


# Social Support in a Virtual Community: Analysis of a Clinic-Affiliated Online Support Group for Persons Living with HIV/AIDS

Tabor E. Flickinger<sup>1</sup> · Claire DeBolt<sup>1</sup> · Ava Lena Waldman<sup>1</sup> · George Reynolds<sup>2</sup> · Wendy F. Cohn<sup>1</sup> · Mary Catherine Beach<sup>3</sup> · Karen Ingersoll<sup>4</sup> · Rebecca Dillingham<sup>1,5</sup> 

2017 Nov;21(11):3087-3099. doi: 10.1007/s10461-016-1587-3.

© Springer Science+Business Media New York 2016

**Abstract** Social support can improve outcomes for people living with HIV (PLWH) and could be provided through online support groups. The Positive Links smartphone app is a multicomponent intervention that allows users to interact in a clinic-affiliated anonymous online support group. We investigated how social support was exchanged in a group of 55 participants over 8 months, using an adaptation of the Social Support Behavior Code. Participant interviews assessed their experiences and perceptions of the app. Of 840 posts analyzed, 115 (14 %) were coded as eliciting social support and 433 (52 %) as providing social support. Messages providing support were predominantly emotional (41 %), followed by network (27 %), esteem (24 %), informational (18 %), and instrumental (2 %) support. Participants perceived connection and support as key benefits of the app. Technical issues and interpersonal barriers limited some participants in fully using the app. Mobile technology offers a useful tool to reach populations with barriers to in-person support and may improve care for PLWH.

**Keywords** HIV/AIDS · Online support group · Mobile app · Social support

## Introduction

Despite recent advances in care, many patients continue to face significant challenges in coping with HIV/AIDS. Social support can help to improve outcomes for people living with HIV/AIDS (PLWH) and has been associated with more active coping strategies, improved medication adherence, better immune function, and higher quality of life [1–4]. Perceived social support can improve both physical and mental health for PLWH, through direct and indirect mechanisms, including relief of depressive symptoms [5], which are a common barrier to adherence and retention in care [6]. PLWH are more likely to achieve suppressed viral loads if they perceive informational and emotional support to be available [7]. Informational support refers to the sharing of information or advice, while emotional support refers to the sharing of concern, encouragement, or the expression of caring for others. Social support can also take the form of esteem support (the expression of respect for others or confidence in them), network support (the concept of belonging to a group with similar concerns or experiences), or instrumental support (providing tangible assistance, such as performing a task or willingness to help others in a practical way) [8].

Online support groups may help provide social support and improve psychosocial function for patients coping with illness. Virtual connections may be particularly valuable to patients with barriers to seeking in-person groups, such as geographic or social isolation. In serious, life-threatening diseases such as cancer, patients seek both emotional and informational support online [9–13]. In many chronic

---

✉ Rebecca Dillingham  
rd8v@virginia.edu

<sup>1</sup> Department of Medicine, University of Virginia School of Medicine, Charlottesville, VA, USA

<sup>2</sup> Health Decision Technologies, Oakland, CA, USA

<sup>3</sup> Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, MD, USA

<sup>4</sup> Department of Psychiatry and Neurobehavioral Sciences, University of Virginia School of Medicine, Charlottesville, VA, USA

<sup>5</sup> UVA Center for Global Health,  
P.O. Box 801379, Charlottesville, VA 22908, USA

diseases, informational support tends to dominate online forums [14–16]. However, evidence of benefit is mixed, due to lack of high quality studies and studies that include online support as part of more complex interventions [17, 18].

For PLWH, use of the internet to seek health information and social connection is becoming increasingly common [19–21]. There is growing evidence that online tools using peer-to-peer support can help patients struggling with adherence to antiretroviral therapy (ART) [22], encourage risk reduction [23], and promote patient empowerment and psychological health [24, 25]. Social support in online networks appears to increase with the frequency of contacts between participants [26]. In one prior study of social support within a publically accessible online support group for PLWH, the most frequent types of posted messages were related to information support, followed by emotional, esteem, network support, and tangible assistance [27]. More evidence is needed to guide the development of technological interventions to promote social support for PLWH [28].

The Positive Links project offers a unique opportunity to observe social support mechanisms within a private, clinic-affiliated online support group, with assessment of user and non-user perspectives. The Positive Links smartphone app was developed with the input of patients seeking HIV care at a university clinic and includes the ability for users to interact on a community message board through anonymous user names. In this exploratory analysis, our research questions were (1) How is social support exchanged in a clinic-affiliated online support group for PLWH? (2) How do users and non-users of the online support group perceive its benefits and limitations as a source of support?

## Methods

### Development of the Community Message Board

Positive Links is a Smartphone app developed as part of a multi-component intervention intended to improve linkage and retention in care for PLWH in southwestern Virginia. Key features of the app include tailored educational resources; daily queries of stress, mood and medication adherence; appointment reminders; access to the study team for individualized counseling and assistance; and the opportunity for participants to interact anonymously on a community message board (CMB). Participants selected user names for themselves to protect anonymity, although participant's chosen user names were known to study investigators. This allowed the investigator team to monitor the board regarding posts that reflected mental health concerns, including suicidal content, as well as for

misinformation or inflammatory comments, and to communicate with participants privately, as needed. Positive Links staff members monitored the board daily by reading all posts. If a concern was identified, the staff member referred the issue to a licensed clinician to follow up with the participant and address the issue, for example, offering the participant individualized counseling or case management. The study team was able to link participants' user names to their study identification numbers, in order to facilitate analysis of users' demographic and clinical information. However, participant identities remained private on the board. Under their anonymous user names, participants could start new conversations on the board or respond to older conversations. The Positive Links team also introduced new conversation topics on HIV or general well-being. Participants could receive notifications on their app's main screen letting them know that a new post had been made.

