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What does it mean to be youth-friendly? Results from qualitative interviews with health care providers and clinic staff serving youth and young adults living with HIV

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Purpose: Given the consistent associations between younger age and numerous suboptimal clinical outcomes, there is a critical need for more research in youth living with human immunodeficiency virus (YLWH) and tailoring of health care delivery to the unique and complex needs of this population. The objective of this study was to examine the facilitators of and barriers to engagement in care among YLWH at the system and provider/staff level, as well as the barriers to using technology-based forms of communication with YLWH to improve retention and engagement in care.

Patients and methods: We conducted in-depth qualitative interviews with health care providers and staff members at the clinics and organizations serving YLWH in the San Francisco Bay Area.

Results: We interviewed 17 health care providers and staff members with a mean of 8 years of experience in providing clinical care to YLWH. Interviewees noted various facilitators of and barriers to engagement in care among YLWH, including the environment of the clinic (e.g., clinic location and service setting), provision of youth-friendly services (e.g., flexible hours and use of technology), and youth-friendly providers/staff (e.g., nonjudgmental approach). With regard to barriers to using technology in organizations and clinics, interviewees discussed the challenges at the system level (e.g., availability of technology, clinic capacity, and Health Insurance Portability and Accountability Act compliance), provider/staff level (e.g., time constraints and familiarity with technology), and youth level (e.g., changing of cellular telephones and relationship with provider/staff).

Conclusion: Given the need for improved clinical outcomes among YLWH, our results can provide guidance for clinics and institutions providing care for this population to enhance the youth-friendliness of their services and examine their guidelines around the use of technology.

Keywords: HIV, youth, young adults, health care provider, technology, barriers

Introduction

In 2015, in the USA, those aged 13–24 years accounted for ~22% of all new human immunodeficiency virus (HIV) infections.¹ In 2014, among 13–29 year olds living with HIV, only about 41% were aware of their HIV status, of whom 62% linked to care within the first 12 months of diagnosis, and among those who initiated antiretroviral therapy (ART), only 54% had suppressed plasma HIV RNA.² Therefore, <6% of all youth living with HIV (YLWH) in the USA were estimated to have achieved

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viral suppression. These figures are dramatically lower than those for older adults living with HIV³ and have contributed to ongoing transmission of HIV and worse clinical outcomes among youth.

Research has shown consistent associations between younger age and numerous suboptimal clinical outcomes, including lower adherence, lower likelihood of achieving virologic suppression, a higher hazard of virologic rebound, and higher risk of virologic failure.⁴ Once linked to and engaged in care, virologic suppression in YLWH has been estimated to be as low as 30.5%–50.5%.⁵ A consequence of suboptimal virologic suppression in YLWH is increased risk of HIV transmission and a future generation of immunodeficient adults with drug-resistant virus.

Substance use and mental health issues occur frequently in YLWH and disrupt the continuum of HIV care at every stage (e.g., decreases in linkage to and retention in HIV care, decreased engagement in care, delays in ART initiation, poorer ART adherence, and HIV disease progression and transmission).^{6,7} Due to a 50% increase in acquired immunodeficiency syndrome (AIDS)-related deaths in youth from 2005 to 2012,⁸ there is a critical need for more research in youth and tailoring of health care delivery to the unique and complex psychosocial and physical health needs of YLWH.

Technology-based methods of communication (such as text messaging and video chat) have shown promising health results in YLWH.^{9,10} As early adopters of technology, youth and young adults are more apt to use technology for communication and these methods of communication may allow for a variety of opportunities to promote health outcomes.¹¹ Therefore, the goal of this research was to examine the facilitators of and barriers to engagement in care among YLWH at the system and provider/staff level, as well as the barriers to using technology-based forms of communication with YLWH to improve retention and engagement in care.

Patients and methods

We conducted qualitative individual in-depth interviews (IDIs) with health care providers and clinic staff at the organizations serving YLWH in the San Francisco Bay Area. Interviews examined the facilitators of and barriers to engagement in care among YLWH at the level of the system and the provider/staff. Based on our a priori hypothesis that the use of technology (e.g., text messaging and video chat) would be an important facilitator for improving engagement in care among YLWH, we examined the barriers to the use

of technology in health care settings. The objective of these interviews was to understand the reason behind the discrepancies among the health care settings with regard to their use of technology. Health care providers and clinic staff included physicians, nurses, social workers, clinic management staff, and other key stakeholders from the clinics and organizations serving YLWH.

