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Introduction

- Despite the relatively convenient oral antiretroviral therapies (ARTs) available today, treatment challenges persist for people living with HIV (PLHIV)
 - Treatment effectiveness may be compromised with sub-optimal adherence^{1,2}
 - HIV is associated with stigma and discrimination^{3,4} and it can be difficult for some PLHIV to be discreet when taking a daily oral treatment regimen
 - PLHIV often experience stress and anxiety around having to comply with daily dosing⁵
- A long-acting injectable (LAI) regimen of cabotegravir plus rilpivirine is in development for monthly or every other month administration
 - Non-inferior efficacy compared to daily oral regimens and an acceptable safety profile have been demonstrated in virologically suppressed HIV patients.^{6,7} Further, patients in the clinical trials reported a higher preference for the LAI (523/532; 98%) versus daily oral.⁸
- Because preferences for ART could influence treatment adherence, which may in turn impact outcomes, it is important to understand patients' perspectives

Objective

- The purpose of this study is to examine perceptions of daily oral and long-acting injectable routes of ART administration through analysis of online discussions among PLHIV

Methods

- Qualitative thematic analysis was conducted to examine online discussion threads posted by PLHIV in POZ Community Forums
 - Of the 19 HIV-related forums, 3 forums limited to PLHIV were selected as most relevant to the study objectives:
 - Living with HIV
 - Questions about treatment and side effects
 - Research news and studies
- All topics created in the selected forums between Jan 2013-Jun 2018 (5122 threads) were retrieved using Ruby, an open-source programming language
- Threads containing keywords in 7 categories were imported into qualitative data analysis software (ATLAS.ti 8 Windows) and reviewed for relevance
 - Keywords: (1) injection (eg, injection, inject, injectable, shot, needle); (2) long-acting or long-lasting; (3) monthly (eg, monthly, every month, once a month); (4) dosage or dose; (5) oral medication (eg, pill, tablet, oral); (6) daily (eg, daily, every day, once a day); (7) cabotegravir or rilpivirine
- Each quotation within the threads received 3 codes:
 - Route of administration code (oral or injectable)
 - Sentiment code (positive, negative, or neutral statements)
 - Concept code (based on identified codes to categorize the quotes, Table 1)
- Discussions about treatment efficacy and medication side effects were not coded; these concepts are considered effects of the medication rather than directly related to route of administration

Results

- Analyses identified 684 relevant discussion threads, including 2626 coded quotations posted by 568 PLHIV
- Route of administration was frequently discussed: oral (2515 quotations) more so than injectable (110 quotations), as expected given that LAI medications are still investigational
- Quotes about pills were more likely to be coded as neutral or negative, whereas a greater proportion of quotes about injections were coded as positive (Table 1)
- Tables 2 and 3 give examples of positive and negative quotations for the 5 most common concept codes for oral and injectable routes of administration

Table 1. Number of Quotations by Concept Code and by Route of Administration for ART

Concept code	Quotes about oral route of ART administration			Quotes about injectable route of ART administration		
	Positive	Neutral	Negative	Positive	Neutral	Negative
1: HCP visits	0	0	0	5	1	7
2: Pain	0	0	0	2	6	4
3: Needles	0	0	0	3	5	8
4: Strength of dosage	6	14	21	0	4	1
5: Diversion	25	91	5	0	0	0
6: Access	25	127	106	2	0	3
7: Stockpiling	25	101	0	0	0	2
8: Traveling	20	160	107	6	0	3
9: Food requirements	115	310	126	4	4	1
10: No. pills for HIV	276	220	124	0	0	0
11: No. pills for other conditions	4	11	13	0	0	0
12: Frequency of doses	245	199	107	34	4	10
13: Schedule issues	153	433	131	1	0	1
14: Control of dosing	10	55	53	1	0	2
15: Adherence concerns	20	143	97	6	0	2
16: Adherence reports	25	121	121	0	0	0
17: Adherence strategies	46	170	36	0	0	0
18: Storage issues	15	43	47	0	0	0
19: Medication error potential	0	6	17	0	0	0
20: Ingestion issues	32	18	37	0	0	0
21: Privacy/confidentiality (stigma)	9	101	100	1	0	0
22: Source of pride/control	59	4	0	0	0	0
23: Visible reminder of HIV status or treatment	12	1	23	3	0	0
24: Emotional impact	86	54	166	7	1	6
25: Ease of use	146	16	6	2	0	0
26: Convenience	35	11	11	6	0	5
27: Unspecified preference	0	1	0	7	0	0

HCP, health care professional.