During an iterative formative phase, patients seeking care at the university-based Ryan White HIV Clinic provided input on app design and features. During the current pilot phase of the study, participants were recruited from the clinic and from area AIDS service organizations (ASOs) and HIV testing sites. Eligibility criteria were focused on ability to use the app (either a score of 40 on the Wide Range Achievement Test (WRAT-4) or passing a subsequent reading test) and risk of falling out of HIV care (either HIV diagnosis since January 2012 OR at risk of falling out of care as determined by their care provider). The reading test corresponded to a fourth grade reading level and design of the app was tailored to accommodate low literacy. Providers assessed risk of falling out of care based on their experience with patients' missed appointments, difficulties with adherence, and psychosocial barriers to retention in care. Providers referred patients to the program by contacting the study team, who then made contact with patients to assess eligibility. Participants were given Samsung Galaxy 2 or Galaxy 3 phones with the app installed and a voice/data plan with unlimited minutes, texting, and data for the 18-month study period. Phones were encrypted and password protected and had a remote locate and wipe functionality. The app was also password-secured. The study team continued to refine the app using the feedback of participants. IRB approval was obtained for the study.

### Participant Characteristics

Enrollment for the current phase of the Positive Links study began in September 2013 and was ongoing through the study period. During enrollment, individuals consented to participate in the study, completed the WRAT-4 literacy test, and answered baseline questions. Participants were

then instructed in how to use the phone and Positive Links app. Participant training in using the phone and the app took approximately 10 to 15 min. Participants were not prompted to use the board at any particular time or frequency. They were informed of how to use it at enrollment and had the option to use it if they wished to do so. Participants then completed usability interviews after 3 weeks of enrollment to address any technical difficulties and obtain feedback on use of the app. Overall, participants were followed for 18 months and completed assessments at 6, 12, and 18 months. They received \$25 for completing the 12-month assessment and \$25 for completing the 18-month assessment. They did not receive any compensation for using the community message board. The project budget allowed for recruitment of 75 participants, which was our ultimate enrollment target. Enrollment took place on a rolling basis, with total recruitment of 77 participants achieved over the course of September 2013 to May 2015. This paper concerns our interim analysis performed on data collected up to May 2014. At that time, enrollment included 55 participants. This interim analysis timing was chosen as approximately half-way in the study follow-up period for the earliest enrollees. This time point was far enough into the study so that participants had the opportunity for interactions to occur on the CMB but early enough that changes could be made to the CMB app feature if it did not appear to be functioning as intended. The approach used was consistent with the study principles of following an iterative, user-driven process to optimize the app for participants.

Participants' demographic characteristics included age, gender, race, transmission risk behavior, time since diagnosis, and religious belief. Socio-economic variables included education, insurance status, employment status, and self-reported income. Participants also completed the Wide Range Achievement Test (WRAT-4) to assess literacy [29], the Perceived Stress Scale [30], and the Berger Stigma Scale [31]. Social support was evaluated using the Social Support Appraisals (SS-A) Scale, which has demonstrated good reliability, convergent and divergent validity with other social support measures, and predicted associations with psychological wellbeing [32]. Religious belief was assessed by self-report as an exploratory question of the role of religious belief in coping with HIV. During the formative phase of app development, religious and spiritual themes were frequently cited by clients of the clinic as important aspects of their HIV experience. Stigma was assessed using the Berger Stigma Scale, which has been previously validated and shown to be a possible mediator of engagement in care [31]. Participants were categorized as "newly diagnosed" if they were enrolled in the study less than three months after their HIV diagnosis.

Clinical data were extracted from the electronic medical record.

### Analysis of the Community Message Board

After 8 months, CMB posts were downloaded and analyzed. In order to evaluate social support messages on the CMB, content analysis was performed using the Social Support Behavior Code (SSBC) developed by Cutrona and Suhr [8]. This coding framework categorizes content intended to provide five types of support: information support (information or advice), esteem support (expressing respect or confidence in others), network support (belonging to a group with similar concerns or experiences), emotional support (expressions of concern or empathy), and instrumental support (providing tangible assistance). Subcategories were adapted from coding methods used in prior analyses of social support on a publicly accessible online support group for PLWH [27] and a Facebook group for HIV-infected youth [33]. We added further subcategories during our codebook development to capture additional types of expression that were prominent on the CMB: community companionship (as a subcategory of network support) and prayer (as a subcategory of emotional support). We also adapted coding methods used to assess posts seeking social support in three categories of information, emotional, and instrumental support [34].

Validity of the coding method was enhanced by using a previously established system for categorization of social support (the Social Support Behavior Code) and by expert consensus of the study co-authors on the adaptation of this coding system to our data set. Our expert team included the perspectives of an HIV care physician (RD), a clinical psychologist (KI), and an investigator in public health sciences with expertise in evaluation methods (WC). Team members were part of the Positive Links project and had access to the data. Reliability was assessed by using 2 independent coders (TF and CD) and an iterative process for development of the codebook. Analysis of the codes was performed by a primary analyst (TF) in discussion with a secondary analyst (CD), and presented for further discussion with the expert team (RD, KI, WC) in order to assess the validity of interpretation during the analysis process. This analysis categorized the types of support expressed and examined the context in which support-related posts occurred, focused on the interactions between posts seeking support and subsequent posts providing support in response. Team meetings during the analysis phase included updates on the themes elicited, categorization of themes, and synthesis of findings, as well as resolution of any discrepancies between the primary and secondary analysts. Final results were composed by the primary analyst (TF) and reviewed by all co-authors.