We asked questions regarding barriers to providing care to YLWH at the system and the provider/staff levels; facilitators for engaging YLWH in care; use of technology to engage YLWH as part of clinical care; and barriers to use of technology at the system, provider, and patient levels. Interviews lasted about 60–90 minutes and participants were reimbursed \$60 for taking part in interviews. We received approval from the University of California San Francisco Institutional Review Board for the conduct of this research and received verbal informed consent from all participants as approved by the Institutional Review Board.

All IDIs were audio-recorded and transcribed verbatim. We used a two-phase data analysis approach. Codes were developed both a priori (e.g., related to technology as a modality for engagement in HIV care) as well as inductively. Inductive codes were developed through a process of identifying themes that emerged from the data. The authors developed a coding system using an iterative process and met to clarify and further define codes that were developed a priori and those that emerged through the inductive process. The transcribed interviews were analyzed using Transana (version 3.02; Wisconsin Center for Education Research, Madison, WI, USA).

Initially, one author coded all transcripts. Once the initial coding was completed, we chose a convenience subsample of one-third of the transcripts to be double-coded ($n=7$).¹² Following a second round of coding, we established intercoder reliability by comparing the codes independently by each coder, identifying differences and involving the research team in discussions in order to reach consensus in the coding process.¹³ Ultimately, all coauthors participated in ongoing discussions through the analysis to clarify, refine, and define all the codes. Data saturation was reached in our interviews and our coding process.¹⁴

Results

We conducted 17 IDIs with health care providers and clinic staff from different clinics and organizations in the San Francisco Bay Area with experience and expertise in providing clinical care to youth and young adults living with HIV. These sites included Larkin Street Youth Services; East

Bay AIDS Center; Kaiser HIV Consultation Clinic; Positive Health Program at San Francisco General Hospital; San Francisco Department of Public Health Linkage, Integration, Navigation, and Comprehensive Services; San Francisco Department of Public Health Treatment Access Program; University of California San Francisco Adolescent and Young Adult Clinic; and Women Organized to Respond to Life-Threatening Diseases. Table 1 includes the characteristics of the study participants.

We identified a range of themes that were related to our overall study questions of what facilitated and hindered engagement in care among YLWH at the level of the system and the health care providers and clinic staff. We identified three overarching themes in our analysis of the facilitators of and barriers to engagement in care: 1) environment, 2) youth-friendly services, and 3) youth-friendly health care providers and clinic staff. These themes and corresponding subthemes are displayed in Table 2. Here, we provide details of these themes along with exemplary quotes.

Environment as a facilitator of or barrier to engagement in care

The environment included both geographic location and service setting (e.g., clinic waiting room or other individuals present in the waiting room). The following quote describes a barrier to engagement in care in one of the community-based

Table 1 Characteristics of interviewed health care providers and clinic staff serving youth and young adults living with HIV (N=17)

Professional role, n (%)		
	Physician	5 (29)
	Nurse practitioner	3 (18)
	Peer navigator/retention specialist	3 (18)
	Social worker	2 (12)
	Registered nurse	1 (6)
	Youth advocate	1 (6)
	Substance use counselor	1 (6)
	Program manager	1 (6)
Gender, n (%)		
	Female	8 (47)
	Male	8 (47)
	Transgender	1 (6)
Race, n (%)		
	White	11 (65)
	Multiracial	3 (18)
	Black	2 (12)
	Asian	1 (6)
Latino, n (%)		4 (24)
Years of professional experience, mean (SD)		8 (7)

Table 2 Themes related to the facilitators of and barriers to engagement in care

Theme	Subtheme
Environment	Clinic location Service setting
Youth-friendly services	Flexible clinic services Confidentiality Transition of care Using technology Additional clinical services Team-based approach
Youth-friendly provider/staff	Building a relationship beyond direct medical care Nonjudgmental approach

service settings and the neighborhood where youth come for HIV services:

The location here, uh-uh. Come on, people are selling crack around here. And, you know, [name] Street is right there [...] it's known for prostitution [...] I'm going to step out. I've got to go do things. I've got to go find a job [...] and then get triggered by crack or meth [...]. Move them somewhere where the neighborhood is totally different, where they can stay motivated, where they can see hope and change. [Transgender female, substance use counselor]

