**The Experiences of Newly Diagnosed Men Who Have Sex with Men (MSM) Entering the HIV Care Cascade in Lima, Peru, 2015-2016: A Qualitative Analysis of Counselor-Participant Text Message Exchanges**

Erik Bayona[a], Luis Menacho[c], Eddy R. Segura [b,d], Gitau Mburu[e], Fernando Roman[c], Consuelo Tristan[c], Elizabeth Bromley[a], Robinson Cabello[c]

[a]David Geffen School of Medicine at University of California, Los Angeles

[b]Department of Medicine, Division of Infectious Disease, University of California, Los Angeles

[c]Asociación Civil Vía Libre, Lima, Peru

[d]Escuela de Medicina, Universidad Peruana de Ciencias Aplicadas, Lima, Peru

[e]International HIV/AIDS Alliance, Hove, United Kingdom

Corresponding Author

Erik Bayona

Email: EBayona@mednet.ucla.edu

The David Geffen School of Medicine at UCLA

10833 Le Conte Ave. Los Angeles, CA 90095

818- 730-7425 (mobile phone)

**Running title**: patient experiences during early hiv care in peru

**Abstract**

Mobile phone technology (mHealth) is a promising tool that has been used to improve HIV care in high-riskpopulations worldwide. Understanding patient perspectives of newly diagnosed men who have sex with men (MSM) in Lima, Peru during linkage and engagement in the HIV care continuum can help close the gaps in care following initial HIV diagnosis and ensure retention in continuous care. From June 2015 to March 2016, as part of a randomized controlled trial, 40 MSM participants were linked to care with an mHealth intervention within 3 months of HIV diagnosis at Via Libre clinic. For 12 weeks, participants agreed to receive weekly predetermined, standardized short message service (SMS), WhatsApp[a], and/or Facebook[a] messages from an assigned HIV counselor. Text messaging was bi-directional, meaning participants could also send messages to their counselor at any time. In this qualitative study, we coded and thematically analyzed 947 SMS, 918 WhatsApp, and 2,694 Facebook bi-directional messages. Mean age of participants was 29.8 years (20–50); with 70 percent reporting some post-high school education and 73 percent self-identifying as homosexual. We identified six recurring themes that emerged from the data: (a) mental health symptoms; (b) coping behaviors; (c) interpersonal support; (d) physical symptoms; (e) HIV knowledge; and (f) care coordination. Participants sent text messages describing depressive symptoms and seeking mental health services during this initial stage of HIV care. For newly diagnosed MSM entering the HIV care continuum, a bi-directional mHealth intervention provided support to facilitate care while eliciting deeply personal mental and emotional states. Future interventions could benefit from using mHealth interventions as ancillary support for clinicians.


**Keywords**: mHealth, eHealth, HIV, HIV care continuum, MSM, recently diagnosed

**Introduction**

In Peru, men who have sex with men (MSM) are disproportionately affected by HIV, with an incidence of 3.5% and a prevalence of 12.4% among MSM in metropolitan Lima[1]. HIV care in recent years has been guided by the finding that initiating early anti-retroviral treatment (ART) is preventative[2]. A treatment paradigm known as the HIV "cascade", or continuum of care, has defined a stepwise sequence to guide care: early diagnosis, linkage to care, retention in care, early ART initiation, and attainment of an undetectable viral load[3].

Unfortunately, the delivery of HIV care worldwide has struggled to fully realize the benefits of treatment as prevention due to drop offs occurring in the early stages of the cascade during linkage, engagement, and retention[4]. The drop offs in the cascade are especially relevant for socially marginalized groups such as MSM who persistently have elevated incidence and prevalence rates of infection compared to the rest of the population. A recent estimate of the 2015 Peruvian HIV care continuum calculates a 64.9% rate of retention in care among MSM and transgender women (TW) who have been diagnosed as HIV-positive[5]. Previous studies have shown that linkage and retention are difficult to achieve, with as many as one in five HIV-positive patients choosing not to establish care after their first clinic visit[6].

