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A necessary conversation to develop chatbots for HIV studies: Qualitative findings from research staff, community advisory board members, and study participants

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Abstract

Chatbots are software applications that increase business productivity by handling customer conversations instead of human agents. Productivity gains provide similar rationale for chatbots in the healthcare sector, especially for health coaches who deliver care through conversation.

Chatbots are nascent in healthcare due in part to unanswered questions about patient acceptability. Study findings for healthcare chatbots have been mixed in terms of engagement and their impact on health outcomes. Questions also remain as to chatbot acceptability with health coaches and other providers who would use chatbots to communicate with clients; studies have focused on study participants as end users.

To better understand perceived benefits of chatbots in HIV interventions we conducted virtual focus groups with research staff (n=13), community advisory board members (n=8), and end users of young adults living with or at high risk for acquiring HIV who participated in HIV intervention

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The institutional review board at the University of California, Los Angeles provided ethical approval for all study procedures. All participants provided verbal consent to participate.

Declarations

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Chatbots afford anonymity that can be harnessed through interactive media to provide sensitive information and provide counseling services. Researchers built a chatbot that provides educational information to high-school aged adolescents on sex, drugs, and alcohol use (Crutzen et al., 2011). Adolescent participants favored the chatbot over traditional search engines because of perceived anonymity and superior information quality. Another chatbot was designed to guide users through an HIV counseling and testing session and was positively received by participants (Heerden et al., 2017). Topics that are more taboo to youth, such as sex or drug use, seem more acceptable with chatbots (Maenhout et al., 2021) and youth report finding chatbots useful with these discussions (Crutzen et al., 2011; Wang et al., 2022). Literature reviews indicate that digital healthcare for youth dealing with sexual transmitted disease and HIV prevention, care, and services, has been increasingly essential, even prior to the pandemic (Cao et al., 2020; Hall et al., 2015; Nguyen et al., 2019; Touger & Wood, 2019) and the need will only increase.

The COVID-19 pandemic accelerated chatbot development in the healthcare sector through telehealth adoption (Wosik et al., 2020), and the roll-out of COVID-19-related information bots to the public (Almalki & Azeez, 2020). Telehealth adoption began before COVID-19, especially among health coaches where the frequency of direct contact with clients could reasonably be reduced (Bala et al., 2019; Hurst et al., 2021; Markert et al., 2019; Markert et al., 2021). The need for telehealth and improved digital communication tools will remain as COVID-19 becomes endemic (Bestsenny et al., 2021), especially among youth. We recently conducted health coach-based intervention trials for youth and young adults with HIV and at high risk for acquiring HIV (Arnold et al., 2019; Nielsen-Saines et al., 2019; Swendeman et al., 2019) that underscored such a need. Health coaches carried heavy caseloads of up to 60 study participants, limiting intervention scalability beyond research settings. Participant preferences for SMS (text message) communication with coaches addressed caseload volume in part by expediting two-way communication between study visits, e.g., to schedule study visit appointments. SMS also provided opportunities for chatbots to streamline communication and motivated the current study to inform the development of a chatbot to facilitate communication between staff and participants in future HIV studies.

Despite potential chatbot benefits, mixed study findings call for additional insight. Studies have shown chatbots to positively impact some mental health outcomes and not others among adolescents and young adults (Gabrielli et al., 2021; Greer et al., 2019; Stephens et al., 2019). Greer et al. (2019) found their chatbot helped to reduce anxiety but did not demonstrate an effect for depression, positive or negative emotion. Stephens et al. (2019) found high chatbot engagement while Maenhout (Maenhout et al., 2021) found modest engagement. Chatbot acceptability and usability is an ongoing concern (Adamopoulou & Moussiades, 2020; Almalki & Azeez, 2020). Not surprisingly, youth have different expectations for a successful chatbot than adults including the need of assurances of confidentiality (Maenhout et al., 2021), more chatbot interaction and wider function (Crutzen et al., 2011; Maenhout et al., 2021), and different types of questions (Mariamo et al., 2021) to optimize engagement. Scaling chatbots for marginalized populations of youth beyond current offerings, mostly for incentivized study participation or public health campaigns, will require a nuanced understanding of their chatbot perceptions and

preferences to maintain relevance outside of these limited engagements. In addition to youth as end users, the chatbot perceptions and preferences of other stakeholders, such as health coaches, need to be considered in chatbot designs for better scalability.

