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ORIGINAL PAPER

Evaluating Dual Process Decision-Making Along the PrEP Consumer Journey: New Insights for Supporting PrEP Use

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Abstract

With the rise of new and emerging Pre-Exposure Prophylaxis (PrEP) modalities, greater attention is needed to better understand how people who could benefit from PrEP make decisions to initiate, stop, pause, or switch PrEP regimens. In this study we borrow from the field of consumer research to create a consumer-derived PrEP Consumer Journey Model that describes key decision-making touchpoints a PrEP consumer moves through within and outside of a clinical context. Using in-depth interviews ($n=29$) with gay and bisexual men who have sex with men, we evaluate which system 1 (emotional) and system 2 (cognitive) attributes are used for decision-making at different touchpoints along the PrEP Consumer Journey. Our results suggest system 1 attributes, such as feeling protected, reducing anxiety, enhancing pleasure, social norms, and taking ownership over health were more salient when consumers moved from pre-contemplation to information gathering, as well as evaluating post-uptake experience. System 2 attributes, including cost, side effects, dosing schedule, and sexual frequency, were present throughout the PrEP Consumer Journey, but particularly influential in the information gathering stage and when pausing, switching, or opting out of PrEP. We contend the PrEP Consumer Journey, and our findings related to decision-making, can help orient medical providers to anticipated patient concerns around PrEP use and ultimately provide more supportive and engaging PrEP counseling and services.

Introduction

Pre-Exposure Prophylaxis (PrEP) is an evidence-based biomedical intervention highly effective at preventing the transmission of HIV. First approved by the FDA in 2012 as a daily oral medication, PrEP has more recently become available in new modalities and dosing schedules in the form of an injection administered every eight weeks, and as a pill taken orally before and after sex, known as event-driven PrEP. Other modalities such as subdermal implants, douches, and a monthly oral pill are currently under investigations in various clinical trial stages. The growing catalogue of PrEP modalities allows us to imagine a future in which individuals who benefit from PrEP can choose an option that best aligns with their personal preferences, behaviors, and sexual, socio-cultural contexts, resulting in high population-level coverage of HIV prevention [1].

Yet, despite over ten years of dissemination of oral PrEP, and several years of multiple modalities and regimens being available in the United States (US), in 2022 only 36% of people who could have benefited from PrEP were prescribed it [2]. Current public health strategies for promoting PrEP uptake (e.g., risk assessments and/or cognitively-focused education) have done little to engage high priority populations [3]. Furthermore, high discontinuation within the first 6 months of PrEP initiation and increased HIV and STI incidences after stopping PrEP suggests that additional attention is needed to identify strategies to counsel patients on when it might be appropriate to start, stop, or switch PrEP modalities, and to ensure they have support to re-engage in PrEP and sexual health services when needed [4–6]. To better understand how to support people who could benefit

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from PrEP, several models have emerged that conceptualize the patient experience navigating PrEP services and identify key decision-making factors that influence when a patient decides to seek out, initiate, or discontinue PrEP.

Building on the HIV treatment cascade and the Transtheoretical Model of Change [7], Parson et al. [8] developed the Motivational PrEP Cascade. While this model conceptualizes PrEP use in the context of decision-making across time, it lacks external contextual factors and nuance for pausing and switching PrEP. An augmented PrEP cascade was developed by Newman et al. [9] using a cyclical design and incorporating alternate decision-making and psychosocial challenges that better accommodate intermittent PrEP use. More recent PrEP research has utilized end-user journeys and human-centered design frameworks to understand how circumstances impact PrEP discontinuation and persistence [10–12]. In the current study, we conceptualize PrEP as a health product and build on these frameworks, extending them to a "consumer decision journey" as coined by Court et al. [13] to describe a dynamic consumer decision-making process [14].

The cognitive psychology field has revealed that the decision-making process can be characterized through a dual process model, including both intuitive and deliberative processes [15]. Much of the current PrEP-focused literature has focused on cognition-driven (system 2) attributes (e.g., costs, efficacy, side effects) when measuring PrEP-related decision-making among gay and bisexual men, with less consideration for affect-driven (system 1) attributes [16]. Recent studies investigating the PrEP decision-making process among gay and bisexual men through various stages of the PrEP cascade found that systemic healthcare barriers (i.e. insurance, scheduling logistics), social contexts, and perceived HIV risk have all been identified as factors influencing PrEP uptake and discontinuation [17–19]. Considering intuitive and emotional processes, as well as the ways in which gay and bisexual men make meaning out of specific narratives about PrEP, offers new ways to examine gay and bisexual men's decision-making in PrEP uptake and discontinuation over time. Decision-making related to initiation or discontinuation of PrEP does not occur as a singular event, but rather is evaluated iteratively as a journey over time, across contexts in the wake of new experiences.

We merge these two streams of research to (1) create a consumer-derived PrEP Consumer Journey and (2) identify what decision-making factors are important to PrEP consumers with dynamic sexual health trajectories as they progress through the PrEP Consumer Journey from pre-contemplation and information gathering to initiation, switching, pausing, discontinuation, and re-initiation. The present study uses a PrEP Consumer Journey model to better understand how gay and bisexual men evaluate system 1 and system 2 attributes of different PrEP modalities and make decisions around HIV prevention in a new era of PrEP choice.

Methods

This study was conducted at a large academic medical center in New York City. The Comprehensive Health Program (CHP) is a sexual health clinic offering equity-focused, status-neutral, gender-affirming care. Serving over 2,500 patients, CHP serves primarily cisgender men, with 25% of patients below age 25, 16% of patients identifying as Black and 43% as Latino.