Interviewees discussed the clinic waiting room as an important setting to welcome YLWH specifically. As one individual commented:

[...] we just thought that youth would be more comfortable in their own waiting room that's kind of set up differently. And the educational materials are more geared to a youth audience. And things like condoms and lubes are more, like, readily accessible and open. [Female, nurse practitioner]

You know, youth posters on the wall, artwork on the wall. There used to be a couch. You know, it was just more comfortable. [Female, social worker]

While providers spoke at length about creating spaces that were inviting for youth or the importance of the geographic location of services, some discussed the need to have youth health services in distinct locations separate from adult HIV services.

Sometimes, they are preyed upon by older people [...] or they just didn't feel like it was their community and they felt

awkward. So, there would be less of a need for that, even in the waiting room. Like, 'I go into [name of clinics] you're like, oh people are sick, like, I'm not like these people.'
[Female, program manager]

Youth-friendly services as a facilitator of or barrier to engagement in care

Youth-friendly services were described as approaches that were used with youth that differed from those used with adults. These approaches included system-level approaches as well as provider/staff-level approaches. Some of these themes crossed system- and individual-level facilitators such as flexibility in clinic services (e.g., drop-in hours, assistance with medical insurance coverage, and so on). Being flexible, open, and willing to change was an important theme with regard to the clinic's schedules and the daily flow:

[...] the adult model of care does not work for youth. You know, just keeping scheduled appointments, no drop-in hours. [Female, social worker]

[...] we try to accommodate youth, because they're more drop-in, and so try to accommodate [...] you know, 'You don't have an appointment? Okay, let's see how we can fit you in. What are your needs today?' So, we have a lot of services. [Female, nurse practitioner]

[...] it's trying to work with people around their schedules. Trying to get people in, in ways that may not be as official [...]. And you know, having HIV and well-managing it, especially if you're on government-assisted programs like ADAP [AIDS Drug Assistant program] to pay for your medications and you're dependent on those, it's a big undertaking [...] so convincing them that this is something that's worth their time and making it as easy as possible would be what I would say is the way to make these services youth friendly. [Male, registered nurse]

I think that improving access requires a lot of flexibility when dealing with the youth, and you know, understanding that they're probably not going to be able to make a Monday-through-Friday, 8-to-5 appointment, because of their work schedules, depending on what kind of work they do. [Male, registered nurse]

One of the themes that described youth-friendly services included the developmental milestones of youth transitioning to adult medical care and the importance of familiarity of the youth with the new provider or the continuation of care with the same provider.

[...] we have three adult teams, and then we have one youth team [...] but every youth provider is also on an adult team. Because we feel like that would make the transition easier – when someone sort of ages out of the youth program, they don't have to necessarily change providers. That wasn't the case in the past, when someone turned 25 and suddenly they had to have another provider. [Female, nurse practitioner]

Participants also stressed the importance of maintaining confidentiality and the need for YLWH to access care privately, without the knowledge of their parents, family, or other members of their community. As one provider shared:

[...] I [...] first think of like confidentiality and having youth feel like, you know, they can come to a place where they can get services without their parents finding out necessarily. And so, in our clinic, we are sort of working to improve that aspect. And again, it all comes down to insurance status. So, patients with MediCal, they can sort of get, you know, mental health counseling, reproductive health services without sort of any breach in confidentiality for their parent. For privately insured patients, if they're insured under their parents' plan, their explanation of benefits does get sent to their parent. So, say, if they're getting substance abuse counseling, their parent could definitely find out about that. So, we're actually implementing some steps in sort of contacting their insurance companies and having them send the EOBs [explanation of benefits] elsewhere. [Female, physician]

So, I think confidentiality is one. Thinking of other youth-friendly [...] I think about is sort of having this clinic space where there's like all types of people. So, making sure that LGBTQ [lesbian, gay, bisexual, transgender, and queer], transgender patients sort of feel comfortable. [Female, physician]

As hypothesized, technology was described by the participants as a way to be youth-friendly and to demonstrate that they (providers/staff) were speaking the same language as their clients/patients who are younger. Some participants used technology to facilitate engagement in care and as a method of communicating with youth as described below:

[...] for us to be able to engage a lot more that way, because that's the way people – young people – are communicating now, is through texting, through getting information from the Internet on their phones. So, I think we're way behind here. I think we've got a long way to go to catch up. [Female, social worker]

It sounds like using the technology they use, like Pokémon, and using the style they like to communicate, which is text messaging, I think, ends up being a very strong way we can engage. [Male, physician]

I think some of it is just using technology in the first place – like, lends itself to being a little bit more youth-friendly because it's sort of the norm for them that it's sort of creating services in that norm. I think, you know, figuring out ways that those tech-based services can be monitored or, you know, still active in nontraditional hours. [Male, nurse practitioner]

Another perspective that was expressed by many of our participants was that the care for YLWH should be organized around the needs of youth and includes a range of services, for example, medical care, food services, and information about housing access. That these services be provided in one place was an important concept in the theme of youth-friendly care and an important strategy to engage youth.

Our program is specific to that age group living with HIV. So, when a young person comes into our program and they come into our [...] space – which has a clinic, case management, food services, all of that – all of the other people in that space who are not staff are under the age of 25 and they're all HIV-positive. So, there's a lot of peer support and connection, and a little bit more – so I think that takes away some of that vulnerability of sort of maybe being paired with older adults in a more generalized clinic space. It also really informs our services. Like, we don't have to be sort of a one-size-fits-all clinic. [Male, nurse practitioner]

And also, that it's kind of about other things than just their physical health and just their HIV. When they come to our program, you know, they get housing, they get case management. They have access to meals, peer support. There's a place to hang out, use computers, sleep on the couch. They have other things. And that's how we end up engaging them in medical care. [Male, nurse practitioner]

Beyond services, participants also discussed the need for youth to know the medical team, knowing who is providing their care, and feeling comfortable with these individuals.

[...] when a young person comes to the clinic, we introduce them to the team. That way, there's always one of us available, because sometimes, they just drop in. Plus, I have another nurse and another social worker assigned to me [...]. [Female, nurse practitioner]

[...] usually, we arrange that face-to-face meeting, and then the navigator will start talking, texting them, arrange to

bring them to an appointment [...] escort them somewhere. And these navigators have been great, have been really, really great in getting people engaged. And the patients really connect with them. [Female, nurse practitioner]

Youth-friendly health care providers and clinic staff as a facilitator of or barrier to engagement in care

In addition to system-level facilitators for care engagement, participants also discussed the need for health care providers and clinic staff themselves to exhibit youth-friendly qualities. These qualities were described as the ability of the health care providers and clinic staff to build a relationship beyond medical care and distinct from the skills and approaches taken with adults. Participants discussed this as an individual-level behavior that was genuine and needed in order to establish trust and create a welcoming and caring experience for youth. As one participant said:

And that's another thing that's also important in this age group in general – is not just sitting back and waiting for them to come to you always, but to being really engaging on your own and to try to draw them in. And even if they don't respond, to keep trying. You know, not totally making them pissed at you. 'I'm just checking in.' You know, 'I'm thinking about you and wanted to see you when you have time.' I think that's really important for this age group because finally they're like, 'All right, you really kind of do care.' [Male, nurse practitioner]

Participants also talked about expanding the experience for youth beyond just medical care and focus on medication, for example:

They wanted to have like artworks and music and things like that [...] I think for me, 'more youth-friendly' means 'more accessibility'. Easier access and the ability to [...] to be consistent. To be somewhat parental, in a way [...] if the behavior's not okay, so you discuss the behavior, but you don't break the relationship. Maintain that consistency of relationship, that you care about them [...]. Because they have been so disappointed by so many adults in their life [...] think that's really kind of the most important thing, is that they have someone that's going to stick with them. [Female, nurse practitioner]

So, recently, before we were doing a lab draw of somebody who was like, 'I'm not really excited about this,' we're like, 'Let's watch some YouTube videos. Who's your favorite artist right now?' And he's singing along and telling me. You

know, and so it's just some level of kind of building a social connection within boundaries and having to have staff who understand how to do that because it's a little blurry with this age group. There's a part that's really appropriate for them to want to identify you as a friend that's going to be beneficial to you keeping them in care and meaning to keep a professional boundary [...]. And there are some things that are not appropriate for us to talk about [...]. So, it becomes a balance. [Male, nurse practitioner]

Finally, participants noted that a key quality for youth-friendly health care providers and clinic staff was honesty and being genuine. They noted that providers who treated youth as respectable individuals, involved them as decision makers in their own care, and were forthright yet nonjudgmental toward the youth's personal life and risk-taking behaviors were the most successful in engaging them in their health care.

