

# “That courage to encourage”: Participation and Aspirations in Chat-based Peer Support for Youth Living with HIV

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## ABSTRACT

We present a qualitative study of a six-month pilot of WhatsApp-based facilitated peer support groups, serving youth living with human immunodeficiency virus (HIV) in an informal settlement in Nairobi, Kenya. Popular chat apps are increasingly being leveraged to make a combination of patient-provider communication and peer support more accessible beyond formal healthcare settings. However, how these interventions are experienced in Global South contexts with phone sharing and intermittent data access is understudied. The context of stigmatized illnesses like HIV further complicates privacy concerns. We draw on chat records and interviews with youth and the facilitator to describe their experience of the intervention. We find that despite tensions in group dynamics, intermittent participation, and contingencies around privacy, youth were motivated by newfound aspirations and community to manage their health. We use our findings to discuss implications for the design of chat-based peer interventions, negotiation of privacy in mobile health applications, and the role of aspirations in health interventions.

## CCS CONCEPTS

• Human-centered computing → Empirical studies in HCI.

## KEYWORDS

peer support; health; aspirations; chat apps; WhatsApp; Kenya

## ACM Reference Format:

Naveena Karusala, David Seeh, Cyrus Mugo, Brandon Guthrie, Megan Moreno, Grace John-Stewart, Irene Inwani, Richard Anderson, and Keshet Ronen. 2021. “That courage to encourage”: Participation and Aspirations in Chat-based Peer Support for Youth Living with HIV. In *CHI Conference on Human Factors in Computing Systems (CHI '21)*, May 8–13, 2021, Yokohama, Japan. ACM, New York, NY, USA, 17 pages. <https://doi.org/10.1145/3411764.3445313>

## 1 INTRODUCTION

In recent years, personal chat apps such as WhatsApp, WeChat, Telegram, and Viber have extended beyond social spheres to serve many other functions. Attesting to their ease and flexibility of use, the same tools used for socializing are now being used to broadcast news [13, 42], run small businesses [81], mobilize voters [83], communicate in the workplace [77, 124], and, increasingly, manage one’s health [52]. Recent work in Human Computer Interaction (HCI) and Human Computer Interaction for Development (HCI4D) has started to detail how chat and features like chatbots can be used to enable patient-provider communication and peer support [53, 92, 133, 144]. This work ties into the larger movement towards using social media to forge online health communities, which embodies an approach to health that is accessible and cognizant of how patients find community around health outside of formal healthcare settings [54]. Further, across the Global South and North, health services are becoming increasingly stressed and the incidence of chronic conditions that require long-term management is rising [11, 103] (not least highlighted by the ongoing COVID-19 pandemic). This presents challenges around supporting the personalized follow-ups and psychosocial support that are essential to health outcomes like adherence [103, 117]. Considering how chat apps’ pervasiveness allow them to support this communication, it is important to understand how chat-based health interventions can be better designed for patients and healthcare providers.

Prior work in HCI has extensively studied how to improve the design of online health communities, on both existing and bespoke platforms, to meet the needs of peers (e.g., [35, 89, 92, 109, 133]).

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*CHI '21*, May 8–13, 2021, Yokohama, Japan

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ACM ISBN 978-1-4503-8096-6/21/05...\$15.00

<https://doi.org/10.1145/3411764.3445313>

As these communities move to personal chat apps, there are new design aspects to consider, such as having a single space for group communication. Additionally, there is room to understand how chat-based health interventions can be successful in Global South contexts characterized by phone sharing [4, 15, 111], high turnover in mobile phone and SIM ownership [140, 141], and intermittent internet access [10, 74, 143]. These patterns of use shape engagement with chat-based interventions, impacting users' experience of them. They also complicate the use of mobile phones for addressing highly stigmatized health concerns, such as HIV, mental health, or sexual and reproductive health, since privacy can be a serious concern among people experiencing these health concerns. These contingencies pose the question of whether and how chat-based peer support groups can be useful to members given the realities of participation.

In this paper, we present a pilot of facilitated WhatsApp-based peer support groups for youth living with HIV in an informal settlement in Nairobi, Kenya. For six months, a facilitator trained in HIV counseling posted weekly messages, facilitated group discussion, and addressed members' questions and concerns in two peer support groups differentiated by age group. The six-month period was bookended by introduction and closing meetings that offered participants the opportunity to meet in person. We describe participation in and perceptions of the peer support groups, based on a qualitative analysis of the chat records and interviews with a subset of group members and the facilitator post-intervention. We describe how participation was shaped and sometimes limited by unique social dynamics, intermittent access to the groups, and privacy concerns, all of which contributed to the work that the facilitator needed to do to support the group. And yet participants overwhelmingly reported benefits from being in the group, most notably, becoming motivated by newfound aspirations and a sense of community to overcome challenges in management of HIV. We contribute to scholarship in HCI and HCI4D by describing implications for the design of chat-based peer support that accounts for the work of the facilitator and participants' patterns of use. We also discuss privacy concerns in mobile health applications and how safety could be fostered in diverse ways. We end with takeaways for fostering social support for aspirations in health interventions.

## 2 RELATED WORK

Our paper draws on work in HCI and HCI4D on health messaging and technology-mediated peer support, including as it relates to HIV. We also describe work at the intersection of health, technology and internet access, and privacy.

### 2.1 Health Messaging

A whole slew of studies in both the Global South and Global North have sought to understand how messaging can be useful in health-care, so far mostly using experimental trials to describe the effectiveness of voice messages [51, 104], patient portals [122, 151], or (most commonly) SMS (e.g., [31, 56, 65, 80, 100, 101, 148]) for communicating with patients about a wide range of chronic health concerns, including HIV (e.g., [22, 27, 66]). One-way automated SMS has been used to send patient education [16, 65, 129], tips for managing one's condition [23], reminders about personal goals

and adherence [12, 31, 33, 36, 40], and brief quizzes [22, 148]. Two-way messaging additionally allows healthcare providers to directly counsel patients between visits [66, 90]. For example, Perrier et al.'s two-way, semi-automated SMS intervention in Kenya showed that automated messages prompted greater engagement and questions from pregnant women to the nurse [100]. Studies that target HIV, many of them in sub-Saharan Africa, have used SMS to send information and reminders about appointments or taking antiretroviral therapy (ART) [12, 27, 33, 36, 51], conduct large-scale campaigns to promote testing [22], and support communication with an HIV clinician [27, 66, 100]. These studies have found positive outcomes [75], such as increased ART adherence and CD4 cell count [33, 36, 44, 75], decreased viral load [44, 66], and general engagement such as asking medical and logistical questions [76, 100]. While these studies underscore the importance of periodic messaging, they have yet to address the possibilities that group-focused settings offer.

### 2.2 Chat-based Peer Support

Increasing access to smartphones and data have allowed messaging to move to mobile chat apps like WhatsApp, and chat-based peer support groups have been created organically among youth in parts of countries like Kenya and South Africa [2, 8, 93]. These apps do not cost per message, allowing for relatively more engagement if data is available. More features open up avenues for richer interactions among peers and healthcare providers while still being relatively lightweight compared to many online forums. Early studies have found that chat apps are useful for multimedia learning around health topics, patient-provider communication, and peer support [46, 57, 68, 133]. For example, Li et al. found that using WeChat to share multimedia educational material to Chinese expatriates in Niger supported malaria literacy [68]. Hay et al. interviewed mentor mothers in an HIV peer support network in the United Kingdom about their use of WhatsApp, finding that it was convenient compared to in-person meetings, but that there were challenges with the cost of data and privacy [43]. Among studies on chat-based peer support, some discuss the design of interventions that only involve peers [86, 92], such as O'Leary et al.'s design work on guided and unguided peer support chats for mental health [92]. Other studies explore facilitated groups [21, 46, 133]. Some of these studies show improved clinical measures [21, 46] but in-depth qualitative work characterizing these groups and users' perceptions of them is scarce. Wang et al. recently shed light on the work of nurses who facilitate a WeChat group for IVF clinic patients in China and recommend ways to support the nurses in handling the extremely large volume of patient messages [133].