Towards this goal, we conducted focus groups with HIV research staff, community advisory board (CAB) members, and HIV intervention trial participants to ascertain their chatbot preferences and perceptions for how chatbots could be used to support HIV research and study participants' health needs. This study addresses literature gaps by triangulating focus group findings across stakeholders, rather than to solely evaluate the chatbot perceptions of study participants and the impact of chatbots on their health outcomes. We aimed to inform the utility and scalability of future chatbots to support HIV research. We also anticipate that findings will be useful for the development of chatbots to serve the needs of adolescents, including those from marginalized groups.

2. Methods

2.1 Overview

We conducted virtual (Zoom) focus groups between May 2020 and July 2021 to inform the development of a chatbot to support communication between HIV research staff and study participants. We examine perceptions towards chatbots and how they might be integrated into HIV research studies. The institutional review board at the University of California, Los Angeles provided ethical approval for all study procedures. All participants provided verbal consent to participate.

2.2 Participants and procedures

The current study purposively sampled participants and staff who were part of intervention trials conducted through the Adolescent Medicine Trials Network for HIV/AIDS Interventions in Los Angeles and New Orleans (ATN CARES). The participants would be likely the end users of a chatbot, and staff would be the likely user of a chatbot to communicate with study participants. Due to social distancing ordinances related to COVID-19, we were unable to conduct in-person focus groups. Eligible participants needed access to a phone or computer with internet connectivity to participate in a virtual focus group. We posited that this eligibility requirement focused recruitment on individuals who would also be more likely to use chatbot technology by way of access to and proficiency using technology resources. Additional eligibility requirements were imposed by recruitment from one of the following three stakeholder categories:

1. *HIV research study participants.* We recruited seven young adults who were *ATN (CARES) participants*. The recruiter emailed information about the focus group study to ATN participants they deemed likely to participate based on recommendations from *research staff* (i.e., intervention coaches and study interviewers). Staff recommended participants who were reliable based on scheduled study visit attendance and able to converse based on communication over the course of the ATN study. ATN participants willing to participate were sent an email invitation to the virtual focus group.

2. *Research staff* (n = 5 in Los Angeles (LA) and n = 8 in New Orleans (NOLA). ATN project directors identified staff from the LA and NOLA study sites who were available to serve as focus group participants, experienced in their roles, and who would provide diverse representation based on their gender and sexual identity.
3. *CAB* (n = 8). We conducted a focus group with national CAB members supported by the Adolescent Medicine Trials Network for HIV/AIDS Interventions, referred to as Youth Experts and Advocates for Health.

Table 1 presents the sociodemographic characteristics of the study participants and underscores the diversity of the sample in terms of race/ethnicity, gender and sexual identity. We conducted separate focus groups for LA research staff, NOLA research staff, CAB members, and five out of the seven ATN participants. Two ATN participants were unable to join the ATN participant focus group due to scheduling conflicts. We conducted separate one-on-one interviews with them using the same focus group discussion guide we used during the virtual focus groups. Their responses aligned with ATN participant focus group discussions and are grouped with focus group responses in the results. Focus groups were led and facilitated by two of the co-authors (Comulada and Flores). We present discussion guides for staff/CAB members and ATN participants in Supplemental Tables 1 and 2, respectively. Prior to the start of the ATN participant focus group, we gave them an opportunity to change their screen name to mask their name to others in the group.

