

WhatsApp Peer Groups to Support Youth Living with HIV: Motivations and Functions

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A thesis

submitted in partial fulfillment of the
requirements for the degree of

Master of Public Health

University of Washington

2020

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Program Authorized to Offer Degree:

Department of Global Health

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Abstract

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Young people age 10-24 are disproportionately affected by HIV. Social support has been identified as a factor that can improve HIV outcomes. Access to mobile devices is high worldwide making mobile health (mHealth) interventions a feasible way to provide social support to youth living with HIV (YLWH). This study aims to characterize the unmet needs of YLWH based on the perspectives of youth living with HIV, their caregivers, and healthcare workers (HCWs); to determine the perceived benefits of a WhatsApp group and how it meets the previously identified unmet needs; to observe the content of organically initiated WhatsApp support groups with the goal of comparing content in the groups to what youth, caregivers and HCWs reported. The primary needs of YLWH were related to companionship and emotional support. Youth reported that their current support systems primarily address informational and instrumental support. Participants most frequently identified that WhatsApp groups have the potential to offer companionship support to YLWH. Analysis of WhatsApp group messages are consistent with our findings from interviews, in that the primary type of support given in both groups was companionship support. In summary, WhatsApp groups for YLWH appear to be a way to fill the unmet need of companionship support that YLWH experience.

Specific Aims:

1. To characterize perspectives of youth living with HIV, their caregivers and their healthcare workers (HCW) on unmet needs of youth in HIV care.
2. To determine the benefits and functions of a WhatsApp support group for youth living with HIV, as perceived by youth, HCWs, and caregivers.
3. To observe how two WhatsApp support groups are used by youth and determine congruence between observed use and the needs and benefits identified in Aims 1 and 2.

Background and Significance:

The WHO defines youth as individuals between the ages of 10 and 24.¹ Globally, around 5 million youth are living with HIV (YLWH), the vast majority (85%) in sub-Saharan Africa.^{2;3} Young people are acquiring HIV at an alarming rate: in Kenya, a little more than half (51%) of all new cases of HIV in 2015 among people age 15 and over occurred in young people age 15 to 24.^{4;5} Youth experience worse outcomes than adults at all steps of the cascade of HIV care: fewer know their HIV status, they have greater difficulties accessing care, they have lower ART adherence, they are less likely to be retained in care, they are less likely to be virally suppressed, and they experience higher rates of adverse psychological outcomes and social isolation.⁶⁻¹¹ A number of factors have been shown to contribute to poor youth HIV outcomes, including difficulties with HIV status disclosure, experiences of stigma, logistical challenges with clinical follow-up, and treatment adherence as major challenges associated with their HIV status.^{6;7}

Social support has been identified as a factor that improves adherence to ART, retention in HIV care, linkage to HIV services, understanding of one's HIV diagnosis, HIV disclosure, psychological health, and ability to live a healthy life despite one's HIV status.^{8;12-15} Social support is conceptualized as having multiple domains; for this study we are using four: emotional, instrumental, informational, and companionship.^{8;14;15} Emotional support encompasses encouragement, acceptance, and reassurance; instrumental support involves receiving something tangible to reduce barriers such as appointment reminders or help with transportation to attend appointments; informational support includes knowledge, advice, or guidance; and companionship support is defined as belonging, leisure, and distraction.^{8;14;15} A qualitative study with newly diagnosed YLWH found that youth reported receiving social support from a combination of formal (health care staff) and informal sources (family, peers, significant others) and that this support was identified as a factor in improving their health and wellbeing.⁸

One method to reach young people is through mobile health (mHealth) interventions, broadly defined as the use of mobile technology to deliver health services. mHealth interventions have been shown to be useful in a variety of contexts and for a multitude of health issues.^{5;11;16-21} Mobile phones have become globally ubiquitous, making mHealth

interventions feasible strategies to reach youth internationally. A 2019 study on global mobile phone ownership found that 88% of people age 18-34 in Kenya owned a mobile phone.²² A global report on digital technology use and access showed that 45% of the entire global population are active social media users and youth ages 13-24 represent around 34% of users.²³ Several mHealth interventions have been shown to improve virologic suppression among youth and adults living with HIV.^{5;11;16;18-21} In addition, a systematic review conducted in 2018 (of studies mostly conducted in high-income settings) found that youth perceived mental health interventions delivered over social media to be beneficial, engaging, and easy to use.¹⁷ Interventions delivered via mobile technology may present a targeted way to reach youth with health information and support.

Starting in 2014, YLWH at two health clinics in Nairobi started informal support groups via WhatsApp. WhatsApp is a free mobile social media application that allows groups of people to communicate by voice or text messages using mobile phone data. Creation of these youth-developed support groups suggests that YLWH have unmet needs that peer social support may fill, and that the mobile application WhatsApp is a viable method to address them. The Vijana-SMART study aimed to develop a formalized WhatsApp support group that integrates peer and healthcare worker (HCW) support, inspired by these youth formed WhatsApp groups.

In this paper, we analyze formative data from the Vijana-SMART study characterizing YLWH's needs and their use of organically created WhatsApp groups. We explore what YLWH, caregivers, and HCWs identify as gaps in care for YLWH and, based on interview responses from HCWs, caregivers, and YLWH, as well as WhatsApp messages from organic, youth-led support groups, determine whether and how a WhatsApp peer support group might address the identified gaps.

Methods:

STUDY PARTICIPANTS

Data sources are summarized in Table 1. Three types of qualitative data were collected: in-depth individual interviews (IDIs), focus group discussions (FGDs), and messages from two organic, youth-led WhatsApp groups. Data were collected at three Nairobi hospitals, two with existing WhatsApp groups (Sites 1 and 2), and one without a WhatsApp group (Site 3).

IDIs were conducted with YLWH who were members and non-members of the organic, youth-led WhatsApp groups at Sites 1 and 2. Eligible participants were YLWH who were aware of their HIV status, had access to WhatsApp, and were age 14-24.

Following the IDIs, the study team developed prototype content for the standardized Vijana-SMART intervention and conducted a round of FGDs with YLWH and HCWs at Site 3, and caregivers of YLWH at Sites 1, 2 and 3. YLWH were eligible to participate in FGDs if they were aware of their status, had access to WhatsApp, were between the ages of 14 and 24, and were not currently involved in a WhatsApp support group. Eligible HCWs were age ≥ 18 and involved

in the care of YLWH. Eligible caregivers were age ≥ 18 and the primary caregiver of a YLWH. YLWH FGDs were stratified by age (<18 vs. ≥ 18) and gender (male participants only, female only, and mixed gender).