### 2.3 Online Health Communities and Technology-mediated Peer Support for HIV

Prior work in HCI has extensively explored group interactions in online health communities targeting a wide range of health conditions. This work has largely focused on spaces such as online forums, bulletin boards, Reddit, Facebook, and Instagram. While our work offers a perspective of how peer support plays out on more lightweight, unstructured, and closed forms of communication like chat apps, there are a number of themes in HCI scholarship on online health communities that we draw on. Some studies have

described the mechanism for how these communities support users, for example upholding experiential knowledge, or supporting a sense of community empowerment [34, 35, 98]. Studies have also analyzed content, noting tensions in whether and how users are able to meet each others’ support needs [48, 53, 71, 85, 115, 131], as well as beliefs and practices that exacerbate the very problems users came to resolve [67, 106]. Prior work has looked at the rhythms of user engagement, noting how intermittent or brief engagements in these communities can be purposeful and useful to participants [3, 72, 73]. Few studies deeply describe or address the role of peer or expert moderators [47, 49, 64, 73]. Huh and colleagues explore how to semi-automate clinicians’ work on forums [49] and how moderators might better support patients who ask about clinical questions [47]. A subset of this work focuses on disclosure and particularly sensitive health concerns like depression, substance abuse, and menstrual health, noting the importance of private channels, developing privacy norms, constructive moderation, and diverse levels of readiness to discuss sensitive topics [6, 109, 128, 145, 146].

HIV is a particularly stigmatized illness. Fear of stigma and associated mental health concerns can prevent people from learning about it and seeking care [26, 60, 84, 88, 119]. Long-term care itself can be daunting, requiring ART adherence, monitoring viral load and CD4 cell count, and patient education. Even with treatment, issues like negative experiences with healthcare workers can affect adherence [121]. In light of these issues, Natarajan and Parikh [88], as well as others, suggest a focus on peer support, outreach work, and digital resources for HIV that consider emotional and safety needs [25, 37, 60, 69, 118]. Lockwood et al.’s study of youth living with HIV in Kibera, an informal settlement in Nairobi, found that social support helped with a wide range of issues, including ART adherence, self-acceptance, and positive living beyond management of HIV [69]. Prior work on online peer support for HIV has largely been in medical and communications journals and chat-based interventions are rare [107]. Interventions on Facebook [7, 24, 28, 29, 32, 70], Weibo [19, 20, 38, 39, 116, 134], MXit [45], and other forums [30, 50] explore the content of these groups, network analysis of communication among members, and clinical and educational outcomes such as getting tested or improved HIV knowledge. Dulli et al. briefly note charging phones or buying airtime as barriers to participation on a Facebook group for youth living with HIV in Nigeria [29], but there is room for in-depth qualitative work on how these contingencies shape participation.

## 2.4 Stigmatized Illnesses, Technology Access, and Privacy

Prior work has noted the large range of privacy concerns for health technologies [52]. Such concerns become amplified in the context of online health communities for HIV. In general, prior work has found that anonymization, granularity and flexibility of privacy controls, and avoiding visible markers of HIV-related content are important [17, 60, 88, 123]. For example, Natarajan and Parikh and Kumar et al.’s work with people living with HIV in India note the incredibly high stakes of one’s status being found out. They recommend strategies for safe communication in health interventions, such as ambiguous wording that avoids mention of HIV [88] or anonymization of online identities [60] (ambiguity is also discussed

in other contexts [41, 114]). At the same time, prior work has suggested that privacy and anonymity are not absolute but rather, can be outweighed by trust and the desire for support in health management [133, 150], or satisfied through social contracts that are negotiated between people [108]. This negotiation becomes especially salient when tying sensitive health information to popular apps, as Warner et al. and Hay et al. have pointed out in their lines of work on technology use and users’ HIV status [43, 135, 136].

Privacy becomes further complicated where intermittent access and phone sharing are the norm, as has been documented in Kenya, as well as other parts of sub-Saharan Africa and South Asia [4, 15, 91, 111, 137]. Both quantitative and qualitative work in Kenya [91, 137] has found that phone sharing is gendered and more common among low-income people and rural residents. Phone sharing by youth has been documented in urban and rural parts of Ghana, Malawi, and South Africa—maintenance issues or lack of airtime can often prompt sharing family members’ phones, even among youth who own their own phone [102]. Wyche and colleagues’ work in rural and urban Kenya detail such maintenance issues, high risk of theft, and changing economic situations that contribute to high handset turnover and intermittent service [140, 141, 143].

Prior work has uncovered how intermittent access and sharing affect the everyday use of phones, apps, and data (e.g., [9, 74, 78, 79, 142]), highlighting the human infrastructure that makes technology work for people [113]. However, a major theme has been the implications for women’s privacy. Ahmed et al.’s study in Bangladesh found instances of men monitoring wives’ phones or parents monitoring daughters’ [4]. Sambasivan et al.’s extensive study of the privacy practices of women in South Asia found that they used strategies like phone locks, app locks (which password-protect individual apps), and deletion of data to handle privacy breaches from monitoring or sharing, though visible protections like app locks could still garner suspicion [110]. Other work has discussed the importance of default privacy settings and the need for same-gender online spaces [1, 87]. Phone sharing also necessitates strategies for privacy in mobile health interventions for people with sensitive health concerns or jobs [88, 100, 107, 114, 144]. Sambasivan et al., in their broadcast system for outreach to urban sex workers, used multiple calls and ambiguous wording to address phone sharing and use of multiple phones [114]. Looking at SMS, Ronen et al. found that acceptability among Kenyan women of receiving HIV-related SMS messages depended on whether they had disclosed their HIV status and whether anyone else had access to their phone [107]. Similarly for chat, Yadav et al. speculate that women using a health chatbot might require features to account for sharing, such as private modes and configurable notifications [144]. Perrier et al.’s study shows that phone sharing does impact the use of an intervention—women who shared a phone with their partner found it hard to always read and respond to SMS sent to them [100].

## 3 METHODS

This study aimed to understand the experiences of youth and the facilitator with WhatsApp-based peer support. We describe the formative work that informed the intervention design, the procedures used to pilot the groups, and the data collection and analysis presented in this paper. All stages of this study were approved by institutional review boards in Kenya and the United States.

### 3.1 Background on Formative Work

Formative work took place in 2017 and 2018. In the first phase (December 2017 to March 2018), we conducted semi-structured interviews with youth living with HIV who attended two clinics in Nairobi. We asked about their experience managing HIV and with peer support. We also did a content analysis of the WhatsApp-based peer support groups that youth at each clinic had created. Based on these findings, we created a prototype of a structured intervention that combines healthcare worker support with peer support to improve youth's adherence to ART. The second phase (August 2018 to September 2018) was at a third clinic in Nairobi. Youth attending this clinic did not have an online peer support group of their own. Youth and healthcare workers at this clinic, along with caregivers at all three clinics, gave feedback on multiple iterations of the structured intervention through focus group discussions. Amidst this process (December 2017 to April 2018), we also conducted a survey at all three clinics to understand youth's technology use.

These phases informed the design of the intervention described in this study. Youth in the existing groups were comfortable participating despite not knowing many members, and WhatsApp was also more pervasive compared to apps like Telegram or Signal. Thus, we used WhatsApp as the platform for peer support due to its demonstrated feasibility. When asked about forming a facilitated group, youth wanted to establish interpersonal norms around confidentiality and wanted to meet in person, which informed the introductory meeting as a way to develop shared norms.