At the start of the focus groups, the facilitators introduced themselves, the purpose of the study - to inform the development of a chatbot for future HIV research studies – and ground rules for how the focus groups would be conducted (e.g., to converse with other participants and facilitators in a respectful manner). The facilitators then introduced the concept of a chatbot and presented a five-minute demonstration of a chatbot. Facilitators communicated with the chatbot by typing questions and responses on a computer screen viewable by participants. We demonstrated text-based communication in line with chatbots that could be accessed through websites and text messaging to optimize access for individuals seeking HIV-related care (Braddock et al., in press). Once the demonstration was complete, the facilitators presented the group questions regarding the feasibility, benefits, and barriers of using chatbots to discuss and answer as a group. Focus groups lasted approximately an hour and were both audio and video recorded. ATN participants received an electronic \$50 gift card for their time. Research staff and CAB members were not compensated.

2.3 Qualitative analysis

The research team constructed semi-structured focus group discussion guides with four primary domains that facilitators used to guide focus group discussions: *previous experience with chatbots*, *chatbot acceptability*, *chatbot functionality in future HIV research studies*, *potential chatbot benefits* and *concerns*. Two research assistants ((RAs; Rezai and Sumstine) conducted an inductive thematic analysis on the video recordings to generate substantive codes and sub-themes that emerged from the focus group discussions. The RAs used open and axial coding with the goal of creating an analytic blueprint of the relationships between the major themes, ideas, and concepts that emerged. They coded the recordings

independently and came together to discuss any discrepancies in findings. The principal investigator (Comulada) reviewed and signed off on all the themes identified.

3. Results

Focus group themes converged, which led us to group findings by three topic areas rather than to present separate findings for each focus group. We first discuss prior chatbot experiences across focus groups in (3.1), followed by perceived benefits (3.2) and drawbacks (3.3). We present quotations from individual participants to illustrate key findings in Tables 2 to 4 and use arbitrary participant numbers to differentiate participant quotes, e.g., CAB 1 to indicate the first CAB member in the CAB focus group to provide a response.

3.1 Previous chatbot experiences

Participants reported using chatbots and automated response systems to interact with businesses (e.g., banks; Table 2). Some participants indicated a preference for chatbots over human communication when pressed for time to avoid waiting to speak to a live person. Participants also shared negative chatbot sentiments. Youth saw them as a barrier when they wanted to speak with a human. One staff participant felt uncomfortable with an automated response system where they asked for her contact information and a representative contacted her later. Other staff elaborated on this point that providing contact information felt like being scammed. In contrast, other staff saw the utility in providing call-back contact information.

3.2 Perceived chatbot benefits

Participants noted multiple beneficial functions that chatbots could provide. Staff provided examples where chatbots could facilitate appointment scheduling for study assessments, provide referrals for housing and other needs, disburse health information (e.g., to address nutrition, sexual health, and hormone-related questions from transgender participants), and facilitate in-house or community referrals (Table 3).

3.2.1 Scheduling—Staff described how chatbots that automatically scheduled appointments with ATN participants could help their workflow. CAB members described how automated scheduling could also offer convenience for ATN participants.

3.2.2 Referral—According to participants, the chatbot can connect or redirect ATN participants to community resources (i.e., housing, mental health care, substance use treatment) or provide basic HIV or STI information (i.e., testing sites, symptoms). Participants recommended that the chatbot be programmed to identify local services that are readily available to ATN participants. Staff described how chatbots programmed to identify local resources would free up time to work on other tasks.

3.2.3 Round-the-clock availability—From the perspective of staff, utilizing chatbots would alleviate effort during non-work hours and would be helpful for them to implement boundaries with how much they're supposed to interact with ATN participants. They noted how chatbots may provide quick feedback and reassure ATN participants they are not being

ignored. The chance to give quick feedback to ATN participants was described in ways that were both for the sake of convenience and for more dire situations. Similarly, ATN participants expressed interest in using chatbots during off-peak hours where study staff are not available to answer questions.

3.2.4 Tailorability—Study results indicate that a benefit to using chatbots is that it may be customized to ATN participants' personalities, service preferences, or preferred mediums of choice. A general consensus among study participants was that staff should still be able to offer both human interaction and the chatbot depending on each ATN participant's unique disposition and study components that could reasonably be automated, such as completing web surveys.