DATA COLLECTION

FGDs and IDIs:

Participants were purposively recruited through in-person outreach at each of the healthcare facilities. Participants provided written informed consent to participate and to be audio-recorded. Caregiver permission was obtained from adolescents age <18 who were not emancipated by marriage, pregnancy or parenthood in accordance with Kenyan regulations, and whose caregiver was attending the clinic with them. IDIs and FGDs took place in private rooms at the healthcare facility at which participants were recruited. They were conducted by trained qualitative interviewers who were fluent in both English and Kiswahili. All IDIs and FGDs were audio-recorded, transcribed and translated into English.

WhatsApp chats:

Researchers gained permission to join existing organic, youth-led WhatsApp groups at Sites 1 and 2 for six weeks. Because of the large size of these WhatsApp groups (up to 256 participants), obtaining individual informed consent from all group members was not feasible. The following process was therefore completed: 1) youth administrators of the organic WhatsApp groups were approached to request permission to join the group for a 6-week period and encouraged to consult other members of the groups, 2) the administrators of the organic WhatsApp groups provided written informed consent. Prior to the 6-week observation period, an announcement of the upcoming observation was sent to the WhatsApp group to allow members time to reach out to the study with questions or concerns before the study joined. During the 6 weeks of observation, the study account sent no messages to the group. At the end of the 6-week period, all chats were downloaded, and the study left the group. All identifying information such as phone numbers and names were permanently deleted from the messages and the messages were stored on a secure server.

ETHICAL APPROVAL

Ethical approval was obtained from the University of Washington and University of Nairobi / Kenyatta National Hospital institutional review boards.

CONCEPTUAL FRAMEWORK

Social support theory was used in developing the research study intervention and guided coding and analysis of data in this analysis.⁸ The conceptual model for the Vijana-SMART study (figure 1) holds that interactions with peers and a HCW facilitator via WhatsApp will bolster the four domains of social support: instrumental, informational, companionship, and emotional support, leading to improved HIV treatment outcomes by improving intermediate psychosocial outcomes (increased motivation and reduced depression).

DATA ANALYSIS

The goal of this analysis was to characterize the needs and challenges faced by YLWH, understand their current support systems, and determine how a WhatsApp support group for YLWH could address the gaps in care. FGD and IDI transcripts were uploaded into Dedoose²⁴ and WhatsApp messages were organized into a spreadsheet with one message per row. A phenomenological approach was used to develop codes for thematic analysis. A code book was developed using a combination of inductive development by the first author (EH) from the text,²⁵ and structural codes for each domain of social support (Figure 1).

The coding process for IDIs and FGDs occurred as follows: 1) the first and senior authors (EH and KR) developed a codebook to address the above aims; 2) consensus coding was performed by EH and KR to ensure agreement in application of the codebook ; 3) transcripts were coded by EH, KR, AM; 4) coded excerpts were organized and synthesized into thematic memos.

Content analysis of WhatsApp messages was conducted to identify alignment between the ways participants were observed to use the organic, youth-led WhatsApp groups and the ways participants described their potential utility in IDIs and FGDs. Social Support theory was used to guide the analysis and new codes were developed deductively through reviewing the group chat text. The Social Support codes and codes to describe the topics discussed in the organic, youth-led WhatsApp groups (content codes) were the same for the WhatsApp chats and the IDIs and FGDs. Codes were assigned to each WhatsApp message and the number of times each social support domain occurred was summed. WhatsApp messages were double-coded by two authors who met to determine coding agreement (EH, AL).

Results:

Thirty-five interviews were conducted with YLWH. A total of 11 FGD were collected: 6 with YLWH, 2 with HCWs, and 3 with caregivers of YLWH. Table 1 summarizes the data collected and Table 2 summarizes participant characteristics in each dataset.

Results have been organized into four sections: needs and challenges experienced by YLWH; current support systems YLWH have to overcome their challenges; WhatsApp group structure and functions through which YLWH can provide support; and observations of support provided in WhatsApp groups. In each section, the results will reference the four domains of social support (companionship, emotional, instrumental, and informational), and highlight which of the domains were the most prevalent. Figure 2 depicts the associations between the findings and the domains of social support.

I: Needs & Challenges:

Youth, caregivers and HCWs discussed challenges YLWH experience, often in the context of how a WhatsApp group could meet YLWH's needs. Some challenges raised by participants were uniquely related to having HIV, others were associated with adolescence independent of

HIV status, many were related to the intersection of the two. Challenges faced by YLWH represented all domains of social support: companionship, emotional, instrumental, and informational. Companionship and emotional support emerged as more prominent needs than those related to access to information or instrumental support.

Lack of companionship support

Stigmatization and discrimination were frequently discussed by youth, HCWs, and caregivers as challenges faced by YLWH. Participants discussed YLWH's fear of disclosing their status due to potential abandonment or rejection in friendships or romantic relationships.

"I used Facebook Messenger to say hi to a guy. It made us to start chatting so after a while he organized for us to meet. We went for supper [and I] told him I'm HIV positive...he was so shocked, he said we can't be friends."

-IDI with youth current-member, site 2, female, age 19

"In my school we have challenges... you know girls when they find something or hear something it will, in one way or another, get to everybody. So, if they find out that you are sick everybody in school is going to know, everybody in school is going to know you and you are going to be secluded."

-IDI with youth current-member, site 2, female, age 16

Fear of stigma and rejection was cited by youth, caregivers, and HCWs as impacting youth's ability to adhere to their medications. Participants discussed youth's fear of disclosure if peers saw them taking their medications, noting that this impaired their adherence.

"You can be afraid of taking the medicine because you can go out with friends and then your time for taking the medicine comes. Right there, you can be afraid of telling them, 'Let me go back home. There is something I want to do.' They will discourage you."

-FGD with youth non-member, site 3, female, age 18

"As this child grows and goes away to school there might be instances where the child wants to take the drugs but then another child spots him and goes telling others or asks what the drugs are meant for, that can discourage the child."

-FGD with caregivers, site 1, female, age 50

Many youth and some caregivers and HCWs discussed the impact of social isolation due to youth's HIV status.

