sexual transmission.

2.4. Sampling

The MSF study team purposively sampled participants for the FGD component of the study from the population of young people aged 18-25 years old who attended support group meetings at Clinic X. The researcher purposively sampled interviewees for the IDIs from participants

identified during the FGDs. Male and female individuals aged 18 to 25 years old who had been diagnosed HIV-positive, were enrolled in pre-ART or ART care at Clinic X Youth clinic and were participating in a youth club were included.

2.5. Data collection

Data collection was conducted at the youth clubroom at Clinic X in Khayelitsha where youth club meetings are held monthly. The clubroom was within the youth clinic, which itself had a relaxed and vibrant ambiance, with a steady stream of clients and trendy house music playing in the waiting area. While the youth clinic was generally lively and busy, the youth club room offered a private quiet environment with ample space for group discussions to be held in comfort. Refreshments were provided to participants during the focus group discussions and at the end of the FGDs and IDIs all participants received a voucher valued at fifty Rands (approximately USD4) redeemable at a local supermarket. Two phases of data collection were conducted and these are described below.

Data collection phase 1

Focus group discussions:

The focus group component of the first data collection phase was conducted among the following comparison groups:

(1) Participants attending the clinic-based youth club only.

(2) Participants attending the youth club and enrolled in the WhatsApp group, the FaceBook group or both of online youth groups.

The members of the clinic based youth clubs who did not use the WhatsApp or Facebook groups served as a baseline comparison group against which the experiences of the online group users could be contrasted. Group lay-counselors from MSF recruited participants during regular youth club meetings over a period of four months between August and December 2015. This allowed all youth club members the opportunity to choose to enroll if they wished to as some youth clubs only met every two months while others met monthly. The participants were a mix of ART ineligible youth club members and youth club members who were already on ART.

While conducting the FGDs the researcher identified participants who were either positive or negative outliers, that is, people whose views differed from other members of the group, who had been exposed to the online groups and those who had not. After reviewing notes taken during the FGDs, the researcher, through the MSF lay counselors, invited some FGD participants to the IDIs.

In December 2015 the researcher collected data through a FGD with nine participants and semi-structured IDIs with participants who had been active on the WhatsApp group, the Facebook group or both groups. A second FGD was held with 11 non-adopters of the online youth groups, which was followed by in-depth interviews with a sample of FGD participants who had not been using the online groups. The FGD as a data collection method explores group dynamics and how normative views amongst peers are expressed. The group setting of the FGD included ice-breaking games and thus simulated the youth club format to which the young people were

already accustomed from their monthly meetings. This made the participants more at ease to express themselves freely and comfortably. Each FGD lasted between 60 and 90 minutes. The researcher used a FGD guide with questions and probes related to the study objectives (Appendix A). The guide included prompts to note positive and negative outliers, as well as any distinctions between the responses of young people on ART and those not eligible for ART.

In-depth interviews:

In the second stage nine participants from the FGDs were invited to participate in IDIs. The sample that was selected for IDIs comprised a mix of participants who had been exposed to the online group and those who had not. They were selected on the basis of having demonstrated an ability and willingness to articulate issues that were sensitive or complex regarding their experiences of youth club membership and their perceptions about group dynamics within these clubs.

Five participants using the online platforms were selected for IDIs, and one non-adopter of the online groups was interviewed. IDIs enabled participants with varied levels of exposure to the online clubs to describe their personal experiences and perceptions and shed light on the dose effect of online youth club membership, if any. IDIs offer a more nuanced understanding of young people's experiences of inclusion or exclusion (Flanagan et al. 2015), types of social support and the influence these are perceived to have exerted on the young people's behaviour. IDIs also offer a confidential environment for participants to discuss personal behaviour and sensitive issues (Grund and Hennink, 2012) and allowed the researcher to gain insights on contextual factors in the young people's lives. Each IDI ranged from 45 to 60 minutes.

Data collection phase 2

Following analysis of the data from Phase 1 data collection, a second set of in-depth interviews was conducted with five interviewees in November 2016 to further understand the online behaviours of the study population. To facilitate the IDIs the researcher used an interview guide (Appendix B) with questions and probes aimed at enabling participants to relate their experiences and perceptions of social support and cohesion resulting from youth club membership as well as their behaviour. A second interview guide (Appendix C) was developed to facilitate the second round of in-depth interviews aimed at further understanding their general online behaviours and other sources of support. A male programme manager from MSF conducted the second round of data collection.

During FGDs and the IDIs the researcher used a digital recorder to collect verbatim recordings of discussions and made handwritten notes of her observations of group dynamics, body language and other non-verbal cues of the participants in how they expressed themselves. A back up recorder was also used to mitigate against potentially poor quality of sound recording.

While fluency in isiNdebele, a Nguni language, proved to be advantageous for the researcher in understanding some of the dialogue of the participants, language differences did present a small barrier between the researcher and the participants whose natural speech patterns involved regular code-switching between English and isiXhosa. The presence of a youth club facilitator at all times provided a familiar interface for the youth to translate some of their colloquialisms and in certain instances contextual information that was of use in better understanding the youth.

2.6. Data management and analysis

2.6.1 Data management

After the first FGD the researcher checked the quality of the recording and sent the recording to a transcriptionist who transcribed the recording of the discussion verbatim. The researcher read the transcript to ascertain whether any revisions to the focus group discussion guide were necessary for subsequent FGDs, based on how participants interpreted and responded to questions or probes. Two professional transcriptionists in Cape Town and Pretoria transcribed the recordings from subsequent FGDs and translated dialogue from Xhosa into English where it occurred. The transcripts from the two transcriptionists were compared to each other to verify the accuracy and quality of the transcription and translation. The documents were saved on a password-protected cloud-based storage platform as MS Word transcripts. The researcher listened to each recording and verified that the transcriptions were true to the raw data. The same process was applied for data from the IDIs. The researcher filed all hard copies of transcripts and field notes and the MSF study team filed all the signed consent forms in a locked file cabinet to be archived for a minimum of five years in accordance with standard practice.

2.6.2 Data analysis

The researcher imported and organized all the transcripts of interviews and observational notes in MAXQDA, de-identifying names and any other personal information. The researcher had a detailed reading of the transcripts from the FGDs and the IDIs. Using MAXQDA, the researcher

developed a draft-coding scheme catalogued as a codebook in Microsoft Excel identifying each code along with a definition of the code and an example of text matching the code. When coding the data, a priori codes on types of support and perceptions on group cohesion based on the literature were used for objectives 1 and 2, while inductive codes were generated for objective 3 and any unanticipated themes that emerged as the researcher read and explored the text (Attride-Stirling 2001; Fereday & Muir-Cochrane 2006).

The draft-coding scheme was discussed in detail with the researcher's academic supervisor and shared with a colleague. The researcher finalized the coding scheme based on their feedback and inputs as a means to validate the trustworthiness of the study.

Following finalization of the coding scheme the researcher employed thematic content analysis to analyze the data taking guidance from Atteride-Stirling's (2001) approach of thematic network analysis. The researcher began by reading the transcripts several times over an extended period of time to get an overall sense of the data and make highlights and memos of key ideas that occurred to the researcher while engaging with the data (Attride-Stirling 2001; Fereday & Muir-Cochrane 2006). In step 1 of the thematic network analysis approach, the researcher coded segments of text. In the second step the researcher identified basic themes emerging from the coded data. The third step was the construction of a thematic network in which the researcher organized and linked basic themes together under more abstract organizing themes. Through this process the researcher determined that the themes emerging from the data elegantly lent themselves to the use of the socio-ecological model as an organizing framework for the first objective around experiences of social support. Placing the individual youth at the centre of a

socio-ecological network, the researcher organized themes as nodes at varying levels of the social network inhabited by a youth club member ranging from the internal individual-level, to the interpersonal and community-level as shown below:

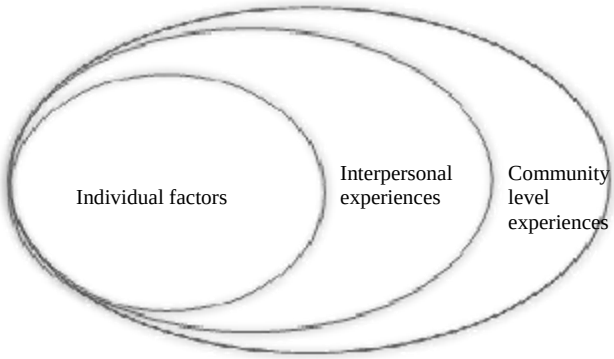

Figure 1: Organizing framework for themes on social support

The researcher read the text again and deduced conceptually abstract overarching global themes about social support, social cohesion and behaviour of YPLHIV in support groups. The researcher then described and explored the thematic network, identifying text segments that most aptly supported the descriptions. The researcher continued to explore the text, exploring the linkages and patterns in how the young people understood, described and interpreted their interactions. The final level of analysis was in making linkages between the young people's lived experiences, perceptions and reported behaviours and the existing literature on social support, youth and adolescent social behaviour, and social media.

For the second objective the study explored perceptions about and experiences of group cohesion amongst youth club members. Themes about a sense of belonging or exclusion were explored as indicated by narratives about identification with the group, membership duration, intention to

remain in the group, and whether or not there exists a sense of having shared values among group members. The second objective of the study sought to explore social cohesion. In the analysis, such themes included participation in group activities, susceptibility of group members to peer influence and the patterns of interpersonal ties amongst individuals in the groups, such as friendships outside of the youth club context (Friedkin 2004). In addition, the study explored levels of trust or the lack thereof among group members (Friedkin 2004). For the third study objective, the analysis sought to elucidate if and how youth club members believed their behaviours or behavioural intentions had been influenced as a result of participating in the face-to-face and virtual clubs. The kinds of behaviour of particular interest in this study included risk behaviour such as missing health appointments, inconsistently taking medication, substance abuse, et cetera. Protective behaviours of youth club members such as ART adherence, protected sex, exercise, youth club attendance and disclosure of status fell within the scope of the study. The study sought to provide insights on not only what young people's reported actual and intended behaviours were but why participants believed this to be the case and how they believed being in a support group played into their own perceptions of HIV-related risk and protective behaviour.

2.7. Ethical considerations

Ethics approval was received from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand on October 12th, 2015 (Appendix D). Approval to conduct research at Clinic X was provided by the City of Cape Town City Health Department on November 18th, 2015 (Appendix E).

Participant consent: The study team obtained the informed written consent of all participants (Appendix F) and provided and discussed an information sheet explaining the study (Appendix G). The researcher ensured that all participants were continually reminded of the voluntary nature of their participation during the discussions and that they were at liberty to choose to stop participating at any point with no repercussions. They were also required to sign a separate audio consent form before any recording took place (Appendix H).

Emotional distress: The researcher and study staff were at all times fully cognizant of the deeply personal nature of some of the issues discussed with the young people participating in the study. Counseling staff with whom the participants were already familiar and comfortable was therefore present throughout the focus group discussions and on hand to respond to any cases of emotional distress that may have arisen during the interviews. There were no incidents of distress during the focus group discussions or the interviews. Furthermore, the researcher debriefed participants at the closure of each interview session to ensure that participants were satisfied with the experience. The youth reported that they had enjoyed themselves and learnt some new things during the interviews.

Confidentiality: During FGDs the facilitator requested participants to undertake to respect each other's confidentiality and not divulge the contents of the discussions to anyone not present during the discussions. However, the researcher also highlighted the fact that while it was expected that all participants would honor their peers' confidentiality, this could not be guaranteed, as was the case with their usual youth club meetings. The researcher assured all IDI participants of the confidentiality of the interviews within the parameters of National Department

of Health (NDoH) ethical guidelines (2015). In this vein, researcher de-identified all transcripts and maintained the anonymity of the study facility and participants by using pseudonyms. The researcher filed all hard copies of transcripts and field notes and the MSF study team filed all the signed consent forms in a locked file cabinet to be archived for a minimum of five years in accordance with best practice.

Role of MSF in the study: MSF supports the City of Cape Town Department of Health to run the youth clubs at Clinic X. The study was funded by MSF who commissioned the research and financed the researcher's travel from Johannesburg to Cape Town and accommodation during Phase 1 of data collection. MSF also contracted a transcriptionist in Cape Town to transcribe data collected in Phase 1. Furthermore, MSF staff supported the study by recruiting participants during youth club meetings. During the focus group discussions, MSF provided catering for the participants and provided the researcher with supermarket vouchers to hand to the participants at the conclusion of each interview or focus group discussion. A youth club facilitator assisted with ice-breakers and language interpretation during the focus group discussions. To avoid misperceptions, the researcher was conscientious about explaining her role as a student with no affiliation to MSF beyond their facilitation of access to the clinic and its patients. The researcher was explicit about being a student of the University of the Witwatersrand with no decision-making ability or influence on MSF's programming. MSF staff took a secondary and supportive role at all times allowing the researcher to lead all processes.

Chapter 3: Findings

3.0. Overview

This chapter presents the findings from the analysis of data collected in the study in accordance with the study objectives. It begins with a broad examination of young people's experiences of social support from various sources, including their participation in the youth clubs and online groups. Following this, the chapter explores the various dimensions of support that young people experienced within the support groups and their perceptions about using the online groups on WhatsApp and Facebook to either solicit different kinds of support from or provide support to peers. The data emerging for this objective were analyzed and found to lend themselves to a socio-ecological framework with the young person at the centre. The diagram below represents the findings on experiences of social support organized according to this framework:

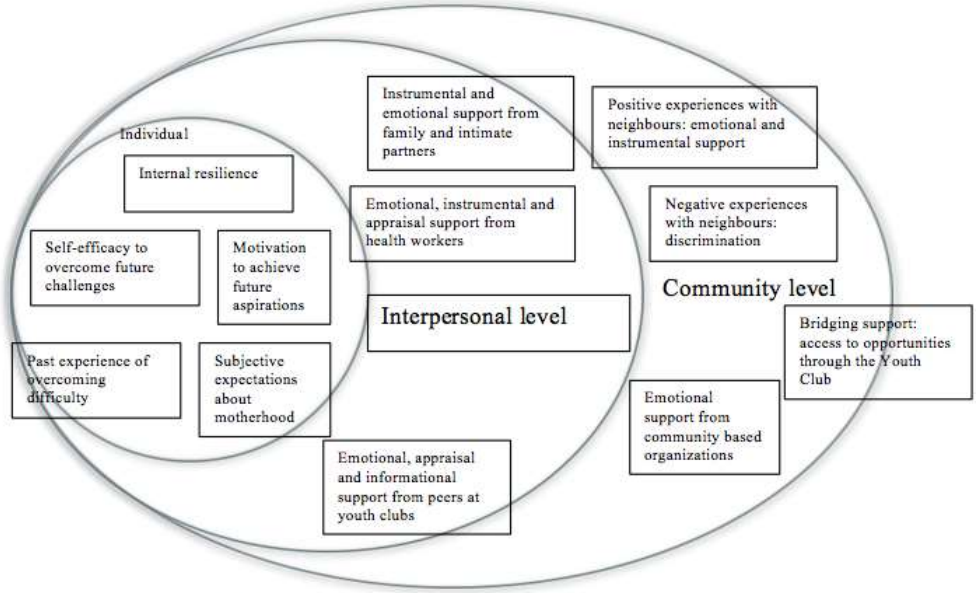

Figure 2: Socio-ecological representation of YPLHIV's experiences of social support

The chapter then presents findings on the nature and quality of the relationships among young people participating in youth clubs and their perception about the influence of online contact and interactions on their relationships with each other. This is in line with the second study objective, which aimed to explore social cohesion within the groups. Finally, in response to the third study objective the chapter presents young people's perceptions about whether support group membership affected their social and health-related behaviours.