Using convenience sampling, participants were recruited from a prospective, observational PrEP engagement study (Stick2PrEP) at CHP from April 2021 until May 2022. Care coordinators identified patients interested in participating in Stick2PrEP and then put them in touch with research staff who introduced the study. Stick2PrEP participants were then asked if they would like to participate in a qualitative interview as part of a sub-study on HIV prevention decision-making. Those who provided informed consent were enrolled into the study.

One member of the research team (BL) conducted 60-minute in-depth interviews over Zoom. Interviews sought to learn how people make decisions about HIV prevention and what factors are important to them as they consider their options. The interview guide was composed of 11 questions exploring participants' HIV prevention and PrEP decision-making process from pre-contemplation and information gathering to initiation and post-uptake evaluation. After each question participants were probed for system 1 and system 2 attributes associated with their decision-making process. Participants were also asked about sources of HIV prevention information, knowledge and attitudes toward PrEP, and reactions to new and emerging PrEP modalities. Participants received a $25 gift card as compensation for participation in the study.

PrEP Consumer Journey Framework Development

A preliminary codebook was developed using a priori codes identified from the stages in the Motivational PrEP Cascade [8], augmented PrEP cascade [9], PrEP user journey [11], and consumer journey [13]. The research team (BL, HF, NN) familiarized themselves with the data by reading and annotating five transcripts with the preliminary codebook. A matrix was created listing out all stages associated with each framework and compared against the annotated transcripts. Duplicative codes were condensed and renamed, and the codebook was iteratively refined until a final consumer

journey framework was agreed upon. The PrEP Consumer Journey codebook was then turned into a diagram (Fig. 1).

Analysis

Data was analyzed by two members of the research team (BL and HF) using Braun et al.'s [20] six-phase approach to thematic analysis. A priori decision-making codes were identified using system 1 and system 2 factors described by Bauermeister et al. [16]. Using notes from the familiarization process, additional preliminary decision-making codes were added to the codebook. Parallel coding was used to code segments of text with both system 1 and system 2 factors along with touchpoints and decision-making trajectories from the PrEP Consumer Journey. Next the research team made individual PrEP Consumer Journeys for each of the 5 transcripts, by placing codes and quotes on a diagram of the PrEP Consumer Journey. Visually placing codes along the PrEP Consumer Journey led to deeper insights into how system 1 and 2 attributes distributed across the journey. Three more transcripts were coded using the final codebook to ensure inter-coder reliability. After all transcripts were coded in Dedoose, excerpts tagged with system 1 and system 2 codes were then clustered together in a data matrix by stages of the PrEP Consumer Journey. The research team met repeatedly over the course of several months to review the matrix and develop the themes presented below.

Ethics

This study was approved by the Institutional Review Board at Columbia University Medical Center.

Results

Participant Demographic

Sample characteristics are described in Table 1. Out of the 29 participants, 19 (65.5%) identified as White, nine (31%) as Black, and nine (31%) as Hispanic. All participants were cisgender men, with 28 (97%) identifying as gay. Participants ranged in age from 19 to 39 years. Almost half of the participants were privately insured (48.3%) and a majority had a bachelor's degree (65.5%). Most participants were using daily oral PrEP (72%). Time spent on PrEP ranged