"...Now many people do not know that I use the medicines [ART] apart from the manager and teachers. For students, none of them knows... I choose not to tell them because like on our school, I am the only one who uses the medicines [ART]. If I tell them, they will isolate me."

-FGD with youth non-member, site 3, female, age 17

“There is a challenge that [YLWH] go through because it is like some feel that they are alone, like mine sometimes ask why the other sibling is not on medication yet he is taking. So I see it challenges him a lot because of the condition.”

-FGD with caregiver, site 2, female, age 37

Lack of emotional support

Mental health challenges were frequently discussed by youth, HCWs, and caregivers, often interwoven with other challenges such as social isolation and ART adherence. The most common mental health challenge discussed by youth was a feeling of hopelessness due to their HIV status. In addition, participants said that youth faced challenges with depression, stress, and low self-esteem. Some youth expressed that YLWH need emotional support.

“I think a lot of people are going through emotional challenges. Some of them are under depression, some of them have not accepted who they are or their status.”

-IDI with youth non-member, site 1, female, age 19

“[Youth] may have lost hope, they are not attending school because they have HIV and they think they are dying the following day...”

-FGD with HCWs, site 3, female, age 36

Often the challenge of adhering to HIV medication was interwoven with emotional struggles faced by youth. Some youth said that they experienced a loss of hope due to their HIV status and stopped taking their medications as a result, or that they felt alone in their HIV status and thus had trouble adhering.

“There is a debate that we had in school that those people that have this AIDS, they can’t live. So I said I have this disease and I know I can’t live. Why should I drink this medicine? So like for one term I said I will not drink [my medicine].”

-IDI with youth current-member, site 2, female, age 14

Lack of informational support

We did not identify information as an unmet need without prompting. However, when asked what should be discussed in the WhatsApp groups, youth wanted information about navigating a partnership with someone who is negative, whether YLWH could marry, the possibility of having an uninfected child, and methods to prevent onward HIV transmission. In addition, some youth expressed confusion about ART medications and their side-effects as well as what behaviors they could safely engage in given their HIV infection. These results will be discussed more below in the section on WhatsApp Function.

Lack of instrumental support

Similar to informational support, youth infrequently identified instrumental support needs without prompting by the interviewer. However, when asked how the WhatsApp group could provide support, youth, HCWs and caregivers described poverty as a material challenge faced by YLWH. Increased access to employment opportunities was mentioned as a desired component of a WhatsApp support group, and lack of financial resources was discussed as a

barrier to participating in a WhatsApp group. Some participants identified remembering to take medication as a challenge and suggested the WhatsApp group should help youth remember to take their medications. These results, again, will be discussed more below in the section on WhatsApp function.

II: Current Support Systems:

Participants discussed ways that many of the informational and instrumental needs identified were addressed by relatives, caregivers, and HCWs. While friends and in-person support groups offered some companionship support, fear of stigma and discrimination led to youth feeling isolated from these sources of support. In-person support groups were presented as offering punctuated companionship support for youth, but left significant unmet need between meetings.

Companionship support:

Youth and occasionally HCWs and caregivers named friends and in-person support groups as two sources of companionship support. These two sources were often interwoven in that it was unclear if friends youth were referring to were from in-person support groups or from other parts of their lives. Companionship support was the most common type of social support that youth, HCWs, and caregivers identified being provided by friends and in-person support groups. Participants discussed friends and peers providing a place for youth to share challenges, helping youth realize they are not alone in their diagnosis or problems, and being a source of fun.

"Youth Days. They really help. Because... the same youth come together, they like doing activities together and share. They really help."

-IDI with non-member, site 1, female, age 19

"...The [support] group proved to him that he was not the only person affected because they were many..."

-FGD with caregivers, site 1, male, age 50

Emotional support:

When youth were asked about their current support systems, some youth expressed that their caregivers and other relatives provided emotional support. This support was often described as encouragement to continue to adhere to their ART and motivation to not lose hope due to their HIV status.

"[My sister] worries about me and checks on me."

-IDI with youth non-member, site 1, male, age 19

"[My mom] tells me, 'You see those people that you see at the hospital, they are many who have that disease. They can make it, even you can make it. Even me, I knew I had this disease since when I was in form four...'"

-IDI with youth current-member, site 2, female, age 14

Informational support:

Some caregivers and HCWs identified HCWs as sources of support for youth, primarily by providing informational support through education on matters related to HIV such as adherence, disclosure, and safe sex.

"I get some information from the doctors and maybe from reading from books"

-IDI with youth non-member, site 2, male, age 18

"When [youth] come [to clinic] at least they are taught about that [sex], you [HCWs] can teach them what we [caregivers] may not be able to."

-FGD with caregivers, site 2, female, age 37

Caregivers also identified that they themselves were sources of informational support for YLWH.

"We can assist these youths especially the adolescents, we must explain to them about their adolescent age - how it's a bit sensitive - and we educate them of the consequences they face because of their status. For our daughters who we are still living with, we usually tell them that once you have unprotected sex then the outcomes are either, one, you get pregnant or two you get some disease. So, if you know that you must have sex then you must be protected."

-FGD with caregivers, site 1, female, age 50

Instrumental support:

One of the most commonly identified sources of instrumental support was family members, especially parents or caregivers, but also siblings and aunts. YLWH primarily described receiving instrumental support in the form of medication reminders or helping youth attend clinic appointments. Caregivers described the instrumental ways in which they supported their youth, such as making nutritious meals and helping their youth with ART adherence through medication reminders.

"When I feel sick, s/he [relatives] can take me to the nearby hospital."

-IDI with youth non-member, site 2, female, age 14

"She [mom] reminds me to take the drugs, the importance of the drugs."

-IDI with youth current-member, site 2, female, age 17

III: WhatsApp Function & Structure:

Youth, caregivers, and HCWs were asked how the WhatsApp group should function and be structured. Participants described the type of content that should be provided in the group, as well as how it should be structured to best support YLWH and meet their needs.

FUNCTIONS:

The proposed and current functions of the WhatsApp group for YLWH reflected each of the four domains of social support (companionship, emotional, instrumental, and informational), as well as combinations of these domains. Additionally, behavioral modeling, a related construct that is not typically viewed as a domain of social support, was highlighted.

Companionship Support:

Most commonly, WhatsApp groups were viewed as *virtual* venues for YLWH to build friendships and community. Youth, caregivers and HCWs frequently highlighted that a WhatsApp group would enable YLWH to talk about their problems and see that they are not alone in their challenges.

