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## I wanted it as soon as possible: A qualitative exploration of reactions to access to same day ART start among participants in San Diego’s ART-NET Project

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### Abstract

Rapid, if not same-day, start of antiretroviral therapy (ART) is quickly becoming a best practice around the world. In the US, multiple programs exist to facilitate rapid start of ART, but little is known about the experiences of newly diagnosed individuals receiving these recommendations and services. Twenty participants (19 men who have sex with men and 1 transgender woman) from an early ART start program (ART-NET) at the University of California San Diego were interviewed to better understand experiences with access to same-day ART. Interviews were analyzed for main themes emerging in three general areas: reasons to start, reasons to delay, and factors influencing early ART adherence. Participants reported starting anywhere from right away (same visit as diagnosis) to within a few weeks (median 10.5 days). Reasons to start right away included fear of what could happen if not treated, personal health, influence of people/resources at the clinic, and study participation. Most had small delays in ART start because of structural (insurance, costs) and intentional delays (getting additional medical consultations or additional information/resources). Adherence facilitators included desires to improve CD4/viral load and strong positive beliefs in benefits of suppression. Participants were largely supportive of rapid ART start and appeared to rely on CD4 and viral load data as “proof” of need for ART and its impact. Providing evidence for the impact of HIV on one’s body may be particularly helpful for asymptomatic, newly diagnosed individuals considering immediate ART start.

### Keywords

ART-start; rapid; immediate; newly diagnosed; MSM; qualitative interviews

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## INTRODUCTION

Rapid antiretroviral therapy (ART) initiation after HIV diagnosis is becoming the standard of care in the US for individuals newly diagnosed with HIV (Saag et al., 2018). The myriad of potential benefits resulting from rapid suppression of HIV, rather than waiting for deterioration prior to starting ART, include preservation of immune functioning, reduced accumulated exposure to chronic immune inflammation (Hoenigl, Chaillon, & Little, 2016; Siegfried, Uthman, & Rutherford, 2010), better health outcomes, longevity, well-being (Danel et al., 2015; Eholie et al., 2016; Lifson et al., 2017; Lundgren et al., 2015), and control of transmission to uninfected partners (Cohen et al., 2011; Cohen & Gay, 2010; Hoenigl, Chaillon, Mehta, et al., 2016; Hoenigl, Chaillon, Moore, et al., 2016). Starting ART same-day as diagnosis, or as close as possible to it, is not without controversy or mixed findings in terms of retention and adjustment (Ford et al., 2018), as individuals may feel unprepared to start ART and hence struggle with adherence during initial adjustment periods (Christopoulos et al., 2013). At time of diagnosis individuals may be dealing with strong reactions to learning of their diagnosis, which could prevent establishing positive attitudes or motivation towards treatment. To date, there has been relatively little data to characterize the experiences of being offered rapid (same day as diagnosis) and near rapid ART start.

Using semi-structured interviews, we characterized the experiences with same day or near immediate ART start among newly HIV diagnosed participants participating in the ART-NET program.

## METHODS

Qualitative interviews were conducted between December 2016 and March 2017 with 20 individuals (19 self-identified as MSM and 1 transgender woman) living with HIV. Interviewees were recruited through the San Diego Primary Infection Resource Consortium (SD PIRC, NIH AI106039), which follows individuals newly diagnosed with HIV infection. Since mid-2014 all participants of the SD PIRC are offered access to same day ART (starting on the day of HIV diagnosis or at first clinic intake following HIV diagnosis) without charge as part of a collaboration with Gilead Sciences (CO-US-236–1557). All ART-NET participants received at least 12 weeks of ART, as part of the ART-NET study (NIH MH100974) (Hoenigl, Chaillon, Moore, et al., 2016). ART-NET study participants were recruited through the SDPIRC Early Test HIV screening program, which offers free-of-charge, voluntary, community-based HIV screening in San Diego, California (Hoenigl, Chaillon, Mehta, et al., 2016; Hoenigl, Graff-Zivin, & Little, 2016). All participants were ART naïve ( < 7 days of ongoing ART, excluding pre-exposure prophylaxis [PrEP] and post-exposure prophylaxis [PEP]) at the time of testing.

### Participants and Procedures.

Potential participants in this qualitative study were adult SD PIRC participants who were newly diagnosed with HIV within two years prior to the interview and offered same day ART. Due to slow enrollment, inclusion criteria were extended to include 3 participants diagnosed >2 years before the interview. Those agreeing to participate were scheduled for 1.5-hour long interviews. Interviews were audio-recorded and transcribed.

**Measures.**

A semi-structured interview guide was used by a single interviewer trained in qualitative data collection. Topics included experience with HIV diagnosis, finding appropriate care, starting treatment, and rationale for starting ART immediately or postponing the start of medication.