3.1. Experiences of social support as a young person living with HIV

The following section presents the findings that emerged from the data that relate to the first study objective: to identify the dimensions of social support experienced by HIV positive young people, aged 18-25, in clinic-based, WhatsApp and Facebook support groups – hereon referred to as "youth clubs" - at Clinic X in Khayelitsha during 2015/2016. The section presents the youth club members' reported sources of social support and the various dimensions of social support that they have experienced in the youth clubs as well as amongst each other online. This will be presented in accordance with the socio-ecological framework, starting with the self as a source of internal resilience, and then extending to interpersonal relationships with friends -in and outside of the youth clubs- as well as family members and intimate partners. The final level of analysis will be on experiences of the youth at the community level, with institutions such as the youth clinic, other community-based organizations and amongst neighbours.

3.1.1 "I am a fighter." Internal resilience within the young person living with HIV

A universal theme that emerged both during the focus group discussions and the in-depth interviews was young people's self-efficacy to overcome any challenges they faced and a determination to protect their wellbeing, both mental and physical. For a number of the youth, the experience of having overcome difficult situations in the past, such as loss of loved ones and sexual assault, served as evidence to them that they had the capacity to overcome difficulties in the present and future:

> *… I knew my status. And even when I found out, my parents were surprised about how I reacted. Because when they [the people at the hospital] told me that am HIV-positive, I just said 'okay fine' just like that… I think it is because of the challenges that I had already faced in the past, because I told myself that every challenge that I face now, I will defeat them because I always tell myself that I'm a fighter and every fighter wins, I do not lose a battle but I would be a winner.* John_IDI_18-25_YouthClubOnly

Like John, many of the youth recognized that knowing their HIV status was in fact empowering, as it positioned them to live healthy lives, to seek and obtain information that would protect their health and that of their partners and children.

Gendered dimensions of internal resilience

During the in-depth interviews, a distinction emerged among male and female participants in that when exploring their internal resilience the young women invariably mentioned their desire to be good mothers or to one day start a family. Ensuring the wellbeing of their babies was an

important topic that came up, particularly with respect to how they felt about being on treatment, the kind of topics they valued from youth club discussions and more importantly, their desire to remain healthy. One young mother's sense of maternal responsibility made her so determined to breastfeed her baby that she was willing to risk selling her body to earn an income while she fulfilled her duty as a mother.

> *A difficult decision…was when I had to stop working, because I was breastfeeding and at home by that time there was no fridge so that I can express... the milk so that some will be left with my child [while I am at work]. So I had to stop working, resign at work and start looking after my child… I did it by myself. Because I knew that this is my child. I don't want to infect my child for the something I did… it was stressful because I never had money and I never had support from his father and even at home it was not much support but I did a sacrifice that even if I have to sell my body I will if I have to feed my child.*
>
> - Rea, IDI_24-year-old Facebook user

Neither parenting, parental responsibility nor the desire to start a family was stated in how the male participants framed their motivation to remain healthy or to continue attending youth clubs and remaining on treatment.

Dealing with problems in day-to-day life alone

This deep-rooted internal drive to do what they believed to be the right thing regardless of difficult circumstances was not only expressed by participants who were mothers or had maternal aspirations, but rang true for many of the young people participating in the study. Such

resilience in the face of difficult circumstances required the youth to employ mechanisms to cope on a continuing day-to-day basis. The capacity to compartmentalize problems- setting them aside until they could be solved or addressed later – was among these. Statements about *"making light of problems"* and *"telling stress to wait"* point to some of the internal mechanisms by which the youth temporized problems before reaching out for help either from their youth clubs or from other *"supporters."* In considering how to respond to difficulties confronting them whether it be willingness to sell one's body to earn an income or not immediately dealing with stressful situations the youth evaluated their ability to bear certain risks as strength and not a potential threat to their wellbeing.

3.1.2 Youth club members as an important source of social support

"You know you're talking to people who understand." **Emotional support among peers during youth club meetings**

All the young people participating in the study were members of the youth clubs, attending meetings either monthly or every other month. Overwhelmingly, the youth expressed appreciation that the youth clubs enabled them to "*share"* amongst peers who were "*the same*" and being "*understood*". The participants felt like they were the same because of their HIV status and having common experiences of being young and living with HIV. Participants felt that the youth clubs were a source of support where they felt safe and supported when they shared their problems. Stress in their daily lives was an issue for the youth and the youth clubs were a forum in which they were able to experience some relief from their stress and not only share but play

and have fun. As a result, the youth club was one place where most participants reported feeling "*happy*".

A near unanimous perception regarding the youth club meetings was that young people relied on them as a source of emotional support in "*coping*" with various aspects of their lives. The nature of emotional support was wide-ranging, for example many participants said that they found it comforting just to know that they were "*not alone*" and that other people were "*in the same situation*." It was common for participants to say, "*we are the same*" in response to questions about how they felt about being in the youth clubs or as a response to questions about why they liked the youth clubs. Simply knowing that one was not unique in being HIV-infected seemed to offer the youth some form of emotional catharsis. Outside of their youth clubs, the majority of young people expressed feeling an isolation that arose out of not being completely understood and not having anyone to relate to about living with HIV, whereas when talking about the youth clubs, the phrase "*we understand each other*" was used repeatedly and linked with "*feeling free*." It was clear that to the youth this understanding that they found comforting and unifying arose out of a perception that they understood each other better than someone not living with HIV might have. This perception of an elevated shared understanding freed them to share their actual lived experiences more comfortably than they would be able to with people who do not have to live from day to day with the condition of being HIV-infected. One participant provided an illustration of this that proved instructive on the level of enhanced understanding that the youth in the clubs yearned for and could only experience with each other:

> *Even if we were to talk about treatment you won't be like 'I wonder how much they know about treatment.' They know that we know the ins and outs of taking the treatment but we would be sharing things like, 'Last night I went out and I forgot to my treatment.' You know you're talking to people who understand what is going on so you don't feel shy but you just talk.* - Suku_ FGD,_WhatsApp and Facebook

This illustrated that even for those who have disclosed their status to friends or family, a scenario such as forgetting treatment would be difficult to discuss and navigate emotionally. Who better to relate to and understand the worry or the remorse that one would feel having missed treatment after going out socializing like any other young person would than other peers living with HIV who also live with the daily challenge of maintaining strict adherence to treatment? The positive perceptions of the youth club members about youth clubs thus went beyond the affect of having a group that they could identify with. It included the added component of being able to have conversations that were simply not possible with others. It is this level of relating that provided the youth club members with an emotional connection enabling them to open up to each other:*"When we are together, we feel open and we talk about everything we want to talk about including our personal lives." (FGD Participant, WhatsApp and Facebook)*

Youth club members, while placing great value on their relationships with each other, perceived their bond as being *"connected by HIV"* and distinguished these from other friendships. Insights from one participant, a mentor, suggested that communication with peers outside of the youth club meetings occurred but was associated specifically with the relationship arising out of being

HIV positive and not necessarily as a result of club members seeing themselves as friends, even despite being youth club members for a long time.

> *Some of my peers in my group are also one (sic) of the mentors so whenever I have difficulty with my mentee, I will just WhatsApp Charlie or call Zama or call someone and be like, 'What's happening? Can you please help me with this?' So it is a relationship that is connected about (sic) HIV, it's not the one that I have with my friends.* IDI_18-25_WA&FB_Female

While the young people did not necessarily consider each other as friends, the connection through HIV status and youth club membership did create a bond among them that did not exist in relationships with people not in the youth clubs. This is exemplified by one focus group participant's explanation that she would not talk to HIV-negative friends about anything, especially regarding her health and HIV because, *"it is more comfortable to talk to someone who knows how you would feel."*

While they clearly appreciated the group as it provided a space where they felt *"understood,"* they were all the *"same"* and had *"similar problems"* and *"situations"* the participants also expressed a yearning to be understood by "*others*" within their wider social networks. Speaking of *"others"* commonly referred to people who were not in the youth clubs, who either did not know their HIV status or were HIV-negative, who were either their friends or members of the community. A number of young people held a belief that other people did not know about HIV and expressed a desire for programmes to be developed to educate *"others"* in the wider community so that they could better understand those living with HIV.

Youth club members' experiences of emotional support on Facebook and WhatsApp

The Facebook group served as a facilitator for the development of *"HIV-connected"* friendships for one participant who reported having posted a picture of her \self on the group along with her phone number for the purpose of gaining new friends who would understand her condition:

> ***Rose:*** *I posted a picture because I was asking for friends who are in the same situation that I am in and I left my number there and I got a few friends.*
>
> ***Interviewer:*** *How do you feel about that?*
>
> ***Rose:*** *It is quite good because they are in the same situation so it is easy to talk about anything that I feel like talking about.* – Rose_FGD participant

A prevailing perception was that opportunities for emotional care and support outside youth club meetings were more limited among peers not using online platforms compared to those who were. This was particularly in light of the fact that receiving emotional support outside the youth club would be contingent on the young person having disclosed his or her status. One Facebook participant clarified that she was able to talk about "*almost anything*" with her Facebook friends, however in the case of an issue concerning her health she would only be comfortable to post it on the private Facebook group for youth club members.

All the participants in the focus group discussions for online users were subscribed to the Facebook group, while only one of them was using both Facebook and WhatsApp. Most study participants using the Facebook group were ambivalent about the idea of posting original posts and engaging with each other on a social level using the Facebook group. Many voiced a preference to use the Facebook group for updating themselves on news in the groups or to

engage in interactions such as “liking” or commenting on posts. This appeared to be linked in part to the fact that they already had contact with each other directly,

> *…Mostly because (we) have Lily’s number [a youth club counselor] and some of us in our groups we have each other’s number so if you have something to talk about then I will just inbox that person and tell the person what is happening and that person respond to me there.* - Litha, FGD participant_18-25_WhatsApp and Facebook users

Youth club members who used Facebook or WhatsApp were able to express a conceptual appreciation of the use of the platforms for provision and solicitation of various kinds of support, including advice and emotional support. They made statements such as, *“Asking for advice on Facebook is something that I do almost every day,”* yet most of them struggled to come up with specific examples of having used the platform for advice or any other type of social support when requested. Predominantly, the participants using Facebook named informational support as the type of support that they experienced. That is, they used Facebook as a means of viewing announcements posted by youth club staff regarding club activities. Further probing revealed that in general, the youth preferred to use Facebook to post positive content, such as links to articles and motivational statements as well as pictures of themselves. They held more intimate conversations out of the public eye in private Facebook messages. In trying to understand why they posted content on Facebook at all and what reactions they aimed to garner from their audience on the platform the youth were comfortable with receiving “Likes” for their posts and actual comments were not as important.

One participant, a peer mentor, spoke of how youth club members participating in a mentorship program run by MSF were using WhatsApp to provide each other with peer-to-peer support. MSF has set up a peer mentorship system in which young people who have been in the youth club programme for longer are paired with newly diagnosed youth. The participant described how mentors communicated using WhatsApp to provide each other with support in mentoring their assigned mentees. A mentor was thus able to discuss a particular challenge he or she was experiencing with a mentee, and peers who had experienced similar challenges with their mentees would provide advice or share insights on how the challenge could be resolved. Mentors perceived value in these interactions that enabled them to in turn support newly diagnosed youth. For example, one mentor spoke of the usefulness of being able to reach out to fellow mentors and counselors,

> *I sometimes find that maybe one of them has gone through the same problem that I have so they will come up with a solution in the same way that they did and for me to try it as well. Or I will ask Sis Lily [a youth club counselor] to help me out. – Thandi*_FGD Participant_18-25_Facebook user

Young people not participating in the online platforms held a perception that their opportunities for accessing information and emotional and support outside youth club meetings were limited compared to peers who were using online platforms. Even though they had not been participating on either the Facebook or WhatsApp group, there was consensus that the online groups were a valuable means of staying in touch and an assumption that those who were in touch with each

other online were receiving support outside of youth club meetings. One focus group participant's views capture this sentiment:

> *On the positive side the group allows us to talk to each other and if someone has something that they need to talk about before or after the group has met then we are able to share that issue on the group either on Facebook or on WhatsApp.*

The participant went on further to recall a specific incident in which she regretted not being a member of the Facebook group, stating,

> *One of the reasons that I would have liked to have been on Facebook, when I was admitted to hospital (is that) I would have been able to communicate with the group and inform them that I am in hospital and I have this problem because I saw other people who were members of other youth clubs there getting visits from their group members and my visitors where only my family members.* - Sazi_FGD participant_ 18-25YouthClubOnly

This sentiment prompted a wholehearted response from the other focus group participants who expressed empathy, one of whom highlighted that not being aware of each other's challenges and experiences outside meetings posed a threat to youth club members' perceptions about the value of belonging to the youth clubs at all:

> *It's sad because when we do not see you in the group it may also give you the impression that we do not care about you and you may even feel like why did you join the group anyway, because you are not getting much from it because now you were sick and you*

needed the group but they were nowhere to be found. Yet we might not have known as your group members that you are in hospital and Lily [a youth club counselor] would have told us or put up an announcement that guys, so and so is in hospital so maybe we should go and visit her so that she feels like she is part of a network that cares for her. - Rethabile_FGD_Participant_ 18-25 years old_Youth Club Only

Evidently, the young people, both those participating online and those not, (1) had a desire for contact with each other outside of the youth club meetings, (2) had an understanding of why the online groups were created and (3) were able to identify different kinds of support that were potentially available through Facebook and WhatsApp. However, evidence from the discussions with the youth actually participating in the online groups suggested that they had not in fact used the online platforms to reach out to each other in that way.

While the young people using Facebook did not express having experienced emotional support from the closed group set up on the platform for youth club members. However, their other Facebook friends or contacts who were not in the closed group for YPLHIV provided emotional support on various issues that they would post about. For a few less inhibited youth some of the issues they shared with their wider social networks on Facebook included HIV-related issues, such as disclosure of status. Among such users only positive responses were reported from their Facebook contacts. The Facebook group also enabled the experience of emotional support among users by putting youth from different youth clubs in contact with each other and thus creating opportunities for new friendships to form and be pursued offline.

"We equip ourselves." Experiences of informational support in youth clubs

In addition to emotional decompression, playing and having fun, the clubs also allowed youth to talk about HIV-related topics

> *Most of the topics that we talk about are based on HIV/AIDS. For example we would talk about how to disclose your status to your boyfriend or to your family.*
>
> - Suku_18-25 years_ WhatsApp and Facebook-users

During the focus group discussions participants described youth club topics as mainly relating to HIV, covering topics such as how to take care of oneself, treating or preventing sexually transmitted infections, planning to start a family and how to disclose one's HIV status to family, friends or intimate partners. On Facebook, the youth reported that facilitators provided group members with information and reminders about up-coming events, reminding them to attend youth club meetings.