Mobile health (mHealth) interventions, such as text messaging, have been a promising avenue for improving HIV care and have recently been utilized to support patients who are at the highest risk of disengaging from care[8]. According to World Bank data from 2015, Peru is classified as an upper-middle income country with 40.9 per 100 people in Peru being internet users, defined as accessing the internet at least once from a computer or mobile device[9]. Similarly, telecommunications research shows that at the end of 2016 Peru had 113% mobile phone penetration, with many urban dwellers having multiple phone lines, yet

approximately one-fifth of the population with no mobile phone access whatsoever[10]. Previous mHealth interventions targeting MSM have shown high acceptability among this marginalized group[11,12,13,14], however these past Peruvian mHealth interventions have emphasized only two steps of the HIV cascade, mainly diagnosis and treatment. Although early diagnosis and treatment initiation are key steps in the cascade, it has been increasingly recognized in recent yearsthat patient attrition at the intermediate steps of the cascade poses barriers to the treatment as prevention approach[3, 7]. Specifically, poor patient engagement in care, delayed linkage to care, and low retention in care have been demonstrated to increase viral load and overall mortality[7].

Additionally, past Peruvian mHealth interventions have also not addressed sub-groups that are at increased risk for disengaging in care such as MSM who have been recently diagnosed with HIV infection. Relatively few qualitative studies have been conducted to assess Peruvian mHealth interventions, and when they have, they were narrowly focused on measuring HIV testing and ART adherence outcomes[11,12]. As a previous study has pointed out, the HIV care cascade has been constructed by healthcare providers and is limited by their worldview that is different from that of patients[22]. Thus, it is crucial to gain a deeper awareness of the patient experience at each step of the HIV care cascade in order to understand why drop offs occur and how to prevent them. The objective of this qualitative study is to analyze data generated from an existing mHealth intervention to gain a more detailed understanding of patient experiences during the early stages of the cascade, including linkage, engagement, and retention in HIV care among recently diagnosed MSM.

**Methods**

*Original Study Design and Participants*

The data analyzed in this study were collected from a randomized controlled trial testing a text message-based (mHealth) intervention aimed to increase linkage and retention in HIV care among adult MSM attending an HIV Clinic (Via Libre NGO) in Lima, Peru. From June 2015-March 2016, we enrolled HIV-positive MSM (n=80) diagnosed within the last 3 months who owned a mobile phone to either establish bi-directional text message communication (n=40) or not (n=40), with both groups also receiving standard HIV post-test counseling. We analyzed text message conversations in Spanish from the 40 participants in the intervention group.

Participants were recruited from the Via Libre clinic within three months of testing HIV positive, with 75% of the total 80 participants being linked to care on the same day of their diagnosis. We defined linkage to care as the first clinic visit with an infectious disease specialist after initial diagnosis. Participants were offered two free clinic visits and a discount on lab services for agreeing to participate in the study.

*mHealth Intervention*

The bi-directional text message intervention was designed to facilitate access to care with the goal of improving linkage, engagement, and retention along the HIV care continuum. Participants in the intervention arm agreed to receive weekly messages for atotal of 12 weeks through short message service (SMS), WhatsApp©, and/or Facebook© platforms from an assigned HIV counselor. Via Libre NGO counselors were trained to provide emotional support, answer questions, and identify participants that needed immediate medical care from a physician. A set of 24 standardized text messages were created with the help of current

HIV-positive MSM receiving treatment at Via Libre clinic and were later validated by the research team through personal interviews with a second group of long established clinic patients.

Text messages were tailored to elicit barriers and facilitators of care while encouraging in-depth conversation. Participants used their personal mobile phones to send and receive text messages. This intervention allowed for bi-directional communication with an assigned HIV counselor meaning that participants could respond to messages and initiate conversations at any time during the study period. In addition to sending participants weekly standardized text messages, the study counselors also provided feedback, support, and suggested coping strategies in response to participant questions and comments. This study was reviewed and approved by both the UCLA and Via Libre IRB.