**Analyses:**

De-identified transcripts were coded in Dedoose (V8.0.35 Los Angeles, CA: SocioCultural Research Consultants, LLC) using a modified thematic identification approach. In addition, brief summaries from field notes were transcribed. Drawing from grounded theory and thematic content coding (Charmaz, 2014; Sankar, Cho, Wolpe, & Schairer, 2006; C. Schairer et al., 2017; C. E. Schairer, 2011; Strauss & Corbin, 1997), transcripts were iteratively reviewed for main themes emerging from interview discourse.

Informed consent was obtained from all participants and the study was approved by the UCSD Human Research Protection program.

**RESULTS**

**Participants.**—Qualitative interviews were conducted with 20 participants in ART-NET. Among participants interviewed, ages ranged between 22–51 years of age, with 90% in their 20s and 30s (Table 1). As indicated in Table 1, all participants were assigned male sex at birth and almost all reported male gender, with the exception of one reporting female. All 19 males reported sex with men, while 2 males reported also sex with women and the one transgender woman reported sex with men and women. Nine of the interviewees were Latino/a (regardless of race), with the remaining 10 reporting White (non-Hispanic) and 1 reporting Black (non-Hispanic). Overall, 8 of 20 participants were diagnosed during acute HIV infection, 2 during early HIV infection, and 10 during chronic HIV infection. Most (17 of 20) participants completed the interview within 2 years of HIV diagnosis.

**Categories of content**

We report on three main themes for interview content: reasons to start ART immediately, reasons for waiting to start ART, and motivators for early adherence to ART (Table 2). Among these three content areas, numerous themes emerged.

**Themes for reasons to start immediately**

Nine interviewees reported same day ART start. Reasons participants provided for starting ART right away could be organized into four dominant themes; (1) fear delaying therapy, often informed by personal experiences seeing someone living with HIV deteriorate without treatment, (2) desire to maintain health through maintained immune function, (3) having support from trusted providers and access to a well-regarded treatment clinic, and (4) some aspects of having been part of a study when diagnosed (thus having facilitated and free access to medications and treatment) and continuing on as a participant in the ART-NET project. Table 2 presents each theme in this area and examples of excerpts within that theme.

### Themes for reasons to delay ART

Twelve interviewees reported delaying ART, but none of the interviewees delayed for a substantial period of time; most requested to delay start only by days or weeks. When delays in ART start were discussed, 2 main themes emerged: (1) needing/wanting to confirm insurance or drug access and coverage for long term use; and (2) noting that the delay in ART initiation gave the participant “time to absorb” the diagnosis. Although some explained important conversations with providers that addressed fears of side effects like those experienced by individuals taking earlier formulations of ART, generally participants discussed confidence in the efficacy of the medications. The timeline for those who had delays appeared largely due to logistics, such as confirming drug coverage or awaiting medical tests results (e.g., genotype test results). Among the few reporting intentional delays of several weeks, discourse centered on wanting to gather their own information. Participants did report concerns about short and long-term side effects of ART medications, but these were more in relation to discussions about early experiences with ART than as reasons for delaying ART start.

### Early Adherence

In discussions about early experiences with taking ART (Table 2), participants shared feeling motivation and commitment towards ART adherence, which appeared to center on monitoring of HIV and treatment effects and a strong desire to reach and sustain an undetectable viral load. Participants discussed learning of poor immune function (ie., CD4 counts) as “proof” of need for medications, being knowledgeable and aware of potential negative effects on immune functioning, and, although less common, desires to prevent onward transmission.

## DISCUSSION

Participants interviewed from SDPIRC provided rich descriptions of their experiences learning of their HIV diagnosis and starting ART. Consistent across participants were themes of feeling ART was essential to recovery of health, with very few noting strong desires to intentionally avoid ART start. The sample was clearly well-informed, and many were knowledgeable about where to find additional information and second opinions as well as interpreting CD4 count and viral load results. All interviewees participated in the ART-NET project, which involved patient-centered protocols for delivery of HIV-test results, education and facilitation of immediate and early ART-start, which may have contributed to high levels of health literacy. Even in this context of added support, however, some participants still noted structural barriers related to ensuring financial coverage and the ability to manage co-pays for those privately insured. Some participants facing a short delay used the time to continue to gather information and prepare themselves for starting ART. It is worth noting, however, that at least one of the 21 interviewees described some degree of anxiety while waiting as they had wanted to start as soon as possible.

Participants discussed high levels of motivation and commitment to adherence in the context of immediate and early ART-start that were often tied to CD4 count and viral load results. Participants reflected on how experiencing fear and anxiety around low CD4 count and high

viral load values and, related to this, seeing changes in these values motivated continued adherence. It is possible that reviewing objective measures like CD4 counts or viral load with patients who do not have HIV related symptoms holds particular value. While measures of disease progression have long been a vital part of HIV care in the US, using them when discussing rationale for immediate ART start and early adherence may have unique relevance in the era of same day ART.