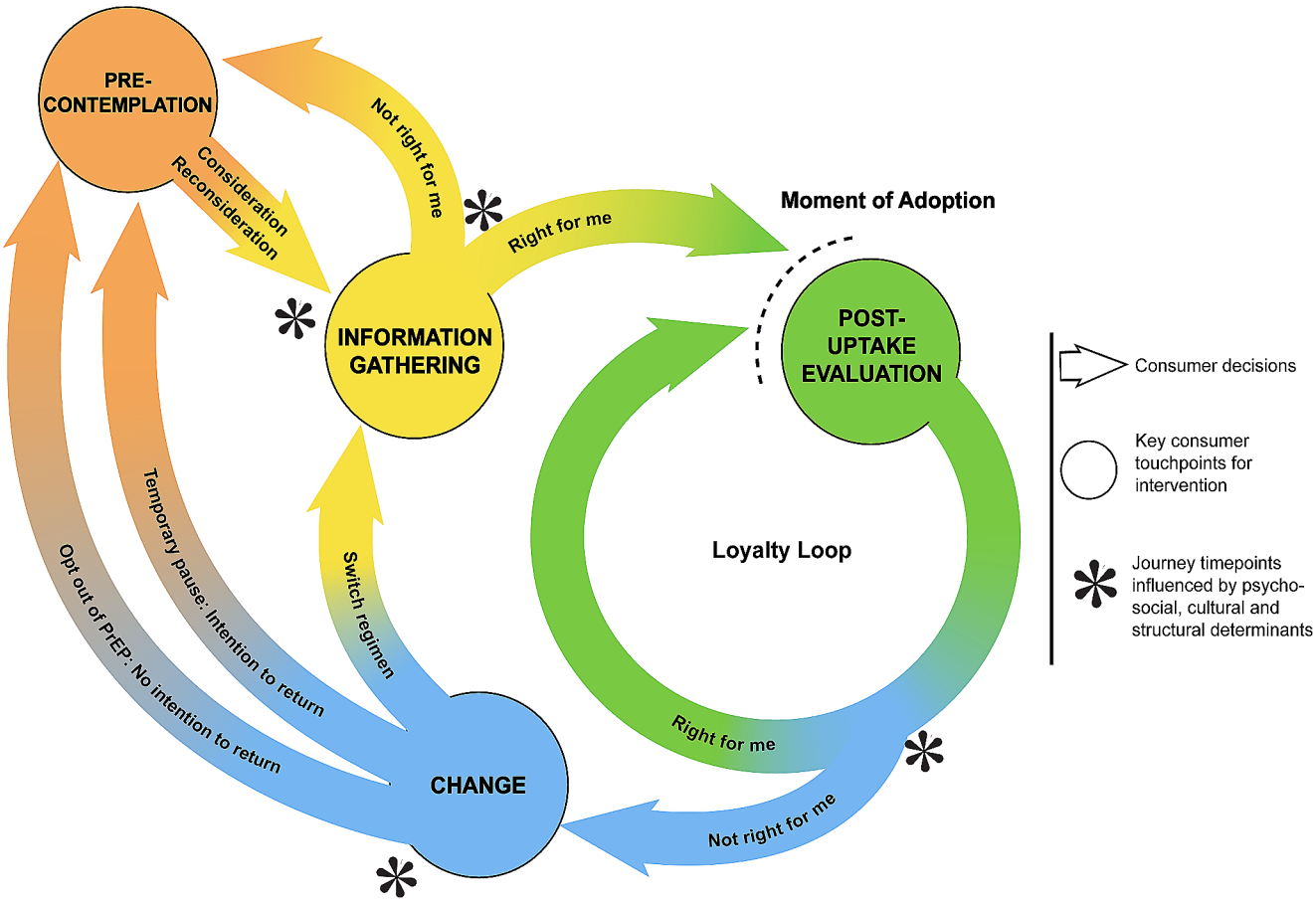

Fig. 1 A PrEP Consumer Journey framework with key consumer decision-making trajectories and touchpoints for intervention

Table 1 Sociodemographic and PrEP use characteristics among gay and bisexual men in New York City, April 2021-May 2022 ($N=29$)

Variable	*N*	Percent
Age (mean, range)	29	19–39
Gender		
Male	29	100%
Sexuality		
Gay identifying	28	97%
Not gay identifying	1	3%
Race/Ethnicity		
White	19	65.5%
Black	9	31.0%
Hispanic	9	31.0%
Other	2	6.9%
Insurance		
Private health insurance or HMO	14	48.3%
Medicaid	9	31.0%
None	5	17.2%
Other	1	3.4%
Education		
High school graduate or GED	1	3.4%
Some college credit, no degree	5	17.2%
Associate's degree	2	6.9%
Bachelor's degree	19	65.5%
Master's degree	2	6.9%
Income		
≥ $80,000	3	10.3%
$60,000 – $79,000	4	13.8%
$40,000 – <$60,000	7	24.1%
$20,000 – <$40,000	8	27.6%
$10,000 –<$20,000	4	13.8%
< $10,000	3	10.3%
PrEP Modality		
Daily oral PrEP	21	72.4%
Injectable PrEP	3	10.3%
Event-driven PrEP	5	17.2%
Longest continuous amount of time on PrEP		
0–3 Months	12	42.9%
4–11 Months	2	7.1%
1–3 years	10	35.7%
> 3 years	4	14.3%
PrEP Break		
Took a break from PrEP four weeks or less	14	48.3%
Break from PrEP for longer than 4 weeks	8	27.6%

from a few days to eight years. Most participants had taken at least one break from PrEP (75.8%) at some point in their PrEP journey, with about half of participants (48%) taking a break less than four weeks and a quarter reporting taking a break from PrEP more than 4 weeks (27.5%).

PrEP Consumer Journey Framework

This proposed framework consists of four touchpoints connected by a series of decision-making trajectories (Fig. 1). A touchpoint is a value-producing incident [21], where an individual is most susceptible to deciding if a given PrEP regimen is right for them or not right for them. Touchpoints may include experiences such as seeing a PrEP advertisement on the subway, learning your sexual partner is on PrEP, discussing PrEP side effects with a provider, visiting the pharmacy to refill a prescription, or forgetting to take a daily pill. A lasting impression of PrEP that influences future use is created as consumers move through a collection of these touchpoints.

Pre-Contemplation. Everyone begins their PrEP Consumer Journey in pre-contemplation, and may cycle in and out of this touchpoint over the course of their life. Individuals at this touchpoint are either unaware of PrEP or are aware of PrEP but are not interested in starting it at this moment in time; this may include previous PrEP consumers.

Information Gathering. After becoming interested in PrEP, the potential consumer begins to learn more about what PrEP is, how it works, and how to get started.

Post-Uptake Evaluation. After the consumer takes their first PrEP dose, they begin to evaluate how PrEP impacts their life, including advantages and disadvantages to being on the medication. The cadence of evaluation is dependent upon regimen choice, where daily oral PrEP consumers make a decision every day to continue with PrEP. In contrast, an event-driven consumer makes a decision around the time of a sexual encounter and the injectable-PrEP consumer makes a decision at the time of scheduling or showing up for their monthly or bimonthly injections. Consumers satisfied with their experience on PrEP enter the loyalty loop upon receipt of their next prescription.

Change. After evaluating their experience on PrEP, consumers dissatisfied or unable to continue their current regimen are faced with three options: 1) opt out of PrEP with no intention to resume; 2) temporarily pause their regimen, with the intention to resume in the foreseeable future; or 3) switch to a new regimen. Option 1 and 2 return the consumer to pre-contemplation and option 3 leads the consumer to the information gathering touchpoint where they begin to learn about other available PrEP regimens.