*Data Analysis*

Over 12 weeks, participant-counselor text message exchanges took place resulting in 947 SMS, 918 WhatsApp, and 2,694 Facebook messages. Our analysis followed the general principles of a thematic approach[15,16]. The first step was immersion in the data by a Spanish-speaking author (EB) to ensure a complete review of text message transcripts[16, 18]. Upon iterative review of the transcripts, preliminary coding ensued using an inductive approach, consistent with grounded theory, and employing the constant-comparative method for open coding of keywords and repetitive concepts originating in the data until saturation was reached[15,16,17, 18, 19].

A second Spanish-speaking author (LM) conducted a separate in-depth, detailed reading of the transcripts to refine the preliminary codes. Coding disagreements were resolved by

creating new codes and removing existing codes as needed. All coding and interpretation was performed manually. Once the entirety of text message transcripts was coded, recurring themes were identified, sorted, and organized. The research team completed the analysis after several meetings to discuss the accuracy of the themes, resolve disagreements, and further refine the themes.

**Results**

*Participants and Main Themes*

Mean age of the 40 participants in the mHealth intervention was 29.8 years (20-50); with 70% reporting some post-high school education and 73% self-identifying as homosexual. Most participants used WhatsApp and/or Facebook for messaging, although six participants did not respond to Facebook messages. Our findings reflect that among the 918 WhatsApp messages exchanged, 523 (57%) were sent by the participants while 395 (43%) were sent by the counselors. Similarly, out of the 2,694 Facebook messages exchanged, 1,411 (52%) were sent by the participants while 1,283 (48%) weresent by the counselors. In our study, SMS was used less often and a total of four participants did not reply to SMS messages. Among the 947 SMS messages analyzed, 426 (45%) were sent by the study participants while 521 (55%) were sent by the counselors. Regardless of platform used, all participants initiated a conversation at least once with their assigned HIV counselor at some point during the 12 week follow up.

We found that a qualitative analysis of participant-counselor text message exchanges was important to reveal not only the nature of support provided by the counselors during this mHealth intervention, but also to reveal concerns, challenges, and solutions that were most impactful during the early stages of the cascade for our recently diagnosed MSM participants.

Our coding of themes reflected the typical topics of conversation that emerged naturally, with an emphasis on understanding how participants utilized the mHealth intervention and identifying opportunities to provide support during the early phases of the cascade. We found that six themes emerged from the data: (a) mental health symptoms; (b) coping behaviors; (c) interpersonal support; (d) physical symptoms; (e) HIV knowledge; and (f) care coordination. Table 1 demonstrates representative quotes for each of these themes, with a summary of the codes comprising each theme.

*Mental health symptoms*

The first theme, mental health symptoms, included depression, anxiety, affect, positive mind states, and negative mind states. Although our study did not screen for depression or co-morbid mental illness, the majority of patients sent text messages to their counselors expressing content fitting this theme of mental health symptoms. Many participants explicitly used the word depression in their text messages to counselors, with one participant even saying "well, I left my job because I was so depressed about the news of my diagnosis." The anxiety code was applied if a patient expressed feeling panic, nervousness, or anxiety.

If patients referred to more general emotional states or mood, then the text message data were coded as affect. Positive mind state and negative mind state codes were applied when participants expressed cognitive patterns that produced either a state of positive or negative outlook. The text message exchanges that occurred within this theme emerged from natural conversations that developed either from participant initiated messages or as a reply to personalized messages sent by the counselor. The distribution of these exchanges usually ranged between 30 to 90 minutes for a typical conversation within this theme.

*Coping behaviors*

The second theme, coping behaviors, was comprised of the codes of disclosure, diet changes, exercise, attending therapy, and lifestyle modifications. Text messages within this themerepresented overall positive coping strategies for living a healthier life (eating a balanced diet, eliminating harmful habits) and promoting a sense of wellbeing (relaxation activities, talking to a therapist). Some participants texted their HIV counselors about their ongoing engagement in gestalt therapy or other psychological counseling, while a few other participants sent text messages requesting mental health services at Via Libre NGO with the staff psychologist. The text message exchanges that occurred within this theme emerged from both participant responses to standardized messages and from natural conversations. The distribution of these exchanges in time ranged from a single message response stating "I am fine thanks, I have started taking vitamins and eating better" to a more in depth conversation lasting up to 45 minutes.