The results from interviews among interviewees in San Diego engaged in the ART-NET project may largely reflect reactions to immediate and rapid ART start in communities where there is trust in efficacy of ART and resources for community support. A recent synthesis of the literature on rapid ART start suggested that individual-level barriers to ART start, such as concerns about accuracy of test results, dealing with stigma, partner reactions, domestic violence, and needing time to process the diagnosis, were identified as issues predominantly observed in African studies (Ford et al., 2018). That research, similar to our findings, also noted that side effects, adherence and pill burden were not factors deterring ART start.

Important limitations to the findings and conclusions of the current research include small sample size, only one interview from a transgender woman, potential for recall bias, and selection of the sample from a specific program offering same-day ART initiation. The content from the interviews did, however, appear to converge and reach saturation. Of note, only one transgender woman was included in the sample. While we did not find noteworthy discrepancies between the experiences shared with ART start by MSM interviewees and the one interviewee who was transgender female, the data collected and presented clearly best represent experiences of MSM. We elected to include all interviewees as valuable contributors, rather than eliminate data from any one participant. Experiences specific to transgender women should be explored in further research. Finally, discourse may have been different if we had interviewed participants immediately after starting ART, or during the process of initiating ART.

Intervention programs that assist people in securing access to affordable ART and build health literacy and agency at time of diagnosis appear particularly important. Results from these kinds of interventions (Colasanti et al., 2018; Labhardt et al., 2018; Pilcher et al., 2017) show benefits such as reducing time to ART start and time to viral suppression. Rapid ART programs rolling out around the globe may be improved by building strong HIV and treatment literacy and offering opportunities for informed and shared decision making.

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**Table 1:**

Demographic and Clinical Characteristics of Cases and Controls at Baseline.

Characteristic	Total (N=20)	
Age	Range	22–51
	Median (IQR)	32 (25–35)
Sex	Male	19 (95%)
	Female	1 (5%)
Race/ethnicity	Hispanic (Regardless of Race)	9 (45%)
	White (non-Hispanic)	10 (50%)
	Black (non-Hispanic)	1 (5%)
HIV Infection Status at Diagnosis	Acute HIV	8 (40%)
	Early HIV	2 (10%)
	Established HIV	10 (50%)
Highest Education	High school diploma	4 (20%)
	Some College	9 (45%)
	Bachelors degree	7 (35%)
	Some postgraduate	1 (5%)
Number of Sex partners in Last 3 months	Range	1–30
	Median (IQR)	3.5 (2–14)

Table 2.

Themes and excerpts for reasons to start ART same-day and reasons to wait.