Psycho-social, cultural, and structural determinants. Decision-making rarely happens in isolation. We acknowledge that decision-making is influenced by external contextual factors that either enable or constrain access to PrEP information, services, and related behaviors.

System 1 and 2 Attribute Mapping

Along the PrEP Consumer Journey, system 1 and 2 attributes appeared more and less salient at different points. While system 2 attributes spanned the entire journey, system 1 factors were more salient during pre-contemplation and post-uptake experience (Table 2). We present key findings for system 1 and 2 attributes organized by the 4 touchpoints of the PrEP Consumer Journey: (1) pre-contemplation, (2) information gathering, (3) post-uptake evaluation, and (4) change: pause, switch, opt out. Illustrative quotations are labelled with a participant number, PrEP modality, and participant age. See supplementary Fig. 1 for PrEP Consumer Journey figure integrated with salient system 1 and system 2 factors.

Pre-Contemplation: Consideration

The system 2 attribute, sexual frequency, was a key factor in the PrEP decision-making process. Most participants decided to initiate PrEP either due to increased sexual activity or an intention to become more sexually active. Participants connected the increase in the number of sexual partners with an increase in condomless sex, which left many participants feeling vulnerable to HIV acquisition.

> *Then, I had a 2-year stint where I was completely single and like catching my prey in the wild at bars and things like that and I was like I should probably you know, things were getting wild, and I had some nights where I just had unprotected sex and that wasn't great. I need to not do that and probably get on PrEP. PID 186, Daily Oral PrEP, Age 33.*

> *I'm being a lot more promiscuous in my personal life and am notoriously not very good about using protection, so I thought that this would be something that's safe for me to be on, just as a precaution. PID 152, Daily Oral PrEP, Age 29.*

Table 2 Salient system 1 (emotional) and system 2 (cognitive) attributes identified at different touchpoints of the PrEP Consumer Journey

	System 1	System 2
Pre-Contemplation	• Feeling protected • Intimacy • Social norms	• Sexual frequency
Information Gathering		• Side effects • Cost
Post-Uptake Evaluation	• Reduce anxiety • Peace of mind • Social norms • Ownership	• Dosing schedule • Access
Change: Opt out		• Sexual frequency • Side effects
Change: Pause		• Access
Change: Switch		• Side effects • Dosing schedule • Sexual frequency

After hearing about PrEP, either from a friend, provider, or on social media or dating app, participants described a conscious self-evaluation of HIV risk, where an increase in sexual frequency, or change in sexual practice drove participants to want to feel more protected in their sexual behavior.

> *I was engaging in a lot of casual sex… and having, quite honestly, like a lot of unprotected sex. And a friend of mine, said, "Hey, I think you should really get on PrEP." He said I would feel safer if I was on it. And that phrase is really what pushed me to start looking into how to get PrEP. PID 127, Daily Oral PrEP, Age 25.*

At the same time, many participants articulated their longstanding fear of HIV tied to the legacy of AIDS in the lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ) community. These fearful thoughts of HIV acquisition usually presented around the time of a sexual encounter and when getting tested for HIV and STIs. PrEP offered one potential strategy to reduce anxieties around HIV acquisition (a system 1 process) allowing for peace of mind during sex and the day after a sexual encounter.

> *I think it will be nice to be able to say "yeah it's cool, I'm on PrEP," in sexual encounters. It feels comforting. And also giving peace of mind in a daily way or the next day sort of thing. PID 152, Daily Oral PrEP, Age 29.*

> *I hadn't heard of PrEP until him, he told me about it, and it eased a lot of my concerns. He was undetectable and took care of his health and everything, but it just gave me peace of mind. PID 43, Daily Oral PrEP, Age 32.*

Reduced anxieties around HIV acquisition and feeling more protected in a sexual encounter increased these participants' sexual pleasure, giving them a greater sense of freedom to have sex with more partners and try out new sexual activities, including condomless sex.

> *I wasn't sexually active for a very long time and then when I became sexually active, it was one of those things where like okay if I'm going to do this and enjoy it, I don't want to have the thought [of HIV] in the back of my head [wondering if] I trust this person. PID 151, Daily Oral PrEP, Age 29.*

After I broke up with my boyfriend…I got better at bottoming and got really comfortable with it and started to seek it out, I was like, I need to be on PrEP. PID 161, Daily Oral PrEP, Age 25.

All participants were PrEP consumers, however one participant described how he initially never considered starting PrEP because he didn't know any other Black men on PrEP. Racial inequities in PrEP access and uptake shaped his perceptions of who could and could not be on PrEP.

The majority of people who were on PrEP were predominantly white gay men who had white collar jobs. So that made it really unattractive to me because of the social inequalities […] White gay men on PrEP can have sex with people who aren't on PrEP, and it's like they don't need to worry about their status because they have access to healthcare, as opposed to people of color who don't have that same access. All the burden falls on us. PID 86, Daily Oral PrEP, Age 26.

While the system 2 factor, sexual frequency, was consistently cited as a major driver of PrEP uptake, system 1 factors, including feeling protected, reducing anxiety, achieving peace of mind, and being able to enjoy sex were more widely evoked in the formative moments of decision-making. Participants articulated an associative connection between pill taking and the promise of achieving a desired sexual lifestyle or health goal.