*Interpersonal support*

The third theme, interpersonal support, included the codes of family support, partner support, and partnership conflict. Text messages were coded as family support if participants expressed any family member responding positively to provide a sense of comfort or stability. We used the codes for partner support and partnership conflict to distinguish between positive responses by their partners resulting in wellbeing and strengthening of the partnership and negative responses by their partners which created distrust, quarrels, and ending the relationship. The text message exchanges that occurred within this theme emerged from both replies to standardized messages and natural conversations. The distribution of these exchanges in time tended to be longer and it typically took between 30 to 120 minutes for a natural conversation within this theme to develop.

*Physical symptoms*

The fourth theme, physical symptoms, included the codes of medication reactions, physical symptoms, co-infections, and clinical support. Text messages were coded as medication reactions if participants described rashes, headaches, or nausea that developed as a direct result of taking anti-retroviral medication. The code of physical symptoms was applied to messages concerning any other physical ailment such as pain, fevers, malaise, body aches which were not directly related to anti-retroviral medications. Co-infections referred to messages in which patients described being diagnosed with a sexually transmitted infection in addition to HIV. Messages by counselors that either provided reassurance or directly setting up clinical services were coded as clinical support. The text message exchanges that occurred within this theme emerged from both replies to standard text messages and natural conversations. The distribution of these exchanges in time typically ranged between 10 to 60 minutes for the conversation to take place.

*HIV knowledge*

The fifth theme, HIV knowledge, included the codes of transmission, misinformation, and clinician expertise. Messages in which participants expressed what they knew or understood about HIV modes of transmission were coded as such. The code of misinformation was used when messages described false beliefs, stereotypes, or other false information about HIV that was regarded as true by participants. Messages were coded as clinician expertise when participants described a doctor or nurse explaining and clarifying HIV information to them or when counselors provided education to participants. The text message exchanges that occurred within this theme emerged from both replies to standard text messages and natural conversations. The distribution of these exchanges in time ranged from a single message

reply by participants to a 30-minute text conversation.

*Care coordination*

The sixth theme, care coordination, included codes of economic concerns, scheduling appointments, and laboratory follow up. Messages were coded as economic concerns when participants asked questions about the cost of services and expressed concerns about being able to pay for treatment. Messages involving scheduling and rescheduling were coded as such. The laboratory follow-up code was applied when either participants or counselors discussed lab or exam results. The text message exchanges that occurred within this theme emerged from both responses to standardized messages and natural conversations. The most common patient initiated message was related to scheduling issues. The distribution of these exchanges in time ranged from 10 to 90 minutes for the conversation to take place.

**Discussion**

In this qualitative study of an mHealth intervention examining the experiences of MSM newly diagnosed with HIV navigating the early steps of the HIV care continuum, we gained important insights from a patient perspective that are not evident in the provider-defined care model as is currently applied in the Peruvian context. The six themes that emerged from our analysis of the text message data showed that participants expressed concerns about mental health symptoms and asked questions about coping skills during the linkage and engagement steps in the HIV care continuum. Additionally, the themes we identified captured the potential of an mHealth intervention to be used as ancillary support for clinicians through participant reporting of mental health and physical symptoms, dissemination of accurate HIV information by counselors, and enhanced care coordination. These results are especially significant given that this is the first qualitative study, to our knowledge, to present patient

experiences of MSM who have been recently diagnosed with HIV navigating the early and intermediate steps of the Peruvian HIV care continuum.

One of the main overarching themes emerging from our analysis of the text message data was related to discussions centering on mental health symptoms. Our results show that despite our study not screening for depression, the majority of our participants self-disclosed feeling anxious, having depressive symptoms, or explicitly used the word depressed to describe how they felt. This finding complements other studies that have found the prevalence of depression among HIV-positive patients to be as much as twice that of patients who are HIV-negative, and more specifically that up to two-thirds of patients who are newly diagnosed and not yet linked to care screen positive for depression[23, 24].