[...] at our clinic, our providers are awesome – every single one of them. So, I think the relationship that the person develops with their medical provider is really a huge key to keeping them in care. You know, someone that's genuine, listens to them, patient, you know, [...] not down-talking to people [...]. So, I think that's such a huge piece of what keeps our people in care – is the staff here. You know – caring, interested [...] not punitive. [Female, social worker]

And as I've been reminded multiple times, it turns out that not everybody likes working with adolescents and young adults. So, when you're actually working in a clinic and program space that is tailored to just this population, you're attracting a staff that is passionate or likes working with this age group, which is different if you're just sort of on a general appointment schedule at a general clinic. And then you get somebody, whether it's the front desk person, whether it's a medical assistant, a nurse, a provider, a pharmacist, whomever. And along the way was like, 'Oh. You're all my trigger points as a 19 year old. I don't like you. Get off your phone. Do what I say.' [...] that can be really off-putting for a young person. And they're like, 'I'll never see you again. I'm out of this clinic. Bye.' [Male, nurse practitioner]

I think 'youth-friendly' also means people that are comfortable with them, because teenagers can smell fear [...]. It's just someone who just feels comfortable with them, who's not intimidated by them, who can sort of feel like you can speak to them without talking down to them. Sort of treat them as a human and not, you know, some mythical child-beast. [Female, physician]

Table 3 Themes related to barriers to technology use

Theme	Subtheme
System level	Availability of technology Staffing and clinic capacity Clinic regulations and HIPAA compliance
Provider/staff level	Personal privacy Time constraints and defining limits Familiarity with technology and personal comfort
Youth level	Changing/loss of cellular telephones Trust and relationship with provider/staff Access to technology (e.g., data, text, Wi-Fi)

Abbreviation: HIPAA, Health Insurance Portability and Accountability Act.

[...] part of the thing, too, is finding providers that like to work with young people. So, that's the key, because not everybody wants [...] or wants to understand them. And then, the way you approach STI screening [...] I have had patients tell me that they have gone to some of the community places and been reprimanded [...] because they're having unprotected sex. [Female, nurse practitioner]

In addition to the facilitators of and barriers to engagement in care that included the environment, youth-friendly services, and youth-friendly health care providers and clinic staff, our respondent also discussed services that prioritized youth in particular, improved communication, and were responsive to their needs. One such service was the use of technology to improve communication with YLWH. Therefore, we examined some of the challenges or barriers for technology use in health care settings to further understand why technology-based services were not used similarly across all settings. We grouped these responses into three themes: 1) system-level, 2) provider-level, and 3) youth-level barriers to the use of technology in health care settings. These themes and corresponding subthemes are presented in Table 3. Here we provide further details on each theme and exemplary quotes.

System-level barriers to using technology as an engagement in care tool

Participants expressed interest and awareness of how technology could be used to support engagement in HIV care and highlighted some of the system-level barriers to using technology. This theme included the availability of technology in health care settings, the level of staffing that would be

required to use technology or the capacity of the clinics to implement technology, and the clinic- or system-level regulations (including Health Insurance Portability and Accountability Act [HIPAA] compliance) on the use of technologies that may transmit protected health information.

Participants talked about how youth used technologies (such as text messaging), but that given the lack of sufficient cellular telephones in health care settings, health care providers and clinic staff had to share cellular telephones to communicate with their patients or had to connect with their patients through another clinic team member who had the clinic's cellular telephone:

[...] she [case manager] has probably a handful of youth who, like, love to text [...] I asked her if I can borrow her phone so we can actually go over some of the text messages. [Male, physician]

Limitations around the capacity of the clinic or system for using technology to communicate with patients were expressed by several participants:

I tell my patients that I'm only looking at this phone during work hours, you know. I make that pretty clear, because, yeah, there's no guarantee that I'm going to be looking at it. [Male, physician]