## Analysis of the Participant Interviews

Usability interviews for the participants (both users and non-users of the CMB) were transcribed for analysis. The focus of analysis in this study was to assess perceptions of potential benefits and barriers to the CMB as a source of social support. The interview guide included open-ended questions asking what users liked most about the app, which features they used, what problems they might have experienced, and what suggestions they might have for further improvements to the app. The interviewers explored responses further with clarification questions. The analytic method for the usability interviews used a constant comparisons approach to identify emerging themes from the qualitative data. Relevant themes to this analysis were categorized as perceived benefits of the app, negative aspects of the app, and barriers to using the app. Validity of this coding scheme was assessed by expert consensus, as described above. Reliability was assessed by using two independent coders and an iterative process for development of the codebook.

For both phases of analysis, codebooks were refined until excellent reliability was achieved (kappa 0.90 for social support message coding and kappa 0.84 for interview coding). Analyses were performed using NVivo qualitative data analysis software (QSR International Pty Ltd. Version 10, 2012).

## Results

### Participant Characteristics

Table 1 shows demographic and clinical characteristics of the study participants. Among the 55 participants in this analysis, mean age was 39 years (SD 11.68). Thirty-seven participants were male (67 %), seventeen were female (31 %), and 1 transgender male to female (2 %). Twenty-seven participants identified as black, non-Hispanic (49 %), 18 as white, non-Hispanic (33 %), 5 as multiple/other races (9 %), 4 as Hispanic (7 %), and 1 as Asian (2 %). Many participants were unemployed (45 %) and did not have insurance (35 %). Most participants identified themselves as religious (38 %) or spiritual (47 %). Thirty-three participants (60 %) had unsuppressed viral loads. At baseline, participants had unmet needs for social support, with mean scores of 43.51 (SD 12.38) on the Social Support Appraisal (SS-A) questionnaire [32]. This instrument measures perception of support received from family, friends, and others with a standardized scale up to a maximum score of 100. For comparison, mean scores have been reported in studies of alcohol dependence, ranging

from 37.7 to 64.7 among patients categorized as having low social support [35].

### Frequency of Posting on the Community Message Board

Of the 55 participants in this analysis, 24 posted on the board at least once. Due to rolling enrollment, participants were in the study for varying durations at the time of the 8-month interim analysis. Posters had been in the study for a mean of 23 weeks, ranging from 8 to 34 weeks. Posting frequency fluctuated over time, with the highest numbers of posts during the 28th week (71 posts, primarily among 3 users with 11, 19, and 21 posts each) and the lowest number of posts during the first 3 weeks of the study (0–2 posts). Total posts declined after the peak of 28 weeks, but use continued with 5–10 posts per week from week 30 onward. The number of posts per user per week was calculated, in order to account for the changing denominator of total users over time. On average, users posted 1.3 times per week, with a median of 0.5. The 3 highest utilizers posted on average 3.8, 4.8, and 5.1 times per week.

### Social Support on the Community Message Board

Of the 840 messages on the CMB, 115 (14 %) were coded as eliciting social support and 433 (52 %) as providing social support. Table 2 presents each category of social support messages, with definitions, examples, and frequency of occurrence. Participants' use of abbreviations and non-standard spelling and grammar has been retained in quoted messages.

Messages seeking social support were predominantly related to emotional support (74 % of messages seeking support; 10 % of total messages). These included posts asking for encouragement, comfort, congratulations, praise, empathy, concerns, or gratitude. Posts seeking information support were less common (26 % of messages seeking support; 4 % of total messages) and included posts asking for medical or health-related advice, guidance, or news. There were no posts classified as seeking instrumental support, though a small number of posts (1 % of total messages) did offer to provide instrumental support in response to messages that were primarily emotional in nature.

Messages providing social support were predominantly focused on emotional support (41 % of messages providing support; 21 % of total messages). Of subcategories of emotional support, the most common were encouragement (51 % of messages providing emotional support), expressions of care (41 %), and prayer (38 %). The subcategory of prayer was added during codebook development to

**Table 1** Characteristics of participants

Characteristic	All participants (n = 55)
Age in years: Mean (SD)	39 (11.68)
Gender (n[%])	
Male	37 (0.67)
Female	17 (0.31)
Transgender Male to Female	1 (0.02)
Race (n [%])	
Black, non-Hispanic	27 (0.49)
White, non-Hispanic	18 (0.33)
Multiple/Other	5 (0.09)
Hispanic	4 (0.07)
Asian	1 (0.02)
Education (n[%])	
Did not complete 12th grade	9 (0.16)
Completed high school	46 (0.84)
Sexual orientation (n[%])	
Has sex with men	39 (0.71)
Has sex with women	9 (0.16)
Has sex with both men and women	6 (0.16)
Declined to answer	1 (0.02)
Transmission risk (n[%])	
Men who have sex with men (MSM)	27 (0.49)
IV Drug User (IDU)	2 (0.04)
Not MSM (Includes heterosexual, Transgender)	26 (0.47)
Insurance (n[%])	
Public	24 (0.44)
Private	12 (0.22)
None	19 (0.35)
Employment status (n[%])	
Employed	30 (0.55)
Unemployed	25 (0.45)
Poverty: Mean % of federal poverty level (SD)	60.05 (78.79)
Religious practices (n[%])	
Spiritual	26 (0.47)
Religious	21 (0.38)
Neither	8 (0.15)
CD4 Count (n[%])	
Participants with CD4 < 200	13 (0.24)
Participants with CD4 > 200	42 (0.76)
Viral Load (n[%])	
Suppressed VL (VL < 50)	22 (0.40)
Unsuppressed VL (VL > 50)	33 (0.60)
Enrollment type (n[%])	
Newly diagnosed	13 (0.24)
Not newly diagnosed	42 (0.76)
Owens a cell phone (n[%])	
Owens a cell phone	43 (0.78)
Does not own a cell phone	12 (0.22)
Literacy level (Wrat Score): Mean (SD)	55 (9.25)
Perceived Stress Score: Mean (SD)	28.49 (9.16)
Social Support Score: Mean (SD)	43.51 (12.38)
Stigma Score: Mean (SD)	101.53 (17.97)