The youth club meetings also served as an opportunity to advise the young people on education or career-related issues. Participants in the online groups also reported that the youth club facilitators used the Facebook group to provide information to members regarding work and study opportunities and how to access these. In discussing this, one participant stated that their role was to then "*share*" such links to opportunities with their networks on Facebook, reinforcing the idea that Facebook is perceived by the youth as an information dissemination platform.

Topics discussed in the youth clubs stimulated debates and engaged the youth in a way that helped them to help each other in not only understanding how to take care of themselves but also how to make decisions and solve problems for themselves. The youth spoke of advising each

other on decisions ranging from if and how to disclose their HIV status to intimate relationship issues. This level of openness was based on their shared experiences and a certain level of trust they held amongst each other and which they placed in the youth club facilitators.

Nevertheless, not all participants felt they could fully open up to their peers in the youth clubs, with one participant saying her club members were *"naughty"* so she tended not to share with them when she had a problem she was dealing with as she did not trust them to provide sound advice. Other participants echoed similar sentiments, that they enjoyed the camaraderie and company, however they did not necessarily trust their fellow youth club members to maintain their confidentiality or to provide meaningful advice if they shared very intimate problems.

"When I need something like money…" : Experiences of instrumental support among young people on Facebook

When probed on whether they would be able to ask for help on Facebook or WhatsApp for something material like money it was clear that in the case of money or other material assistance, asking for help from each other is something that they would not think of doing on a "public" forum such as the Facebook group, even though it is a closed group:

> *I do not see it as an avenue I would go to, to ask for money. Perhaps I can do it on WhatsApp, where I send someone a WhatsApp message asking for money; maybe Sis' Lily [youth club counselor], I would send her a message and ask her where she is as I need some money or I would check on Anita [a fellow youth club member]. But posting on Facebook would be the last thing that I do.* - Suku_FGD participant_18-25 years_WhatsApp and Facebook user

> *When I need something like money, I don't know about groups on Facebook, I just talk to the people around me and say that… but Facebook, it would the last thing I would think about*. - Lindo_FGD participant_18-25_Facebook user

The reasons why participants would or would not consider the Facebook group as a place where they could ask their peers for material support revealed mixed perceptions. For some, it was clear that they view Facebook as a platform where they obtained information and did not necessarily interact socially, hence it simply would not occur to them to request money online. A number said they would prefer to ask individuals directly either in person or through one on one direct messaging on WhatsApp as opposed to in the WhatsApp or Facebook groups. One participant went so far as to say she could ask a stranger "on the promenade" for money to get home if she were stranded while Facebook would be the "*last place*" she would think of to ask for something like money. Another participant expressed a sentiment alluding to the notion that asking for monetary assistance from the group would be was an indication of being of inferior economic and therefore social status:

> ***Sheila:*** *I would be shy. I wouldn't do that.*
>
> ***Interviewer:*** *You would be shy?*
>
> ***Sheila:*** *I would not do it.*
>
> ***Interviewer:*** *Why would you be shy?*
>
> ***Sheila:*** *It would lower my standard (My status would go down*). - Sheila_FGD_18-25_ Facebook user

This exchange was met with a combination of silence and assent from the rest of the group, barring one participant who, in an effort to diffuse the discomfort in the atmosphere, exclaimed

that the group was too serious and advised that they should be able to make jokes out of tough situations and just ask for help as one never knew where it would come from. Having said that, she herself was not able to recall ever having done this. This suggested that while they may have been comfortable to connect and share with each other on the basis of commonalities, such as HIV status and shared experiences around living with HIV, the young people using Facebook preferred to steer away from topics that might reveal differences that could alienate them from the group. This was the case as the Facebook platform was perceived to be a public platform, even though it was functionally a closed group open only to members of youth clubs.

The youth who were not using the online groups were able to identify ways in which the online groups could access instrumental support:

> *For example, if you see that your treatment is about to be depleted and you're not around you can talk to other people who are around and say that your treatment is about to finish so that person might be able to help you to get your treatment for you so you might get help in that way*. Thula_FGD participant_ 18-25YouthClubOnly

Preferences about using Facebook and WhatsApp

Youth using the online platforms also expressed views regarding how they felt about using the two platforms. Among the youth who had previously used WhatsApp and left the group and the one participant who was still using both groups, a key turn-off for using WhatsApp was the fact that they had no control over when they saw content, as participants' messages would just be sent directly to their phones in real-time. This often meant that they would be privy to conversations that were not always interesting or relevant to them. For instance, if group

members used the group to post two-way messages, these messages would be automatically downloaded resulting in other group members incurring massive mobile data consumption for content that they felt was not relevant to them.

> *WhatsApp is using my data like nobody's business. Data bundles were going like crazy because you find that this conversation that is happening I might not be interested in or even relevant to you but it is chowing your data bundles like that so I just quit.*
>
> Suku_IDI_24 year old WhatsApp and Facebook user

In contrast, with the Facebook group, the youth were able to choose when to log on to their accounts and access the group, controlling what information they accessed and when. Previous-users of the WhatsApp group also cited that the fact that there was a constant stream of messages throughout the day and often well into the night. This was not only a disturbance, especially in the case of when members used the group for private conversations, but one participant pointed out that in the case of those among them who had live in partners to whom they had not disclosed their status, these messages raised the suspicions of their partners and compromised their relationships. That the WhatsApp groups were *"bombarded"* with messages suggested that the platform was in fact a popular and acceptable medium for engagement beyond just viewing announcements, which is how Facebook was being used. However, this same popularity ended up causing *"too much contact"* and being off-putting to participants who elected to leave the WhatsApp groups. Participants suggested that having a cut off time and implementing rules about the topics that people could post could improve the WhatsApp groups. With respect to improving engagement on the Facebook groups beyond using it to view announcements,

participants indicated that they would be more inclined to engage more meaningfully if MSF staff initiated facilitated discussions on the platform.

Privacy and maintaining the confidentiality of their HIV statuses were major factors affecting youth's decisions to join or not join the online groups. Among participants who had joined the Facebook group, visibility of the group to other people not in the youth clubs was a concern that had made them reluctant to join the groups. However, after realizing that the Facebook group was closed to the public and that posts, newsfeeds and comments were only visible to group members, they were comfortable to join the group.

> *I wanted nothing to do with this group before because I told myself that everyone will see me and then they will know my status and so I didn't want to join but now that I am in the group I see that it is only us in the group who see what we write on there.* Suku_ FGD_18-25years_ and Facebook

On the other hand, among participants who had decided not to join the online groups, privacy was also a reason for not joining. Those who cited privacy as their reason for not joining the online groups were uncomfortable with the fact that the Facebook group was open to all young people living with HIV who belonged to youth clubs, regardless of which particular club they attended.

> *At first I thought it was only my group, my club only. But there were other clubs. So I say if someone knows me from other clubs, you know. I won't feel comfortable, you understand. Because there is someone from other groups who knows me. And eventually she will know it's me because I've got my surname and my number even my profile*

picture, you understand. So that's why I did not join the group. - Rethabile_Youth club only

This contrast in how privacy impacted young people's decisions to join or not join the online groups suggested that for some participants, the sense of cohesion and trust they experienced existed primarily amongst peers within specific clubs and not more generally amongst peers in different youth clubs, despite their common condition of being HIV-infected.

Another manner in which concerns about privacy posed a barrier for some participants' uptake of the online groups, and specifically the WhatsApp group, was the risk of raising the suspicions of their partners. Participants were wary of partners discovering *"secrets"* and *"things they are not supposed to see"* if they were curious about the activity keeping their sexual partners occupied. Beyond the risk of having to disclose their status to the sexual partners before they were ready, some participants felt that the constant stream of messages well into the night in the WhatsApp group would actually cause their partners to suspect infidelity. This was a sentiment expressed by the older participants in the focus group discussion among non-users of either FaceBook or WhatsApp.

3.1.3 "They do not isolate me." Who else provides support to YPLHIV besides their youth club peers?

While clearly an important source of camaraderie and support, the youth club was not the only source of social support for the young people in the study, who also identified family, friends, nurses and counselors as sources of advice, emotional and other types of support. Due to the fact

that youth club meetings were held either once a month or every two months, youth expressed the importance of engaging with other people during their day-to-day life. Moreover, where they had disclosed their status to a trusted contact, they were able to benefit from instrumental support in maintaining their health for example, reminders for taking medication and clinic appointments.

Emotional and instrumental support from family or intimate partners

The youth whose family members knew their HIV status had mixed experiences with respect to being able to receive support. Some of the young people mentioned their mothers, fathers and siblings as sources of support in day-to-day life and helping them to come up with solutions to problems related to managing their conditions. One participant described the emotional relief she felt when she eventually disclosed her status to her mother and was received with support:

> *[My mom] was welcoming and she hugged me and told me that it is not the end of the world. She encouraged me to be myself and just get my treatment and that it would be fine… I felt like there was a heavy load that just collapsed (sic) over me because she pushed me and she told me not to worry. I thought she would say something like 'get out of my house' or something but she was welcoming*. – Shumi_FGD_18-25_Facebook user

In contrast, one participant, Suku, felt that she could not confide in or reach out to her parents for support because they *"worried too much,"* resulting in her preferring to reach out to a trusted cousin. In her view the parent-young adult dynamic in her family made her feel like her parents were overbearing. This showed that while they were an important source of support, parents could have the disadvantage of being too closely invested in their children's wellbeing to be able

to see them as young adults and provide them the space and independence to open up about their personal struggles. The notion of parental over involvement emerged as an important barrier for some of the older youth in being able to accept support from those closest to them, as echoed by Thandi who felt that constant *"nagging"* and *"do like this, don't do like that*" was in fact *"burdensome."* It emerged that in their quest to protect and support their HIV-infected adolescent children, families could inadvertently end up doing the opposite, disempowering the youth, by treating them differently from other people and thus negatively impacting their sense of dignity:

> ***Thandi:*** *So if you would give the extra support is (sic) boring, understand. Yah!*
>
> ***Interviewer****: Okay, it's boring because it makes you feel like what?*
>
> ***Thandi:*** *It makes me feel small. Humiliated.*
>
> ***Interviewer:*** *You prefer…?*
>
> ***Thandi:*** *Someone who's understanding; someone who will not nag me about it; someone who will treat me the same like other people.*
>
> - Thandi_IDI_24 year old Facebook user

On the other end of the spectrum some youth were not received with compassion when they disclosed their HIV status to their parents and this resulted in an increased reliance on clinic staff and friends in the youth club as sources of emotional support.

Differences between the genders emerged in how the young people related to intimate partners. For the young women who had disclosed their status to their current boyfriends, experiences of being cared for and supported were universal, while none of the young men had disclosed their

status to their girlfriends. One male participant revealed that he had not disclosed his HIV status to his girlfriend because the relationship was still new and he did not as yet trust her. Overall, the discussions revealed the pivotal role of disclosure in increasing the number of potential sources of support to which the young people had access. However, it was also clear that it was not the number of connections in a young person's life that made a difference, but the quality of even just a few trusted and non-judgmental connections.

Emotional and instrumental support from friends outside the youth club

Friends who were not members of the youth clubs played an important role for more intimate contact because youth club meetings occurred in a group setting during which the dynamics among the different personalities were not always conducive to sharing what was on their minds. This was alluded to by one participant:

> *I have a friend who is older than me. I usually choose to speak to her (more) than my own family if I have something to talk about but I do not wish to discuss it at the club. In my club, the people there are naughty (laughs)…We laugh about things and Kathy sometimes says things in a joking way so sometimes even when I wish to say something, I just decide otherwise.* - Talitha_FGD __18-25 year old WhatsApp and Facebook users

Other participants also spoke of how their friends were a source of companionship and support, both practical and emotional, reminding them of appointments, keeping their confidentiality, not being judgmental and "covering" for them at school when they had to go to the clinic. The youth who spoke of receiving support from their HIV-negative friends especially valued that their friends, in addition to supporting them to manage their condition reassured them about their

friendships and did not reject them as friends. Being accepted by their friends proved to be a powerful source of support for the youth as illustrated by John:

> *We have been friends since grade 5 but he did not know that I am HIV positive, but I did tell him that I was HIV positive and he did not tell me that I must go away. Instead he drew me close and told me that it is fine, I am not going to die or nothing bad is going to happen to me.* -John, IDI_18-24 years_youth club only**.**

Support from health workers

The role of health workers, such as nurses, counselors and youth club facilitators came up not only in the context of providing the participants with health services, including supporting treatment and providing care and advice on their health, but for most of the youth, they seemed to serve an important and intimate emotional support role. It was the nurses that helped them overcome the physical challenges of being HIV-infected, the counselors that helped them cope with the emotional burden of discovering their HIV status, and the youth club facilitators who coached them on lifestyle issues and advised them on how to disclose their status. The health workers bore witness to the youth at their most vulnerable, providing them with support and guiding them into the care system by introducing them to the youth club programme, following up on them, reminding them of appointments and critically, steadfastly keeping their confidentiality, thus earning their trust. This resulted in the youth forming strong bonds with their nurses or counselors. For example, Suku remained in close contact with a nurse in another province who had been her first source of support two years prior when she had been diagnosed

with HIV following a sexual assault. The bond she formed with this nurse resulted in her still turning to him for support telephonically even though she was now living in a different province and illustrated how close health workers became with the youth.

> *Even though I am very talkative, when it comes to talking about myself, I am very, very sensitive, I only have one person that I find I can talk to about anything and about my problems... I met him through my counseling because I found out that I was HIV positive after I was raped. So I was attending counseling about that and he is the only person that I find I can talk about anything that I come across; even though my mother was there at the time when I went to get tested, she knows that I am HIV positive and my father also knows but that kind of support I only get it from him.*
>
> - Suku_18-25_WhatsApp and Facebook users

The youth club counselors also provided instrumental support such as small amounts of money when the youth were hungry or in need of transport money. Reaching out to their youth club counselors for material help was something that some participants mentioned, without any reservations or indication of being uncomfortable with such a dynamic.

YPLHIV's social interactions amongst members of the broader community

One of the biggest "*secrets*" of the participants was their HIV status. Living in close knit communities, a participant's choice to disclose his or her HIV status was mediated by community attitudes towards people living with HIV, whether perceived or experienced directly. Some of the young people in the focus groups reported that their encounters of negative attitudes

regarding people living with HIV within their communities prevented them from being able to share their HIV-related issues and elicit support specific to living with HIV. One participant described being able to talk about HIV in a general manner with her neighbours who "*talk badly about people with HIV,"* adding that even members of the community living with HIV were not free to talk about HIV amongst themselves.