Information Gathering

After expressing interest in PrEP, nearly all participants referenced system 2 factors when describing their experiences seeking out additional information to better understand PrEP's attributes. Most of the information gathering was done with a healthcare provider, with a few participants searching for information online or reading clinical trial data. Side effects and long-term consequences of PrEP were the most commonly-mentioned concerns amongst participants as they reflected on their decision to initiate PrEP.

A little bit of initial hesitation was like I don't know what this is that I am putting into my body…like what are the long-term effects of this? What will it be like in 40 years? Are there going to be commercial like "Did you take PrEP between the years of blah, blah, and blah? PID 89, Event-Driven PrEP, Age 34.

I had pretty much heard from most people that were on it that it didn't cause any problems for them and I had been doing my own little bit of research and it seems like there are virtually no side effects and the side effects that are there aren't awful or pretty slim that you'll get them so I wasn't particularly worried about that. PID 172, Daily Oral PrEP, Age 25.

Some participants were hesitant to try new formulations of PrEP given that there was less long-term, real-world data available compared to more established options. Injectable PrEP in particular was perceived as a riskier choice, since it was only recently approved in 2021.

After the studies have commenced, I'm the type of person that does not want to be the first guinea pig. I'd rather wait until more research has been done. So, it would definitely affect my decision to take the injectable, but it would have to be after that span of clinical trials that says this is the amount of time that it takes for this particular long-acting drug to metabolize out of your body, then that way I can make a decision that is informed. PID 269, Daily Oral PrEP, Age 36.

I know Descovy has less data out there, and so for me, that data is important. I'm very logical. I'm a software engineer, so I work on numbers and like visually seeing the logic. And to me, it was like, OK, I see the numbers and I see that it would make more sense to go with Truvada. PID 130, Daily Oral PrEP, Age 31.

In addition to side effects and potential long-term health consequences, cost of PrEP was another concern and perceived barrier to PrEP initiation. A few participants described doing research on how they could feasibly finance the cost of daily oral PrEP for an extended period. Whether it was free at the clinic, discounted through a patient assistance program, or covered by private insurance, the prospect of free or inexpensive medication was often described as a deciding factor when initiating PrEP.

I wasn't sure if my insurance would cover it fully or not, but the case worker told me that if it didn't fully cover it, that this extra insurance through the clinic would cover it. So the fact that it was free, I thought, well, I might as well just take it. PID 72, Event-Driven PrEP, Age 30.

During the information gathering phase, there was often a moment of cognitive deliberation where participants weighed the costs (potential side effects, dosing-schedule, clinic visits) against their desired sexual future. For some participants, this moment lasted a few seconds or minutes in

the doctor's office, while others took weeks processing the information at home.

> *I didn't want to take it the first time that they told me…I said I'll think about it…. And seeing the research and stuff like that also like helped me make the decision and just be like, OK, let me just take PrEP. And then I came again for my monthly visit and they explained it to me again. And then that's when I just said, OK, makes sense, I'll start using it. PID 68, Daily Oral PrEP, Age 25*.

The dosing schedule of different modalities was one of the more common system 2 attributes used to evaluate different available PrEP options. After hearing about the daily, bi-monthly, or as needed dosing regimens of PrEP by their provider, many participants were able to evaluate which modalities were not right for their lifestyle.

> *It's just the reason that I would be less interested in that is having to go to the doctor every two months [for injectable PrEP]. Just the logistics of that, as opposed to just having a bottle of pills here with me. PID 72, Event-Driven PrEP, Age 30*.

> *An injectable definitely appealed to me a lot more than taking a pill every day. You know, like, I didn't have to worry about having to get up and remembering to like, oh, gotta take my pill. Like 'cause sometimes I forget to take my vitamins that day. You know, so, at least with this, like I could just take it [injectable PrEP] every eight weeks and it still does the job right. PID 232, Injectable PrEP, Age 33*.

> *I think I'm a little too scatter brained to do that version [event-driven]. It just feels like there's a lot of planning going into it and I just figured I would do the daily one because it seems like an easier habit to always be in. PID 152, Daily Oral PrEP, Age 29*.

Some participants, who were long term consumers of daily oral PrEP, acknowledged the importance and novelty of new PrEP modalities; however, they conceded that if their current regimen was working, they were not interested in trying something new.

> *I was glad to see that there is progress being made and different options available… but it's not difficult for me to take the pills so I'm not necessarily seeking out a new way to take PrEP. PID 34, Daily Oral PrEP, Age 29*.

While all of our participants were PrEP consumers, some described not being interested in PrEP when they heard about it for the first time. Most of these participants used the system 2 factor, sexual frequency, to determine PrEP was not right for them. These participants believed it was not worth starting PrEP because they did not have sex frequently.

> *When I got STI tested in March, the doctor talked to me about it, but my primary partner is a woman, and I honestly was like I'm having sex so infrequently with guys, maybe once every month or so on average, and I want to use condoms anyways, so I really don't want to take this pill too*. *PID* 251, Event-Driven PrEP, Age 25.

> *My partner and I were safe in other ways, and I don't know, just like the ratio of taking a pill every day to like how much we were actually having sex outside of our relationship, like it maybe happened like once a year*. *PID* 152, Daily, 29.

Post-Uptake Evaluation

After their first dose of PrEP, participants entered the post-uptake and re-evaluation stage where they used a combination of system 1 and system 2 factors to assess their experience on PrEP and whether it was worth it to continue taking the medicine. When asked about their experience in the first weeks or months on PrEP, many participants described the dosing schedule of their chosen PrEP modality to assess its feasibility and acceptability. For some, daily pill taking was easy to routinize into a morning routine that already involved taking a daily vitamin, while others described daily pill taking more of a burden that was incongruous with their unpredictable lifestyle.