Table 2. Examples of Quotations: Oral Route of Administration

Category	Positive	Negative
Food requirements	<i>I take Triumeq, which is once a day and never worry about taking it with food or anything...</i>	<i>Complera isn't an option because of its solid food requirement. I have an unpredictable schedule. ... I can force a small snack but not a 400-calorie meal.</i>
Number of pills for HIV	<i>I got my prescriptions refilled yesterday and they give me the 800-mg Prezista instead of the 2 x 400 mg/day...now I only have to take one.</i>	<i>The downside to moving from Atripla to Prez/Nor/Tru is the amount of pills. I forget what my exact dosage was but I was taking a total of 5 pills a day...</i>
Frequency of doses	<i>When I was choosing my first combo, I...knew I wanted a once-a-day combo.</i>	<i>I wouldn't want to do anything I'd have to take twice daily.</i>
Schedule issues	<i>I'm very happy with it, and taking my pill in the morning with a nice breakfast suits me well.</i>	<i>If I'm taking one pill a day, how much deviation can I have with when I take it? Is a 4-hour window too much of a window?...I'm new to all this, am I worrying for nothing? Or have I been committing egregious errors the last few weeks without even realizing it?</i>
Emotional impact	<i>I have been on Triumeq for about a year already and I love it! 1 pill a day compared to 4 pills twice a day for the first 2 years after being diagnosed.</i>	<i>It's something that I run to my bag and grab. There is no privacy when you work in retail... Just frustrates me that they would be so involved in my medicine.</i>

Table 3. Examples of Quotations: Injectable Route of Administration

Category	Positive	Negative
HCP visits	<i>Obviously a 3 monthly shot would fit nicely with routine clinic visits.</i>	<i>Having to go to the clinic every few weeks for a shot would be more invasive to me than taking a pill per day I think.</i>
Pain	<i>Oddly, this week's rilpivirine shot wasn't painful. I was surprised.</i>	<i>...the Rilpivirine stick can be painful.</i>
Needles	<i>I don't mind needles so I'm really interested in the injectable.</i>	<i>I too have a terrible fear of needles... you'd think I'd be used to it. NO!!!! I always have to be reading something so I can be distracted and I never, ever look. At the needle or the draw itself.</i>
Frequency of doses	<i>Personally, I'll be happy to toss my current HIV meds out the window the day they finally develop that once-a-month drug (even if it is an injectable).</i>	<i>I would consider it an option only if it were a one-year shot. But, since I only need to go to my ID clinic once or twice a year, and they give me a 6- to 12-month supply of medicine, why bother?</i>
Emotional impact	<i>I would happy dance the nerdiest nerd dance all over town for days if I could get an injection every few months and not have to bother with daily pills.</i>	<i>I'm a bit anxious about these injections.</i>

HCP, health care professional.

- PLHIV expressed both positive and negative views of their oral medication regimens
 - Positive statements commonly referred to ease of use, small number of pills in their regimen, and convenient dose frequency, which was often only once daily
 - Challenges included food requirements (eg, taking medication with meals) and difficulty accessing medication, particularly when traveling
 - Negative emotional statements (eg, frustration, anxiety, fear, anguish) appeared in 166 quotations, some due to oral medication being an unwanted daily reminder of HIV
 - For some PLHIV, daily oral treatment raised concerns with confidentiality because they try to keep their medication hidden to avoid stigma that may be associated with HIV
- Many PLHIV discussing the injectable viewed the potential new route of administration as a convenient alternative to oral regimens
 - PLHIV welcomed the less-frequent dosing, stating the injections may eliminate the daily reminder of HIV while reducing the treatment adherence problems that can occur with oral medication

Discussion

- Challenges with daily oral ART discussed in the forums are consistent with studies linking HIV stigma to difficulties in adherence to oral regimens⁹
 - A substantial number of PLHIV reported concerns about treatment adherence with daily oral medication and examples of when they had not been adherent
- The expectations of long-acting injections discussed in the forums are consistent with reports of 27 patients who described the convenience and emotional benefits after receiving these treatments in a phase II trial⁵
 - Some PLHIV said they would prefer to keep their daily oral treatment regimen, rather than begin injectable ART, sometimes mentioning fear of needles
 - Others have difficulty with oral treatment and hope to try the long-acting injectables
- Pre-existing online discussion forums allow researchers to assess patient perspective without outside influence, providing a unique view into patient perceptions and experiences
- Limitations include unknown participant demographics and the extent to which quotes extracted from online forums represent the broader HIV patient population. Further, the sentiment of each quotation (ie, positive, negative, neutral) was coded from the patient's point of view, which may diverge from the clinical, regulatory, or payer perspective in some situations.

Conclusions

- This innovative, qualitative approach for obtaining and analyzing unsolicited comments from social media shows that PLHIV have a wide range of concerns and preferences related to ART
- While some PLHIV were satisfied with their oral regimen, others focused on challenges of oral treatment and said they would welcome the less-frequent dosing of injectable ART
- Choice of ART may depend on the needs and preferences of each individual patient
- By prescribing treatments that patients prefer, clinicians can help foster better patient satisfaction and treatment adherence, which could lead to improved health outcomes

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