**Table 2** Types of social support sought and provided on community message board, with definitions, examples, and frequencies

Support category	Definition	Example	Number of posts	% of total posts
Seeking support (n = 115)				
A. Emotional support	Post asks for encouragement, comfort, congratulations, praises, empathy, concerns, or gratitude	“How can I feel good to talk about my HIV status with my roommate who is also a best friend to me?”	85	10.12
B. Informational support	Post asks for information on a particular subject, including medical or health-related advice, guidance, news, or findings	“Me to do u ever feel like u gain wait on it and do u ever think differently on it” (About a medication)	30	3.57
C. Instrumental support	Post asks for tangible aid		0	0
Providing support (n = 433)				
A. Emotional support (communicating love, concern, empathy)	Provides the recipient with hope, optimism, and confidence	“We are all blessed and can show the ENTIRE world that even though they may consider us to be less that we are stronger and even in better health than they are...”	178	21.19
Encouragement			90	10.71
Expression of care	Conveys supporter’s engagement of recipient’s wellbeing	“Thank you [X] hope all is well with you and just know that you have a friend in me”	73	8.69
Prayer	Offers prayer or blessings for the recipient, reminders of faith	“I thank the lord for another day healthy... I pray that you continue to bless... other people who deal with the same thing I do. I pray that you continue to give us the strenght to fight and get healthy again in Jesus name I pray AMEN...”	68	8.10
Empathy	Expressions of understanding the situation and/or discloses similar experience in a way that conveys understanding	“[X] I’d b untruthful if I told you that I understand bc I don’t but I could only speculate what’s like 2 do this without someone to hold...”	27	3.21
Virtual affection	Physical affection expressed (but virtual)	“We are here for you! *hugs*”	8	0.95
Sympathy	Conveys sorrow for the recipient’s distress	“Hey [X]... it will make you feel better to talk to someone close to you. I had to do the same it was hard but once I got it out I felt better”	6	0.71
Confidentiality	Keeps the recipient’s problem in confidence		0	0
B. Network support (communicating belonging to a group of persons with similar concerns or experiences)			115	13.69
Community companionship	Indicates community’s unique position to share experiences, importance of community closeness, and gratitude for community support.	“I remember when I first came on to the site [X] told me some things that actually helped me tremendously. And to this day I still think her everyday”	71	8.45
Presence	Presence of listeners and reminders that others are available to offer support	“ENJOY YOUR NIGHT MY FRIEND, IM ONE CLICK AWAY...”	52	6.19
Access	Messages that appeared to broaden recipient’s social network by establishing access to new members; “welcome” messages	“[X] here welcome to the fam”	19	2.26
C. Esteem support (gives positive feedback, communicating respect and confidence in abilities)			77	9.17
Compliment	Conveys positive assessments of the recipient and his or her abilities	“[X] that sounds like a great idea”	57	6.79
Validation	Acknowledges agreement or emphasizes similar views with recipient	“Ameen brother. We have HIV. It dosnt have us” (in response to another user’s posting)	25	2.98

Table 2 continued

Support category	Definition	Example	Number of posts	% of total posts
Relief of blame	Conveys that a particular action is not the fault or complete fault of the recipient		0	0
D. Informational support (gives information on a particular subject, including medical or health-related advice, guidance, news, or findings)			55	6.55
Advice	Suggestions or guidance for coping with difficulties associated with HIV or AIDS	"[X] they have curches that helps with food check out sum churches in ur area because its very important that you stay on trac with ur meds"	21	2.50
Situation appraisal	Reassesses or redefines a situation, often in a way that makes it more positive or shows new information that could be helpful	"...that's right [X] and believe it or not it could b worst..."	17	2.02
Sharing own experience	Conveys experience in a way that demonstrates specific knowledge of particular condition, such as changes in CD4 count or viral load	"[X], my cd4 was also very low, didn't find out I was hiv positive until a month ago. I was the walkingdead, still working and didn't know why I was so tired..."	12	1.43
Referrals to experts	Includes directing the member to a specific source, community resource, or website	"I asked the doctor about the zside effects to my med and got her to print out all the imfo on them. U should do so as well"	8	0.95
Teaching	Includes feedback that gives information or facts about the disease		0	0
E. Instrumental support (provides or offers to provide performance of a task, goods, or services directly related to the stress)			8	0.95
Active participation	Offers to join the recipient in an activity; includes concrete plans or planning to do something together	"[X] Hay bro hiking sounds awesome... Lets get something started for a Spring outing..."	5	0.60
Perform a task	Member actually performs an action on behalf of the recipient or the group	"1-800-555-5555 this numer is for those who need help. I talked with her. Please call if you need help"	2	0.24
Express willingness	Expressing willingness to help recipient	"If you think I can help you then please let me know how I can help"	1	0.12
Loan	Member loans money or object to another member		0	0



capture the prominence of spiritual expressions of support on the CMB.

Network support was offered in 27 % of messages providing support (14 % of total messages). These messages included posts establishing access (such as welcome messages to new members) and posts affirming the presence of community members available to listen and help. The subcategory of community companionship (62 % of messages providing network support; 8 % of total messages) was added during codebook development to include posts demonstrating the community's unique position to share experiences, the importance of community closeness, and gratitude for community support. The original subcategory of "relationship" under emotional support was incorporated into "community companionship" due to significant overlap between these concepts in the CMB posts. An example of this was observed in the evolution of a community identity, referred to by participants as the "Positive Links Posse" (PLP) or "Positive Links family".