I think that if we had more staff that could develop relationships with people and check in with them [via text], I think that would be really good. [Female, social worker]

So, yeah, we have a reduced staff now, for the youth team, and, you know, just more patients. So, it's harder to spend as much time as I used to be able to spend with people. And a lot of people coming in – a lot of new people coming in. So, unfortunately, my main way is the phone – telephone. [Female, social worker]

Another system-level concern to using technology was the lack of protocols and clarity of the rules around using technology and guidelines with patients to encourage engagement. Participants who did not communicate via text message with their patients often cited HIPAA compliance as the reason. Therefore, health care providers and clinic staff who wanted to use text messaging as a way to communicate with their patients felt inhibited by the institutional policies and regulations. For example:

But I think because the policy and regulations of the hospital are really strict and I think our clinic is afraid of that whole thing, the HIPAA violations and all of that. I would love to use it but our policies are strict and I don't really want to deal with it. [Male, peer navigator]

So, any kind of communication outside of the hospital has to be very regulated and monitored. So, that's why I'm just not sure if the organization – if the corporation would approve of such a thing. [Female, social worker]

If I could text my patients, that would be so helpful. I can't. It's against the law for me to use my phone and text them. And my patients, I will call and leave them a message, and just like every millennial, and I'm a millennial myself, so I will say this: They don't check their voicemails. They don't even read them, now that iPhone translates them. They're just going to text. [Male, registered nurse]

Even though some participants acknowledged the potential loss of privacy, they noted that they had to use technology at times to stay connected to their patients:

And every now and then – I know this is not necessarily HIPAA-compliant, but I will check Facebook to make sure someone's not dead. I will check Facebook to make sure that something crazy hasn't happened in that person's life or they haven't moved across the country. Because it's been six months and they haven't responded. And most often or not, I can find out they're still around and they're just ignoring me. And I'd rather find that out than anything else. But if there was a way to somehow, like, work with Facebook, since it is literally taking over the world, that would be great. [Male, registered nurse]

In addition to the lack of clear institutional regulations around the use of technology with patients, participants noted the institution's lack of understanding around youth's methods of communication by attempting to enforce a one-size-fits-all approach to patient communication.

Well, and the entire, like, all that kind of HIPAA craziness, comes crashing down on this, right? Like, there are major disincentives to going our way. In fact, we're probably not supposed to be doing what we're doing, right? Even as much as we kind of try to honor our thing. So, part of that is, you know, a massive disincentive from the institution to go that way. It's like, 'Oh, no, can't you just have them sign in to [patient portal]?' I was like 'No, I cannot have these guys sign into [patient portal].' Like, or to log in through these portals that are like infuriating. Like, it's like zero. Like, they're going to get one step and they're never going to go there. [Male, physician]

Provider/staff-level barriers to using technology as an engagement in care tool

In addition to the system-level barriers, our data indicated that for some health care providers and clinic staff maintaining

personal privacy, time constraints and the lack of limits to availability, and discomfort and unfamiliarity with using technology for engagement in care were important barriers.

Participants who did not share their direct contact information with youth noted some of their methods for maintaining their personal privacy:

I definitely call patients from my personal cell phone. I, like, star-6-7 it and make a phone call, so they don't have my number. But that's okay. But I would never text a patient with, like, 'Hey, I want to talk about your results.' [Female, physician]

Participants who did not share their direct contact information with youth were also worried about the time that it would take them to respond to messages from patients, yet other participants who had shared their direct contact information stated that they had set limits regarding messages after hours or on weekends.

[...] providers here get emails that are absurd, and one of our doctors, for example, clears out his inbox every single day, and within 12 hours, there's a good 50 emails in there that he has to respond to again. So, I could understand doctors not wanting to give out their cell phone number. [Male, registered nurse]

I tell people my phone is only from 8:00 until 5:00. I won't respond to anything before or after that. Of course, if it's an emergency don't be calling me. Because if you're calling me I'm just going to tell you to hang up and call 911, right, or go someplace like urgent care [...]. But all of us have had phone calls in the middle of the night. [Male, patient navigator]

Some participants acknowledged their lack of access to or familiarity with technology as well as the personality of other colleagues who felt more comfortable with the use of technology despite, what the participant believed, may be HIPAA violations.