Past studies have shown that depressed patients are more likely to disengage from care, and depressionis a strong predictor of missed appointments[22]. The fact that participants in our study shared intimately personal details about their emotional and mental state with their assigned HIV counselor shows the potential role that a bi-directional text messaging intervention can have for engaging patients during the early steps of the HIV cascade. Additionally, these findings are consistent with a previous Peruvian study that found no difference in mHealth acceptance and mobile phone use among HIV patients whether they were depressed or not[13].

The results of our study serve to broaden the existing literature on the Peruvian HIV care cascade, and provide deeper insights from the patient perspective on the early steps of linkage and engagement in care. The findings from our study show that MSM recently diagnosed with HIV frequently asked questions about coping skills during the early phases of the care

continuum. One of the most common questions was related to making diet changes and the safety of taking vitamins and supplements. Other participants were interested in entering either individual or couples therapy to work through personal issues regarding their diagnosis. By initiating conversations with their assigned counselor and in responding to standardized messages, participants were able to elicit and manage their interpersonal support to bolster their wellbeing. Additionally, patients were able to schedule and re-schedule appointments and ask questions about lab results by sending text messages to their counselor. Overall, these conversations reflect that participants were actively engaging in their own care.

In order to further understand the Peruvian HIV care cascade, our study focused on recently diagnosed HIV-positive MSM (£3 months), a sub-population with a high risk for disengaging from care[7,8, 22]. Physical symptoms emerged as another overarching theme from the data and were the most common text message topic sent by participants to their HIV counselors. Although the majority of our patients did not experience medication-related physical symptoms, there were several that developed rashes after starting ART. In a study by Curioso et al, medication side effects were among the most important barriers to ART adherence, and subsequently retention in continuous care[21].

The results of our study reveal a potential role for an mHealth intervention to serve as ancillary support to clinicians, especially when patients are entering the ART adherence step of the HIV cascade during which they may experience medication side effects. The participants in our study sent messages describing their symptoms and counselors were able to ask questions to determine whether an emergency was occurring and needed immediate clinical attention, or if the person could wait until the following day to receive care. The

added capability to send and receive photos was especially helpful in assessing rashes and improved patient understanding of their own symptoms.

Our study has some limitations which must be considered when interpreting our results. First, all participants in this study were recruited from a single site which can limit the generalizability of results. Also, as a descriptive qualitative study, our results serve only to illustrate major themes regarding experiences of MSM recently diagnosed with HIV in the early phases of care but determining the effectiveness of this mHealth intervention will require further investigation. Despite these limitations, our study has several strengths. First, participants actively utilized the bi-directional component of the intervention, demonstrated signs of increased engagement, and even utilized the mHealth intervention as a type of telehealth intervention by sending images of acute rashes they experienced. Participants also expressed feeling supported with the personal nature of text messages and overall felt pleased with theircare. Additionally, participants did show signs of engaging in their care and thus this type of mHealth intervention may be used to further elucidate gaps in the HIV care continuum at these crucial stages of linkage and retention in care.

**Conclusion**

This is the first study, to our knowledge, to report qualitative findings of barriers and facilitators of the early and intermediate steps in the Peruvian HIV care continuum among recently diagnosed MSM. Our study underscores the importance of intervening during a critical phase of this disease, in a recent diagnosis, when vulnerability and potential for disengagement from care is high. Additionally, our qualitative analysis of data from an mHealth intervention contributes insight into the mind states of recently diagnosed MSM, which further highlights the most crucial barriers and facilitators of HIV care in this

population. The use of technology interventions has the potential to reveal the most personal

feelings and thoughts of such a vulnerable population during a critical stage of care.