For a small number of the participants who had managed to disclose their status and were received with care and warmth, their networks of support stretched beyond immediate family and friends and included neighbours, who provided encouragement and would often remind the youth about clinic appointments or to take their medication. One participant had strong ties with a community-based organisation run by and for people living with HIV, where she had been supported to disclose her HIV status. She held positive perceptions about being in a community of HIV-infected people who appeared healthy and had a positive outlook on life and felt encouraged that she too could be healthy. This kind of positive peer influence is one of the draw-cards mentioned by the youth for their participation in the youth clubs, as mentioned earlier.

3.2 Perceptions about social cohesion within the youth clubs

The following section presents the findings that emerged from the data that relate to the second objective of the study: to explore perceived social cohesion of young HIV positive people aged 18-25 who participated in WhatsApp and Facebook support groups compared to those who only participated in clinic-based support groups (youth clubs) at a Clinic in Cape Town during 2015/2016. For this objective, discussions held with the youth covered themes linked to whether the youth club members felt a sense of belonging or isolation, their perceptions about their

membership in the youth clubs, and the extent to which group members were able to exert an influence over each other.

3.2.1 A shared identity: when "I" and "they" become "we"

The youth participating in the online groups demonstrated a sense of oneness with not only their peers in youth clubs but with the youth club institution as represented by youth club facilitators and other MSF staff. In their descriptions of youth club activities, the young people employed language that indicated a sense of belonging to the groups, making no distinctions between themselves as participants in the youth club programmes and the staff who plan and facilitate the youth club sessions. For example, when referring to activities planned by the youth club counseling staff, Sipho took great pride in the fact that the youth had recently conceptualised and executed a group social outing, saying "*we designed this for ourselves,"* while Ashley, rather than saying that youth club facilitators invited guest speakers to inform youth club members about opportunities, articulated a scenario in which the youth prepared *themselves* for life, stating:

> *We equip ourselves school wise, work wise and I think two or four months back we had a visitor from False Bay College. She was here to tell us about some of the courses that they offer and how to get in.* – Suku_FGD_WhatsApp and Facebook

The youth participating on the online groups did not demonstrate differing signs of feeling like a part of the whole than those who only took part in the youth club meetings. This finding was consistent with online participants describing the Facebook group as a platform for information

dissemination and not one that they used for social engagement per se. Participants in both focus group discussions reported that initial participation in the youth clubs was not easy for new members but invariably, after some time, all participants felt included and happy to be in the groups, looking forward to meetings and feeling "*the same*".

Conversely to the feeling of sameness and oneness that the youth experienced within the youth clubs, the participants reported feeling closed off from their broader communities. Among community members they held the perception that they were unable to fully open up because "*people talk badly about people with HIV*." Experiencing stigma within their communities drove the youth club participants even closer together as the youth club then became a space in which they described themselves as being "*free*," "*open*" and "*happy*." One participant commented that she preferred to have an HIV-positive boyfriend because she felt "intimidated" by the possibility that an HIV-negative partner would leave her in favour of someone HIV-negative. This pointed to the effect of self-stigma among youth in closing them off from others and bringing them closer together.

3.2.2 "It's not my issue… It's not our fault": a collective rejection of deviance

To explore social cohesion, the focus group participants were asked to consider how they would respond to a group member informing them of having had sex without a condom, given that having protected sex is a behaviour which all youth club members are strongly advised to do if they wish to engage in sexual relations. The question to those participating in the Facebook

group was posed in such a way as to elicit whether they would comment to a post on the group in which someone claimed to have had unprotected sex, and what their comment would be.

The responses from the Facebook group indicated a lack of interest in and disengagement from the hypothetical demonstration of deviant behaviour, with none of the participants saying they would try and discourage their peer from behaviour that was out of line with what they had been taught in the youth clubs. These views were in spite of the fact that participants had expressed the understanding that the online groups existed to enable them to share and support each other with all kinds of issues. Participants expressed the view that they would not comment because it was "*pointless*" to try and correct the deviant peer since they were already aware of the risks and consequences of having unprotected sex as this is often discussed in youth clubs. One participant expressed the opinion that such action on the part of a peer was not the group's "*issue*" or "*fault*" and so he would not comment on it. In her in-depth interview Suku provided further clarity, saying that in the specific instance of an issue relating to their health, she would not comment on a negative behaviour but would be happy to comment on and advise her peer on a topic such as if her peer had slept with a friend's girlfriend. This revealed the gravity with which the group regarded health behaviour and was illuminated by her response:

> *It would be like this person is making a joke out of whatever because they would be making us fools because every time that we are here, we are told that don't do this, do this and do this this way. Like for example if you say, 'I slept with my friend's girlfriend' then I can comment on that and ask the person to think about what it would do to their*

friendship and stuff but if it has something to do with your health, that means that you do not care. - Suku_IDI_18-25 years_WhatsApp and Facebook

In Suku's view, to act in defiance of what one knew to be health promoting behaviour was not only indicative of not caring about oneself but was an affront to the group itself and the positive behaviours encouraged in the youth clubs. Such a deviant would thus not be worthy of attention from the group by way of a response of any kind.

Co-occurring codes in the conversations revealed an additional insight regarding the rejection of deviant peers. Reservations about engaging with deviants tended to be linked to a fear that acknowledging them by engaging with their non-conformity to the accepted behavioural norms could open up group members to negative influence from such deviants. This is explored further in the following section 3.2.3.

3.2.3 Susceptibility to influence from the group

The interviews following the focus group discussions revealed that while the youth valued the positive relationships amongst group members and felt a sense of belonging and acceptance, there were limits to the extent to which they felt impressionable by each other. Participants perceived themselves as able to retain their individuality and reported being able to exercise agency in the face of their peers' opinions. One study participant stated this bluntly:

Interviewer: *How easy would it be for you to do something if you knew that the rest of the group disagreed with it?*

***Suku**: How easy it would be? *Laughs* Wow! If I feel like it is good for me then, whether they agree or disagree with that, I would go with it.* - Suku_IDI_24 year old WhatsApp and Facebook user

Another participant was even resolute in continuing with a harmful behaviour regardless of his youth club's attempts to dissuade it:

***Rudzani**: For me, my group members told me to stop smoking but I do not want to stop smoking at all.*

***Interviewer**: So what did the group members say to you?*

***Rudzani**: They said I must stop smoking and I said no.*

- Rudzani_FGD participant _ Youth club only

The sense of connection that young people experienced amongst each other as a group weighed against the need of individuals to protect themselves from potentially harmful influence from the group posed a tension for some youth club participants. This was illustrated by John's views regarding whether he felt confident in his ability to remain on treatment for the rest of this life. John acknowledged that it was not always easy to take the treatment but that he was sure that he could continue to take treatment because of the support he had from his family and a good friend. While he had self-efficacy to remain on his treatment, he was of the view that not all the members of his youth club had the same capacity and was reticent to try and encourage such

people to stay on their treatment. The reason underlying his reticence was the desire to protect himself from their negative influence on his behaviour:

> *Because they would cause me not to take my tablets. Maybe they would say that we should not take the tablets because they are horrible so let us throw them away. I think they would make me think twice about my treatment and that would make my viral load go up then I would end up sick. I trust those who actually take their treatment, they are the people who I would want to speak to.* – John_IDI 18-25years_Youth Club Only

This concern about being susceptible to negative influence from their peers indicated the young people's awareness of their own vulnerability and a proactive means by which they thus sought to protect themselves and to protect their health at all costs.

3.2.4 Perceptions about youth club membership

The youth gave mixed responses to how they felt their lives would be different if the Facebook groups were to be discontinued. There was a perception that it would be difficult because it would mean that the youth club counselors would have to send them individual reminders to attend meetings as opposed to simply posting on the group. A dissimilar view was that it would not make a difference if they no longer had the Facebook group because they would still be able to contact the youth club counselors and other MSF staff directly as they had their mobile phone numbers. Another perception was that it would result in the youth incurring financial costs related to buying airtime so that they could reach out for help from counselors or from friends in the youth club if they needed help. Whether they thought it would be a negative thing or were

indifferent to the idea of an end to the Facebook group, all the youth were clear that such dissolution would simply drive them to communicate with their counselors and peers directly by using other means. In contrast, when asked how their lives would change if the youth club meetings were ended, most participants had a strong emotional reaction, exclaiming that their lives would be very different as they would no longer see each other, support each other and they would no longer have their own space to receive care separately from the adults attending the clinic. While this was the predominant sentiment, one participant was confident that she would not suffer any ill-consequences if there were no longer any youth clubs because she had a trusted circle of *"supporters"* outside of her youth club. Amongst these she mentioned her partner, colleagues, members of her community and another community-based organization with which she had previously been involved. This suggests that the youth club is perceived as less socially important amongst young people with a more extensive network of social contacts.

The unique value of the youth clubs to the participants was made evident by the fact that all of them indicated that they intended to remain in the groups indefinitely. Most of the participants also expressed being happy with the frequency of the youth club meetings as either monthly or every other month. However, a small number of outliers emerged who would have preferred to meet more regularly, as they considered the youth clubs a source of diversion from their ennui and enjoyed spending time with their peers. Another reason given by one participant for her preference for more frequent meetings was that it was easy to forget the things they had learnt in meetings if they spent too long away.

One interview illuminated the existence of a relationship between family support and youth club membership or regular participation in youth club meetings. The participant expressed the view that the most important source of support for a young person living with HIV was the family. In her view youth who did not enjoy the support of their parents in particular had a more difficult time dealing with their situation and without family support they would have a lower motivation to go to the clinic and obtain their medication and other clinical care. Adding,

> *So I think like if families, elder people, like relatives could support us as young people who are living with HIV, then the possibility would change for young people who are going to the clinic so that if they get the support from home, they will usually go to the clinic and get their medication on time… I met a girl a few months ago, she told me about her story. That her mother usually calls her names, since she's like HIV positive. So her parents would actually call her names on the streets, in the community. That doesn't sit well with her. So she ended up leaving home and living with friends and ended up not going back to the clinic and taking her medication.* - Siba, Female, 18-24years old, Facebook user

3.3 Perceptions about influence of support groups on HIV-related behaviours

The following section presents the findings that emerged from the data that relate to the third and final objective of the study: to explore perceptions of HIV positive young people at Clinic X in Khayelitsha regarding the influence of support groups on their behaviour during 2015/2016. One

of the key protective behaviours of interest was youth club attendance. The reason for this is that by regularly attending youth clubs, YPLHIV were provided with opportunities for a suite of clinical services including collection of ART, monitoring of CD4 counts and viral loads, treatment of opportunistic infections as well as psycho-social support from counselors and peers during youth club meetings. Treatment adherence was another important protective behaviour explored in detail along with the motivators for young people's intention to adhere to protective behaviours. These were all described by youth.

3.3.1 Accurate knowledge lead to improved decision making and positive behaviour

A key ascribed impact of youth clubs membership was that it provided youth with information that helped them to understand their condition and to make informed, health-enhancing decisions about their lives. For example, knowing that to engage in a sexual relationship would require him to use protection at all times, and understanding the potential value and risk of disclosing his status to a sexual partner, John made the decision to abstain from sex with his girlfriend. Attending the youth clubs had helped him to understand the importance of establishing trust as the basis for a sexual relationship. As has already been mentioned, motherhood emerged as an important issue for the young women participating in the study. One of the main benefits that the youth expressed having received was the knowledge that they could still choose to have children in spite of being HIV-infected. The youth club meetings provided them with information and knowledge on how to start a family as a woman living with HIV as well as how to protect their babies in the instance that they chose to breastfeed them.

3.3.2 Youth club participation enhanced mental health and protective behaviour

By and large, the youth reported experiencing an emotional relief during youth club meetings whose effect on their mental health was that it diminished their stress and "*lessened the load,*" allowing them to decompress and "*make jokes out of problems*" with people who understood each other. All the youth reported that they always looked forward to the youth clubs and this anticipation of the positive effects of interacting with their peers in the youth club meetings was so strong that it affected their mental health beyond and health behaviours outside of youth club meetings themselves. This is elucidated by John's reflection in which he established causal links between his ability to take medication daily, his mental condition and the positive influence of youth club membership on his mental condition.

> *Because sometimes when you're taking those pills and you're not going to the youth club… many thoughts that going through your head but if you know that you have youth, you know that everything that is going on was going to be clear and you're going to be relieved and every question that you have is going to be answered because you will be given the right advice.* - John_IDI_18-24Years

Another finding demonstrating the influence of the youth clubs was the manner in which they provided the youth with models of positive living, thus encouraging them to stay in care by continuing to attend youth club meetings. By being able to see other young people who like them were living with HIV, who appeared to be happy, healthy and optimistic about life, who had relationships and were starting families, participants found themselves looking forward to the youth club and motivated to continue attending meetings. One participant described how starkly

the youth she found in the youth club meetings differed from her mental image of what it would be like to live with HIV when she was newly diagnosed and the impact that this had on her own motivation:

> *At first I was like… I saw how beautiful the ladies there were and I was like maybe people are playing and they may be getting paid just to make us feel good… I was expecting to see some of the people that I used to see in Gugulethu, like sick, sick and then I came here and I was like, 'No man, these people are getting paid.' And you will see that she is beautiful and she is healthy and she doesn't even care when saying 'HIV positive, HIV positive!' And then I kept coming and I saw that they are taking their pills and I saw that we are on the same page."* – Suku_IDI_18-25 years_WhatsApp and Facebook user

3.3.3 Gendered motivators for positive behaviour

The males among the participants, while able to identify protective behaviours such as staying on treatment, exercising, eating well and having a positive outlook on life, were less inclined to reveal their personal motivations for preserving their health and staying away from risky behaviours. An exception was Vuyani, who when talking and how some people took themselves off their medication just to see what would happen and if indeed they would die, was resolute about his intention to maintain his treatment regimen because he was scared of dying. While Vuyani was motivated by his fear of death, John's motivation was diametrically opposed. It was the prospect of a full life and a future encouraging and inspiring other young people that

motivated his eagerness to remain as healthy as possible. It was Khanyo who provided a glimpse about the extent to which conceptions about what it meant to be a man influenced the motivation to stay on treatment.

> ***Interviewer:*** *How does she [your mother] help you to keep taking your pills even if it's difficult?*
>
> ***Khanyo:*** *Just let me to think, 'if you don't drink these pills, who gonna look after me in future? Who gonna buy me a house?' I see my mother and then laugh and say 'I'm a man in this house so I'm gonna take care of these things'. She say, 'Yes you are the man but you must drink the pills if you want to be a real man.' And then every day I just think on my mother and my goals, on just my mother. – Khanyo, Youth Club Only*

For the young women in the group, their drive to adopt positive behaviours also varied. Like their male counterparts the female participants identified behaviours such as having protected sex, staying on treatment, exercising and maintaining a healthy diet as being important to their health. Themes that came up in discussing the reasons why they wanted to be healthy were more nuanced. For example, exercise and diet were mentioned in relation to looking attractive and maintaining one's figure while treatment and babies consistently emerged as co-occurring themes in the individual in-depth interviews as well as in the focus group discussions. As already discussed a number of females mentioned the importance of treatment not only for themselves but to ensure that they would have healthy babies in the future. Their plans for starting families motivated them to come to the clinic to monitor their health so that when they decided to have children they could do so safely. It is important to note that while they found different sources of

motivation to stay on their treatment and health regimens, both the males and the female participants found it difficult to remain motivated but recognized how important taking their treatment was to fulfilling any goals they had for their futures.