> *It did get harder when I got my airline job because that's constant chaos. [The pill] gets taken, I would just say it's not the same time every day, like if I'm in the middle of working on a plane, and I can't be like, "hold on guys." PID 102, Daily Oral PrEP, Age 25*.

Alongside dosing schedule, side effects were also significant when characterizing the participants' post-uptake experience, where many participants evaluated their time on PrEP by the presence, duration, and severity of PrEP related side effects. Some participants reported they experienced no side effects, while others described monitoring their nausea, fatigue, or rash as part of their decision whether to discontinue.

It's getting better but I'm still just over a month, so I'm giving myself a bit of time to still adjust… I'm going to give it 2.5 more weeks and if something doesn't change, then I'm going to be like maybe Descovy, I don't know, it could be a little less harsh. PID 186, Daily Oral PrEP, Age 33.

I remember at first, being like oh, it's making me sick, I think I'm going to stop but you know it wasn't until I was able to realize like okay, no, this is like a new drug in my system and of course my body's going to react certain ways, so it's all about adaptability. PID 132, Injectable PrEP, Age 31.

It was super quick [PrEP injection]. It wasn't that painful. I felt like a little soreness, maybe a day or two after, but I go to the gym so it's kind of just felt like you know when you do legs? PID 19, Injectable PrEP, Age 26.

System 1 factors were also key determinants when people reflected on their PrEP journey. Expectations for more peace of mind around a sexual encounter were fully realized for most participants, as they described the positive emotional impact that PrEP had on their sex life and how they approached sexual encounters.

The first time that I had sex without a condom, [and the HIV test] was negative. I say, OK, well, this looks like it works…. It made me feel good. Like, I'm not that panicky anymore… Before if there was a rapid test, I'm just like sweating. PID 115, Daily Oral PrEP, Age 38.

Because I do feel more protected in a way and that has also just calmed my mind mentally so that I don't go into an interaction with someone who is undetectable and have that be them as a person, or them as an identity. PID 186, Daily Oral PrEP, Age 33.

My friend was like, dude you haven't even been sexually active, like why are you still taking PrEP and I'm like, well if I do want to engage in sexual activity, I'd rather have that security, like I'm already covered versus like oh, I need to hold off on this spur of the moment feeling because I didn't make better decisions or because I decided to oh, stop taking it. PID 132, Injectable, 31.

As some participants became accustomed to the reduction in anxiety and feeling of protection afforded by PrEP, they described their inability to conceive of a sex life without PrEP. PrEP was often described as a way to take ownership over one's health, and also took on moral overtones signifying that someone was "responsible."

I think now people kind of wear it as a badge of honor, like it's very prominent on people's profiles and Grindr and Scruff and yeah inevitably in a conversation it will come up like "neg and on PrEP." PID 43, Daily Oral PrEP, Age 32.

I feel like it's more stigmatized, at least here in New York, to<u>not</u>be on [PrEP] if you're hooking up with people. That's been my experience. Just like not being vaccinated, to say that you're not on PrEP but you're still hooking up. I feel like people, because it's easy to get on it, people are more hesitant to be intimate with someone who isn't on PrEP. PID 172, Daily Oral PrEP, Age 25.

For these participants, satisfaction with PrEP and the social norms surrounding PrEP use in gay culture acted as a mechanism pushing participants into the loyalty loop where they repeatedly chose to initiate another PrEP prescription. Many perceived PrEP as being fully embedded within gay culture and normalized on gay dating and hook-up apps. In an era of PrEP, many participants noted a pervasive, negative cultural response toward using condoms. While some participants enjoyed condomless sex, others lamented that their sexual partners assumed they would have condomless sex if they were on PrEP. One participant admitted to lying about not being on PrEP to justify condom use.

I definitely like using condoms any time I was having penetrative sex. Sometimes it was easier to lie about not being on PrEP, so I wouldn't get as much push-back about using condoms. PID 69, Daily Oral PrEP, Age 33.

The narrative within the gay community is sometimes anti-condom use with HIV. It's sort of like if you're on PrEP, then we don't need condoms anymore…I went to a drag show, this one guy made a joke, if you're going to have sex with me you have to take the condom off, or something like that. And it's this narrative of having sex without a condom, that is sometimes singing in the back of my head and prevents me from even introducing the question, or introducing the point of like, "hey, we should use one." PID 127, Daily Oral PrEP, Age 25.

Change: Pause Current Regimen

Among participants who were satisfied with their PrEP experience, some needed to pause their PrEP use due to extenuating circumstances such as a change in insurance coverage, the COVID-19 pandemic, or moving to a different state and needing to seek out a new medical provider.

> *I was on [PrEP] in college and then what happened was I moved to New York for work and then that was when I was trying to find a provider… that was the only reason there was a break because I didn't have anybody writing the script. PID 102, Daily Oral PrEP, Age 25*.

> *I'm an actor so there are times when I'm not in New York and traveling, and I was on a cruise ship so it was trickier to get the prescription filled…so there was just a break where I didn't take it for like 3 months and as soon as I got off and got back to the city, I started back on it and have just constantly been on it since. PID 34, Daily Oral PrEP, Age 29*.

> *It was also during the height of the pandemic, so it was not like I was really being sexually active anyway. I checked with my doctor and said I'm thinking about taking a break because I won't need it right now*. *PID* 150, Daily *Oral PrEP*, Age 35.