**References**

1) Country progress report: Peru 2014. Retrieved from:

http://www.unaids.org/sites/default/files/country/documents//PER_narrative_report_2014.pdf

2) Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 infection with early antiretroviral therapy New England Journal of Medicine 2011; 365: 493–505

3) Gardner EM, McLees MP, Steiner JF, Del Rio C, & Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clinical Infectious Diseases 2011; *52*(6): 793–800

4) Ayala G, Makofane K, Santos GM, et al. HIV treatment cascades that leak: Correlates of drop-off from the HIV Care continuum among men who haves sex with men worldwide. Journal of Aids and Clinical Research 2014; 5(8): 1-8

5) Chow JY, Konda KA, Borquez, A, et al. Peru's HIV care continuum men who have sex with men and transgender women: opportunities to optimize treatment and prevention. International Journal of STD & AIDS 2016, 0(0): 1 PubMed -10

6) Fleishman JA, Yehia BR, Moore, RD, et al. Establishment, retention, and loss to follow-up in outpatient HIV care. Journal of Acquired Immune Deficiency Syndromes 2012, 60(3):249-59

7) Gardner EM, Daniloff E, Thrun MW, et al. Initial linkage and subsequent retention in HIV care for a newly diagnosed HIV-infected cohort in Denver, Colorado. Journal of the

International Association of Providers of AIDS Care 2013, 12(6): 384-90

8) Rana AI, van den Berg JJ, Lamy E, Beckwith CG. Using a Mobile Health Intervention to Support HIV treatment adherence and retention among patients at risk for disengaging with care. AIDS Patient Care and STDs 2016, 30(4): 178-184

9) WorldBank. DataBank, Peru: Internet Users. 2015. Retrieved from: http://data.worldbank.org/indicator/IT.NET.USER.P2

10) Lancaster, H. Peru- Mobile Market- Insights Statistics and Forecasts. 2016. Retrieved from: https://www.budde.com.au/Research/Peru-Mobile-Infrastructure-Broadband-Operators-Statistics-and-Analyses

11) Blas MM, Menacho LA, Alva IE, Cabello R, Orellana ER. Motivating Men Who Have Sex with Men to Get Tested for HIV through the internet and mobile phones: a qualitative study. PLoS ONE 2013, 8(1): 3 PubMed -8

12) Menacho LA, Blas MM, Alva IE, Orellana ER. Short Text Messages to Motivate HIV Testing Among Men who have sex with men: a qualitative study in Lima, Peru. The Open AIDS Journal 2013, 7(1): 1-6

13) Krishnan A, Ferro EG, Weikum D, et al. Communication technology use and mHealth acceptance among HIV-infected men who have sex with men in Peru: implications for HIV prevention and treatment. AIDS Care 2014, 121: 1-10 PubMed

14) Ruiz EF, Ponce OJ, Curioso WH. Seccion Especial: Tecnologias moviles para la salud publica en el Peru: Lecciones aprendidas. Revista Peruana de Medicina Experimental y Salud Publica 2015, 32(2): 3-4

15) Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006, 3(2): 77–101

16) Crabtree BF, Miller WL. (1999) *Doing qualitative research*. New York: Sage Publications

17) Saldaña J. (2015) *The coding manual for qualitative researchers*. New York: Sage Publications

18) Creswell JW. (2012) *Qualitative inquiry and research design: Choosing among five approaches*. New York: Sage Publications

19) Miles MB, Huberman AM, Saldana J. (2013) *Qualitative data analysis: A methods sourcebook*. New York: Sage Publications

20) Christopoulos KA, Massey AD, Lopez AM, et al. "Taking a half day at a time:" Patient perspectives and the HIV engagement in care continuum. AIDS Patient Care and STDs 2013, 27(4): 223-30

21) Curioso WH, Kepka D, Cabello R, Segura P, Kurth AE. Understanding the facilitators and barriers of antiretroviral adherence in Peru: a qualitative study. BMC Public Health 2010,

20(5): 1039 PubMed -1048


22) Traeger L, O'Cleirigh C, Skeer MR, et al. Risk factors for missed HIV primary care visits among men who have sex with men. Journal of Behavioral Medicine 2012, 35(5): 548-556


23) Bhatia R, Hartman C, Kallen M A, Graham J, Giordano T P. Persons newly diagnosed with HIV infection are at high risk for depression and poor linkage to care: Results from the steps study. AIDS and Behavior 2011, 15(6): 1161–1170


24) Ciesla JA, Roberts JE. Meta-analysis of the relationship between HIV infection and risk for depressive disorders. Am J Psychiatry 2001, 158(5): 725 PubMed -30