3.4 Conclusion

This chapter has presented the study findings and analysed how YPLHIV in face-to-face and virtual youth clubs at Clinic X experienced social support in 2015/2016 and their perceptions about the impact of their membership in youth clubs on their HIV related behaviours. The following chapter discusses these findings in the context of available literature on the key issues emerging.

Chapter 4: Discussion

4.0. Overview

In this chapter, the study findings are discussed in light of the existing literature and what can be further learned from the social support experiences by HIV positive young people from a clinic in Khayelitsha. This chapter explores the specific types of support the youth described (emotional, appraisal, informational and instrumental) in light of what is known about different formats of support, both online and in person. Secondly, we discuss whether the study's findings about participating in virtual support groups and cohesion amongst youth, particularly the nature and strength of the relationships between youth club members, is similar to other studies. Finally, the findings discuss how support group membership was perceived to impact their HIV-related behaviours in the broader context of social and behaviour change interventions.

4.1. Support groups provide young people living with HIV with experiences of social support among peers

The findings showed that young people benefitted from various forms of social support from their peers within the youth club support groups during monthly meetings as well as using the online platforms. Existing literature highlights several forms of social support, including emotional, instrumental, informational and appraisal support (Mo & Coulson 2008; Gaysynsky et al. 2014; Berkman et al. 2000). Of these, the forms of support raised most frequently in relation to the youth club support groups in the study were emotional support and informational support. This is congruent with findings of studies on virtual support groups for HIV positive

people in the United States where the most frequently provided support was informational and emotional, while there was little exchange of tangible or instrumental support among support group members (Gaysynsky et al. 2014; Coursaris & Liu 2009).

Informational support: a key form of support to online users

The Facebook group and youth club meetings lent themselves very well to the provision of informational support, with online participants identifying this form of support as being a primary outcome of their engagement on Facebook. Similarly, where online support groups have been set up for other conditions such as breast cancer, fybromyalgia and arthritis a study found that being better informed about their illnesses was a major positive outcome cited by participants (van Uden-Kraal; 2008).

One of the key outcomes of youth club participation was that the youth felt being better informed to make decisions about their behaviours that would protect their wellbeing in their day to day contexts. To be considered useful by the youth in this study, the information shared had to be relevant and practical, such as information on the nearest clinics where they could access medication if they were out of town visiting rural homes during the festive season. Youth also found benefit in information that was highly specific to their challenges and aspirations to lead normal lives like other young people. From the study, examples of this kind of information were specific strategies on how to enjoy their social lives, such as going out at night while still maintaining adherence to ART. That the youth were able to point to such examples adds weight to the claim of Magnezi et al. (2014) who assert that information and knowledge are foundational to the process in which the ability to self-manage their conditions is developed by people living

with chronic health conditions. This capacity to effectively manage their health conditions and make the decisions that enhance their health is defined as "patient activation" and such patients are more likely to adhere to health promoting or protective behaviours (Magnezi et al. 2014; Coursaris & Liu 2009; Hibbard et al. 2004). Informational support combined with social learning through the modeling of peers within the group (Bandura 1971; Willis and Royne 2016) has the power to contribute to YPLHIV's health. Through this YPLHIV can develop self-efficacy to manage the rigours of living with HIV. It is thus an important programmatic consideration for responding to the needs of young people living with HIV, particularly in the context of preparing them for the transition to adult care.

Another finding was that engagement on the Facebook forum tended to be one-directional, with the youth being more likely to consume information or react to posts made by facilitators as opposed to posting their own content and initiating dialogue amongst each other. This finding is resonant with previous research on the use of online health-related support groups that claims that users are more interested in obtaining information from these forums than in interacting with each other (Magnezi 2014; Thackery et al., 2003). Thackery et al. (2003) in a US study of adults unexpectedly found that the consumption of information was a predictor of low patient activation. The researchers speculated that this could be a reflection of the behaviours of patients who were early in their diagnosis and that it is possible that over time the level of activation would increase (Thackery et al. 2003). Tracking levels of enagagement was not within the scope of this study, thus further research would be required to ascertain whether pre-ART youth do in fact become more engaged over time, and whether this is linked to increased self-efficacy to remain in care and on treatment.

Emotional Support: the glue that holds YPLHIV together in support groups

The youth clubs offered YPLHIV emotional support that positively impacted their mental health in much the same way other support groups have been found to function in other settings. Specifically, the common experiences of being HIV-positive fostered feelings of connection and the mutual disclosure a sense of relief (Cohen 2004; Holtzman et al. 2015; Mupambireyi et al. 2014; Greifinger & Dick 2011; Lam et al. 2007; Dageid 2014). The young people's mutual positive affective associations with each other provided motivation to attend the youth club meetings (either monthly or every other month). Such findings suggest that the model of provision of treatment and other clinical care in combination with youth club meetings is an effective approach for retention in care. This is supported by quantitative evidence from Wilkinson et al. (2016) that found high retention rates among young people living with HIV who were participating in the youth clubs at the same site where this study was conducted. Retention was significantly higher among those on ART (86.4% of new ART initiates and 94.3% of youth stable on ART) than those not yet initiated on ART – 52.9% of those not yet eligible for ART retained in care (Wilkinson et al., 2016).

Appraisal support: limited impact on youth behaviour

Support groups offer YPLHIV a forum for facilitated discussion with peers on decision-making issues that they grapple with such as when and how to disclose their HIV-status to intimate partners or families, if at all. Appraisal support is the provision of support in making decisions or advice in evaluating decisions (Mo & Coulson 2008; Gaysynsky et al. 2014; Berkman et al. 2000). While present, this was mitigated by the strong sense of self and desire to do as they saw

fit even if they asked for advice. The youth club setting is acceptable to members as a source of advice on issues regarding HIV but less so for non-HIV related decisions. Taking into consideration the fact that adolescence in general is a time when a young person's identity formation is in process (Wilson et al., 2005; Gould et al., 2004; Erikson; 1968; Campbell and MacPhail, 2005), provides insight on why the youth would express openness to receiving advice on decisions but simultaneously hold fast to their agency to do whatever they saw fit.

Is positive self-presentation a barrier to exchange of instrumental support?

Positive self-presentation may act as a barrier to the exchange of instrumental support by negating feelings of sameness otherwise experienced by peers within the support groups. Asking each other for material assistance was a difficult thing for the youth to do, particularly online. While youth were able to name examples of receiving instrumental support from family members or the clinic staff, the online groups were not considered a potential platform on which youth could ask for help of this nature. While this finding is in line with existing literature on the kinds of social support exchanged online in other settings (Gaysynsky et al. 2014), there is little exploration of why this might be the case. This study found that participants were comfortable with requesting instrumental support such as food or money from people whom they trusted, for example clinic counselors, in person. However, asking for material help in the virtual groups engendered feelings of social inferiority.

Support groups are constituted on the basis of similarity in a key domain, such as a health condition, and support group members may differ on other dimensions such as socio economic status or personality (Cohen et al. 2000). The homogeneity underpinning the support groups for

YPLHIV is that of the youth being of similar age and having the HIV-diagnosis, thus emotional and informational support are exchanged in relation to experiences common to being young and having HIV. These common experiences include affective states, relationship issues, treatment support, positive prevention, et cetera. From the study, asking for money online created cognitive dissonance among the youth who recognized that most young people often needed help of that nature, were aware of the purpose of the online groups as being a source of additional support but had never used them to ask for material help.

Drawing from literature on self-presentation and belonging on Facebook, it may be the case that asking for help in front of a group of people some of whom were from different support groups and thus strangers, threatened group members' positive self-presentation of belonging to the group by virtue of being similar to the rest (Seidman 2013; Baumeister & Leary 1995; Cohen et al. 2000). Indeed, Newman and others (2011) conducted qualitative research in which users of online health communities found it difficult to share their problems on Facebook because of perceptions about it being a platform for people to portray themselves in exclusively positive terms, without revealing weaknesses or problems (Newman et al. 2011). However, they were able to share their problems on online sites created specifically for the purpose of people with shared health condition to share experiences and information (Newman et al. 2011). From a messaging perspective, it may thus be prudent for facilitators on the online platforms to post messages aimed at changing perceptions about what it means to ask for material help from peers or prompting those who need this kind of help to approach programme staff directly.

Online youth clubs create a perception of increased access to support

The study expected that there would be a difference in experiences of social support comparing users and non-users of the online social networking platforms. Boase and others (2006) reported that Internet users were more likely to receive support from core members of their social networks than non-internet users. Contrastingly, this study found no real difference in support between the virtual platforms and those who only attended youth clubs. Both groups reported similar experiences of support and identified having similar sources of support. However, there was a *perceived* difference in access to support in that those who were not using the online platforms thought that those who were using the online platforms were receiving more emotional and instrumental support. It is worth mentioning that perceived availability of social support has been identified as being potentially more important than actual social support experienced (Cohen, 2001; Rosengren et al., 1993). Rosengren's (1993) research involving Swedish men demonstrated that the deleterious effect of stressful life events on mortality was markedly reduced by the *perception* of availability of social support (Rosengren et al., 1993). In the case of YPLHIV, it would thus follow that the perception of having more support, whether or not it was actually experienced may result in more positive outcomes for those who used the online groups compared to those who do not. Further research would be needed to understand if indeed there is a relationship between perceptions about support and outcomes such as retention in care as well as treatment adherence and mental health in young people living with HIV.

4.2 Young people living with HIV situate themselves in a wider web of social support

Young people living with HIV are not solely reliant on peers from online support groups for their social support needs. The online support group platforms comprised peers who were HIV-positive youth attending monthly youth clubs. If the youth at times seemed indifferent to the role of the online support groups to their lives it was because they located themselves within a wider network of social support that extended beyond support group peers to their friends, family, intimate partners, health workers and wider community. Research has indeed found that users of online support groups with fewer sources of support were more likely to use online groups and obtain benefit from them and that online support groups are valued by members to the extent that they are able to supplement gaps in real world support (Maloney-Krichmar & Preece 2005; Turner et al. 2001; Cummings et al. 2002). That being stated, there is also evidence from a 2005 study of members of an online support group for knee injury sufferers, that even among members with high real world support online peer support groups have the benefit of providing a ready, empathetic audience allowing members to talk in tremendous detail about their experiences with the condition, a level of detail that family members could find tedious (Maloney-Krichmar & Preece 2005). Research in the Netherlands on older people's perceptions about face to face versus online social interaction for a number of illnesses not including HIV showed a preference for face-to-face contact and was thought to be a consequence of older people's distrust of the Internet (van Uden-Kraan et al. 2013). In a multi-country survey administered online more PLWH preferred discussing their HIV status with their peers online (93%) or their doctors (87%) than family, friends, or colleagues (Longinetti et al. 2017).

This study dealt with youth who were all infected with HIV through sexual transmission. For such young people family members and intimate partners play a complex role in the provision of social support, as the youth do not always choose to disclose their sero-status. Literature shows that the reasons for this are varied and include self-stigma (Earnshaw et al. 2014), fear of reprisal and censure by parents for sexual activity (Mburu et al. 2013), especially for younger adolescents who may be below the legal age of consent to sex (Bekker et al 2014). In the study all the youth who reported disclosure to parents, intimate partners or friends had positive experiences, however they were able to describe instances where YPLHIV that they knew had negative experiences and linked these to poor health outcomes among such youth. The importance of family support in improving health outcomes has been outlaid in research on YPLHIV, but there is a need for families to be capacitated to provide support to YPLHIV (Proulx-Boucher et al. 2017; Bhana et al. 2014; Massavon et al. 2004). For example, a pilot of VUKA, a family-based intervention in South Africa to promote YPLHIV's wellbeing resulted in significant gains in ART adherence, knowledge on HIV treatment and perceptions of YPLHIV about external stigma (Bhana 2014). Research has found that the role of family can also be linked to negative health outcomes for people with chronic illnesses as they may feel guilt about the burden their conditions place on their families, or they can feel criticized and nagged (Gallant 2007; Walen and Lachman 2000). Atukunda and others (2017) found similar responses among adults living with HIV in rural Uganda. The experiences of the YPLHIV in this study are thus consistent with literature on the positive and negative outcomes of family support.

Health workers also played a very prominent role in the network of support of the youth in this study, and this was particularly the case in the absence of family where the youth had not

disclosed to family members or where family and community members had ostracized them. The importance of health workers in the young person living with HIV's life has been emphasized in the growing body of literature on young people and mental health. Indeed, a study in the United States showed that when HIV-positive youth rated high levels of satisfaction in their relationships with and services received from health care providers this countered the negative effect of stigma on their adherence to treatment (Martinez & Chakraborty 2014).

Facebook facilitates opportunities for Bridging Social Capital

Participating in social networking sites such as Facebook provides opportunities for young people living with HIV to access bridging social capital (Ellison 2007) that is of relevance to issues they face in addition to their health. The youth in this study were satisfied with minimal interaction (liking, commenting on or sharing existing posts) and preferred to use Facebook as a means of accessing and sharing information about youth club logistics or other opportunities. Kraut (2007) suggests that low level interactions on Facebook (for example liking existing posts) facilitate the generation of more bridging social capital. In particular, in viewing their role as being that of serving as conduits and sharing information about career opportunities with their wider networks they gave credence to the research of Ellison and others who in a 2007 study found that there was a strong relationship between the use of Facebook and bridging social capital. They found that while there was a relationship between Facebook use and three types of social capital, namely, bonding, maintenance and bridging social capital, the strongest correlation was with bridging social capital (Ellison et al., 2007). Similarly, this research shows that while they understood its potential as a means to nurture relationships, the value of

Facebook to the YPLHIV was as a platform through which they could access information about career, educational and extra curricular opportunities and share such opportunities with their wider networks, as well as stay informed about club activities and recap subjects discussed in meetings.

Making use of its bridging role, an effective use of the Facebook platform rather than necessarily strengthening the peer bonds amongst youth club members could be in linking them with sources of help and counsel in dealing with day to day issues such as chat-lines and other free services available promoting adaptive coping mechanisms. Additionally, by providing young people with access to opportunities for further education, training and employment, online platforms such as Facebook groups can impact mental health outcomes. This is because the young people who are most at risk of mental health problems are those without links to employment and education (Rickwood et al., 2007). Given South Africa's high youth unemployment rate of over 50% (World Economic Forum 2015), it stands to reason that increasing access to opportunities that would otherwise be inaccessible to young people living with HIV in resource-poor settings is a powerful form of social support with measurable impact on mental and physical wellbeing. This is validated by the findings of Campbell and MacPhail's (2005) research on young people living in a South African township that recommended addressing poverty and unemployment as a means to empower young people to take charge of their wellbeing in ways that do not risk their health and are consistent with their life aspirations.