Esteem support (24 % of messages providing support; 9 % of total messages) included posts giving positive feedback or communicating respect and confidence in other participants' abilities. Most of these were compliments, followed by validation. The subcategory of relief of blame was included in the codebook, as part of the categorization scheme used in other studies of social support, but no messages of this type were posted on the CMB.

Informational support was offered in 18 % of messages providing support (9 % of total messages). Most of these were advice, situational appraisal, or sharing of experience. A few posts did include referral to experts, such as directing others to seek input from their clinicians or staff at local support organizations. None were classified as teaching posts.

For each message coded as seeking support, an average of three responses was posted in reply from other participants providing support. For example, one exchange among participants began with a post seeking emotional support: "times are not easy doing it on my own I try to smile to hide my pain sometimes it's not that easy it's easy to just want to give up." Within a few minutes, other participants responded with multiple forms of support, including encouragement, prayer, virtual affection, empathy and expression of care, for example: "Its okay cry, just remember that god loves you & so do I, hugs I KNOW your day will get better"; "I know how u feel I but one thing I can say there is light at the end of the tunnel but all ur troubles on god shoulders and he will get u through trust me I know". The first participant followed up with more detail on struggles with adherence and meeting basic needs: "trying to stay on my meds but it-s hard with no food to eat". Others responded with additional emotional support, such as "When u feel u feel like this burden is to

much to bare and u feel there is no hope say a silent prayer god does not gives us wat we cant handle we all have come along way and givin up is not a choice so stay strong keep the faith and lets continue to fight we will overcome our struggles", and informational support with advice, such as "they have churches that helps with food check out sum churches in ur area because its very important that u stay on track with ur meds".

### Participant Perceptions of the Community Message Board

All study participants completed usability interviews 3 weeks after enrollment, even if they did not post on the CMB or use other app features. Of the 55 participants, 51 (93 %) reported a benefit from the app, 50 (91 %) described a potential barrier to using the app, and 24 (44 %) reported a negative aspect of using the app. Table 3 shows categories of benefits, barriers, and negative aspects. Participants could mention more than one category, which were not mutually exclusive, so frequencies may add up to more than 100 %.

In their interviews, 64 % of participants cited connecting with others and 42 % cited support as a benefit of the app. Connection was defined as expressions of user's ability to connect with others going through a similar experience or increased feelings of universality. Support was defined as expressions of giving, receiving, and observing others give or receive support.

In discussing the perception of connection, one participant said: "Like if I need someone to talk to, I can talk to someone, like someone is there, right there". Another said: "getting to see other people's perspective on life, let me know that I'm not going through this by myself, there is other people out there like me, it's good". One participant described difficulty in communicating with counselors, stating that "I don't feel connected to them only because they can guess at the situation but without them actually living the situation it's hard for them to really understand what's going on", whereas other users of the app could directly share the experience of living with HIV. This participant also reported that "I have a hard time expressing myself vocally anyway so it's always better that I can type out something have them type back". Making connections with others electronically appeared to be particularly important for those who had trouble doing so in person.

When asked what they liked most about the app, one participant said: "If I'm having a bad day, I can get on there and vent or whatever and then like it's real people that actually reply to my post and stuff and reply to how I'm feeling making me feel better...it's good to have somebody to talk to, even if it's just a text it's good to have



**Table 3** Types of impact reported by participants, with definitions and frequencies

Categories of impact	Definition	Number of people (n, %)
<b>Benefits</b>		
Self-monitoring	Describes benefit from ability to monitor mood and stress; describes increased self-awareness after monitoring	41 (74.55)
Keeping track of meds	Describes being more capable of keeping track of meds daily, finds that app supports adherence that was already good, or feels improved adherence to treatment regimen as a result of the app	39 (70.91)
Privacy	Feels that app is very secure and private and safe to have on a phone	35 (63.64)
Connecting with others	Likes ability to connect with others going through a similar experience; user has experienced increased feelings of universality	35 (63.64)
Connecting to the clinic	Benefits from appointment reminders, has improved engagement in HIV care, feels more connected to the clinic, benefits from the phone numbers for clinic being readily available	34 (61.82)
Easy to use	Reports that the application and/or the phone is easy to use	32 (58.18)
Benefits of phone	Reports using the phone for a variety of purposes in addition to the app	32 (58.18)
Resources	Reports learning from posted resources on the app, including resources on the CMB	26 (47.27)
Support	Benefits in giving, receiving, and seeing others give/receive support	23 (41.82)
Positive outlook	Develops more positive outlook as a result of the program	16 (29.09)
Experiences	Reports learning from the experience of other participants	9 (16.36)
Improved outside interactions	Describes that the application helps them better interact with people that do not have HIV, their partners, or people outside of the app	7 (12.73)
Fun	Describes that app can be entertaining, mentally stimulating, and/or fun	6 (10.91)
Goals	Reports liking the goal setting feature or having more success because goal-setting feature	3 (5.45)
Improved self-care	Reports improved self-care, outside of medication adherence; for example, user reports eating better or exercising more	2 (3.64)
Writing	Reports they find it easier to express self through writing or texting than they do vocally, and the app enables them to do so	2 (3.64)
<b>Negative aspects</b>		
Feelings of obligation	Describes feeling “forced” or obligated to use the app	10 (18.18)
Complaining	Discusses how CMB posts can seem to have a lot of complaining	9 (16.36)
Suicidal posts	Describes negative impacts of suicidal posts	5 (9.09)
Outsider	Describes disappointment with not receiving responses to posts	5 (9.09)
Vulgarity	Describes discomfort with vulgarity, poor language, or taboo topics on CMB	1 (1.81)
Too personal	Describes feeling uncomfortable with amount of personal information posted	1 (1.81)
Religiosity	Describes feeling uncomfortable with the level of religiosity on the CMB	1 (1.81)
<b>Barriers</b>		
Technical problems with application	Describes problems with application, such as difficulty navigating between screens, difficulty following conversations on CMB, having to scroll through screens, clearing notifications, appearance of newsfeed vs substance of message. They might also describe lack of awareness, such as not knowing about particular features	36 (65.45)
Phone problems	Describes difficulty with things related to the actual phone, like battery life or texting	24 (43.64)
Privacy concerns	Describes user concerns about privacy	12 (21.82)
Time constraints	Describes that user doesn’t have time to participate or review features of the app	10 (18.18)
Personal readiness	Describes a feeling of having no limitations except themselves, for example not feeling personally ready to discuss their HIV, not yet ready to interact on the application, or that they are in the process of “getting comfortable”	7 (12.73)
Communication rules	Describes limitations in participation on the CMB due to defined “cliques” within the CMB or unclear communication etiquette	7 (12.73)
No immediate feedback	Expresses frustration with lack of immediacy in feedback	3 (5.45)
Own phone	Describes that having two phones makes the Positive Links phone seem redundant	3 (5.45)
Other users	Describes knowing another user personally and feeling uncomfortable interacting with them	2 (3.64)
Participation	Describes being frustrated with lower levels of participation of other users	2 (3.64)