Aside from personality-driven factors, ATN participant needs and preferences were brought up in regard to which platform chatbots should be integrated with (i.e., study website, stand-alone text messages, Facebook chat, etc.). Participants noted that the more platforms were offered, the better it would be to overcome any obstacles ATN participants may face when using the chatbot.

3.3 Perceived chatbot drawbacks

In contrast to the multiple benefits noted above, participants also described negative attributes or downsides to relying on chatbots when interfacing with ATN participants (Table 4). Major concerns were the potential for chatbots to further separate marginalized populations from human contact, employ automation that is not personable, not reflect real-world language and fail to perform as intended.

3.3.1 Potential tool for neglect—Participants were cautious in their support of chatbots. For example, participants noted that certain subpopulations who have a history of being neglected may view the chatbot as another form of neglect since they would be interacting with a bot instead of an actual human. To prevent these subpopulations from viewing the chatbot as a barrier, targeted deployment could be used depending on the needs and history of the participant.

3.3.1 Automation is Not Personable—Nearly all participants shared their concerns about the automation via chatbots being impersonal and possibly eliminating the personal and warmth that study staff extend with direct interaction. Participants were concerned about a “clunky system” that does not effectively communicate and understand the needs of the user. Staff noted how automation may not fully capture nuances and specifics since it is a programmed interaction and not an adaptable human conversation.

Similarly, ATN participants shared these same concerns and described them in their own contexts. They were forthcoming about their unique needs that chatbots may not be able to address.

3.3.2 Threat of losing real-world language—From the perspective of staff and ATN participants, the language of chatbots might not reflect real-world ways of conversing with key groups, such as adolescent populations. Focus group participants overwhelmingly

stressed cultural relevance and how vernacular language changes so frequently. For them, there is a threat of disengaging with ATN participants and losing them due to reliance on unrelatable, technical and robotic language. Relatedly, participants were weary of chatbots' efficacy in engaging with ATN participants whose native language is not English.

3.3.3 Fallibility of technology—There was also concern that the lack of personal communication could lead to errors in automated scheduling and referrals. For example, staff indicated assessments generally take 30 minutes, but can take longer. Therefore, if a chatbot were to schedule back-to-back appointments every 30 minutes, it would cause delays in appointments and may overwhelm staff.

4. Discussion

This is one of the first qualitative studies to explore the potential integration of chatbots into HIV prevention and care studies, especially in the inclusion of HIV study participants, research staff, and CAB members. Staff and CAB members provided crucial insight from their experience working with HIV study participants; many staff had implemented the ATN CARES health coaching intervention over two years. They were keenly aware of the lived experiences of HIV study participants, including their unique healthcare communication needs and challenges. Despite the differences in their roles and experiences, participants in each focus group expressed similar perceived chatbot advantages and disadvantages.

Our findings support prior research suggesting that chatbot functionality in business is transferable to healthcare and public health (Abashev et al., 2017). The benefits articulated by participants mirrored those described in the business literature (Chung et al., 2021; Drift et al., 2018). Focus group participants saw value in automated scheduling, the ability to coordinate visits without speaking to someone, and access to referrals and information outside of traditional business hours. Interestingly, participants did not question HIV study participants' abilities to interact with a chatbot. Given their widespread use in commerce and business transactions, all our participants had previously interacted with chatbots in normal day to day activities such as banking and e-commerce. Most youth and young adults have smart phones, are adept at using social media, and conduct routine daily activities on-line (Joshi et al., 2019).