### 3.2 Study Design and Participants

The pilot of the intervention was conducted with youth at the third clinic (referred to as Site 3 from here on) as follows. Starting January 2019, we conducted outreach through healthcare workers at Site 3 to recruit youth; youth were eligible if they were aware of their HIV status, receiving treatment, had access to WhatsApp, and were literate. Recruited youth signed a consent form that detailed the study procedures and measures taken to anonymize and securely store data collected from the study. The form also outlined potential risks of loss of confidentiality from joining the group, namely access to sensitive information on the chat not just by group members but by other people with access to a group member's phone. The form had recommendations to password-protect their phone, use a non-identifiable WhatsApp profile picture and name, and delete sensitive messages. Participants were then added to the appropriate WhatsApp group based on their age in late March 2019. There were two groups: "Group 1" for youth between ages 14 and 17, and "Group 2" for youth between ages 18 and 24. We do note that one 18-year-old participant was erroneously assigned to Group 1. Both groups were generically titled "Youth Support Group" on WhatsApp. All titles and names of youth participants are anonymized. Participant IDs are listed with age, gender, and group number throughout the findings.

The groups were facilitated by the second author David, a researcher with background in public health and HIV testing and counselling. Once participants were added to the groups, the facilitator messaged both groups to invite all members to an optional introductory meeting held in early April 2019 at Site 3. The event was meant to allow participants to meet, co-create group norms

around privacy and communication, and determine when would be a good time for the facilitator to send the weekly message. Thirty participants attended and were reimbursed KES 400 for their time and transportation expenses. This marked the beginning of the six-month pilot period. In November 2019, participants were invited to a closing meeting, which also had 30 attendees. This event was intended to facilitate a discussion of the youth's experience with the groups and to have everyone nominate a group member and healthcare worker at the clinic to take over facilitation of the group. Attendees were again reimbursed KES 400. We provided a guide to support the new facilitators, with guidance on sample messages, suggested structure and norms of the group, and what to do in common scenarios like low activity or mediating conflict.

The facilitator followed the study's standard operating procedures, tailored to national guidelines and local practice standards. He was in charge of manually sending the pre-written weekly messages—prompts on topics such as future goals, strategies for remembering to take medication, or any troubles that were on members' minds. He was expected to respond to messages directed at him within 12 hours, respectfully clarify any misinformation posted on the chat, avoid HIV-related terms (such as ART or CD4) except in direct messages, and refer any questions about symptoms to a clinic. Any members with questions about symptoms or distress were supposed to be referred to the clinic or followed up with. In general, the study team supported the facilitator in answering any questions that he was not sure how to respond to, as well as discuss what to do about any behavior from members that was not in keeping with group norms. Finally, if the facilitator learned from members about any third-party access to their or another member's phone, he reached out to the affected member to understand if social harm had been done and corrective action was needed.

Not including the facilitator, Group 1 had 28 members (14 female, 14 male) and Group 2 had 27 members (21 female, 6 male). Participants were from low-income backgrounds. Participants 18 or younger were students and most did not know their family income; two participants reported KES 5000 and KES 12000, respectively. Among participants older than 18 who said they were employed (50%), they made a median of KES 8000 monthly (IQR 3500-12500, 15% missing). Forty percent of participants reported sharing their phone, including 48% of participants 18 and younger and 30% of participants older than 18. Participants reported using SMS (92%), phone calls (92%), Facebook (61%), and WhatsApp (61%) to contact family and friends; some mentioned Facebook Messenger (32%), email (16%), Instagram (7%), and Snapchat (3%). Among participants who bought their own mobile data, they spent an average of about KES 153 per week. There were 13 participants, all older than 18, who had children.

### 3.3 Data Collection and Analysis

Data was collected through surveys, notes, chat records, and audio-recorded interviews. Upon enrollment, participants took a survey on demographics, phone use, and HIV knowledge and management. At the introductory and closing meetings, we took written notes on what attendees discussed. During the pilot, the facilitator downloaded and backed up all chat records weekly, for both the group and any one-on-one conversations he had with participants. He also

took notes on any events that required follow-up with participants or clinic referrals. After the pilot, participants from both groups were recruited for in-person, semi-structured interviews where we asked about their experience with the group and feedback on its design. Interview participants were selected to understand various behaviors, such as high engagement, low engagement, leaving the group, or sharing distress on the group. In total, 20 members participated in interviews: seven from Group 1 (four females and three males) and 13 from Group 2 (eight females, five males). The first author Naveena, who conducted data analysis, also did a phone interview with the facilitator to understand the full scope of his work and connect it to the rest of the data. All data, including chat records, were anonymized for storage using numerical participant IDs. Chat records and interviews were in the language that participants chose to use—Kiswahili, English, or Sheng, a slang composed of mainly Kiswahili and English that originates among urban youth in Nairobi. Interview translation and transcription were done by the interviewer, and chat translation was done by two research assistants who joined the study team for a follow-on study after the pilot was over.

We first analyzed the post-pilot interviews using thematic analysis [14]. The first author conducted open coding, creating a codebook that categorized the codes by themes, such as “factors that shape engagement: going to boarding school” and “privacy concerns: fear of stigma from group”. These themes and codes were discussed with the study team, a process through which we tweaked the codes to better represent the data. We then wanted to compare participants’ perceptions to what was observed in the chat. The first author analyzed the group and one-on-one chat records, similarly coding messages and finding recurring themes around types of interactions members had, the facilitator’s work, and rhythms of engagement over time. She also then read through the facilitator’s notes on significant events that participants were going through, matching dates to the chat group to contextualize what happened. Understanding the dynamics of the chat group and notable events, she revisited the interview transcripts. She then synthesized themes from this analysis, such as how social dynamics of the group shape engagement. These themes were discussed with the last two authors Keshet and Richard, who provided feedback on the connections between what participants said and what happened in the chat.

### 3.4 Self-disclosure

We are composed of researchers in HCI and global health and health practitioners. We are based in the United States and Kenya and have conducted research in parts of the United States, Kenya, and India. Our combined expertise is in technology design and health messaging, interventions to improve HIV care for youth, and counselling for youth living with HIV. David, Cyrus, Brandon, Megan, Grace, Irene, and Keshet conducted the pilot and formative work. Naveena worked very closely with Keshet to gain context for the data as needed during analysis.

## 4 FINDINGS

Our findings describe the social dynamics, forms of participation, and contingencies around privacy in the peer support groups and the resultant work that both the facilitator and youth do to support

engagement in the group. We also describe how despite these contingencies, youth saw significant benefits of participating in the group, tied to developing aspirations, gaining a sense of community, and the simultaneous presence of both peers and a facilitator.

### 4.1 Social Dynamics of Facilitated Peer Support

At a high level, the two groups differed in volume of messages but were quite similar in distribution of messages among participants. Group 1 had a total of 1559 messages, with 16 out of 28 members participating in the chat, including the facilitator. Group 2 had almost three times as many messages, with a total of 4349, and 22 out of 27 members sent messages, including the facilitator. In both groups, the top contributor sent approximately 20% of messages, and the top 5 contributors sent approximately 60% of all messages (excluding the facilitator). The facilitator had one-on-one chats with 21 participants. In terms of content, other than the weekly messages, there were health-related questions and discussions, updates about youth’s physical and mental health, and social messages, including greetings, life updates (ranging from returning from school for the holidays to a death in the family), motivational messages, jokes, and WhatsApp forwards. In this section, we describe how participants valued these different topics and how the facilitator worked to ensure all youth could get value out of the group.