**Table 3** continued

Categories of impact	Definition	Number of people (n, %)
Forced anonymity	Describes wishing being able to talk directly with others or in person	2 (3.64)
Potential loss	Describes the potential of lost relationships once the study has been completed	1 (1.81)

somebody there that supports you.” Others expressed similar sentiments, such as: “You get to talk to people who are going through exactly what you are going through. When you are down somebody uplifts you, when somebody else is down you can uplift them, it’s basically like one big family.” In addition to receiving support, participants appreciated the opportunity of providing support for others. One expressed this concept by saying: “Yeah it’s very beneficial to everybody and me personally what helps me is helping others so if I can help somebody that helps me 10 times.” Another said: “you try and uplift someone else cuz they might be having a down day so I really look for all the positive things”.

Reading other users’ posts also provided a sense of support. One participant said: “I mean I may not post like all the time but most of the time I see what everybody is saying and I can relate”. Another expressed that “reading some of the things that the other people post really has opened my eyes that I’m not alone when there have been times when I have felt that I’m sort of in this darker box and alone”. Observing other participants helping each other was “very uplifting to see other people reach out to people they don’t know and literally lift them up and that shows that we are like all in this together”.

Participants were also asked about possible negative aspects of the app during their interviews. Some users felt that by participating in the study, they felt obligated to use the app, making it feel like a job (18 %). Although interactions on the CMB were predominantly positive, some participants did have concerns about posts perceived as too negative or “complaining” (16 %). The study team monitoring the CMB reached out to participants privately regarding posts that reflected mental health concerns, including suicidal content. Some users cited suicidal posts as having negative impacts on themselves, as participants reading the posts (9 %). Participants sometimes perceived some posts as “attacking” other users (9 %) or “too personal” in the content that was shared (2 %). Others felt like “outsiders” in the community (9 %) or felt excluded by the religious content on the CMB (2 %).

Some participants encountered barriers to using the app. The most commonly cited were technical problems with the app (65 %) and technical problems with the phone itself (44 %). Other concerns included privacy (21 %) and personal time constraints (18 %). Some participants

reported they did not feel personally ready to discuss topics on the CMB, even though it would be anonymously (13 %). Some participants reported not using the CMB due to concerns about communication etiquette within the community (13 %). Another potential barrier was the avoidance of forming connections due to concern of future loss of the community at the study’s conclusion (2 %). One participant said: “Well since I really haven’t posted yet, it really hasn’t affected me but I have thought you if you start posting if you start to build a friendship with some of these people, there is no way of knowing who they are even after the program is over”. The anonymity of the CMB was perceived as a benefit in ensuring privacy, but some users desired to meet in person and expressed frustration that this was not possible.

## Discussion

People living with HIV sought social support from and provided social support to their peers through a clinic-affiliated smartphone app with a community message board. Our findings suggest that online support groups on a smartphone can reach PLWH and help them engage in self-management and community building beyond their clinic visits. Strengths of this study include the use of 2 independent coders to enhance reliability of the qualitative analysis and complementing the content analysis with participant interviews, which have not been possible in prior studies of online social support for PLWH [27, 33]. In addition, our intervention targeted PLWH in the rural southern U.S., predominantly of racial/ethnic minorities and socioeconomic disadvantage, who bear a disproportionate burden of HIV and barriers to favorable clinical outcomes [36–38]. Positive Links shows promise in helping to address many of these barriers, including geographic and social isolation, and fostering social support as a means to improve mental and physical health for PLWH.

In our study, emotional support was the most commonly requested and provided form of social support observed. In contrast, a publicly accessible online support group for PLWH was dominated by information support [27]. On a private Facebook group affiliated with an HIV clinic’s young adult program, the most commonly requested type of support was emotional, while the most commonly given

was esteem support [33]. The relatively low proportion of information support exchanged on our CMB may indicate that participants relied on other sources besides their peers for information. Although the sharing of misinformation is a potential risk of online support groups, this was not observed. The involvement of the Positive Links study team may also mitigate this risk, as the team routinely monitored board content and could answer questions or clarify biomedical information.

Some subcategories of social support seen in other studies were not found on our CMB, such as posts seeking instrumental support [33] or posts providing teaching or relief of blame [27]. Subcategories were added to our coding scheme, which were prominent on our CMB but not in prior studies. In particular, community companionship and prayer were surprisingly important to many of our participants. On the CMB, participants appeared to value the community as a group united by shared experiences and referred to the group as the “Positive Links family” or “Positive Links Posse”. Although prayer was not universal to all participants, those who did seek and provide spiritual encouragement were able to support each other. In our sample, most patients identified themselves as religious or spiritual. This likely reflects the demographics and culture of our clinic population in the rural southern United States, which differs from the predominantly urban populations of prior studies of social support among PLWH. Many African-American PLWH in the southern United States report unmet needs for social support from faith communities [39] and may seek this support from more informal connections with peers who are also PLWH. However, it should be noted that religious content on the CMB was perceived as a barrier to some users, who felt excluded rather than supported by it.