However, functionality is only one among many factors to consider for integrating chatbots in HIV research with youth and young adults. As our participants suggested, the quality of the interaction, language usage, the potential for technical glitches and the appropriateness of the information exchanged are also important factors that must be considered for the design of chatbots in HIV research. Unlike the transactional and informational nature of chatbot interactions in business, chatbots designed for HIV research may require more sophisticated programming to better simulate human interactions and effectively address the complexities associated with HIV research in this population. Many HIV study participants come from oppressed and marginalized communities, have experienced discrimination, rejection and stigma, and face more life challenges than typical business consumers. This sentiment underscored focus group themes related to the potential negative impact of chatbot interactions for HIV study participants. Participants were concerned that interacting with a

chatbot rather than a human being may exacerbate vulnerabilities prevalent among youth and young adults who participate in HIV research and may reinforce feelings of neglect or marginalization. Chatbots cannot replace the empathetic and supportive engagement with human beings that is common in HIV prevention and care efforts.

It is important to acknowledge the exploratory nature of our work, starting with the lens through which focus group participants provided insight. They had experienced chatbots in business settings. None mentioned chatbot encounters in healthcare settings. While the chatbot demonstration provided opportunities for feedback, participants didn't use the chatbot themselves. They discussed expectations and perceptions about chatbots in healthcare and HIV research settings rather than actual experience. Other limitations include small sample sizes of each stakeholder group, one-on-one interviews with two of the participants who couldn't join a focus group, and the absence of clinicians as another important stakeholder group. These limitations may have reduced the number of themes that emerged and insights into the benefits and drawbacks of chatbot deployment in HIV research.

Despite these limitations, this study provides basic guidelines for chatbot development in HIV research beginning with proposed functionality that was reiterated across focus group discussions, such as scheduling and referral. Participants reiterated the point that additional resource such as chatbots, so long as they do not replace humans completely, will benefit HIV study participants. Our study also offers a cautionary tale applying prior findings on chatbot acceptability and usability in the general population to HIV study populations. For example, studies that found chatbots to foster engagement and positive ratings from adolescents (e.g., Stephens et al., 2019) may be more applicable to less marginalized HIV populations. Our findings highlight the importance of more systematic examination of the different functions and roles that chatbots could play in HIV research and examining both benefits and challenges. Identifying the specific subgroup of youth and young adults who participate in HIV research and who are likely to reap the benefits of using a chatbot from those who might not is also important. Given the evidence that the benefits of chatbots transfer to healthcare, it is incumbent for researchers to rigorously examine how to best integrate chatbots in HIV research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Sociodemographic characteristics of focus group participants comprised of research staff, community advisory board (CAB) members, and ATN participants.

	Staff / CAB (N=21)	ATN Part. (N=7)
Age in years, min-max	21–38	20–24
Race/ethnicity, n		
Black	10	1
Latinx	6	3
Biracial	2	0
Asian	1	0
Pacific Islander/Native American	0	1
White	2	2
Gender identity, n		
Cisgender man	11	5
Cisgender woman	9	0
Transgender woman	1	0
Transgender (man/woman not specified)	0	1
Gender diverse/non-binary	0	1
Sexual identity		
Gay	11	5
Heterosexual	9	0
Not specified	1	2

Table 2.

Study participant quotations from focus group discussions about previous chatbot experiences.

Participant	Quote
ATN Participant 6	Well when you're calling one of those customer service lines the worst thing possible is when a robot picks up. Like I just want to tell a person why I'm calling. I don't want to put in these categories. It's just so annoying.
CAB 1	Most of the communication is streamlined for me and you don't have to wait on the phone for hours. So, the chat, at least I know my question will be answered and at least it streamlines my question.
CAB 6	I'm not a big fan of chatbots when it's something that needs a big explanation. If it's not something that a chatbot can explain to me in detail, then I would just rather talk on the phone with somebody that can explain something to me rather than getting one sentence responses from a chatbot and kind of going back and forth.
LA Staff 2	It [chatbot] popped up when I went to the corporate site. The little box came up and it was really easy, but at the end of the day I never got a response from like an official person. I feel like it was frustrating because my needs weren't met but if someone were to actually reach back out to me then it would have been a more useful experience.
LA Staff 4	That one [banking chatbot] works really well. I use it more than I talk to actual people at the bank.

Table 3.