**4.1.1 Balancing Health and Social Topics.** In each group, participants differed in what they thought was appropriate or useful content. In Group 1, members directly engaged with the facilitator’s weekly messages for the first month but after that, engagement lowered and the bulk of messages were social messages. Most Group 1 interviewees still appreciated the weekly messages, however, noting that they were helpful in introducing new topics, and because they were open-ended, prompting thoughtfulness. Meanwhile, the social aspect of the group was especially helpful in sustaining connection in the face of illness. As P17 (17, F, G1) stated, *“the group taught me that we can mingle with everyone but not locking yourself inside always because of our status, we should always be jovial and even to entertain ourselves.”* In comparison, Group 2 engaged much more with the weekly messages and had more health-related questions. Still, some Group 2 interviewees wanted even more of a health focus, stating that some social messages were *“irrelevant”* (P32, 22, F, G2) to the group agenda and boring to scroll through. P36 (22, M, G2) noted that he would actually feel less motivation to participate when he saw greetings:

*“...you could find even in three days there is no new hot topic for discussion like people are just greeting each other, ‘Hi where are you? I am here. I am just in the house,’ and such like things. So that discouraged me, like when I am seeing such like messages I don’t participate.”*

Social threads could in fact become extensive in Group 2. A recurring thread started out with greetings and would extend into discussions of what members were having for dinner and even inviting each other over to eat. However, even among members who did not prefer the social messages, there was an understanding that the group is meant for social interaction and that disallowing *“irrelevant”* messages would not have been preferable. These members generally also agreed that the intervention could be improved

if the facilitator sent a topic of discussion more often than once a week, even daily.

**4.1.2 Balancing Inclusion and Open Discussion.** In both groups, participants sometimes felt excluded from conversations in the group. Participants explained how there were times when it seemed a conversation was too intense, or between a few members who were closer to each other, and so it seemed better not to engage. In Group 1, there were periodic tongue-in-cheek arguments between a few members who were friends and knew each other offline. The following conversation in Group 1 started a series of almost 400 messages over five days, which made up a significant portion of the total activity in the group:

P17: Hey guys  
 P22: Which guys  
 P17: Don't start with me  
 P22: You too don't start  
 P17: If you are not guys why start backbiting  
 P17: Shut up  
 P20: You guys, you making me laugh  
 P20: oops!! Not guys! <tears of joy emoji>

The seeming exclusiveness of such conversations was in tension with the fact that there was value in sheer activity, especially in Group 1 when multiple days would often go by when there were no or few substantive messages. In fact, P22 (16, F, G1) conveyed how she felt confident playing such jokes in the group because it increased activity:

*"They [other members] thought we don't get along, they thought we were strangers. They would ask why we argue but we never responded to them... There was only one admin and he wouldn't have removed us so we weren't afraid... there were many messages from us."*

The facilitator in fact did not remove them, not just because they were generating activity, but because everyone was welcome in the group: "...we agreed that we were a team." He did work to moderate arguments, however, and this required evaluating the impact the conversation was having on the group—whether it was a joke and entertaining to members or a dynamic that was taking away from other members' experiences. During this conversation, the facilitator would periodically interject to confirm that it is a joke, remind members to be civil (especially when the "jokes" became less light-hearted), as well as attempt to move the conversation towards the weekly topic or a health-related discussion.

There were more serious arguments in both groups, started because of contentious topics such as whether members believed in god, whether it is acceptable to consume drugs or alcohol, or a suggested display picture that a member did not like. For example, in Group 2, three members started a conversation one morning about religion and whether it was helpful or hopeless in coming to terms with living with HIV, a particularly difficult conversation given the prevalence of Christianity in Kenya. The thread ended with one member P29 (24, M, G2) messaging "Wow, I have no words at all!" in response to P49's (21, F, G2) explanation that "I cut my ties with God ever since I turned out positive I blamed him for everything that's why I don't pray neither do I go to church.." In these scenarios, the facilitator worked to reduce accusatory sentiments and reframe

the situation not as a debate, but rather a sharing of opinions with mutual respect. In the evening, the facilitator sought to close the loop on this disagreement, despite members having moved onto other topics that day. The facilitator messaged asking for discussion: "Waaatt.. why do you blame God dear?? This looks serious we need to discuss about it please." Other members, including everyone who discussed the topic that morning, agreed to discuss further. Reopening the discussion eventually allowed P31 (23, M, G2) to add that, though he still believes in god, he also does not attend church or listen to preachers. In response, the facilitator affirmed the common ground among group members and continued to encourage others to open up: "Mmhh seems many are in this state. Howmdo [sic] other members feel?"

The facilitator told us that resolving these social dynamics was one of the most challenging aspects of his work. He explained how there was a balance to be struck among various personalities and strong opinions: "So it is a mixed group, contains a mixture of feelings and of personality and attitudes. So knowing how to balance those emotions and attitudes so that everybody doesn't feel offended, it's the hardest part to balance." The facilitator thus had to ensure that his responses were carefully crafted such that no one felt judged for their opinions or knowledge. For example, P49 (21, F, G2) asked how it would make sense to suddenly disclose to her partner that she is positive. The facilitator responded by asking members to share their experiences, but sought to alleviate any pressure that participants' responses might create: "There are ways we can always go about this when one wants to. I think some of us here know well how to. Any suggestions?? Remember we are just suggesting. It's not like we are telling people to disclose when they are not ready."

## 4.2 Diverse Forms of Participation in Chat-based Peer Support

The full scope of participation in the intervention was best understood by looking beyond active messaging in the group, to other forms of interaction as well. We found that intermittent data and phone access shaped when participants logged on and how they sifted through messages. From the facilitator's perspective, constant engagement with the chat was needed to manage threads.

**4.2.1 Reading Messages, Sidechatting, and Intermittent Use.** In both groups, a majority of members did not message in the groups at all or sent very few messages over six months, but there were other ways that they engaged. P15 (14, F, G1), who was using her mother's phone, never messaged on the group, but said that she read all the messages whenever she was able to, "...expecting that they will send something that will help me." P15's statement shows how even reading messages could help participants see the group as a supportive environment. Participants also reported having many "sidechats" with youth from the main group. P54 (18, M, G1), who sent only three messages, described how sidechats helped him ask for support from the right people: "If I have an issue and someone in the group has a point, I take their number, then we sidechat." Even youth who sent many messages in the group had sidechats, where they could discuss conflicts or coordinate to meet up or collect medication for each other. P43 (22, F, G2) felt that sidechats also offered some members a more comfortable space to discuss sensitive topics: "Some people fear chatting in the group so when you sidechat

*with them they feel free... I had a friend who had a boyfriend but had not told him [about her status]. She wanted me to advise her on how she can ask him to come and test.”*

Contingencies around accessing one’s phone and getting online also shaped participation, contributing to bursts of activity on some days and low activity on others. Throughout the intervention, multiple participants exited the chat—nine times in Group 1 and 18 times in Group 2. This was often because their SIM had changed, or their phone had been lost or damaged. The facilitator would need to follow up with them, sometimes via repeated phone calls, or wait for them to ask to be added back. These gaps in access could take anywhere between a week to multiple months to resolve, with issues like losing one’s phone taking longer in that range. Many of the participants experiencing these issues messaged least in the group chat. However, they still maintained a connection to the group—P44 (24, F, G2), who left the group for two months, said he kept reading new messages once he was added back. Other members only logged on when they were able to buy bundles, while others said they would log on for the weekly message, expecting more discussion then. Group 1 members who attended boarding school only had access to the group during holidays in April and August, while those who attended day school chatted more at night.

Intermediated use also contributed to intermittent logging on. For example, P31 (23, M, G2) and P32 (22, F, G2) were partners, both in Group 2. When P32’s phone broke, she relied on her partner to read messages, which notably still had an impact on her: *“...he told me a lot. Yes, when it reached a time for taking medication, I felt I was low, but after that, at least receiving the messages encouraged me.”* Some participants’ parents or friends in the group encouraged them to read messages, demonstrating in-person support systems as drivers for engaging in online ones. P15’s (14, F, G1) mother would inform her that messages had arrived and if there were bundles, she would read them on weekends. P43 (22, F, G2) would meet up with another member and if she was told there were good discussions happening, she would try to buy bundles to log on and read.