Participants perceived connection and support as important benefits of the app. In particular, the CMB allowed people who previously felt alone to find others who could share their experiences. Participants’ comments about support primarily focused on emotional support, expressing appreciation for the empathy, sympathy, encouragement, and care communicated on the CMB. Network support was also perceived by participants, especially the importance of community companionship. The community felt like a “family” who cared about each other and were present to help. Even those who did not post on the CMB perceived benefit from observing others giving and receiving support in the community. This aspect of the CMB was not visible in the posts themselves but became clear in the usability interviews. Similarly, the value of providing support to others emerged from the interviews, as participants expressed a sense of fulfillment and more positive outlook from their ability to help others in the community.

However, negative interactions on the CMB also occurred and may undermine the potential benefits. Most interactions were positive, but some posts were perceived as complaining too much, attacking others, sharing too much information, or excluding those who did not feel like a part of the group. Barriers to participation were also reported, which may prevent full utilization of the CMB. Technical issues were the majority of barriers discussed, but personal barriers were perceived as well. In particular, some participants may be reluctant to form connections through the CMB, without the ability to meet in person or maintain the community beyond the study period.

This study has several limitations to consider. The project is in a pilot phase with a relatively small sample size. Also, the project remains ongoing, with rolling enrollment since the CMB and interview data were captured for this analysis. The app continues its iterative development process with changes made based on participant feedback in order to optimize its function and usability. With rolling enrollment and changing features of the board, not all users had equivalent amounts of time as a participant in the study. Additionally, various features to improve usability were added as a result of the ongoing development process, making comparison between users challenging. Some participants did not use the board and some within the board posted more frequently than others. Further analysis of patterns of use is planned, for the board and other app features, to delineate how participants interact with the app and with the community over time and to determine if certain patterns of use are more beneficial than others. Finally, the app is affiliated with the clinic and monitored by the study team, which may limit generalizability to other populations or contexts. Generalizability may also be limited by the fact that the phones and data plans were provided to participants with the cost supported by grant funding. Next steps for this project include development of plans for adapting the app for installation on users’ own phones (if they already possess one) and subsidies for phones and service (if needed) in order to make the app accessible to more users. A full cost-effectiveness analysis is also planned at the conclusion of follow-up. This paper presents an interim analysis, for which detailed cost data and longitudinal clinical outcomes are not yet available. These analyses are pending and expected to provide further information on the efficacy of the program and considerations for implementation and dissemination at other sites.

The Positive Links app offers an innovative way to address needs for social support among PLWH. Patients with barriers to accessing in-person support may particularly benefit from the ability to form virtual communities, in which they can seek and provide support to others with shared experiences. Next steps include further longitudinal

follow-up to assess clinical outcomes in participants and implementation of the app in other populations for reproducibility and optimization. Ultimately, the use of technology to connect people and offer social support may be a valuable tool in improving quality of life and outcomes for PLWH.

**Funding** This project was supported by the M.A.C.AIDS Fund and AIDS United. These sponsors had no role in study design; in the collection, analysis and interpretation of data; in the writing of the report; or in the decision to submit the article for publication. There is no associated grant number.

### Compliance with Ethical Standards

**Conflicts of interest** None of the authors declare any conflicts of interest.

**Ethical approval** All procedures performed in this study that involved human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All participants in this study provided informed consent prior to entering the study.