These participants acknowledged taking a temporary break from PrEP with an intention to resume on the same modality after the external circumstances that had caused them to pause had resolved.

Change: Switch Regimen

Participants dissatisfied with their experience on PrEP, used exclusively system 2 factors to describe why they either switched PrEP modalities or discontinued PrEP all together. Most participants who switched modalities started on daily oral PrEP and transitioned to event-driven PrEP, citing a reduced sexual frequency as the main reason. These participants noted how changing life circumstances, such as returning to school, changed their priorities and made them less sexually active. Many didn't see the point of taking a daily medication when they were having sex infrequently.

> *I got put on it, started taking it for a while, like I mentioned, and then at some point I was like, I'm not really doing anything, so I was like "why am I still taking PrEP." And then ever since then it's just been a balance of when I need it, when I don't need it, taking [event-driven], like that. PID 114, Event-Driven PrEP, Age 30*.

In contrast, one participant who switched from daily oral to injectable PrEP did not have a reduced number of sexual partners but struggled to adhere to the daily dosing schedule.

> *I was always really bad about taking pills, like I would forget so it would put a lot of strain on the relationship with my partner. My provider realized I was missing doses and they said there was an injectable coming out and basically if it was something I was interested in, they would put me on a list and let me know. PID 19, Injectable PrEP, Age 26*.

This participant felt confident he could consistently arrive to his appointments on time to receive the injection from his provider. All participants who switched to injectable PrEP discussed how the 8-week dosing schedule was easier to adhere to than taking a pill every day and more convenient since they would not have to think about PrEP in between injection appointments.

Change: Opt Out

Instead of pausing or switching to a new PrEP modality, some participants opted to stop PrEP all together due to entering a monogamous relationship or reduced sexual activity. Unlike participants who temporarily paused PrEP with an intention to resume later, participants who opted out of PrEP had no intention of resuming for the foreseeable future.

> *I just stopped because I wasn't really having sex at the time. I was on new antidepressants that kind of killed my sex drive. If I keep taking it and I'm not having sex, then I'm literally just putting it in my body for no reason. PID 130, Daily Oral PrEP, Age 31*.

Side effects and long-term consequences were also mentioned as a rationale for stopping PrEP or switching modalities. One participant noted a painful rash on daily oral PrEP and therefore switched to an injectable formulation.

> *I had to stop taking it right away, like the first two days, you know. I did two days in a row because like I wanted to see maybe my body needs to get used to the medicine or something and I was just having a lot of burning sensation and whatnot. I felt like someone put Icy-Hot all over my crotch and all over my butt. PID 232, Injectable PrEP, Age 33*.

While others did not experience side effects, they weighed the potential long-term consequences of being on PrEP against the benefits, given their current perceived risk. For example, a few participants brought up the potential deleterious effect PrEP might have on bone density and kidney health. One participant described cleaning up his lifestyle, by eliminating things from his life that may not be healthy like alcohol, processed food, and any unneeded medication, including PrEP. For many of these participants, continuous PrEP coverage (either through daily oral PrEP or injectable PrEP) was not worth maintaining in the absence of an active sex life.

> *I mean, you see some things pop up every now and then about lawsuits and Truvada and bone density loss and whatever. But I know every time you get tested, they try to at least look for some markers that your body isn't handling PrEP well. But even knowing all of that, I'm just like I don't want to put any unnecessary drug in my body if I'm not going through a period where I don't need it. PID 114, Event-Driven PrEP, Age 30.*

Pre-Contemplation: Reconsideration

Amongst participants who discontinued daily oral or event-driven PrEP, several re-started the same modality of PrEP once their lifestyle changed (e.g., leaving or opening up a monogamous relationship). These participants cycled through pre-contemplation to contemplation again as they perceived their risk for HIV acquisition increasing and desired to feel more protected during a sexual encounter.

> *I started PrEP here in 2018…but then in the middle of 2019 I stopped taking it because I was on new antidepressants that kind of killed my sex drive….I didn't have sex all of 2020. And then recently my partner and I decided all right, if I want to have more sex, then I've got to go get tested and get PrEP. PID 130, Daily Oral PrEP, Age 31.*

After restarting PrEP, many participants noted that the dosing schedule was more manageable, and it was easier to routinize into their schedule. Having learned from previous mistakes their first time taking PrEP, some participants adjusted their routines to accommodate the introduction of a daily pill back into their life.

> *Taking it at night for me, that was the biggest lesson. Because I feel like most people would do better if they already have a morning routine and a morning multivitamin routine that they have going. I did that for a while and that's when I started to feel blah during the day, so this time I switched it to night, and I did remember it from the get-go for this one and I'm very glad I did. PID 186, Daily Oral PrEP, Age 33.*

> *I've been on PrEP on and off over the years; probably since I would say 2013 or 2014….I'm a little OCD but I have my steps like first I put this cream on then that cream on and then I have my 3 pills that I take. I take my pills in order of importance, like that is my PrEP, so I don't even think about it. It's second nature at this point. PID 43, Daily Oral PrEP, Age 32.*

Discussion

In this exploratory qualitative study, we sought to better characterize how gay and bisexual men make decisions about HIV prevention products by identifying when they report affect-driven (system 1) and cognition-driven (system 2) factors in their decision-making process. Participants made decisions to either initiate, continue, pause, switch, discontinue, or re-initiate PrEP with different system 1 and 2 factors influencing decision-making along their PrEP Consumer Journey. Our data suggests system 1 attributes, such as feeling protected, reducing anxiety, bolstering peace of mind, enhancing pleasure, social norms, and taking ownership over health were more salient when participants moved from pre-contemplation to information gathering, as well as evaluating post-uptake experience. System 2 attributes, including cost, side effects, dosing schedule, and sexual frequency, were present throughout the PrEP Consumer Journey, but particularly influential in the information gathering stage and when pausing, switching, or opting out of PrEP.