**4.2.2 How Patterns of Use Shape Engagement with the Chat.** Intermittent use often meant logging on to a barrage of messages. Participants who checked messages intermittently reported trying to read as many messages as possible but would sometimes end up skipping chunks of messages. These participants also felt that, though they could read old discussions, they could not ask follow up questions or ask what someone meant by their message since those threads were long over, instead piecing together meaning from context clues. While many participants said they wanted more frequent messages from the facilitator, they also noted that it could lead to too much content to review. In fact, P15 (14, F, G1) shared how not having many messages on the group would be more manageable given how often she checked them: *“...you can’t manage two things at the same time... You know you only have Saturday, the rest of the school days you don’t have access to the phone.”*

As a result of these patterns of use, both the facilitator and group members managed participation as well as the timing of messages to maximize engagement. In both groups, there were numerous, periodic reminders from the facilitator and participants for members to participate throughout the course of the six months. Members would also often try to understand who is online at a given

time, since it could not be assumed that messaging was truly instant for everyone. They would find that a few people would respond quickly, giving participants an idea of who they could converse with at that time—this also adds meaning to greetings as a way of discovering who is online. This discovery process also played out in Group 1 when multiple participants went off to boarding school—the group sent farewell messages to those who would be leaving, and then the facilitator asked for a show of hands from those who could still use their phone and would continue chatting in the group.

From the facilitator’s perspective, he would check for chat messages almost hourly to ensure he was not missing messages. To respond to some threads, however, he could take time, anywhere from a few hours to a day or two. Sometimes this was intentional and signalled in the chat to encourage group members to discuss amongst themselves. In other instances, the facilitator asked for more time in order to answer questions thoroughly. Then there were times when there were simply many messages—multiple members might all be online at the same time and message constantly, while the facilitator was doing something else. In these cases, the facilitator’s strategy when he checked messages again was to continue the most recent conversation, since he did not want to interrupt the flow. However, he then had to sort out old threads and carefully reply to each one or bring the discussion back up to close the loop on it. This process could take up to two hours in some cases. In one instance, after a debate about how it is possible to have discordant couples, the facilitator had to follow up with a member who had exited the group, encourage members to answer someone’s question about medication side effects, and remind members to use app lock (based on the follow up with the member who exited). After about two days and more than 200 messages, the facilitator was able to close the loop on the thread about discordant couples. However, it seems this had little impact on members, who were willing to revisit the topic. Even with multiple conversational threads, the combination of the reply feature, members’ willingness to revisit topics, and the fact that answers could be crowdsourced from members meant that most threads were answered to some satisfaction.

### 4.3 Negotiating Privacy Concerns

At the time of our study, most members had not disclosed their status to others, or only to their parent, sibling, a relative, or partner. However, they did state that they share their phones with people outside of this circle, such as friends. As we described in the methods, the consent form recommended certain privacy measures to help reduce risk. Here, we report on how the introductory meeting allowed participants to additionally address privacy concerns as a group and how the norms they decided upon played out over time.

**4.3.1 Addressing Privacy Concerns and Building Confidence in One Another.** Participants we interviewed reported having concerns at the start of the study about who was in the group itself and what they could do with their information, such as phone numbers. P29 (24, M, G2) wanted to know if the group contained only people who had a positive status, or if it was more public. Others were worried that there could be overlap between people at “home” (their immediate social network) and people in the group—as P44 (24, F, G2) explained, *“I was worried that when I joined the group other*

people would get to know about my issues but I later discovered you can still join but not know those in the group at a personal level, so people from home will not know.” The initial unfamiliarity with group members also made participants wonder how they would discuss sensitive topics. For example, P10 (15, M, G1) was apprehensive about open discussion on the group—he did not know “How we were going to share with each other concerning drugs, which for me I felt was something private.” Meanwhile, P43 (22, F, G2) worried about outright stigma from members, because if there were people older than her in the group, “they will start wondering how I got HIV at my age.”

During the introductory meeting, participants used the opportunity to articulate concerns around privacy and agree on privacy norms as a group. There was an agreement to not share any messages outside the group, though since some of the younger members relied on their parents’ phone, this was inevitable to some extent. Many attendees were more concerned about accidental disclosure, where someone looking at or sharing a member’s phone might find out about the group. Attendees at first suggested a password for the whole phone, but because of phone sharing among some participants, the group agreed to use an app lock on WhatsApp only. P37 (24, F, G2) noted that this motivated her to open up in the group—only her mother and separated father of her child knew about her status, so everyone using the app lock helped her feel that she could open up to others without disclosing to just anyone. Attendees also generally agreed that the title of the group helped disguise it as a general youth group. Content-wise, participants agreed that explicit words like HIV, CD4, ART, VL, or medication names would not be used, to avoid disclosure of HIV status if a third party gained access to the group. Though 30 of 55 group members attended the meeting and so some did not have input into this process, these norms were shared on the groups, and were met with agreement from members.

The meeting also allowed attendees to build confidence, or “being sure of the person you chat with,” as P49 (21, F, G2) described. Listening to one another and seeing others make effort to attend in the first place were positive signs to participants. P37 (24, F, G2) explained how this built a foundation going forward: “If I see you on the road, I cannot pass you, I will say, ‘Hi do you remember me?’ then you will be like, ‘I remember you.’” Some members also opened up quite a bit at the meeting, sharing experiences, words of advice, and offering tangible support. One member shared a memory of how she confidently took medication in front of others when she was on a bus, encouraging others to be open as well. Another member shared how her partner kicked her and their baby out of their home after finding out about her status and that she was willing to house any other women forced to go through the same. Learning about each other’s experiences created a basis for future conversations. P31 (23, M, G2) mentioned that he met one member who had a baby and so he knew he could reach out to her with questions about his own newborn. Not attending the meeting did not necessarily prevent people from interacting in the group. This was partly because sharing on the group itself reinforced an open environment. For example, P28 (24, F, G2) was one of the first people in the group to post even before the meeting, sharing her struggles around breastfeeding her newborn. She noted that

she did not know who messages were from but the group’s openness encouraged her: “It excited me because I saw people were free and were asking what they want.” Other members shared deeply personal experiences early on as well. In another instance before the introductory meeting, P30 (19, F, G2) posted about her feelings around losing her newborn baby and other members of the group quickly offered their condolences and emotional support.

**4.3.2 Enacting Privacy Norms Over Time.** In practice, it was not so easy to enforce privacy norms over time. Based on chat records, members in both groups liberally used HIV-related terms, including the facilitator. Slang such as “groundnuts” to refer to medication and “doing the necessary” to refer to taking medication were used very early on and just a few times by participants, but almost immediately after the introductory meeting, participants referred directly to drugs and their specific names. One to two months into the pilot, the facilitator posted informational resources about HIV using explicit terms, and as participants asked increasingly technical questions about how medication or HIV transmission works, the words were used more frequently in conversation.

Participants reported three instances where people who were not members of the group gained access to a member’s phone, and we provide two examples here. Two months into the pilot, P43 (22, F, G2) exited the chat. When the facilitator reached out, the participant reported that it was because her sister had exited P43 accidentally. However, the sister then claimed that P43’s friend was actually the one who did it, demonstrating the difficulty of tracing any potential impacts of privacy breaches. After this incident, the facilitator sought to be transparent, explaining on the chat why P43 left, and reminding participants of the group’s agreement to use an app lock. P43 was using an app lock, but the reminder was intended to ensure members in general were not getting too lax about privacy. There was also one documented instance of harassment in a sidechat. P49 (21, F, G2), in her interview, described how she was sidechatting another member in the group when things took a downward turn because his wife had been able to access the phone:

*“Let’s not take things personal, like I had an incident when chatting [group member], his wife took the phone away and started abusing me. This is just a group sharing ideas, people of the same status and nothing more. I can’t imagine someone taking my phone, going through messages to abuse people because of their status... I didn’t know things will get out of hand just because he had left his phone at home.”*

She was indignant that someone could have such invasive access to their partner’s phone, noting that even if she had a boyfriend, she would not let him go through her messages. Notably, because this happened on a sidechat, it was unobserved by the facilitator, highlighting the complexity of protecting privacy in this context and how it still impacts participants’ experience of the intervention.