### References

- Burgoyne R, Renwick R. Social support and quality of life over time among adults living with HIV in the HAART era. *Soc Sci Med.* 2004;58(7):1353–66.
- Catz SL, Kelly JA, Bogart LM, Benotsch EG, McAuliffe TL. Patterns, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease. *Health Psychol.* 2000;19(2):124–33.
- Kim SH, McDonald S, Kim S, Foster C, Fidler S. Importance of self-motivation and social support in medication adherence in HIV-infected adolescents in the United Kingdom and Ireland: a multicentre HYPNet study. *AIDS Patient Care STDS.* 2015;29(6):354–64.
- Leserman J. Role of depression, stress, and trauma in HIV disease progression. *Psychosom Med.* 2008;70(5):539–45.
- Bekele T, Rourke SB, Tucker R, Greene S, Sobota M, Koornstra J, et al. Direct and indirect effects of perceived social support on health-related quality of life in persons living with HIV/AIDS. *AIDS Care.* 2013;25(3):337–46.
- Mugavero M, Ostermann J, Whetten K, Leserman J, Swartz M, Stangl D, et al. Barriers to antiretroviral adherence: the importance of depression, abuse, and other traumatic events. *AIDS Patient Care STDS.* 2006;20(6):418–28.
- Burgoyne RW. Exploring direction of causation between social support and clinical outcome for HIV-positive adults in the context of highly active antiretroviral therapy. *AIDS Care.* 2005;17(1):111–24.
- Cutrona CE, Suhr J. Controllability of stressful events and satisfaction with spouse support behaviors. *Commun Res.* 1992;19:154–74.
- Wang YC, Kraut RE, Levine JM. Eliciting and receiving online support: using computer-aided content analysis to examine the dynamics of online social support. *J Med Internet Res.* 2015;17(4):e99.
- Hoey LM, Ieropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. *Patient Educ Couns.* 2008;70(3):315–37.
- Coulson NS, Greenwood N. Families affected by childhood cancer: an analysis of the provision of social support within online support groups. *Child Care Health Dev.* 2012;38(6):870–7.
- Elwell L, Grogan S, Coulson N. Adolescents living with cancer: the role of computer-mediated support groups. *J Health Psychol.* 2011;16(2):236–48.
- Helgeson VS, Cohen S. Social support and adjustment to cancer: reconciling descriptive, correlational, and intervention research. *Health Psychol.* 1996;15(2):135–48.
- Coulson NS. Receiving social support online: an analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. *Cyberpsychol Behav.* 2005;8(6):580–4.
- Coulson NS, Buchanan H, Aubeeluck A. Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. *Patient Educ Couns.* 2007;68(2):173–8.
- Holbrey S, Coulson NS. A qualitative investigation of the impact of peer to peer online support for women living with polycystic ovary syndrome. *BMC Womens Health.* 2013;13:51,6874-13-51.
- Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ.* 2004;328(7449):1166.
- Griffiths KM, Calear AL, Banfield M. Systematic review on internet support groups (ISGs) and depression (1): do ISGs reduce depressive symptoms? *J Med Internet Res.* 2009;11(3):e40.
- Blackstock OJ, Houghton LJ, Garner RY, Horvath KJ, Norwood C, Cunningham CO. General and health-related Internet use among an urban, community-based sample of HIV-positive women: implications for intervention development. *AIDS Care.* 2015;27(4):536–44.
- Horvath KJ, Danilenko GP, Williams ML, Simoni J, Amico KR, Oakes JM, et al. Technology use and reasons to participate in social networking health websites among people living with HIV in the US. *AIDS Behav.* 2012;16(4):900–10.
- Samal L, Saha S, Chander G, Korthuis PT, Sharma RK, Sharp V, et al. Internet health information seeking behavior and antiretroviral adherence in persons living with HIV/AIDS. *AIDS Patient Care STDS.* 2011;25(7):445–9.
- Horvath KJ, Oakes JM, Rosser BR, Danilenko G, Vezina H, Amico KR, et al. Feasibility, acceptability and preliminary efficacy of an online peer-to-peer social support ART adherence intervention. *AIDS Behav.* 2013;17(6):2031–44.
- Muessig KE, Baltierra NB, Pike EC, LeGrand S, Hightow-Weidman LB. Achieving HIV risk reduction through HealthMpowerment.org, a user-driven eHealth intervention for young Black men who have sex with men and transgender women who have sex with men. *Digit Cult Educ.* 2014;6(3):164–82.
- Mo PK, Coulson NS. Online support group use and psychological health for individuals living with HIV/AIDS. *Patient Educ Couns.* 2013;93(3):426–32.
- Mo PK, Coulson NS. Developing a model for online support group use, empowering processes and psychosocial outcomes for individuals living with HIV/AIDS. *Psychol Health.* 2012;27(4):445–59.
- Chen L, Shi J. Social support exchanges in a social media community for people living with HIV/AIDS in China. *AIDS Care.* 2015;27(6):693–6.
- Mo PK, Coulson NS. Exploring the communication of social support within virtual communities: a content analysis of messages posted to an online HIV/AIDS support group. *Cyberpsychol Behav.* 2008;11(3):371–4.
- Pellowski JA, Kalichman SC. Recent advances (2011–2012) in technology-delivered interventions for people living with HIV. *Curr HIV/AIDS Rep.* 2012;9(4):326–34.
- Casaleto KB, Cattie J, Franklin DR, Moore DJ, Woods SP, Grant I, et al. The wide range achievement test-4 reading subtest

- “holds” in HIV-infected individuals. *J Clin Exp Neuropsychol*. 2014;36:992–1001.
30. Koopman C, Gore-Felton C, Marouf F, Butler LD, Field N, Gill M, et al. Relationships of perceived stress to coping, attachment and social support among HIV-positive persons. *AIDS Care*. 2000;12:663–72.
  31. Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Res Nurs Health*. 2001;24:518–29.
  32. Vaux A, Phillips J, Holly L, Thomson B, Williams D, Stewart D. The social support appraisals (SS-A) scale: Studies of reliability and validity. *Am J Commun Psychol*. 1986;14(2):195–196–219.
  33. Gaysynsky A, Romansky-Poulin K, Arpadi S. “My YAP Family”: analysis of a Facebook group for young adults living with HIV. *AIDS Behav*. 2015;19(6):947–62.
  34. Rui JR, Chen Y, Damiano A. Health organizations providing and seeking social support: a Twitter-based content analysis. *Cyberpsychol Behav Soc Netw*. 2013;16(9):669–73.
  35. Bischof G, Rumpf HJ, Hapke U, Meyer C, John U. Types of natural recovery from alcohol dependence: a cluster analytic approach. *Addiction*. 2003;98(12):1737–46.
  36. Mugavero MJ, Pence BW, Whetten K, Leserman J, Swartz M, Stangl D, et al. Predictors of AIDS-related morbidity and mortality in a southern U.S. Cohort. *AIDS Patient Care STDS*. 2007;21(9):681–90.
  37. Pence BW, Reif S, Whetten K, Leserman J, Stangl D, Swartz M, et al. Minorities, the poor, and survivors of abuse: HIV-infected patients in the US deep South. *South Med J*. 2007;100(11):1114–22.
  38. Reif S, Mugavero M, Raper J, Thielman N, Leserman J, Whetten K, et al. Highly stressed: stressful and traumatic experiences among individuals with HIV/AIDS in the Deep South. *AIDS Care*. 2011;23(2):152–62.
  39. Pichon LC, Rossi KR, Ogg SA, Krull LJ, Griffin DY. Social support, stigma and disclosure: examining the relationship with HIV medication adherence among Ryan White Program Clients in the Mid-South USA. *Int J Environ Res Public Health*. 2015;12(6):7073–84.