I am so bad. Because I don't have a cell phone, so I don't text. And I know that that's, you know, such a big deal. Youth'll say, 'The best way to get me is by texting.' [...] And, you know, email is kind of like old-fashioned now – that you don't really email any more. Although, to email out of the hospital, we have to encrypt, so they have to register to receive our emails and then use a password every time. So, that is not youth-friendly, one little bit. [Female, social worker]

So, one of our attendings [physicians] gives out like her personal email and her cell phone sometimes. So, I think one

major issue is HIPAA. So, that [...] for confidential communication, that's actually not appropriate. It actually violates HIPAA. So, [...] that's one reason I don't do it [...]. So, I think under HIPAA, phone calls are okay. I think texting is where it's a little grayer. [Female, physician]

Youth-level barriers to using technology as an engagement in care tool

Participants described some experiences that youth reported to them hindered their communication through the use of technology. In addition to the need for youth to establish trust with their health care providers and clinic staff to communicate with them via text messaging, other barriers included changing or loss of cellular telephones and not having access to Wi-Fi or data plans. Youth's constant changing and loss of cellular telephones was noted by many participants as such:

I mean, actually most of my patients and clients text. So, that's if they haven't lost their phone. [...] This age range for sure is texting, but actually a lot my clients are texting. Then again phones are like water right now and so people just go through them. [Male, patient navigator]

I think the biggest sort of logistic for our particular patient population with technology, mobile technology particularly, is losing phones, their service being cut off. And so anything that requires cellular service, people just go dark and you don't – you know, their phone numbers change all the time, and so you constantly have to update this database [...]. [Male, nurse practitioner]

The only thing I think about it that they change they phone numbers so much, that was the good thing about Facebook and stuff. It stays the same. The phone numbers, the government phones, they make it so easy to get a new phone. So the – that's the only thing I constantly am getting new, updated phone numbers. [Female, retention specialist]

The lack of youth's access to technology such as data plans or Wi-Fi was noted by the participants as being a major barrier to using technology for communication:

[...] but a lot of times they don't have a phone with a plan if they have a phone. Sometimes they have two phones. They'll have a phone that works on wireless only and then they have their Obama phone [a program that gives struggling low income Americans free cell phones, voice minutes and texting¹⁵] like the crap-tastic phone. Then they lose them. [Male, patient navigator]

But it's [connection] usually kind of worse depending on what their network is. They can do it over LTE, but the quality isn't as good. Definitely recommend Wi-Fi. [Male, physician]

Beyond youth's consistent access to technology, participants described the importance of and need for youth to establish a trusting relationship with the health care providers and clinic staff to communicate bi-directionally.

I think it should be someone that they know. And that they already feel kind of safe with. And I think being able to do that via texting would be very helpful. [Female, social worker]

Overall, all participants agreed that technology was a critically important method to connect with YLWH, regardless of the lack of clear guidance on how best to do this or the potential challenges faced when using technology.

Discussion

We conducted in-depth qualitative interviews with a diverse group of health care providers and clinic staff with expertise in serving YLWH from various organizations in the San Francisco Bay Area to examine the facilitators of and barriers to engagement in care among YLWH. Our data show that numerous factors related to the environment, youth-friendly services, and youth-friendly health care providers and clinic staff constitute some of these facilitators and barriers. Therefore, to improve the HIV care cascade among YLWH,² it is critical for the institutions and clinics serving YLWH to pay attention to these factors and strive to implement them when possible.

Participants in our study indicated that to improve engagement in care among YLWH, health care providers, clinic staff, and organizations serving this population could examine their clinic environment by having the clinic situated in a location that did not trigger youths' substance use, a clinic that was welcoming, and separated from adult services. Additionally, clinics aiming to provide care to YLWH would provide flexible clinic hours, maintain patients' confidentiality (especially for those covered by their parents' medical insurance), provide transitional services to adult medical care, use technology to communicate with patients, provide a range of services in addition to medical care, and provide a team-based approach. Finally, facilitators to engagement in care included health care providers and clinic staff who were caring, nonjudgmental, and created a trusting environment for YLWH.