The thin line between resilience and risk

There is a need for strengthened social support structures within YPLHIV's existing social networks outside of regular youth club meetings. The findings showed that in addition to their various sources of social support, the YPLHIV in this study identified their own strengths as being important in remaining motivated to look after themselves, secure their future and their children's wellbeing. Within this internal drive, however, maladaptive coping strategies such as displacing problems from their minds during day-to-day life outside youth club meetings or being willing to risk their own health in order to preserve the health of their children revealed the need for strengthened social support structures within their existing social network outside of the youth club setting. Risk-tolerance is a feature of the transition from childhood to adolescence and young adulthood, as is the need to assert the young person's identity as an individual (Nglazi et al., 2012; Coleman and Henry 1999; Kirchler and Palmonari, 1995). Believing self-reliance to be a positive indication of independence and resilience, young people living with HIV may thus fall into the trap of engaging in behaviours or coping strategies that put their wellbeing at risk rather than reaching out for support from nodes in their social eco-system other than youth club peers. There is thus need to continually reinforce to them the importance of seeking help and to train counselors and facilitators to identify and support youth who may be in need of adaptive coping skills.

4.3 Social cohesion amongst youth club members

There were no indications from the two comparison groups that the online platforms conferred a stronger bond in existing relationships among support group members. However, the Facebook

platform did provide opportunities for new social ties amongst a minority of support group members from different youth clubs whose commonality of being HIV-positive negated the apprehension to make new friends. Such findings are consistent with more recent evidence on social capital and Facebook (Burke et al. 2011b; Ellison et al. 2011; Morris & Aguilera 2012; Ellison et al. 2007). This study adds to the body of evidence by exploring social bonding and Facebook in the context of young people living with HIV. Youth club members formed an *'in-group*' in which the youth could automatically belong and form relationships more easily, shielding them from their subjective beliefs about being stigmatized by HIV-negative people. Social networking sites and other forms of social media have received criticism for contributing to social isolation and the breakdown of real-world in person relationships. However, Ellison and others (2007) found that frequent use of Facebook had small effects on bonding social capital and maintenance social capital, that is strengthening existing social ties of university students surveyed cross-sectionally (Ellison et al. 2007). Similarly, Burke et al (2011) found evidence that Facebook use does not worsen disconnectedness of people with low bridging social capital and that it in fact modestly reduces loneliness for people with weaker social communication skills (Burke et al. 2011a). The findings of this study are thus incongruent with early literature on the effect of the Internet on social integration, which infers that use of the Internet leads to social isolation (Kraut et al., 1998; Morahan-Martin & Schumacher, 2003) and reduction of subjective wellbeing (Kross 2013) for a number of reasons. There have been also been arguments that text based communication precludes nonverbal cues which form an important component of communication, thus making it difficult for real bonds to form between people online (White & Dorman 2001; Maloney-Krichmar & Preece 2005).

Levels of connectedness or cohesion in a network are dependent on the extent to which members are able to communicate authentically, a process that on social networking sites such as Facebook is hindered by privacy concerns (Morris & Aguilera 2012) as well as the desire to self-present in a positive light (Newman et al. 2011). In a context where support group members participate in a closed Facebook group for YPLHIV, wanting to manage their self-presentation and conducting inadvertent social comparison may hinder the extent to which YPLHIV are able to use Facebook to strengthen peer social networks by precluding true intimacy and vulnerability.

4.4 Key influences on YPLHIV's HIV-related behaviours and behavioural intentions

This study shows that informational support obtained from participation in support groups coupled with reinforcing messages on virtual support groups increases the knowledge of YPLHIV on HIV-related issues that are relevant to their lived realities as well as equipping them with knowledge and skills for their future. All the youth in the study were able to name specific behaviours that led to good health including staying on treatment, eating well, exercising and engaging in protected sex among others. Moreover, among young women intending to be mothers, knowledge on PMTCT was expressed with confidence that they would be able to follow the rights steps to prevent the transmission of the virus to their infants when they decided to begin childbearing. As a result of regular exposure to HIV-related messaging in a peer environment, the youth in the study were knowledgeable on HIV and while not empirically measured, their knowledge levels in comparison to the declining levels of knowledge among young people nationally (UNESCO, UNAIDS, UNFPA 2016; Shisana et al. 2014; UNAIDS

2014)) point to an important function served by the support groups model. While knowledge does not predict behaviour, it has been found to reflect underlying attitudes, which do predict behaviour (Ajzen et al. 2011; Fabrigar et al. 2006). Knowledge is thus often considered a pre-requisite for changes in HIV-risk behaviour for young people living with HIV (Shisana et al. 2014; UNESCO et al. 2013). Participation in social health networks enhances the self efficacy of patients of chronic illness to manage their health (Magnezi et al. 2014; Coursaris & Liu 2009; Hibbard et al. 2004). This study found that participating in youth clubs provides YPLHIV with information on living with HIV and the virtual youth clubs prove to be an effective means of reinforcing this information, giving participants the self-efficacy to manage their health.

In terms of the remaining in the continuum of care, all the participants expressed the intention to remain in the monthly youth clubs – and by default remain in care. This was true for pre-ART youth and those on ART. Thus, the results of this study resonate with strong evidence from reviews and studies in sub-Saharan Africa that extended counseling and peer support have positive effects on linkage to HIV care (Govindasamy et al. 2014; Holtzman et al. 2015; Mupambireyi et al. 2014; Greifinger & Dick 2011; Lam et al. 2007; Dageid 2014). Indeed, quantitative findings by Wilkinson and colleagues in 2016 found actual retention in care among youth club members at Clinic X to be quite high - 81.7% overall retention at 12 months (Wilkinson et al. 2016).

However, the intention to remain in care expressed in this study should be received with cautious optimisms as it contrasts with quantitative findings from the literature that show that loss to follow up is high among young people and particularly those not yet eligible for ART

(Bateganya et al. 2015; Mugglin et al. 2012; Nglazi et al. 2012; Arrive et al. 2012; Leeper et al. 2010; Rosen et al. 2007; Phelps et al. 2013; Evans et al. 2013). Results of a large study of 10-24 year old youth from Sub-Saharan Africa showed slightly lower attrition after ART initiation among youth participating in support groups, with little association between participation in support groups in pre-ART phases and attrition from care (Bateganya et al. 2015). Similar quantitative findings emerged from research by Wilkinson and others (2016) in which while overall retention in care was high, pre-ART youth attending youth clubs were more difficult to retain in the care continuum than those already on ART. Fifty-three percent of pre-ART youth remained in care compared to 94.3% among ART-stable youth who were retained in care (Wilkinson et al. 2016). Research has identified the following factors associated with loss to follow up: not having a family member or friend with HIV (Bassett et al. 2010), younger age, being male (Boyles et al. 2011; Bassett et al. 2010), late initiation on ART, pregnancy (Wang et al. 2011) and a number of other clinical factors (Mugglin et al. 2012; Boyles et al. 2011; Bassett et al. 2010; Lessells et al. 2011).

Social comparison theory (Festinger 1954) may explain the attrition of YPLHIV from care, particularly those not yet on ART. The aim of mixing pre-ART youth with those newly initiated and those that are stable on ART is to create an environment where social learning can take place with those not yet on ART being motivated by and learning from those already on ART. Similarly those newly on ART would do likewise with those who are stable on ART. Indeed a study participant on ART expressed being highly impressed and motivated to join the youth clubs by seeing youth club members who looked very healthy and vibrant. This describes the process of upward comparison and is posited to serve the purpose of self-improvement and

information (White 2006; Collins 1996, Wood et al. 1994, Taylor and Lobel, 1989; Festinger 1954). However, upward comparison is only possible if the youth view being on ART as better than not yet being on ART. Research has shown that under conditions of threat, for example, in the case of cardiac patients (Helgeson & Taylor 1993), cancer sufferers (Taylor & Lobel 1989) or people living with HIV (Derlega et al. 2008), the tendency is for individuals to make downward comparisons with those worse off than themselves and moreover, individuals prefer not to socialize with those they consider worse off (Derlega et al. 2008; Taylor & Lobel 1989; Wills, T.A 1983; Festinger 1954). It is possible that YPLHIV not yet on ART actually conduct downward comparison over time and consider their ART-initiated peers as worse off, especially when considering the difficulty of taking the lifelong medication, its side-effects, et cetera, while a pre-ART youth may not necessarily yet have experienced any symptoms of ill health (Mugglin et al. 2012). The interplay of downward comparison with the low risk perception or high risk tolerance that naturally feature in youth (Shisana et al. 2014; MacPhail & Campbell 2001; UNESCO et al. 2016) may actually result in pre-ART youth losing motivation to attend youth clubs as they deem them unnecessary. Festinger (1954) predicts that individuals will move out of groups when they experience conflict in their drive to self-evaluate (Festinger 1954), and this may be the case in youth club settings where establishing who is better and who is worse off is more complex. Testing this through further research would be useful in further exploring the extent to which this may be the case among YPLHIV in the youth clubs, if at all, as there was not clear evidence of this in this cross-sectional study.

Furthermore, the difficulty of retaining youth in care may be attributable to gaps in support outside of the youth club setting, that is, among family and other nodes of the young person's

social network as well as structural factors. In the study, a participant remarked that the lack of support from parents was a reason why some YPLHIV would stop coming to youth clubs. Without support from core members of their social networks YPLHIV lose the motivation and means to continue attending support groups. This is consistent with findings in the body of literature that individuals who do not have HIV-positive family members or friends were more likely to be lost to follow up (Bassett et al. 2010). Indeed, there is evidence that family and friends may cause added stress by minimizing the difficulties faced by HIV-infected individuals or withdrawing from them because of lack of knowledge, fear or stigma (Cohen et al. 2000). It is with this support deficit in mind that many of the youth in the study called for education programmes for the broader community to sensitize them on HIV. Structural determinants such as poverty and unemployment may have an influence on retention in care as Cornell and others (2010) found that having an income reduced loss to follow up (Cornell et al. 2010). The high levels of youth unemployment and poverty in the study population have already been discussed and would certainly be a factor in attrition of youth from care. Thus without reliable sources of instrumental support, YPLHIV may drop out of care despite having had the intention of continuing their participation.

From a programming perspective, it is worthwhile to note that YPLHIV's motivation for maintaining health behaviours is not always directly related to being HIV-positive. The youth in the study pointed to various motivators for adhering to their medication and other means of staying healthy such as exercising and eating well. Their motivation to engage in health-enhancing behaviours was gendered and closely linked to the young people's subjective norms about their social roles. Among the female participants body ideals and motherhood were

important. Adolescence and youth are developmental phases in which individuals begin to negotiate their sexuality, seeking acceptance not only from peers but from sexual partners (Sawyer et al. 2012; Li 2009). Thus their physical image grows increasingly important driving them to seek to present themselves as attractively as possible, and in the case of adolescent girls and young women, engaging in various weight control regimens (Kinsman et al. 2015; Mchiza et al. 2015; Gitau et al. 2014). Wanting to look good may also reflect a desire by young women to distance themselves from the image of sickly, frail AIDS sufferers that is the root of many stigmatizing experiences of people living with HIV (Rao et al. 2007). The desire for motherhood, too, is an important driver in HIV-positive young women's motivation to remain healthy and remain in the care continuum. Information on sexual health, contraception and prevention of parent to child transmission is of great importance in increasing the self-efficacy of young women living with HIV to yearn to fulfill the role of being a mother just like their HIV-negative peers (Mburu et al. 2013; UNESCO et al. 2013).

4.5 Stigma and confidentiality remain an issue for young people living with HIV

Most of the youth in the study were residing in the same township therefore concerns around confidentiality and involuntary disclosure arose as a barrier for uptake of the online service. The youth were clear that they exist in a context where social stigma for people infected with HIV remains high. Stigma has resulted in highly detrimental outcomes for young people with HIV particularly with respect to adherence to Antiretroviral Treatment (ART), whether the stigma is perceived or actually experienced (Berger et al., 2001, Martinez et al., 2012). A service where youth can maintain anonymity may result in higher uptake of the virtual support group model.

One illustration of such an intervention is Project Khuluma, where youth participating in SMS-based YPLHIV support groups are drawn from different geographic locations across South Africa and do not necessarily attend the same clinic and reside in the same locale (Simpson et al., 2017). A study of the youth participating in Project Khuluma reported reductions in internalized stigma and increases in perceived social support and self-reported treatment adherence (Simpson et al., 2017). More broadly, concerted efforts to change attitudes and norms about HIV are required at higher levels of the socio-ecological environment in which the youth reside, that is among family and community members.

4.6 Who bears the cost of YPLHIV's participation in virtual platforms?

As with any other intervention there are costs associated with YPLHIV's participation in interventions that rely on the use of mobile Internet. The young people in the study reported that depletion of data was a disincentive for their engagement on the virtual support groups, especially WhatsApp. While the costs of airtime and data in South Africa have declined since 2008 (de Lanerolle 2015), the cost of using mobile phones has not reduced adequately to make mHealth more accessible to young people, particularly in light of the challenging socio economic conditions faced by youth (World Economic Forum 2015; Campbell et al. 2005). MSF (2014) reports that YPLHIV who were members of the youth clubs at Clinic X participated in a virtual support group on the MXit platform in 2013/2013 and of these 12% of those surveyed cited lack of airtime as a barrier to their use of the platform (Patten et al. 2014) while a 2014 study of the use of mobile phones for health purposes by young people in South Africa reported that young people were sacrificing food and other necessities in order to purchase airtime to use their mobile

phones (49%), with 40% having no airtime at all at the time of the survey (Hampshire et al. 2015). Given that 60% of non-Internet users in a South African survey cited cost as a barrier to their use of the Internet (de Lanerolle 2015), innovative ways of reducing the financial burden of young people's participation in virtual support groups is an important consideration for programme developers. In response to outcries on the cost of data, network operators in South Africa have introduced zero-rated to access to some social networking services albeit on temporary promotional bases (Cowen 2016; Lotz 2017; Ventkess 2017).

4.7 Study limitations

This research is not without limitations and the following should be taken into consideration in interpreting the findings:

Exclusion of minors: The study does not reflect the experiences and views of adolescents under the age of 18 years who were participating in the youth club programme. Adolescents are under-represented in scientific research (Bekker et al. 2014) and yet they have the right to be heard and to participate in matters that concern them (United Nations General Assembly 1990). However, the rights of minors to participate in scientific research must be observed and negotiated in collaboration with their parents, guardians or adult caregivers. South African law permits minors to access medical services without the consent of their parents or guardians, however, participation in research still requires parental consent according to ethical guidelines issued by the South African National Department of Health (National Department of Health South Africa 2004). Hence, while MSF provided health services, including access to support groups to adolescents without requiring their parents' consent, a decision was made not to ask minors to

request their parents consent to participate in this research as it was likely to result in conflict in the case of those who had not disclosed their sero-status to their parents. Future research should seek to identify and include minors who receive care in order to better understand their experiences and needs.

Cross-sectional nature of the study: the bulk of the interviews were conducted and data collected at a single time point after the intervention was implemented. Pre-intervention data on experiences of social support and perceptions about social cohesion would have been useful in interpreting the data collected after the participants had used the platform as they would have enabled a comparison demonstrating any perceived changes in social support, cohesion and health-related behaviour, if any. The researcher addressed this limitation by including a question on whether the study participants' experiences of social support, their perceptions about the relationships among group members or their behaviours had changed since the introduction of the online groups, if at all. While the responses of the participants would have been subject to recall bias, they did provide some level of insight on this.