"Maybe you can send messages to find out how others are doing. Secondly, they can share what they are going through. That way you will feel its normal when find out you are both going through the same thing."

-FGD with youth non-member, site 3, female, age 22

"It [WhatsApp group] will help a lot as he will find out he is not alone; he will be encouraged that there are others going through the same."

-FGD with caregivers, site 2, female, age 35

Many youth said that they would like to have other HIV-positive friends, or that they joined the group so that they could socialize with other youth living with HIV. Participants mentioned isolation and a desire for friendship and people to do activities with. Youth, HCWs, and caregivers all stated that group members should not only chat via WhatsApp, but also arrange times to meet in-person. A few youth and HCW participants felt WhatsApp groups could provide opportunities for members to meet romantic partners.

"It [WhatsApp] can also help you socialize with other positive children"

-IDI with youth non-member, site 1, male, age 15

"I am just afraid of dating, I don't date...I need someone [to date], so those are [my] challenges, so this doctor can handle such challenges [for] me because he can then tell me you need to move on with life ... "You need to have family, you need to have your own generation and this is the method, to start here to move to each step." So, [the WhatsApp group] will help because you will find that you are afraid of none and when you find yourself ah I can do these things."

-FGD with youth non-member, site 3, male, age 23

"I think also it will be a very important platform for them to mingle. And maybe meet-ups for them. I think it is inclusive of both sexes, so it will help them in so many ways. Not only on adherence and all that... some of them maybe meet up from the same [WhatsApp] group [R3: (Whispering) they can get better halves!]."

-FGD with HCW, site 3, female, age 42

Many current members of organically developed WhatsApp groups identified that the group provided companionship support in the ways that non-members, HCWs, and caregivers proposed it should. Youth in the organic WhatsApp groups said that the group reminded them that they were not alone in their HIV-related challenges. However, they also emphasized the groups' role in facilitating social connection and discussions that did not center on having HIV. Many participants said they had made friends with other YLWH through the organic WhatsApp group. Some current members additionally reported that they had met with other group members in-person after building a connection through the group.

"It is a reminder for me... that I'm not alone in this journey, that we are many and we are going through. Because basically before the formation of the group... I was out of Nairobi. I will not be meeting all these people and whenever I meet them it was once in a while. So, it was like to hell who needs the drugs when I'm all alone? Because there was nobody else understanding my situation. But the group acts as a reminder for any problem that we all have, and we face it together."

-IDI with youth current-member, site 1, male, age 24

"I was just looking for a company of someone like me. Someone we can talk about the same thing. You know, not many friends are like you [positive], they are different in the line of what we are talking about [negative]. So, I was looking for people we can start a conversation. You know sometimes you have very many friends, but they do not know about you, and if you tell them about yourself, they may abandon or isolate you. So, I wanted to find some friends who we can talk freely and tell them about what is challenging me."

-IDI with youth current-member, site 2, female, age 22

Emotional Support:

Youth, HCWs, and caregivers frequently proposed that WhatsApp groups should be sources of emotional support for YLWH and provide them with hope and encouragement. Youth wanted the group to motivate those who may be losing hope to continue to live, and to uplift youth to improve their self-confidence. Emotional support provided through addressing mental health issues such as depression, loss of hope, or low self-esteem was discussed more frequently among non-members than members of existing groups. Most of the participants (both members and non-members) said that messages to the group should be encouraging and hopeful, though details on content that would achieve this were rarely provided.

"At least something encouraging, something that can uplift the person, not feel down..."

-IDI with youth non-member, site 2, male, age 17

"You know, this group has been formed to motivate others, so the messages should be motivational. So, they should encourage someone to know that even if one is positive, they should not give up; they can take drugs, be healthy and achieve their goals. That can help because that is the reason we are forming the group."

-FGD with youth non-member, site 3, female, age 22

“When the health workers are there [in the WhatsApp group], maybe [the youth] feel motivated. They feel that maybe people are there for us, they care for us...they feel motivated that the health care workers are there and they assist them in everything, so they get hope to live.”

-FGD with HCW, site 3, female, age 28

Members of existing groups said that encouraging messages were often sent to the group. Some members reported that the group had improved their self-esteem or given them the hope to continue living.

“In [the] WhatsApp group there are many people, so when you get an encouragement from one person another one comes with another one, so when you put all of this together you realize that truly these things are helping me... So, for me being in that group is very helpful and my fellow youths should join the group”

-IDI with youth current-member, site 2, female, age 14

“Let us say, my self- esteem was low. So, when I joined the group, I started attending those youth days, I felt at least lifted.”

-IDI with youth current-member, site 1, female, age 21

Informational Support:

Participants discussed the ways that WhatsApp groups could provide informational support, but these responses were provided less organically than those reflecting other social support domains. Direct questions and probing from the interviewer prompted youth to describe the informational support they could receive from a WhatsApp group, in particular when asked about the role HCWs could play in a WhatsApp groups. Youth and HCWs expressed that the primary role of a HCW in the group should be answer questions that youth are unable to answer and provide medical advice.

“[A HCW] will help because not all members in the group have knowledge but this is someone who has studied about this specific healthcare. Because that person who is a doctor will just advise, he will just send one message but you will find all the people in the group benefiting.”

-FGD with youth non-member, site 3, male, age 23

When youth were prompted for topics they wanted information about, youth expressed interest in learning about general healthcare, HIV treatment and prevention, ART medications and side-effects, and dating/relationships.

“I can ask questions on general health not just only about HIV. Questions on general health like when one is injured.”

-FGD with youth non-member, site 3, male, age 18

“According to me, when you have... medication side effects... you can just send it [to the WhatsApp group]. Maybe you have missed the drugs, what are you going to do?”

-FGD with youth non-member, site 3, male, age 23

“Some questions [for the WhatsApp group] can be based on... let’s say you... get pregnant and then people start advising you against [breastfeeding]... Maybe this person does not have that knowledge on how to [have] an HIV negative child... That expert who has that experience... will explain to you on how to go about it so that the child is not affected.”

-FGD with youth non-member, site 3, male, age 24

Current members of the organic, youth-led WhatsApp groups rarely referenced receiving informational support from the group, but when they did it was about HCWs in the group providing medical advice and information to group members.

“In case if one [group member] has an issue with maybe the drugs or the side effects, [the counselor in the group] chips in by giving us some advice on the way forward.”