Study participant quotations from focus group discussions about the potential benefits of chatbots in HIV studies grouped by themes.

Participant	Quote
Scheduling	
CAB 5	It allows me the control if I need to cancel, it'll let me cancel. If I need to reschedule, I can reschedule. If I'm good, all I have to do is show up.
LA Staff 6	I think it would be helpful to use chatbots to schedule upcoming appointments with participants or to cancel appointments, if they need to cancel or reschedule. ... using a chatbot would be a helpful to confirm appointments with multiple people at once.
Referral	
ATN Participant 7	Testing is always good...If there is access to free STD testing that would be good...Resources [for] places where you can get free condoms? That kind of thing would be great...Mental health services that you can access? Employment resources?
NOLA Staff 5	I do think a chatbot could be really helpful if [participants] are having suicidal ideation or if they're looking for meditation or something like that to give automated mental health support.
Round-the-clock availability	
ATN Participant 4	[It] can obviously be really good for example, if you need something in the middle of the night and you can send a text message and get something instantly instead of waiting for that person to respond when you need something right away.
NOLA Staff 6	I think this [chatbot] could be really useful, especially seeing as this could be applied for off-the-clock situations where someone might not be able to wait until I clock in at 8 o'clock in the morning the next day. [If] they need that suicide hotline [phone number] that minute, [chatbots] could be a good application of that.
Tailorability	
ATN Participant 1	I'm a very outgoing person and can talk to anyone. But for someone who is a little shy or they don't like engaging with people, this [chatbot] is a great tool for them. Once they submit their information, they then can have the option to speak to someone.
CAB 7	Personally, I feel like youth would feel more comfortable talking via text versus in person because sometimes in-person conversations can be a bit intimidating or confusing.

Table 4.

Study participant quotations from focus group discussions about the potential drawbacks of chatbots in HIV studies grouped by themes.

Participant	Quote
Potential tool for neglect	
ATN Participant 3	Something that would be important to me would be that this is not a dead end for people. That if at the end of this when you click through maybe the algorithm can ask you ‘did I solve your problem?’ and [if] you’re like ‘no’, it’ll be like ‘great, we will e-mail you.’ Just so if you get to the bottom of that algorithm and there’s nothing left, we don’t want people thinking “Oh my God I’m left high and dry.”
LA Staff 6	If we’re dealing with participants who we mainly get through transitional living locations or the drop-in centers, like these are groups of people who are used to getting neglected and marginalized and not paid attention to...this [chatbot] interaction with them would just add to that [neglect].
Automation is not personable	
ATN Participant 5	We are dealing with intimate details, from testing to housing, and I don’t know how much compassion I can feel through an automated system. I like having the option to request a person when I need it. But I do miss someone to emphasize with me and recognize when I’m struggling, if I need that. Sometimes we just need some compassion.
LA Staff 1	I’m wary to not sacrifice the human interaction for convenience... it creates ease for some people but a structural barrier, like to have to go through that kind of system.
Threat of losing real-world language	
CAB 2	Who would be responsible for vetting responses from Spanish speakers, because there are dialectic differences in Spanish that some youth would use compared to what is translated in Google.
NOLA Staff 3	I’m not so much a fan of obviously interacting with an automated system that is speaking in vernacular, feels disingenuous. Where is the line where it’s trying too hard? Vernacular changes so quickly, it could quickly become irrelevant. This saying could change in a few months. It can be accessible but not necessarily needs to speak in vernacular.
Fallibility of technology	
NOLA Staff 4	There are some people who I urgently need to see, so I would like it if there is a possibility for me to manipulate some things in there. For example, if I have a person who is at the [start] of their [study follow-up] window who gets an [appointment] space that a person who is at the close of their [study follow-up] window should be getting, then I would like to be able to make a readjustment if that’s possible.
NOLA Staff 8	Let’s say a participant is texting us at night and using this system. I would want to receive a copy of the referral they were given to be able to follow up with that. So if it’s one-sided only, I wouldn’t know to follow up.