Other studies have explored cognitive and affective factors influencing PrEP use. When initiating PrEP, gay and bisexual men consider efficacy and side-effects [17], cost and time [22], accessibility, sexual behavior and taking control over one's health [23]. PrEP use has been shown to include affective benefits like lowering HIV anxiety [24, 25], but system 2 factors like dosing schedule and clinic logistics can impact PrEP persistence [18]. Low copayments and being commercially insured in particular [26] are associated with longer PrEP persistence. However, depending on shifting social norms and sexual behaviors, gay and bisexual men often have a more contextualized and flexible relationship with PrEP [17] that transcends discrete categories of persistence/non-persistence. It is important to note that factors linked to PrEP discontinuation include medication cost, adherence issues, adverse side effects, and lower perceived HIV acquisition risk behavior [27]. Lastly, re-initiation has

been associated with an increased perceived risk of HIV, and removal of at least some structural barriers to PrEP adherence [27, 28]. Our study expands on these findings by locating these decision-making attributes along the PrEP Consumer Journey and organizing them by system 1 and 2 attributes influencing decision-making.

While PrEP is initiated in a clinical setting, it is largely consumed and experienced in day-to-day life. Current PrEP cascade models reflect a clinical interpretation of the patient experience engaging in PrEP services. We re-imagine this and position the patient as an autonomous consumer using a health product in their daily reality. We created a more consumer-centered PrEP Consumer Journey that captures a PrEP consumer's lived experience and decision-making process outside of a clinical context, where the consumer is continually evaluating their PrEP journey against co-occurring psycho-social and cultural experiences. Our model distills a consumer perspective into four main touchpoints that each extend into key PrEP-related decisions. The touchpoints are potential areas for shared decision-making (SDM), where a provider can identify a patient's values and preferences to ensure that health care decisions are in alignment with these values [29].

SDM has been shown to increase patient satisfaction, adherence to a treatment plan, improved clinical outcomes, and reduced healthcare disparities [30–32]. In the field of HIV prevention, SDM may be useful for supporting informed PrEP choice [3, 33], as well as increasing motivation to continue PrEP by engaging patients in discussions of its benefits and its relevance to their sexual health trajectories [19]. A key tenet of SDM models is the bidirectional communication of patient preferences and tailored information offered by a provider. However, SDM models do not specify what information should be shared regarding system 1 (heuristic, image-base, impulsive) and system 2 (analytic, logical, cautious) factors. Bauermeister et al. [16] articulated key system 1 and 2 factors related to PrEP decision-making and suggest that the consideration of emotional and deliberative aspects leads to the most effective decision-making when choosing a PrEP modality. We further build on this work by describing the extent to which the salience of system 1 and system 2 factors change over time as participants move through the different stages of the PrEP Consumer Journey.

We conceive the visual depiction of the PrEP Consumer Journey as a tool primarily to raise provider awareness about system 1 and system 2 attributes that influence decision-making and to help shape conversations with patients based on where they are on the journey. For example, our data highlights how system 1 factors are more salient for participants moving from pre-contemplation to information gathering. This suggests that if a provider is interested in motivating a patient to initiate PrEP early in the consumer journey, they could discuss system 1 attributes to better appeal to their patient's affect-driven concerns. When most of our participants first heard about a biomedical intervention that could prevent HIV, a simple pill became a symbol for a desired lifestyle free of anxiety around HIV acquisition. Understanding the symbolic function of medications, like PrEP, is important for addressing adherence issues and satisfaction [34]. It may be important for providers to identify the patient's affective and symbolic expectations for how PrEP will impact their life early in the decision-making process (i.e., sexual liberation, pleasure, feeling protected) and then follow up on whether PrEP is meeting those expectations during the post-uptake experience. SDM along the PrEP Consumer Journey may help improve patient engagement, satisfaction, adherence, safe discontinuation, and re-engagement as PrEP needs and regimen preferences shift over time.

Conclusion

The socio-behavioral research agenda must prioritize research beyond end-user modality preferences and toward research supporting, engagement, and shared decision-making across time [35]. Our results may help facilitate conversations around PrEP initiation, adherence, switching, discontinuation, and re-initiation, while taking into account deliberative reasoning and intuitive and emotional processes along the PrEP Consumer Journey. Such consideration may ultimately provide more engaging and supportive PrEP services that will move the needle on ending the HIV epidemic.

Limitations

This study was conducted in a well-resourced, urban medical center providing grant-funded PrEP services. Gay and bisexual men living in more rural areas with less access to sexual health services may have different experiences. Furthermore, research participants were all cisgender men, with a majority them identifying as White, which limits the generalizability of our findings. Given how PrEP uptake has been limited in several key populations in the United States, including Black and Hispanic gay and bisexual men, transgender persons, and women, future studies should assess how these populations use system 1 and system 2 attributes to make decisions along the PrEP Consumer Journey. Lastly, all participants were new or experienced PrEP consumers. Non-PrEP consumers should also be included to better understand what factors halt progression from pre-contemplation to information gathering or lead them to believe PrEP is not right for them after gathering information.

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