-IDI with youth current-member, site 1, male, age 24

Instrumental Support:

Instrumental support was the least frequently referenced domain of support mentioned on its own. When referencing instrumental support, youth and caregivers most commonly talked about the WhatsApp group being a reminder to adhere to ART.

“...There are days we have many messages and there are days people are just dormant. However, mostly, the messages are about reminding each other... the time to take medication”

-IDI with youth current-member, site 1, male, age 23

“I used to forget [to take ARVs]. So, we had drug buddies... those of us who take medication at 10, those [at] 6... They would remind you time to take medication, so you would find that it’s time and it is true you had forgotten. So, it assisted me.”

-IDI with youth current-member, site 1, female, age 23

Some youth who were not members of the existing groups and HCWs expressed that the group could provide financial support through integrating a savings and loan group into the WhatsApp support group, though respondents did not provide specific proposals for economic gain.

“I would like to send messages maybe to know if my friends or those other guys are okay, have they taken their drugs and even to remind them.”

-FGD with youth non-member, site 3, male, age 18

“Again, I think we can use this platform for them for economical gain for the above 18 years of age. They can form their groups and make something which can help them economically because at that age, probably they have people to support, they have their own needs. I think... they can come up with ideas on how they can support themselves, economically.”

-FGD with HCW, site 3, male, age 30

Combined Social Support:

Youth frequently discussed WhatsApp messaging content that could provide multiple domains of social support simultaneously. Youth often combined concepts of emotional and companionship support when identifying the functions of the WhatsApp groups. For instance, youth and HCWs suggested that members of the WhatsApp groups should send messages to check on and motivate other members. This demonstrates companionship because group members are part of a community where they may send messages to ensure others are doing well, and emotional support through the provision of motivation. Some youth said that encouragement and motivation from other members could help them adhere. Many respondents did not provide specific examples of how the group should motivate or encourage youth.

"You know sometimes... you are stressed, you are asking yourself, "Why me?" So, when you get courage from others, you are motivated to continue taking the drugs."

-IDI with youth non-member, site 2, female, age 18

The suggestion that WhatsApp groups should feature job listings to potentially help youth financially can be viewed as both informational and instrumental support because it involves youth sharing information about job openings that could help unemployed YLWH find a job. Finally, many youth expressed that the group should be a place where youth can share their problems and get advice from other YLWH or work together to find a solution. YLWH sharing similar challenges and working together to find solutions is an example of companionship and informational support.

"Like in this groups there could be someone who is employed somewhere and then they may see that this other person is qualified and there is a vacancy there, in the process of interaction they can connect the other person to employment."

-IDI with youth non-member, site 2, male, age 19

Like the proposed functions of the WhatsApp groups, members of existing groups confirmed that organic WhatsApp group members sent messages to check-in on other members who were struggling, offering both emotional and companionship support. In addition, current members said that group members shared challenges and provided advice to each other, offering both companionship and informational support.

"I remember this time a certain lady posted to the group saying that that she was depressed basically because she had been sick for a while and during that time I was also sick so I had to inbox her and tell her that all is well you are not alone in this world, all you have to do is to be strong and if not [for] you, do it for your family and everyone around you. There is much to live for."

-IDI with youth current-member, site 2, female, age 22

“The group helped me out and my viral load was about 1000, now its undetectable, yeah. I managed to follow some advices from the friends there, talked to some people privately and they gave me advice”

-IDI with youth current-member, site 1, female age 24

Behavioral Modeling:

Behavioral modeling, the idea that youth could learn from other youth by observing their actions, was discussed by several participants. For instance, youth, HCWs, and caregivers all felt that groups should include members with a mixture of ART history so that youth newer to ART could learn from those who had been adherent for a long time. Behavior modeling extended beyond just ART adherence. Some participants, youth, HCWs, and caregivers, felt that youth may feel encouraged and their hope would be renewed by seeing other YLWH living well despite dealing with similar challenges.

“You can consider [youth] who had stopped the drugs, you mix them with those who started so that they can motivate them not to stop taking the drugs and things like that. Because they had also stopped and they suffered [from illness].”

-IDI with youth non-member, site 2, female, age 18

“Those who started long time ago can set good example for those who have started late to emulate. For example, let us say you started using the drugs long time ago, you are very healthy. So, you can show the one who started late that, ‘I started long time ago and as you can see, I am healthy.’”

-FGD with youth non-member, site 3, female, age 16

Some current members reported that being around other YLWH who were adhering or living well despite their status helped them maintain hope or encouraged them to take care of themselves.

“Sometimes it is fun being there, you find that people are so positive, and this kind of thing motivates you to be like, if they are doing it, why can’t I do it?”

-IDI with youth current-member, site 2, female, age 19

“Yeah it has helped me to adhere to my treatment... because when you see... these are people... the same situation as me. So it will also act like a reminder whereby you’ll not want for yourself to be on a hospital bed as your friends are there enjoying life. So it motivates you to keep taking your drugs”

-IDI with youth current-member, site 1, male, age 24

STRUCTURE:

Youth, caregivers, and HCWs had generally similar ideas about membership composition of a WhatsApp group for YLWH. Consistently participants expressed that the groups should be

composed of only YLWH, of similar ages, a gender mix, and a mixed ART history. While some youth suggested the number of members in a WhatsApp group, suggestions were highly variable. Some youth wanted no limit on the number of group members, while other youth preferred smaller groups.

“There should be no limit. Just give them space so that anyone who wants to join can join as long as they share the same situation with us [i.e. are a youth living with HIV]. Those in similar situation and they want to join can do so.”

-FGD with youth non-member, site 3, male, age 18

“[Ages] 18-24 can be able to understand each other and then another thing, the gender should be mixed”

-IDI with youth non-member, site 2, female, age 18

Youth, HCWs, and caregivers agreed that caregivers should not be included in the WhatsApp groups.

“No, surely [caregivers] should not even be involved coz no one will talk.”

-IDI with youth current-member, site 2, female, age 17

“Our children have challenges that they would wish to share amongst themselves... When they are alone, I think they will be free to share their challenges.”

-FGD with caregivers, site 2, female, age 37

“I also think when you involve the parent, maybe the older teens, the 17 the 18... the 18 won't be free... they will shy off because they know their parents are there and they will be able to access whatever they are chatting.”