## 4.4 The Rewards and Limitations of Facilitated Peer Support

Even with complexities around social dynamics and privacy, participants overwhelmingly reported that the group supported them in



various ways. The group offered emotional support that reduced a sense of isolation and informational support, which contributed to the development of aspirations and the motivation to do difficult tasks such as taking medication. Both peers and the facilitator were integral to this experience, though supporting peers through serious challenges could somewhat temper participants' view of the future.

**4.4.1 Exchanging Emotional and Informational Support.** Emotional support offered acceptance and a sense of normalcy that reduced isolation and supported youth's self-esteem. Some youth had difficult social lives, stemming from not having people around them who shared the same status. P22 (16, F, G1) described how *“...initially my interaction with those at home had been difficult because they isolated me saying I would infect them with HIV.”* She also explained how physical symptoms such as significant weight loss furthered feelings of abnormality and isolation. The group on the other hand was a separate, and sometimes the only, social space where participants could be open about living with HIV. P22's (16, F, G1) sentiment that she now had *“others walking with me”* was shared among many participants. Having the space allowed youth to face and become more comfortable with aspects of living with HIV, such as the need to take medication. P54 (18, M, G1) shared how he did not like discussing medications before joining the group, but group members made him feel that it is normal to take them. The group's support became integrated into participants' daily lives. The group was both a constant companion which reminded participants that they had a support system, as well as a resource that could reach people in the right moment. P17 (17, F, G1), the top contributor in her group, described its steady presence in her life: *“This group helped me to know that I have someone who cares about me and nothing will disappoint because you know someone else somewhere is concern[ed] about your life.”* Meanwhile, P15 (14, F, G1), who never messaged, alluded to how the messages sometimes reached him when needed most: *“Maybe I come from school and am not feeling well and someone sends me an encouraging message, I feel am okay.”*

The group also offered informational support. Members said they valued having access to both experiential and medical knowledge, such as how to manage the side effects of drugs, about preventive medication such as PrEP and PEP, and what makes up a balanced diet. Experiential knowledge in particular could be a way for members to realize that what they are going through is normal, connect over shared circumstances, such as having a newborn, and in some cases, gain perspective on one's own situation. For example, P22 (16, F, G1) mentioned how she learned that she was *“better placed”* than boarding school students who needed to hide their medication, while she could just take hers at home and then go to day school. Members were also introduced to new resources, such as partner notification services, which promote testing in partners of people living with HIV. Myths or misconceptions, such as whether blood type can protect against infection, or whether PrEP can be taken as a one-time event before intercourse, were also cleared up in the chat. In general, sharing advice made youth feel helpful, knowledgeable, and as if they had reliable mutual support. P41 (23, M, G2) noted how thinking through other group members' problems prepared him for concerns he might face in the future, also highlighting the shared struggles members went through: *“It is like I am still helping*

*myself in another way since if a person had a problem today it might be the same problem which I will have tomorrow.”*

**4.4.2 Rediscovering Aspirations and Ways to Achieve Them.** Participants said the group supported them by motivating them to do challenging things, especially adhering to medication. A major source of this motivation was realizing that they can aspire to life goals they had given up on. Toyama defines aspirations as a “desire that is persistent and aiming for something higher,” providing empirical examples such as buying a house, starting a business, or growing one's family [126]. Participants told us about aims such as studying further, getting married, having children who are not positive, being responsible for their children, and living a long life. Being in the group and meeting peers of the same status expanded participants' conceptions of the future. P49 (21, F, G2), who had found out she was positive only a year before the study, shared how those who had been living with HIV much longer were sources of encouragement and helped her imagine a future with her child:

*“...I always thought I will die now. When other people said how long they've lived like 20 years, 10 years positively, then I felt there's hope... I am just 22 years. If I add another 20 years, I will see my child grow to be of the same age just as I am now, and that will be a blessing.”*

Members would also try to convince one another to expand their aspirations. For example, some members were convinced no one would marry them because of their status, or that they could only marry someone who was also positive, but others would explain why that did not have to be the case. P36 (22, M, G2), who said he sometimes felt discouraged about dating, felt more optimistic about the future knowing that there were members who were part of discordant couples: *“...that encouraged me that I can live a healthy life... And I can have a partner, we can have children, and we can live. So that changed my view.”*

Drawing from Kumar's notion of avenues as ways of reaching aspirations [58], the group helped youth see the connection between their aspirations and taking avenues towards realizing them—tasks like adhering to medication and using appropriate contraception or medication like PrEP with partners. Even if youth theoretically knew the importance of these tasks previously, the connection was made more concrete in part by seeing evidence of how managing one's health could make a difference in one's life. P10 (15, M, G1) shared how he used to have to be pushed to take medications and would often miss them, but he became more proactive about taking medication after the group showed him that wellbeing was a real possibility: *“It helped me a lot because there are people in the group who are doing well and it motivated me to work hard to be like them.”* Experiential knowledge was especially helpful in ensuring that members sustained their efforts towards healthy living. As P37 (24, F, G2) shared, members now had a place to ask for advice in managing their health, rather than giving up on these tasks. For example, members asked the group about experiencing side effects from medication, having trouble getting their partner to use protection, or finding it difficult to disclose to their partner.

Formulating aspirations, learning how to work towards them, and having a support system built on each other. Younger participants told us they could more independently manage their health.

P16 (14, F, G1) described how knowing she was not alone made it easier to collect drugs from the facility on her own instead of relying on her mother. P17 (17, F, G1) explained that learning the importance of taking medication improved her life in a number of ways: *“For now, I am well, I don’t complain of my problems because I no longer contract malaria, cold, and flu every other time. I am strong, I can even help my mother in some activities at home... I even did well in my studies.”* Some participants felt they were now the same or even healthier than people who were negative, because they cared for their health more. However, the realization that people living with HIV could achieve the same goals as anyone else was not necessarily a tool for combating stigma as much as it was for conforming to societal standards of normalcy. As P37 (24, F, G2), a hairdresser, explained, one of her learnings was being able to cope with stigmatizing comments, to the point where she could go along with them:

*“I think we even learned more on how to live with people. You know, you know your status and maybe other people around you don’t know theirs, so somebody could start a topic like maybe somebody who has HIV cannot do my hair and you could get hurt thinking that they are talking about you. But now you also go with the flow and say that you also can’t get your hair done by such a person. You will just encourage them in what they are saying because after all she doesn’t know your status...”*

The benefits of the group were tied to the fact that there were both peers and a facilitator. As P48 (22, F, G2) described, peers were different from others supporters: *“...not everyone will have that courage to encourage you like them... the one that doesn’t have the experience will just tell you things are just okay, but they don’t want to tell you in which way.”* This attests to the importance of experiential knowledge, and how members took time to understand each other’s struggles. A facilitator who was seen as an expert but approached conversation like a peer was also valuable. Many participants saw him as someone who brought important topics to the chat and could offer expertise if members did not know the answer to something. This contrasted with experiences with healthcare workers who were more authoritative. P17 (17, F, G2) shared that before she joined the group, she was more stressed about managing her health, explaining that she *“had been quarreled so much.”* When asked by who, P17 explained, *“Certain doctor. She was asking me why I am not taking my drugs well and I could tell her that I forgot but she could not believe.”* The group also allowed members to resolve questions that hospitals were not helpful with. For example, P31 was distressed about how the hospital was not helping him with medications for his newborn, and sidechatted the facilitator for support in obtaining them. Overall, when asked to reflect on the intervention, most participants told us they wanted both a higher frequency of messages from the facilitator, and more members to make the groups active.