CONTENT AREA: Reasons to start ART immediately		
THEME	DESCRIPTION	EXAMPLE QUOTE(S)
Fear of Alternative	Discourse reflecting personal awareness of untreated HIV progression and desire to avoid this.	<i>Well, we had a friend probably five years prior who had HIV and didn't tell anyone, didn't do anything about it, didn't get treatment and he ended up dying at a really young age. He was 30 years old. And so it was a lot of fear and dread. Almost like, you know, is it a death sentence? I-- 'cause the only person I've really known close to me that had died from it. And so, I was-- it was scary to know, you know, that that's always a possibility. But I mean he had full control of it and he did nothing about it, and I wasn't going to make that same mistake.</i> (White male in his 30's)
Health	Discourse reflecting desires to maintain health.	<i>I had already done some research on it and knew that if I started early enough it would stop most of any of the damage that the virus could sustain that would become long-term.</i> (White male in his 40's) <i>I felt optimistic when I saw [my nurse], because I said, "Okay, if I catch this early enough I can start retroviral therapy soon and get this nipped in the bud."</i> (Hispanic male in his 20's)
Resources at Site	Discourse referring to supportive/trusted providers or treatment programs.	... for me it was like, you know, [CLINIC NAME] is a very good place and the [PROGRAM NAME] has accreditation and people have said good things about it, you know. (Hispanic male in his 20's) I like it here a lot. Especially [NURSE NAME]. She's so awesome... It's been definitely a life-changer, obviously, but if I hadn't come here... I don't think I would have really put that much effort into meds or appointments or nothing like that. I probably would have just not cared. (Hispanic male in his 30's)
Study Participation	Discourse reflecting on experience as a participant in the Early Test project where access to medications were free and facilitated and early starts would contribute to research knowledge.	I tried contacting couple different places. Like, I looked into [another organization], but as soon as the [PROGECT AFFILIATED CLINIC] got back to me, like, I already knew that I'd be able to be getting medication for free and I didn't have healthcare at the time, so it was kind of the optimal choice. (Native American male in his 20's) I have to say the supply of meds, you know. When I was homeless, like, you know, I could barely afford a place to sleep. ... So just they gave, I mean, talk about a lifeline, they gave me my meds. They still give me my meds. So that was the biggest thing. (White male in his 30's) And for me and my husband we both feel the same way about any kind of research that we can help with... So if that happens where they need some guinea pigs I'm all for it. (White male in his 30's) Once they explained that it was a study and that it could help people and everything like that, I went from being afraid of doing it to just like, "If I can help people with this, then why not put forth the maximum effort?" (Hispanic male in his 20's)
CONTENT AREA: Reasons to delay ART start		
THEME	DESCRIPTION	EXAMPLE QUOTE(S)
Insurance and Coverage Considerations	Delays related to confirming insurance and/or drug coverage	<i>I knew what I needed to do. I knew what medicine I was going to go on. ... The medication that we decided with was extremely expensive, and I have to wait till my insurance kicked over again in the first of the year before I could get on it. ... And so knowing I would have to, you know, hit my deductibles and co-pays and then they would just start over again in January would've been extremely catastrophic financially for me. So I decided to wait-- wait that month.</i> (White male in his 30's) <i>I want to say was about two months. Roughly about two months. And I'm the one who chose to wait two months. Because I wanted to meet with my primary care physician first with my insurance. You know, my carrier. Just to make sure that everything was in plan according and let them know.</i> (Race/ethnicity declined male in his 30's) <i>Because that was my whole thing is I just wanted to get on medication ASAP, and obviously I didn't have the health insurance to just go to a doctor to get it taken care of, so I had to wait until that whole process went through, which went by relatively quick. But that was my main concern was just to get on medication as soon as possible.</i> (Hispanic Native American male in his 20's)
Time to absorb	Discourse reflecting use of delays between diagnosis and ART start to gather information, consult with others, and adjust to diagnosis	[The three-week delay] was a period where I was doing the test and I was getting familiar with the fact that I had HIV. So, yeah, I was being prepared for the treatments, yeah. (Black female in her 30's) <i>She [provider] wanted to give me I remember that she wanted to give me time to think about it so the it wasn't a rushed decision. And then she gave me a bunch of stuff to-- she gave me references to look up and review. ... so yeah, that was about seven days she gave me for that. And then on the seventh, when I came back the following week that's when we started them. ... I don't like making rush decisions. So even 24 hours probably would have been fine with me. Within 24 hour I already had my decision because I had done literally left and went online and started reading about the drugs and the drug effects and why should you start the medication immediately and not wait...</i> (White male in his 40's)

CONTENT AREA: Reasons to start ART immediately		
THEME	DESCRIPTION	EXAMPLE QUOTE(S)
		<i>And I asked the other doctor as well, like I said. "Is it," you know, "Is it okay that I want to wait, just to make sure that I also have all the information that I feel comfortable with looking online at side effects and this and that, just to make sure that I am okay and I'm ready to do this?" Like, "Yeah. There shouldn't be any issue." (Hispanic male in his 30's)</i>
CONTENT AREA: Early adherence		
THEME	DESCRIPTION	EXAMPLE QUOTE(S)
Objective markers (CD4 or Viral load) as motivating	Discourse reflecting use of objective markers of immune functioning or virus as supporting adherence.	<i>After hearing the numbers of where my T-cell count was at and all that, I realized that it had affected me so quickly that I didn't understand how bad it was, I guess, prior to actually being told what the numbers were. And then I also couldn't understand how I wasn't already basically dying. I guess I realized how low my T-cell count was and how high the viral load was. And I guess that's what scared me the most, the fact that I just found out, and it's already this. (Hispanic male in his 20's)</i>
Knowledge/awareness of medications preventing immune deterioration	Discourse noting medications and desire to use them as preventing deterioration of one's immune functioning.	<i>Well, I don't want my immune system to run down, so, you know, it's, it protects my immune system. Like, I know that that's why I got so sick. My immune system crashed. .... I mean, I didn't want to be like that, so I knew the medication was beneficial... (Hispanic male in his 20's)</i>
Prevention of onward transmission through viral suppression	Discourse containing reference to medications assisting in prevention of HIV transmission to others	<i>... keep them from getting sick. Yeah, to make them undetectable so that they don't spread-- the HIV to anybody else. 'Cause a lot of people that do have HIV, it's all sexually transmitted most of the time. So, you know, you have to be careful. You have to take care of other people. ... (Hispanic male in his 20's)</i> A 40-year-old White male stated, " <i>The long-term benefits is you take it [ART] and your viral load is suppressed. You become undetectable. The chances of transmit [transmission] is reduced to barest minimum and then you can contribute so it adds to your life expectancy, yeah. (White male in his 40's)</i>