-FGD with HCWs, site 3, female, age 40

Respondents were more supportive of HCWs being involved in the WhatsApp groups, but expressed varied ideas on the role they should play. Many of the current WhatsApp members felt that the groups should be owned and operated by youth themselves, and that HCWs should not facilitate or administrate the groups. Current members said that existing organic, youth-led WhatsApp groups did have members who were HCWs to provide medical advice, but not facilitate. Some HCWs agreed that the group should not be run by HCWs; others felt HCWs should be involved on the grounds that they could provide expert advice. Youth who were not currently members of a WhatsApp group were more likely than those who were members of a WhatsApp group to recommend that a healthcare expert should be in the group and lead it.

“If that doctor is willing to answer the questions that he/she will be asked, or being there to guide or to motivate it can just be okay. And also, he/she [should be] open with people, then know how to socialize.”

-IDI with youth current-member, site 1, female, age 21

“Yeah, when you have a health care worker [in the group] and [youth] have some symptoms they can’t understand... they are free to ask, and they will be given the answer right away.”

-FGD with HCWs, site 3, female, age 28

Youth generally felt that the conversation should be unstructured and allow group members to send messages freely about topics of interest to them. Many of the youth were open to the idea of a facilitator sending questions and topics to guide discussion, but that youth should not be limited in the number or type of messages they can send.

“If you put it like on these days, we discuss these topics, there is somebody who has something else on that day, you are limiting that person. You are telling them keep it to yourself.”

-IDI with youth current-member, site 2, female, age 16

Youth were asked to suggest rules and expectations of group members and how the group should function. The two main expectations were that members keep other members’ information and messages confidential and that all members be active participants by sending messages.

“People should be secretive and that whatever people share in the group, it should not get to other parties.”

-FGD with youth non-member, site 3, female, age 15

Many interview and focus-group participants discussed WhatsApp’s individual direct messaging capability and instances that members may message individual members rather than the group: either to get to know an individual group member better or to send questions to the HCW facilitator privately. Messaging individual members was a more common theme among youth currently in the organic, youth-led WhatsApp groups, and many provided examples of direct messaging that currently occurs in the WhatsApp groups. HCWs and non-member youth more frequently talked about the potential for group members to directly message the HCW than current members did.

“Things that concern all of us you send in the [WhatsApp] group and that which is personal can inbox [the HCW].”

-FGD with youth non-member, site 3, male, age 18

IV: WhatsApp Content Analysis:

The third Aim of this study was addressed by conducting content analysis of the chats from the two organic, youth-led WhatsApp groups. In the content analysis, we looked at the domains of social support that occurred most frequently, as well as the content discussed by

members. We then compared the findings from the content analysis to the themes that emerged from Aims 1 and 2.

Characteristics of the two organic, youth-led WhatsApp groups analyzed are summarized in Table 2. Group 1 had fewer members than Group 2 (60 members compared to 256 members), but approximately twice as many messages were exchanged during the 6-week observation period in Group 1 vs. Group 2. Both of the WhatsApp groups were developed by youth at their respective clinics: group 1 at site 1 and group 2 at site 2. Neither of the groups had external funding.

Despite differences in group size and number of messages exchanged in the two organic WhatsApp groups, the content of messages sent was very similar between groups.

Table 3 summarizes the number of WhatsApp messages sent in each group, classified by social support domain. Similar to the findings from the interview and focus-group analysis, companionship support was the most common support domain demonstrated in WhatsApp messages. In both groups, messages conveying companionship support were observed at least three times as often as the other domains of social support. Messages conveying emotional, informational and instrumental support were observed at similar frequencies. Many messages were coded as displaying multiple support domains.

Table 4 classifies the messages sent by topic. The most common messages sent were greetings (“hello”, “good morning”, “how are you”, and “goodnight”). These messages were coded as companionship support and accounted for many of the messages coded in this category in Table 4. Jokes and requests to meet were also common messages conveying companionship support.

Group 2 sent fewer messages pertaining to HIV and ART than Group 1, and sent more messages related to leisure topics such as music, politics, faith and sports. Group 2 members regularly sent ART reminders (coded as ART in Table 4 and instrumental support in Table 2). Healthcare messages included requests for nutritional advice or how to prevent common illnesses (coded as informational support in Table 4). The messages about healthcare were often distinct from HIV related posts, but were sometimes coded in tandem if members talked about general health concerns but referenced HIV or ART. In both sites, group members shared information about employment or funding opportunities that group members could apply to (informational and instrumental support).

Overall, the content analysis demonstrated similar themes to those discussed in interviews and focus-groups. Youth primarily used the organic, youth-led WhatsApp group to socialize and interact with other YLWH, sending greetings and jokes, and arranging to meet up in person. In addition, youth provided each other with emotional, instrumental and informational support—but these instances were much less frequent. Aside from the ART reminders shared in Group 1, most of the informational and instrumental support shared by members was related to common experiences of adolescent development rather than specific

to the experience of having HIV. Group 2 members' instrumental support content focused more on finding employment and providing healthcare information than discussing HIV and adherence.

Discussion:

This qualitative study explored challenges faced by YLWH from the perspectives of youths, HCWs, and caregivers and determine the ways in which a WhatsApp support group for YLWH could address the challenges not being met by other YLWH's other support systems. In addition, we aimed to organize YLWH's challenges and the potential functions of a WhatsApp support group into the four domains of social support: companionship, emotional, instrumental, and informational. We found that the main needs of YLWH were related to companionship and emotional support, but their current support systems primarily provided informational and instrumental support. Our interviews and WhatsApp chats, suggest that a WhatsApp support group for YLWH could address youths' unmet need for companionship support.

While some gaps in informational and instrumental support were identified, the primary gaps in social support faced by YLWH were in companionship and emotional support. These gaps often presented themselves in the form of social isolation and loss of hope experienced by YLWH. From the interviews, it appeared that many YLWH had difficulties with ART adherence due to feelings of hopelessness and lacking a social community. YLWH current in-person support systems often failed to meet youth's emotional and companionship support needs, and rather addressed their instrumental and informational needs, focusing on ART status and adherence behaviors. Interestingly, even when caregivers reported providing emotional support, they often described the instrumental ways in which they cared for their YLWH, including providing meals and reminding them to take their medication.

"The first thing is love, the child should be loved and know that he his loved, you show love by making sure the child is well fed by enough food. The second aspect is to remind the child about his medication by reminding him that you too you are on medication. You have to tell the child the importance of the drugs to him as a person, tell the child that medication will help him to get education which in turn might secure him a job that will help him in the future when you are gone."