**4.4.3 Feeling the Limitations of Peer Support.** Despite the rewards, there were limits on the extent to which youth felt like they could support one another or even stay optimistic about their own future. The group offered a place to share challenges, but some participants felt helpless when members shared more serious ones. P41 (23, M, G2) explained how the group could only offer so much when a

member posted about suicidal thoughts: *“I was now a bit discouraged because I wondered if we are in the group helping each other. How comes that it has come to a place that she can say that. And yet we were still going on well.”* Members sharing negative experiences could also temper the encouragement that participants got from the group. For example, P36 (22, M, G2) described his feelings when members who had been on treatment for a much longer time than he had were struggling with side effects: *“...you see someone saying that he is in a bad state, and he is on medication, and period he has been taking the medication, and the complications that the person has, so that created fear in me... Like it seems like even me I will just be this way; with time I will be just this way.”* However, he also described how as a result he became more thankful and convinced that his own medication regimen was supporting his health. These findings further demonstrate how meeting peers of the same status affected participants’ views of the future—hopefulness was mixed with the realities of managing one’s health over the long term.

## 5 DISCUSSION

Our findings describe the emerging use of WhatsApp for facilitated peer support, outlining the social dynamics, patterns of use, and negotiation of privacy that shaped participants’ experiences, as well as how they felt the group supported them and their goals for the future. Below, we describe takeaways for the design of future chat-based peer support interventions, discussing ways to support the work of the facilitator and participants’ engagement. We also discuss privacy in mobile health applications in the Global South, and the ways safety could be supported through building trust as well as by design. We end by gleaned lessons for understanding and supporting aspirations in health interventions, drawing on our participants’ experiences with reclaiming aspirations in the context of peer support.

### 5.1 Considerations for the Design of Chat-based Peer Support

Participants overwhelmingly indicated that they would want more messages from the facilitator and more group members in future iterations. This brings up the question of how chat-based interventions can scale to more members or groups. Prior work shows how healthcare providers’ work increases with the addition of patient-provider channels, even with a small number of users, let alone many [122, 133]. In our study, scaling would entail sifting through a higher volume of messages in more groups, moderating more frequent conversations, and following up with more one-on-one chats and participants who need support. The most challenging work for the facilitator was practicing forms of constructive moderation, which has been proposed as a productive way to handle conflicts in already sensitive contexts [109, 132, 147]. Difficult questions to consider in this style of moderation on chat groups are what type of conversation is truly excluding members or making them uncomfortable and how long to allow such conversations to keep going before intervening. Because this was a peer support group and free discussion was encouraged, moderation thus involved a constant evaluation of how conversations were unfolding, in addition to answering specific clinical questions or checking on distressed

members—this is additional or more constant work compared to what has been noted in prior studies (e.g., [49, 63, 133]).

Challenges in the facilitator’s work are compounded by the affordances of chat. Unlike on a forum with threads, a chat group can easily be taken over by a small number of participants, making their conversation the sole focus. Channels or nested conversations could help alleviate problems with the single thread and organize conversations in general, but WhatsApp and most lightweight, personal chat apps do not support this. A single channel also helps ensure that all onlookers see threads being constructively moderated or questions being answered. Knowing when to intervene in threads is also made challenging by the invisibility of how onlookers feel about a conversation on chat—compared to WhatsApp, forums or other chat apps allow members to at least engage through more lightweight means like upvotes or reactions. However, there may also be benefits to reducing judgments about messages in such a sensitive context.

These challenges have implications for supporting facilitators of chat-based peer support groups. Whether healthcare workers are solely working as facilitators of such groups or are facilitating on top of other responsibilities (as in Wang et al.’s study [133]), their burden would increase with scale. One possibility for supporting facilitators in keeping track of threads is to encourage use of existing chat features and social dynamics. For example, starring messages on WhatsApp [139] could help keep a queue of messages that need replies, and the reply feature [138] can be used to let members know which thread is being revisited, even many messages later. Youth members could also take on certain facilitation tasks, such as encouraging engagement, especially given the sense of satisfaction they derived from supporting one another in the group. Further augments to chat apps could also be useful. Periodic, scripted messages such as the facilitator’s weekly message could be automated. Sentiment analysis has been proposed in prior work for determining which patients need follow up [133], and these tools could be adapted to understand the state of a conversation and whether it might need close attention as it unfolds.

On the participants’ side, understanding the full scope of their engagement required looking beyond the chat, at participant perceptions and technology access, one-on-one conversations, and offline interactions. This is a theme that work in HCI4D has explored extensively by looking at the human infrastructure [113] of and offline interactions around health dissemination interventions [59, 82, 114]. Sambasivan and Smythe demonstrate that attending to human infrastructures allows us to design for social and cultural processes [113]. One insight through this approach is the value of interactions outside the chat, such as in-person meetings or phone calls, which could be supported more purposefully by the intervention for participants who feel they would benefit from it. Another insight is that WhatsApp was used intermittently, more like a social media feed than the combination of synchronous and asynchronous use that prior work often discusses. Participants were encouraged by parents or even friends in the group to check their messages or buy bundles in order to log on. This is not to say that participants did not find the group beneficial, evidenced by how a sense of community persisted for many interviewees, even those who would log on weekly or even monthly. However, getting online may be more infrequent and purposeful, as studies have found for other

online health communities [3, 72, 73]. Prior work has proposed features that track and save mobile data when people get online [74, 112, 143], but we also find that curation of content can also be important to ensure that participants get the full value of the community whenever they can get online—this could also be useful for situations where there are simply many messages to check due to bursts of engagement from members. Here, further augments may be useful to provide structure to the chat for individuals accessing it after a while. For example, an interface that allows users to jump between weekly messages so they can navigate a week’s worth of discussion at a time matches the structure of the intervention itself while structuring the chat. Prior work has also designed summaries of chat conversations, which highlight certain types of discourse such as questions or resources [149]. Manually tagging or automatically detecting such messages and aggregating them could allow participants to easily view and jump to interesting questions, advice, or stories from past conversations.

## 5.2 Privacy in Mobile Health Interventions

Our findings around privacy show the value of an online health community articulating and developing privacy norms together, something that has been proposed in prior work in similarly sensitive contexts [109]. The meeting gave attendees a chance to voice the particularities of their situation, such as phone sharing, in order to ensure that privacy norms worked for them—in our case, using an app lock rather than a password on the whole phone. Beyond these notions of privacy, the meeting also allowed participants to become familiar with each other and ensure that they were confident discussing sensitive topics going forward, contributing to a sense of community in the groups. The fact that norms like using ambiguous wording in chat messages did not last long points to how participants’ increased comfort over time and desire to ask more specific health-related questions may have changed their level of concern about privacy, even though risk had not changed. However, we also saw how some expectations remained. P49, for example, explained how she would never share her messages with her partner and had expected the same of the person she was sidechatting with. This complicates findings from prior work that suggest anonymity could be viewed as a social contract between members [108]—even when perceived this way, different privacy concerns may wane while others remain very salient. It might be useful then for groups, even if they are comfortable spaces, to periodically revisit privacy norms to reinforce or update them.

Relying on social contracts among participants did have its privacy risks, bringing up the question of whether platforms intentionally designed for anonymity and privacy would be useful. For our participants, WhatsApp was convenient, and meeting in person was also important for their ability to trust in other members. Prior work has in fact suggested that using existing, widely used apps for communication around HIV helps makes it “ordinary” communication, as opposed to “unordinary”, and reduces the barrier to uptake [43, 135]. However, there can always be non-users of such platforms with good reason, and scholarship in HCI4D, such as studies by Natarajan and Parikh [88], Sambasivan et al. [110, 114], and Kumar et al. [60], describes the high-stakes privacy needs of populations like women whose phones are monitored, urban sex

workers, and people living with HIV in India and other South Asian countries. Taken together, these studies' findings suggest that on-line interactive peer interventions may not always be feasible, or may require more concerted outreach about the benefits of participation. Further, such interventions would likely need to emphasize privacy by design in order to foster a sense of safety.