Transferability: as the study was exploratory and aimed to understand the experiences of a population of young people participating in a bespoke intervention at a single urban youth-friendly clinic, the study participants were purposively sampled from YPLHIV receiving services at that clinic – as a result the sample size was small. However, findings from this study may be transferable to young people living with HIV receiving care from other urban clinics and are also in support groups may be possible as the study was conducted in a large South African township. This study may thus serve as a useful reference in designing support group programmes for

YPLHIV at youth-serving clinics in similar settings around South Africa. The fact that not all adolescents and young people who need HIV-related health services will be able to access health services specifically aimed at them necessitates a nuanced understanding of their needs in order to adequately configure the existing health system. Findings from this research can contribute to that nuanced understanding.

Reflexivity: This research report would be remiss if it did not reflect on a researcher's influence over the study itself. The researcher is a female foreign national in her early thirties, which presented somewhat of a generational gap in terms of age, however, this was not perceived as a barrier by the researcher, having interacted with young people in similar settings in the past. However, the researcher was sensitive to the fact that with a professional background in adolescent health and education interventions, there existed a potential for pre-existing biases to be transferred onto these youth based on experiences with other young people in similar settings. It was thus critical to be aware of preconceptions arising out of having engaged on youth issues for many years and simply allow the young people to express their own realities and experiences. In addition, as an outsider to Khayelitsha the researcher may have been perceived as such by the study group and this, coupled with the researcher's lack of fluency in isiXhosa, may have influenced the manner in which they responded to her.

Further, the second phase data collector was a white, male MSF staff member who was not Xhosa-speaking. This limitation may have potentially been a barrier by causing social desirability bias among interviewees, seeking the approval of an authority figure. However, as the programme manager, his frequent interaction with the youth at the clinic resulted in him

being highly trusted by the interviewees who stated that they were comfortable to be interviewed by him. This being the case, it is understood and acknowledged that his position in the organization that the youth clubs may have influenced the type of responses interviewees provided him.

4.8 Chapter summary

To the body of evidence, this study contributes a qualitative understanding of how young people living with HIV experience social support online, showing that the dimensions of social support they experience are the same as those of participants of online health forums for other chronic conditions, namely information and emotional support. Further, for YPLHIV online support groups may act as a barrier to the exchange of instrumental support, of which YPLHIV may be in need. In seeking to understand why there may be disjuncture between the intention of pre-ART YPLHIV in the study to remain in care and the actual retention reported in numerous studies, the chapter proposes that social comparison, structural determinants and low risk perception may play a role.

Chapter 5

Conclusion and Recommendations

5.0 Introduction

The final chapter of this research report presents the study's key discoveries and concludes with some programmatic considerations and recommendations for future research.

5.1 Conclusions

Because of high pre-ART attrition and poor treatment outcomes (Bygrave et al. 2012; Govindasamy et al. 2014; Nglazi et al. 2012; Lessells et al. 2011) young people living with HIV constitute a key population in need of targeted interventions to support retention in care and overall wellbeing.

The study confirmed existing evidence on the role of peers in supporting young people living with HIV along the continuum of care and further elucidated the dimensions of social support exchanged by YPLHIV within support groups both face-to-face and online. Peer support within support groups is established on the basis of shared experiences of living with HIV as well as a shared identity that develops from being different from other young people and similar to each other. The types of support exchanged in YPLHIV's support groups, both online and face to face are predominantly emotional and informational support. These key types of support enable

young people to relieve their emotional burdens and develop skills to cope with living with their condition. For YPLHIV it is easier to solicit instrumental support in person, through face to face communication with a variety of trusted sources including family, intimate partners, close friends, health workers, and in certain instances, supportive neighbours than it is to request it from peers online. Online platforms do provide an opportunity for YPLHIV to access bridging social capital as they are linked to information and opportunities not existing within their ordinary day to day social networks. Such information includes opportunities for further education, employment or youth development extracurricular activities provided by facilitators. YPLHIV are then easily able to share this information to their networks.

The youth clubs foster a shared identity creating affective bonds among YPLHIV, which form the basis of their sense of belonging, participation in and positive attitude about support group activities. However, this shared identity does not necessarily result in an increase in the extent to which members are susceptible to peer influence. This growing self-determination must be understood as a marker of the cognitive and social development characterizing adolescence and youth (Nglazi et al., 2012; Coleman and Henry 1999; Kirchler and Palmonari, 1995) and points to a need for young people to have multiple sources of social capital from whom they receive consistent and reliable advice and support (Bhana 2013; UNESCO et al. 2013; Martinez et al 2014). The shared identity and social support received during support group meetings exist independently of the youth's participation online and YPLHIV attending support groups express a desire to remain connected to each other through face to face contact via support groups, viewing online groups primarily as information sharing and dissemination services. Without the purpose of the online groups as a means for YPLHIV to spend time with each other online and

strengthen their relationships being explicitly explained to them, YPLHIV will likely to continue to keep their engagement limited to liking or commenting on messages posted by facilitators, missing an opportunity to engage directly with each other .

One of the main outcomes of the support groups, including online groups for YPLHIV, is an improvement in participants' knowledge about issues related to HIV. This includes positive prevention (including prevention of parent to child transmission), sexual and reproductive health, treatment, mental health and disclosure to loved ones. Simply addressing the knowledge gaps and misconceptions about HIV was important to the extent that in the youth in this study considered themselves at an advantage compared to those who did not know their HIV status. Knowledge gained in support groups and reinforced online is a keystone in developing self-efficacy of chronic illness patients to effectively manage their conditions (Magnezi et al. 2014) and this study study found the same to be for YPLHIV. A more nuanced line of inquiry is required to understand the divergence between pre-ART YPLHIV's self-reported intention to remain in care and actual behaviour as reported in various studies, which show that attrition from care in this sub-group is higher than among those on ART. The need for this distinction may however be negated by the implementation of the universal "test and treat" policy in which all patients testing for positive are now eligible to start treatment regardless of viral load, CD4 count or clinical staging (Department of Health: South Africa 2016).

This study has contributed to the body of knowledge on young people living with HIV and one of the roles of mHealth in expanding access to psychosocial support for this growing population in South Africa. South Africa, like other countries in the region, is at the epicenter of the global

HIV pandemic (UNESCO et al. 2013); like other countries in the region the population has an age structure that is high in youth that have begun to transition into working age adults (Statistics South Africa 2015; Statistics South Africa 2017) and have the potential to fuel much needed economic transformation provided they have access to appropriate services and opportunities (African Institute for Development Policy & UNFPA 2015; World Economic Forum 2015; Statistics South Africa 2017). The provision of services that effectively support the health and wellbeing of young people living with HIV can contribute positively to the country's potential to harness a demographic dividend through a cohort of more young people that are in good health and are economically and socially active.

5.2 Recommendations for mHealth approaches to supporting YPLHIV

Based on the conclusions above, the following three key considerations are recommended for using mobile health as a means to support YPLHIV:

5.2.1 Change perceptions about the use of online platforms for social support

Given YPLHIV's reticence to solicit instrumental assistance online, facilitators can post messages directed at shifting perceptions about asking for this kind of help from their peers or they can use the online platform to prompt those who need this kind of help to approach programme staff directly. Furthermore, facilitators can use the youth club meetings to open up discussions between YPLHIV about the kinds of problems they encounter aside from emotional issues or their need for information on handling certain issues. YPLHIV should be encouraged to use the online platforms to initiate new or strengthen existing relationships that can then widen

the resources they can turn to for support outside of youth club meetings. Furthermore, this will also serve to overcome the prevailing perception that the online platforms are for young people to access information and encourage them to post their own content enabling facilitators and programmers a better understanding of their day-to-day issues.

5.2.2 Design community-focused programmes to address gaps in support

The second recommendation is strengthening the natural ecosystem of support that YPLHIV are able to tap into by addressing several issues alluded to by the participants of this study. Parents and families are an important source of support, with the potential to provide many of the dimensions of social support: emotional, appraisal, instrumental and informational support. However, there is a need to engage with them in how they relate to YPLHIV family members, by recognizing and facilitating their increased need for independence but also being aware of the kinds of support they require (Proulx-Boucher et al. 2017; Bhana et al. 2014; Massavon et al. 2004). This means parents and other family members need to be capacitated on how to accept YPLHIV and how to identify the nature and extent of support they need in managing their condition along with the challenges of being young and transitioning into adulthood. Expanding to other nodes of the social ecosystem inhabited by YPLHIV, there are opportunities to engage with communities through institutions such as churches, schools and other community serving organizations to shift stigmatizing attitudes, norms and perceptions about people living with HIV and their needs. This will reduce the need for YPLHIV to rely on their own internal resources and will create an environment that is supportive to their growth and wellbeing, negating the

need for them to use maladaptive coping strategies as they tap into more sources of help outside themselves and learn the power of asking for help when they need it.

5.2.3 Reduce the financial burden on young people using mobile phones

Mobile phones and social networking sites enjoy high acceptability as a communication channel among urban young people living with HIV and are a promising medium for reaching large numbers of YPLHIV in resource constrained settings (Muessig et al. 2015; Levine et al. 2015; Higgs et al. 2014; Crul 2014). However, the costs associated with using mobile phones are prohibitive to the extensive use of mobile phones for health-related services (Crul 2014). This is particularly the case with using social networking sites and apps such as Facebook or WhatsApp, because of their consumption of mobile data, which is expensive for young people with little or no sources of income. There is a need for partnerships to be formed with Mobile Network Operators to enable the provision of access to health-enhancing services to YPLHIV at reduced cost. This will improve the uptake of mHealth services delivered on such platforms as well as improve the retention of YPLHIV as users on such sites. The implementation of universal treatment for all PLHIV (Department of Health: Republic of South Africa 2016) will necessitate innovation in providing treatment adherence support to increased numbers of young people living with HIV who will need psychosocial and instrumental support to prevent treatment failure (Evans et al. 2013; Bygrave et al. 2012; Govindasamy et al. 2014; Nglazi et al. 2012). Mobile solutions may prove to play an important role if the costs can be reduced for users.

5.3 Recommendations for future research

With the dearth of evidence on young people's health needs and experiences, particularly those living with HIV not only in South Africa but also in sub-Saharan Africa, opportunities for further research abound and this cross-sectional study has revealed further questions to be answered. One recommendation of this report is for longitudinal research to quantitatively measure changes in specific behaviours such as retention in care, sexual risk behaviour and treatment adherence as pre-ART youth transition to ART. A final research recommendation is for research within communities to elucidate the how community participation in supporting YPLHIV can be increased in order to strengthen the socio ecological network of support that young people access beyond health facilities.

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Appendices

Appendix A. Focus Group Discussion Guides

FOCUS GROUP DISCUSSION GUIDES

A. FGD Preparation Checklist

The following preparations should be completed before each FGD:

- ☐ 12 extra copies of study information sheets
- ☐ 12 extra copies of consent forms
- ☐ 15 copies of audio-recording consent forms
- ☐ Box of pens
- ☐ Digital audio-recording equipment (tested for working condition)
- ☐ Backup batteries for audio recorder(s)
- ☐ Notebooks for facilitator
- ☐ Private room with at least 14 seats and enough space to arrange seats in a (semi)circle
- ☐ Nametags (for writing down Nicknames)
- ☐ Markers
- ☐ Enough food and drinks for participants

Name and Signature of Study Staff: _____ *Date:* _____

B. Checklist for Facilitator and Note-taker

The FGD shall only progress once the following are confirmed:

- ☐ All study ***consent forms have been signed*** and ***copies given to participants*** 18 and older
- ☐ All study ***assent forms have been signed*** and ***copies given to participants*** 12-17
- ☐ All participants have ***signed audio-recording consent forms***
- ☐ Participants are in the correct group:
- ☐ At least 8 participants in the group
- ☐ No more than 10 participants in the group

Note: Participants without the appropriate consent/assent forms or not meeting the inclusion criteria will be excluded.

Name and Signature of Study Staff: _____ Date: _____

C. Introduction Exercise

Note: Start recording

Once the consent process is complete, to build rapport, have everyone take a seat and in his turn introduce himself using his Nickname (false name for FGD purpose), his age, and something about him that nobody else in the room knows.

Note: Stop recording

Facilitator will go over **ground rules**, e.g. respect, speaking one at a time, no phones on, etc. while the audio check is happening.

Note: During ground rules, note taker should ensure that the recording equipment is working and that everyone is audible.

D. Discussion question guide – (Just a guide – let conversation flow)

Note: Start recording

D FGD Guide

Opening question

1. You are all members of youth clubs that meet either once a month or once every two months. Let's talk about the youth clubs. What happens there?

Probes:

- *What kinds of things are discussed?*
- *What clinical services are rendered?*
- *Do you look forward to support group meetings?*
- *What do you think about the frequency of the meetings?*

Key questions

2. I want you to think back to when you were told that there was going to be a FaceBook group and WhatsApp groups for you to join. What did you think about it?

Probes:

- *Why do you think the groups on FaceBook and WhatsApp were created?*
- *How did you feel about them?*
- *What made you decide to join or not to join the FaceBook and WhatsApp groups?*

3. Some of you have been on the FaceBook group and the WhatsApp group. Let's talk about what happens in those online chats.

Probes:

- *How is it different from the monthly meetings?*
- *If you are still on the online group, what keeps you active?*
- *How comfortable do you feel to discuss personal things on the WhatsApp and FaceBook groups?*
- *If you were in need of information about something would you ask about it on the group? If you needed R20 or if you were feeling sick would you be able to tell group members about it? How do you think they would respond?*
- *If you have left the online group, what made you leave and what would have made you stay?*

4. If the youth clubs disappeared today, how would that affect you?

Probes:

- *How would it affect you if the monthly youth clubs disappeared?*
- *How would it affect you if the online youth clubs disappeared?*
- *What would change in your life personally?*

5. As a young person living with HIV there are certain behaviours that your counsellors, peers and other people in your life encourage you to do and certain behaviours that you have been discouraged from doing. What are some of these and how do you think young people living with HIV decide what to do?

Probes:

- *Risk and protective behaviours – coming to the clinic, taking medication, eating well, exercising, staying in school, using contraception including condoms (give examples of types of contraception), having an older boyfriend, multiple concurrent partnerships, testing and treatment for STIs.*
- *How do young people living with HIV make decisions about their lives – individually, in consultation with family, friends, youth club members, teachers, doctors or other health workers, other community members eg religious leaders.*
- *To what extent does being in a support group and having access to a support group on WhatsApp or FaceBook influence the way young people living with HIV make decisions and the behaviours they engage in?*

Wrap up summary:

If I have understood you correctly you have said that *(summarize the salient points from the discussion).* Have I understood you correctly?