-FGD with caregivers, site 1, male, age 50

This focus may only reinforce youth perceptions of being "other." In the IDIs and FGDs with youth, some youth explicitly stated that a WhatsApp group should not solely focus on topics related to HIV. These youth often requested that the groups engage in activities and should be a place for fun. This was also mirrored through the WhatsApp content analysis, in that many of the messages were not related to HIV and instead demonstrated youth trying to have fun together through jokes and in-person meet-ups. YLWH frequently receive medical related to their HIV status, and virtual connection with other YLWH through WhatsApp groups

may offer an opportunity for youth to socialize and move beyond their status without fearing stigma.

“It should be fun; we should not talk about HIV issues all the time, we should have events and community work”

-IDI with youth current member, site 2, female, age 17

“Okay, for me, I think in the group, we should not [focus] on our status. That is like self-pity. In those groups, we should be engaging in activities”

-IDI with youth current member, site 1, male, age 23

Though friends and in-person support groups offered some companionship support, fear of stigma and discrimination led to youth feeling isolated. In-person support groups were presented as offering punctuated companionship support for youth, leaving significant unmet need. Participants suggested that virtual WhatsApp groups could be used to fill the gap and provide companionship support and a sense of community with other YLWH more frequently than in-person meetings.

Our findings from the content analysis were consistent with what youth, caregivers, and HCWs reported from the IDIs and FGDs. The content analysis demonstrated that members most frequently sent messages that provided companionship support. Many of the messages sent were greetings, jokes, encouragement, and youth trying to organize opportunities to see each other in person. In the IDIs and FGDs youth, caregivers, and HCWs identified that companionship support was the biggest unmet need faced by YLWH and that the WhatsApp groups had the potential to address this gap in care.

Findings from the qualitative interviews and content analysis support the potential for WhatsApp groups to offer youth the companionship support they may be currently lacking. Youth, caregivers, and HCWs all identified the potential for YLWH to make friends with other YLWH through the WhatsApp groups. The WhatsApp groups were identified as a place where YLWH could receive support and motivation from other YLWH that may in turn address the issues of social isolation and fear of stigma previously identified as impeding them from adhering to ART. In addition, the group could offer a place for YLWH to discuss more than just HIV and ART, allowing YLWH to feel normal and “talk freely”, which was demonstrated by youth asking for the groups to discuss content unrelated to HIV and/or their HIV status. Youth-led WhatsApp groups functioned as a place for YLWH to feel like part of a larger community by sending greetings, jokes, and asking members how they were doing. The secondary functions of the group were to provide information on job opportunities and health or send ART reminders. While it did not appear in the content that the WhatsApp groups provided regular emotional support, the interviews demonstrated that YLWH were experiencing hopelessness due to their HIV status and needed emotional support.

Previous literature has shown that the provision of all domains of social support can improve ART adherence and retention in HIV care as well as support individuals in accepting

their HIV status.^{8;12;13;23;24} This study adds to previous research by identifying the specific domains of social support that YLWH, their caregivers and their HCW identify as unmet needs, which may impact their ART adherence and retention in care. Two previous studies showed that informational support was the primary type of social support provided in online HIV support groups.^{23;24} In contrast, our findings indicate that among our research population companionship support appeared to be the most important. It is important to note that the previous studies are both more than a decade old. Access to information about HIV and HIV care has increased over the last decade, which may be why YLWH in this study did not seem to report significant unmet need in informational support. With increased access to phones as well as HIV knowledge, our findings may represent more updated social support needs of YLWH. Additionally, both of these studies analyzed self-help groups for adults living with HIV. Our results may be different from these studies, especially the content analysis results, because the WhatsApp groups were formed organically by youth to keep in-touch with each other, while the adults in the other two studies most likely intentionally joined the self-help groups to receive information and support related to their HIV status.

This study has several limitations. Due to the limited geographic coverage and small sample size of our WhatsApp groups, the findings generated from this research may not be generalizable to a more diverse population. Secondly, this thesis explores the unmet needs people identified and their messaging behavior in a WhatsApp group, which informs hypotheses about what interventions could improve clinical outcomes but does not evaluate clinical impact of their participation in the WhatsApp groups. Finally, the interviews and WhatsApp messages were all translated and analyzed in English, so some nuances of local languages may have been lost.

This study provides insight on how WhatsApp support groups can address unmet social support needs of YLWH and improve youth HIV care. We found that YLWH experience a gap in companionship and emotional support and WhatsApp groups for YLWH have the potential to fill these gaps. The organic, youth-led WhatsApp groups demonstrated that YLWH primarily used the group to address their companionship support needs and mostly discuss topics unrelated to their HIV status, instead of using the groups for more informational or instrumental support related to HIV.

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Appendix

TABLES:

Table 1. Types of Qualitative Data

Data collection	Site	Participant type	N participants
<i>Round 1</i>			
IDI	1	YLWH - WhatsApp group members - age <18	0
IDI	1	YLWH - WhatsApp group members - age >=18	5
IDI	1	YLWH - WhatsApp group non-members - age <18	5
IDI	1	YLWH - WhatsApp group non-members - age >=18	6
IDI	2	YLWH - WhatsApp group members - age <18	4
IDI	2	YLWH - WhatsApp group members - age >=18	5
IDI	2	YLWH - WhatsApp group non-members - age <18	5
IDI	2	YLWH - WhatsApp group non-members - age >=18	5
<i>Round 2</i>			
FGD	3	YLWH - WhatsApp group non-members - age <=18	16
FGD	3	YLWH - WhatsApp group non-members - age >=18	17
FGD	3	HCW	10
FGD	3	HCW	10
FGD	1	Caregivers	9
FGD	2	Caregivers	7
FGD	3	Caregivers	8

Table 2. Existing WhatsApp group overview

Group	Facility	# Members	# Active Members	# Messages
Group 1	Site 1	60	35	745
Group 2	Site 2	256	46	377

Table 3. Social support domains expressed in WhatsApp messages in two existing WhatsApp groups