In discussing the generalizability of our findings, we highlight considerations for supporting safety and interaction, depending on the goal of the intervention. Naseem et al. propose an interactive voice forum as an anonymous and private way for low-income, low-literate women in Pakistan to share experiences around mental health [87]. However, if more facilitation and interaction is desired, there may be distinct benefits to using chat, such as synchronous group discussion (with text or voice), multimedia, and relative ease of navigating messages. For these interventions, masking phone numbers and names or enabling untraceable private modes may be necessary, as suggested by prior work [60, 110, 144]. This is particularly important since app locks, visible or invisible, may not be feasible for people who share apps (such as younger participants in our study) or could otherwise draw suspicion for using privacy measures [110]. Tiered privacy models like Ahmed et al.'s Nirapod [5], which offers both secret and shared versions of a photo gallery app, could be another way to hide traces of the intervention while integrating with existing apps—using this model with chat apps could be explored, for example by allowing certain groups to be marked as part of a separate tier. Speaking to the design of the groups, the group size, mix of genders, and ability to sidechat in our study may not make sense in all contexts—if mistrust is high, too many connections and private interactions may be concerning, and multiple studies have noted the importance of safe spaces for women, especially from men who are strangers [1, 87]. Finally, in terms of interactions in the chat, enforced ambiguous wording (perhaps even through automated replacement of certain words with ambiguous wording) may be needed. Understanding interrelated values around privacy, safety, and sense of community, and how they might change over time, is important for future work on modalities of peer interventions for sensitive health concerns.

### 5.3 Aspirations in Health and Development

Our findings allow us to contribute to a growing body of HCI4D scholarship on aspirations and their role in design. Early work in this space looked at perceptions and use of technology as an avenue for reaching personal aspirations [58, 94–97, 105]. Toyama later made an explicit call to shift from understanding needs to aspirations in HCI4D [125–127]. The premise is that needs are often rooted in negativity, easily projected onto by researchers, and fall into a neoliberal framework of “solving” problems through individualized and quick solutions [125, 126]. Toyama argues that aspirations are rooted in more positive feelings, intrinsically motivated, and focus design on nurturing abilities and shifting attitudes, while highlighting the social forces involved in a problem [125, 126]. As more scholarship in HCI4D focuses on aspirations (e.g. [18, 55, 62, 99]), an open question is how to operationalize aspirations for research and design. Kumar et al. elaborate that aspirations are embedded in and even motivated by power structures, change over time, and have a timeframe that is relevant to design

[62]. In the health domain, Pendse et al. discuss how these qualities of aspirations are intermeshed with mental health [18, 55, 62, 99]. We describe below how horizontal peer relationships contributed to fostering and sustaining aspirations, offering takeaways for health interventions that seek to support and leverage aspirations.

Our work shows that youth developed aspirations that they previously thought were not achievable on account of their status. A major reason for being able to do this was exposure to new information and lived experiences, not through just anyone but through peers, helping youth realize that people just like them can and are living well. Peer support differs in the way it engages with the temporality and embeddedness of aspirations compared to other health-related peer interventions in HCI4D. Prior work on community-led video education, for example, shows how relatability can inspire viewers to use the information they learned when needed [61, 130]. Prior work also shows how focusing on futures inspired by the past is an important strategy for supporting wellbeing of people living with HIV [60]. In our study, we see that peer support *sustains* a view to the future through its consistent presence in participants' lives. In addition to showing youth that aspirations are still achievable, participants were able to work through the everyday struggles of adherence, emotional lows, and other uncertainties. The ability to do this was strongly tied to the context of peer support. Kumar et al. have suggested that role models and mentors can offer support for aspirations [62], and while we did see youth being inspired by others who were doing well in terms of their health, youth had largely horizontal relationships with each other. In fact, youth's hopefulness was also affected by those who were having greater challenges with side effects or mental health. The groups thus encouraged mutual support, as even those who were doing well recognized that they needed to continue managing their health and might need support in the future too. As one participant said, not everyone has “*that courage to encourage*” (P48) unless they have the same experiences too. Peer support also highlights the importance of “*others walking with me*” (P22), as opposed to following someone's lead. These dual values may be important considerations for technology intended to foster social support for aspirations, especially in the context of health concerns that must be supported over the long term.

We found that aspirations, along with a sense of community, could motivate participants to try to stick with difficult tasks. Prior work shows that people can hold aspirations without a roadmap for how to achieve them, listing this as a limitation of the potential of aspirations [105]. However, in our study, aspirations themselves were a motivating factor that made taking medication a more meaningful act. Looking at why such tasks were not personalized previously starts to reveal some of the challenges of existing health services from participants' perspectives. For example, one participant's experience showed how her doctor emphasized broader goals of adherence, but not necessarily personal journeys towards adherence. In contrast, through peer support, youth developed reasons to take medication and also saw that they were going to be understood if they struggled. Understanding these relationships confirms the importance of certain design decisions for supporting aspirations, for example, asking about personal goals or having a facilitator who is more like a peer rather than an authority figure. The importance of this type of support adds to prior work that

shows the potential usefulness of invoking authority in supporting adherence [133]—depending on participants’ prior experiences with healthcare, authority may also stem from commitment to overcoming shared struggles and experiential knowledge. Overall, examining existing social forces and how they do or do not foster aspirations around health can inform how health interventions can create environments that make tasks like adherence more meaningful. We do recognize, however, that we are discussing youth’s experiences and messaging behavior, not HIV treatment outcomes or validated measures of mental health. As Pendse et al. suggest with respect to mental health, such measures could further uncover the relationship between interventions and aspirations [99].

Aspirations in the context of a stigmatized illness like HIV were strongly tied to the desire to live a “normal” life. Though we did not ask about aspirations explicitly in this study, the aspirations that youth did describe were centered around personal goals. Youth were concerned with how they could “live with people” who are not positive, as opposed to how stigma could be ended, as P37’s example of going along with stigmatizing comments shows most strongly. Prior work has also noted how healthy living does not necessarily entail an end to stigma [60], and we find that though personal aspirations were certainly important, considering how youth said they were motivating, they may not entail visions for society. This boundary brings into question whether simply focusing on aspirations instead of needs can help design divest from a neoliberal framework of individualistic solutions [125]. To provide a systemic example, aspirations have been co-opted as a policy tool for furthering individualized notions of social mobility and reducing public resources [120]. Prior work on aspirations largely discusses individuals’ aspirations for themselves [125–127], but Kumar et al. and Pendse et al. show that aspirations are embedded in larger sociotechnical assemblages and ways of conceptualizing the future. It is possible that going beyond what individuals aspire to for themselves can support reflection on this embeddedness, especially in group settings. For example, we might also encourage discussion of youth’s aspirations around health for the communities they are a part of, whether that is their family, peers, school, or neighborhood. This could be a path towards understanding how individuals see their communities playing a role in visions for the future, as well as uncovering differences in those aspirations, aligning with prior work on online health communities as sites for building community capacity for change [98].

## 6 CONCLUSION

We presented a qualitative study of a six-month pilot of WhatsApp-based facilitated peer support groups, serving youth living with HIV in an informal settlement in Nairobi, Kenya. We found that despite tensions in group dynamics, intermittent participation, and challenges around privacy, youth were motivated by newfound aspirations and community to manage their health. These findings offered an understanding of the practicalities of chat-based peer support in terms of the facilitator’s work, participants’ engagement, and establishment (and change over time) of privacy norms. We also discuss how our findings further the concept of aspirations in health interventions, revealing the importance of horizontal

relationships in social support around aspirations and the limits of focusing solely on personal aspirations.

## ACKNOWLEDGMENTS

We are deeply grateful to the youth who brought their experiences, vulnerability, and energy to the groups. We would also like to thank anonymous reviewers for their thoughtful feedback on this work. This work was supported by the National Institutes of Health (grant numbers P30AI027757, K18MH122978, K24HD054314), as well as the University of Washington Global Center for Integrated Health of Women Adolescents and Children (Global WACH).

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