8. Is there anything else you would like to say about the youth clubs?

Appendix B. In-depth Interview Guide

IN DEPTH INTERVIEW GUIDE

A. IDI Preparation Checklist

The following preparations should be completed before each FGD:

- ☐ 1 extra copy of study information sheets
- ☐ 1 extra copy of consent forms
- ☐ 2 copies of audio-recording consent forms
- ☐ Digital audio-recording equipment (tested for working condition)
- ☐ Backup batteries for audio recorder(s)
- ☐ Notebooks for interviewer
- ☐ Private room
- ☐ Food and drinks for interviewee

Name and Signature of Study Staff: _____ *Date:* _____

B. Checklist for Facilitator and Notetaker

The IDI shall only progress once the following are confirmed:

- ☐ Interviewee confirms she is age 18 or older
- ☐ Study ***consent form has been signed*** and ***copy given to interviewee***
- ☐ Study ***assent form has been signed*** and ***copy given to the interviewee***
- ☐ Interviewee has ***signed audio-recording consent form***

Name and Signature of Study Staff: _____ *Date:* _____

C. Introduction Exercise

Note: Start recording

Once the consent process is complete, to build rapport, have the interviewee introduce a little bit about herself without using his/her name, e.g. age, number of siblings and what s/he does for pleasure

Note: Check that recorder is working before proceeding

D. IDI guide

Note: Start recording

1. Can you tell me how long you have been a member of a youth club at Site C Clinic?
    - *When did you start coming to the youth club meetings and why?*

2. What made you decide to join the WhatsApp group or the FaceBook group?
    - Why do you think the online groups were created?
    - *What are the kinds of interactions and/or support did the interviewee expect from the groups?*

3. If the interviewee has participated in both, ask if s/he is still active on both and if s/he prefers one over the other and why.

4. What are some of the things that you've learned from the online youth clubs that have been helpful? What are some things that haven't helped you?

5. How would your life be different if there were no WhatsApp or FaceBook groups that you could participate in outside of the monthly youth club meetings?
    - *Or in what ways is your life different now compared to how it was before you joined the WhatsApp and/or FaceBook groups?*
    - *Are there things that you talk about in your WhatsApp or FaceBook chats that you wouldn't talk about or you don't feel comfortable talking about with anyone else? What are these?*

6. Some people have a lot of contact with other members of their clubs while others have only a little contact. How often do you and other members of groups to which you belong spend time together privately outside of club meetings?
    - *Do youth club members talk to each other privately on WhatsApp? Why or why not?*
    - *Besides being the FaceBook group are you direct FaceBook friends with people from the youth club? Why or why not?*
    - *Do you do things together socially? What kinds of things do you do*

7. As a young person you have many things that you want to do in life and there are also decisions that you make on a daily basis about your life. Let's talk about how you go about making important decisions.
   Probes:
    - *What are some examples of difficult decisions that you have had to make?*
    - *How did you decide what to do?*
    - *Did anyone help you to decide?*
    - *If you had a tough decision to make how comfortable would you feel to talk about it with other youth club members at a monthly face to face meeting? What about on WhatsApp or FaceBook? Why?*

8. What are the kinds of behaviours that you think are important in your life as a young person with HIV that might affect your health and your future as a whole?
   Risk and protective behaviours – coming to the clinic, taking medication, eating well, exercising, staying in school, using contraception including condoms (give examples of contraception), having an older boyfriend.

9. If you told your group members on WhatsApp or FaceBook about something you did or that you were planning to do and they told you that they disagreed with it, how would that make you feel? For example if you told them that you don't want to come to youth club meetings anymore.
    - *How easy would it be for you to do something if you thought that your fellow group club members think negatively about you?*

10. In what ways has being on the WA and/or FB group affected the decisions you make and the way you feel about your behaviour, especially when it comes to behaviour that affects your health?
    - *Confidence to continue on treatment or confidence to start treatment when the time comes*
    - *Decisions to disclose status to significant others*
    - *Confidence to use condoms and other contraception*
    - *Optimism about the future*
    - *Feelings of isolation (not feeling alone)*

11. How do you think the online youth clubs could be improved so that young people living with HIV find them more useful?

If I have understood you correctly you have said that *(summarize the salient points from the discussion).*

12. Have I understood you correctly?

13. Is there anything else you would like to say about the youth clubs?

Appendix C: Interview Guide for Additional In-Depth Interviews

1. Internal resilience

1.1 Would you say that you usually feel like you can control what happens to you in life? Why or why not?

1.3 Do you feel optimistic about your future?

Why or why not?

1.2 Can you think of a time when you faced a difficult situation or challenge? How did you get through it?

2. Sources of instrumental support.

2.1 What do you struggle with most in your day-to-day life?

2.2 Who helps you with your day-to-day problems?

2.3 Do you think other young people in the youth clubs struggle with money for food or to take care of themselves? If so, where do you think they get help?

3. Social comparison, self-construal and positive self-presentation on Facebook

3.1 Aside from the private group on FB, what else do you use Facebook for?

Probes:

What do you normally do when you are on Facebook?

What kinds of things do you like to post on Facebook and why?

What kinds of things do your friends post on Facebook?

3.2 How easy is it for you to be yourself on Facebook and really say whatever is on your mind? Can you give an example?

Probe:

Do you share personal things about what's going on in your life? Why or why not?

3.3 How do your Facebook friends usually respond to your posts?

Is it important for you to get comments and "Likes" on Facebook?

How do your Facebook friends normally react to your posts? How does this make you feel?

How do you think your friends would react if you posted something about a difficult situation you were facing? Why do you think they would react this way?

3.4 Do you personally know all of your friends on Facebook?

Does this have an impact on the things that you are comfortable to post and share on Facebook?

4. Motivators for health behaviour

4.1 The counselors have told you about all the things that you need to do to be healthy. Can you tell me what some of these things are?

4.2 Do you think that you will be able to do all these things to stay healthy for the rest of your life? Why or why not?

4.3 What kind of help or support do you think you would need in order to be happy and healthy?

5. Perceptions about youth club peers – No Facebook or WhatsApp

5.1 Do you wish you could spend more time with your peers from the youth club? Why or why not?

5. Perceptions about youth club peers –Facebook

5.1 Do you wish you could spend more time with your peers from the youth club? Why or why not?

5.2 How has being on the Facebook group affected the way you feel about your peers from the youth club?

Re-cap of discussion to confirm then ask if there is anything he or she would like to add?

[END]

Appendix D: Human Research Ethics Committee (Medical) Clearance Certificate

R14/49 Miss Sandisile Tshuma

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150744

NAME: (Principal Investigator)	Miss Sandisile Tshuma
DEPARTMENT:	School of Public Health Nolungile Clinic, Khayelitsha, Cape Town
PROJECT TITLE:	HIV Positive Young People's Experiences of Particpating in Support Groups on WhatsApp and Facebook and Perceptions of Impact on HIV-Related Behaviours
DATE CONSIDERED:	31/07/2015
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Sara Nieuwoudt

APPROVED BY: Professor P Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 12/10/2015

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004, 10th floor, Senate House/2nd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix E: Research Approval, City of Cape Town, City Health

CITY OF CAPE TOWN
ISIXEKO SASEKAPA
STAD KAAPSTAD

CITY HEALTH

Dr Hélène Visser
Manager: Specialised Health

T: 021 400 3981 F: 021 421 4894 M: 083 298 8718
E: Helene.Visser@capetown.gov.za

2015-11-18

Re: Research Request: HIV positive young people's experiences of participating in support groups on WhatsApp and Facebook and perceptions of impact on HIV-related behaviours (6565) (ID No: 10523)

Dear Mr Hacking,

Your research has been approved as per your research protocol for the Clinic below.

Khayelitsha Sub District:	**Nolungile Youth Centre**
Contact People	Dr V de Azevedo (Sub District Manager)
	Tel: (021) 360-1258/ 083 629 3344
	Mrs S Patel Abrahams (Head: PHC & Programmes)
	Tel: (021) 360-1153/ 084 405 6065

Please note the following:

1. All individual patient information obtained must be kept confidential.
2. Access to the clinics and its patients must be arranged with the relevant Managers such that normal activities are not disrupted.
3. A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 6 months of its completion and feedback must also be given to the clinics involved.
4. Your project has been given an ID Number (10523). Please use this in any future correspondence with us.
5. No monetary incentives to be paid to clients on the City Health premises.

Thank you for your co-operation and please contact me if you require any further information or assistance.

Yours sincerely

DR G H VISSER
MANAGER: SPECIALISED HEALTH

cc. Dr de Azevedo & Mrs Patel Abrahams
Dr Jennings

Appendix F: Study consent forms and information sheets (FGDs and IDIs)

Online Youth Group Study
Participant Information and Consent Form for In-depth interviews

1. Introduction

Good day. My name is Sandisile Tshuma. I am a student from the University of the Witwatersrand in Johannesburg. I would like to invite you to consider volunteering to participate in the above mentioned research study. This study is being conducted as part of my Master's degree in Public Health in collaboration with Médecins Sans Frontières (MSF).

Before volunteering to participate in this study, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, risks, and your right to withdraw from the study at any time.

This information leaflet is to help you decide if you would like to volunteer. You should fully understand what is involved before you agree to take part in this study. If you have any questions, do not hesitate to ask me.

.This consent form may contain words that you do not understand. Please ask me or other study staff to explain any words or information that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

If you agree to take part in this study, we will ask you to sign this form to show that you want to take part. We will give you a copy of this form to keep.

It is important that you understand the following:

- Taking part in this study is completely voluntary.
- You may refuse to take part in this study or leave it at any time. By doing so, you will not lose any benefits you receive now or have a right to receive.
- Your decision to leave this study will not affect the medical care you get now or in the future.
- Your decision will not affect your ability to take part in other research studies.

2. Purpose of the Study

We are inviting you to take part in a research study. This research study is about how young people who participate in the youth clubs at Site C Clinic including the FaceBook and WhatsApp groups provide each other with different kinds of support. It also seeks to understand how the

experience of participating in the FaceBook and WhatsApp groups influences young people, if at all.

This study involves participating in an interview with one interviewer. In this study, we would like to learn more about you, what you think about the FaceBook and WhatsApp groups and the kinds of things you talk about in the groups and how they help you to cope with life, if at all. We are mainly interested in this information because we want to learn how to help you to stay in the program at site C, including staying on treatment if you are already on treatment, coming in for your health assessments and using all the other services available at the clinic that will help you to stay healthy. In particular, the interviewer will be asking you questions about your experiences with the FaceBook and WhatsApp groups.

We are inviting you to take part in this study because you were a participant in the focus group discussions that were held on the same subject and you made some contributions which we would like to explore in more depth so that we can better understand your experiences and views.

3. Length of the Study and Number of Participants

This study is being conducted at Site C Clinic in Khayelitsha. The total amount of time required for your participation in this study is no more than one hour. The interview will take place in a private room and is a one-time event. No other interviews are required.

You will be one of not more than 12 individuals interviewed. All the individuals being interviewed were participants in the group discussions on the same topic.

4. Study Procedures

If you take part in this study, we will ask you to participate in an interview which should take one hour or less. You will be interviewed in English but if there is anything you do not understand or if you would prefer to use your home language there will be someone on hand to assist with this. With your permission, the interview will be audio-recorded so that the interview does not miss anything that you say. The interviewer will ask you a series of questions about the topics already mentioned earlier. Your honest answers to the questions will be used to help us:

- Learn about what kinds of things you talk about in the youth clubs including on FaceBook and WhatsApp
- Learn about what made you choose to take part in the FaceBook or WhatsApp groups and why you have stopped if you no longer use them
- Learn about how you feel about being in the youth clubs including on FaceBook and WhatsApp
- Understand the kinds of relationships you have formed in the youth clubs
- Understand what influences the things you do in life especially with regard to your health

While we hope that you will feel comfortable enough to answer freely, you may skip any questions you don't want to answer.

5. Will any of these Study Procedures Result in Discomfort of Inconvenience?

The interviewer may ask questions or raise issues that are personal and of a sensitive nature that may make you feel uncomfortable or upset. There are no wrong answers in this type of interview. We are interested in your experiences and thoughts. However, you may skip any questions that you don't want to answer or discontinue the interview at any point. There may be other risks and discomforts that are not known at this time.

6. Benefits

You will not benefit directly from taking part in this study. Information gathered from this study may help us learn more about how to improve treatment, care and support services for young people living with HIV at Site C Clinic and in the rest of South Africa.

7. Costs and Reimbursement

There is no cost to you for being part of the study and you will be provided with some money to help you with transport to and from the interview.

8. Right as a Participant in this Study to Refuse to take part

Taking part in the study is your choice. If you decide to take part, you can always change your mind. You can stop taking part at any time.

9. Ethical Approval

- This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (HREC) and written approval has been granted by that committee.
- The study has been structured in accordance with the Declaration of Helsinki (last updated: October 2008), which deals with the recommendations guiding doctors in biomedical research involving human participants. A copy may be obtained from me should you wish to review it.

- This study is sponsored by a foundation called Foresight.

10. Confidentiality

Anything that you share in the interview will be kept confidential in the following ways:

- We will use a code instead of your name for any quotes, which will be transcribed directly from a translated transcription from the audio recording.
- Audio recordings and transcripts of the interview will be stored in locked and/or password protected files and destroyed three years after the study is complete.
- All information obtained during the course of this study, including personal data and research data will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.
- This information will be reviewed by authorised representatives of the study team
- The information might also be inspected by the University of the Witwatersrand, Human Research Ethics Committee (HREC).

11. Sources of Additional Information

If you have any questions about this study, you may contact Ms. Sandisile Tshuma (+27 71 327 3394)

If you have any questions about your rights as a participant, you may contact Prof Peter Cleaton-

Jones at the University of the Witwatersrand, Human Research Ethics Committee: Secretariat

(011 717 1234)

INFORMED CONSENT:

- I hereby confirm that I have been informed by the study staff (_____) about the nature, conduct, benefits and risks of the Online Youth Club Study.
- I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the study.
- I am aware that the results of the study, including any personal details such as those regarding my age and residential area will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system by the researcher or on her behalf.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

PARTICIPANT*:*

Printed Name Signature / Mark or Thumbprint Date and Time

I, _____ herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

STUDY STAFF:

Printed Name Signature Date and Time

TRANSLATOR / OTHER PERSON EXPLAINING INFORMED CONSENT (if applicable):

Printed Name Signature Date and Time

Appendix G. Consent form for audio recording of FGDs

CONSENT FORM- AUDIO RECORDING FOCUS GROUP DISCUSISON

Permission to audio record the focus group discussion

I am aware that the focus group discussion will be tape recorded and transcribed for data analysis purposes.

I understand that these recordings will be preserved for two years after the study results have been published or six years if there is no publication, after which they will be destroyed.

I give permission for my contributions to the focus group discussion to be audio-recorded.

PARTICIPANT:
_____ _____
Printed Name Signature
_____
Date and Time

Appendix H: Consent form for audio recording of In-depth Interviews

CONSENT FORM- AUDIO RECORDING INTERVIEW

Permission to audio record the interview

I am aware that the interview will be tape recorded and transcribed for data analysis purposes.

I understand that these recordings will be preserved for two years after the study results have been published or six years if there is no publication, after which they will be destroyed.

I give permission for my interview with Sandisile Tshuma to be audio-recorded.

PARTICIPANT:

_____ _____

Printed Name Signature

_____

Date and Time