Social support domain	N (%) WhatsApp messages in 6 weeks		Example messages
	Site 1	Site 2	
Companionship	348 (46.7)	220 (58.4)	“How are you beauties and main men”—Group 1
			“Hey guys tomorrow is [group member]'s birthday who will accompany me 2 wish her happy birthday. If there is any inbox me ”—Group 2
Instrumental	123 (16.5)	16 (4.2)	“That reminder made me take drugs 2 minutes early. Thanks guys, morale. I am 8am and 8Pm guy.” –Group 1
			“Hey guys I need your help. I have a friend who is one of us and she needs medical fund.” – Group 2
Informational	110 (14.8)	25 (6.6)	“you get o.i.'s [opportunistic infections] when your immune system is weak and adherence plays a role in it”—Group 1
			“Anybody with triple c hotline number” –Group 1
Emotional	78 (10.5)	22 (5.8)	“Some good news and motivation to upcoming mothers in the group.... 🎉kudos mama [member who just announced her baby was found HIV-negative]”—Group 1
			“Guys, my birthday party is the day after tomorrow, yet i have been admitted (in hospital)” ... “Very sorry for that. Get well soon.”—Group 2
Multiple domains	--	--	“Lets set a target we meet as a fam (family)I think we should work towards undetectable v.l. (viral load)”—Group 1 (companionship and instrumental)

Categories are not mutually exclusive.

Table 4. Content codes expressed in WhatsApp messages in two existing WhatsApp groups

Content Code	N (%) WhatsApp messages in 6 weeks		Example messages
	Site 1	Site 2	
Greetings	166 (22.3)	65 (17.2)	<p>“Good morning frds wish u a lovely day” – Group 1</p> <p>“Morning family” –Group 2</p>
Jokes	99 (13.3)	78 (20.7)	<p>“Hahaha are you going for treatment or you are going for a chicken” –Group 1</p> <p>“Who impregnated this emoji 🤖” ...”you” –Group 2</p>
ART	97 (13.0)	1 (.3)	<p>“The 8pm guys 8pm 🕒🕒🕒🕒” –Group 1</p> <p>“Hi guyz I really like the support u giving each other by reminding on taking medication I take meds at 10pm&am but this *6am guys 6 🕒* keeps reminding me all through let's work towards zero detection” –Group 1</p>
Meet-up	72 (9.7)	48 (12.7)	<p>“Pass by our place you have a cup of coffee” – Group 1</p> <p>“Who is free tomorrow we have a walk?” –Group 2</p>
HIV	64 (8.6)	1 (.3)	<p>“Lets set a target we meet as a fam (family)I think we should work towards undetectable v.l” –Group 1</p> <p>“Thanks God my daughter turned out neg am a happy Mama” –Group 1</p>
Jobs & Income	45 (6.0)	37 (9.8)	<p>“Good afternoon all. See below job opportunities and share... Deadline- Monday 16/4/18 COB. Anchor Marketing is an equal opportunity employer.”</p> <p>Group 1</p> <p>“Vacancies: if you know anyone who can apply, pls forward:...NB: [this] is an equal opportunity employer” –Group 1</p>
Flirtation	27 (3.6)	8 (2.1)	<p>“[member name, F] you declined my offer so that I remain single forever” –Group 1</p> <p>“Yes you are a love bird. You brighten up very much when you see a new girl/lady” –Group 2</p>
Leisure	27 (3.6)	65 (17.2)	<p>“Others like me we are watching football” –Group 1</p> <p>“We are watching Afro Cinema” –Group 1</p>
Chain Messages	25 (3.4)	10 (2.7)	<p>“please repeat this: OH GOD, I depend on you. I have no power of my own. When things are going well for me...DO NOT BREAK! Just do it with faith!” –Group 1</p> <p>“From tomorrow onwards there are new communication regulations. All calls are recorded. All phone call recordings saved... Take care not to send unnecessary messages. Inform everyone about this to take care. Please share it;</p>

			it's very much true. Group admins please be careful." –Group 2
Healthcare	23 (3.1)	14 (3.7)	"What is the remedy for cold and flu"—Group 1
			"[loss of] appetite has become a challenge to wat can I do to boost this"—Group 1
Encouragement	22 (3.0)	21 (5.6)	"If a rose smells better than cabbage, It doesn't mean the rose can make a better stew. Don't try to compare yourself too much to others my friend...Never look down on yourself, keep looking up. "—Group 2
			"Morning guys now may not seem to be going your way but put a smile on coz the day has not ended yet something will brighten up the whole month or year today..... lovely day guys"—Group 2

Categories are not mutually exclusive

FIGURES

Figure 1: Vijana-SMART Conceptual Framework

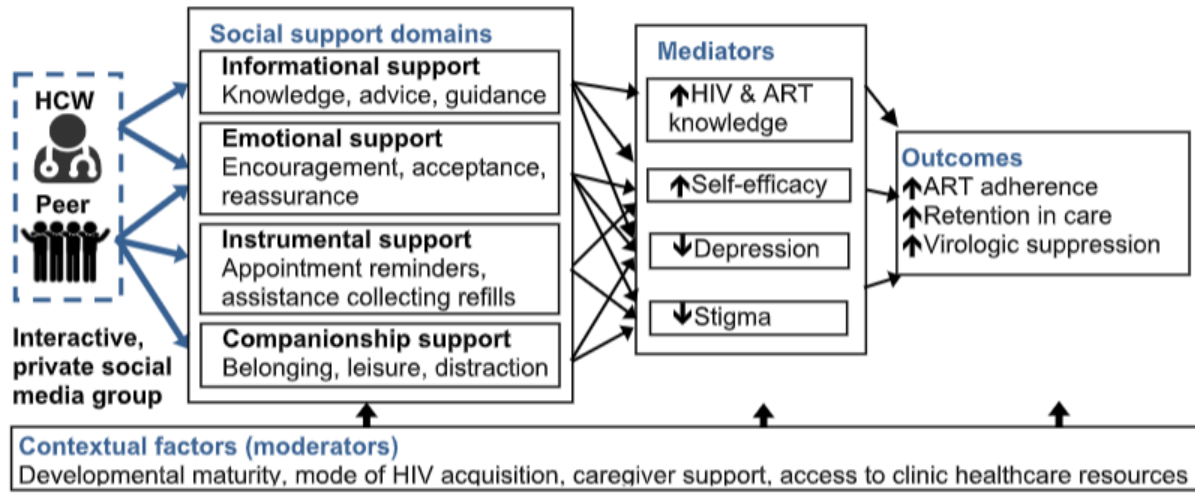


Figure 2: Results and Domains of Social Support