Some of the characteristics of youth-friendly services have been reported in previous publications.¹⁶ These characteristics include confidentiality, accessibility, and provider interaction.^{17–21} Our results were different from those of previous studies^{17,22,23} in that our participants found parental involvement as a barrier to engagement in care for YLWH. Additionally, in our study, technology was noted to be a key method for enhancing youth-friendliness of services, maintaining communication with youth, and improving engagement in care. However, some barriers to using technology at a system-, provider/staff-, and patient-level were noted. One such barrier was the lack of clear guidance from institutions around the use of technology or worries around violation of HIPAA regulations. Studies have shown that nearly 60%–80% of the participating physicians used text messaging for their clinical communications;^{24,25} therefore, it is evident that the understanding of the current guidelines is necessary and health care providers' misconceptions around text messaging of protected health information need to be addressed. HIPAA is technology neutral, meaning that the US Department of Health and Human Services does not have any specific technological requirements for text messaging. However, it is important to note that the HIPAA requires that reasonably anticipated risks of breaches be identified and addressed. Given this broad guidance, compliance can be achieved by setting strong passwords for mobile applications used for messaging, a deactivation capacity for lost or stolen telephones, message encryption, disabling message preview from the locked screen of a device, and removal of patient identifiers.²⁶ Therefore, given that electronic communication will continue to become more prevalent, it is critical for the health care systems to recognize this need and identify ways of minimizing potential risks.

Due to growing up in a technology-dominated era, youth and young adults have a higher propensity toward technological forms of communication. These forms of communication (including text message and video chat) are nearly ubiquitous among youth^{27–29} and can be leveraged to improve engagement in health care and deliver interventions. Other trials have compared a text message intervention to a control condition for increasing ART adherence.^{30,31} In the WelTel Study, a brief bidirectional text message was sent once weekly to assess how the participant was doing and requested a response in 48 hours.³⁰ Those receiving text messages were at lower risk of ART nonadherence at 12 months and at lower risk of virologic failure compared to the control group. Patients and providers indicated that text messaging had the potential for early identification of problems, timely

problem solving, and improved retention and engagement in care.³² In a similar study to adapt the WelTel intervention for patients living with HIV in British Columbia, qualitative interviews revealed that participants found this intervention as a helpful method to communicate with providers, therefore increasing the ability to access services, report side effects, and attend appointments.³³

New technologies are redefining the delivery, accessibility, and scope of care. In addition to text messaging, telehealth is another such technology. A recent survey found that 60% of millennials would use telehealth to video chat with their provider, so they would not have to physically attend office appointments.³⁴ There is growing evidence supporting delivery of psychotherapy and counseling via telehealth, with high patient satisfaction and results comparable to in-person treatment.³⁵ This modality is shown to be cost-effective and well accepted by patients.³⁵ In a study of an Internet-based home care model for the management of HIV, called Virtual Hospital, participants were randomized to the Virtual Hospital or standard care at the day hospital.³⁶ The Virtual Hospital arm had access to virtual consultations, telepharmacy, virtual library, and virtual community. At 2 years, Virtual Hospital was reported to be a feasible and safe tool, with high satisfaction. Patients stated that it improved their access to clinical data and they felt comfortable with the videoconference system. Videoconferencing modalities are promising and cost-effective technologies and are being used with increased frequency.³⁷

Our qualitative study was limited in its generalizability in that we interviewed the health care providers and clinic staff who had years of experience in providing services to YLWH in the San Francisco Bay Area clinics and organizations. Therefore, our results may only be generalizable to locations such as the Bay Area which has clinics and organizations providing resources and services for individuals living with HIV, providers with expertise in providing care to youth and youth adults (particularly YLWH), and a more marginalized patient population that is typically seen in these clinics and organizations. Additionally, our focus was on facilitators of and barriers to engagement in HIV care that were unique to YLWH and around the use of technology; therefore, we were unable to capture all aspects of engagement in care.

Conclusion

In summary, we were able to ascertain important characteristics that identified youth-friendly systems and individuals and the barriers related to using technology to improve engagement in care among YLWH. Future studies should

examine these data from the perspective of youth and conduct randomized controlled trials on the use of these technological advances for improved HIV care cascade. Our results can provide guidance for clinics and institutions providing care for YLWH to enhance the youth-friendliness of their services and examine their guidelines around the use of technology.

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Author contributions

All authors have substantially contributed to the design, data acquisition, or data analysis and interpretations. All authors have drafted this article or critically revised it for important intellectual content. All authors have approved the final version of this article and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

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