Social Media and Implications of Online HIV PrEP Retrieval

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Evolving Treatment Adherence Paradigm
Intersection of PrEP and Social Media

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September 21, 2018
I do not have any conflicts of interest to disclose and I do not intend to discuss off label use of any drug or treatment during this discussion.
Evaluate social media comments from consumers regarding Food and Drug Administration (FDA) approved and non-FDA approved therapeutic options for HIV pre-exposure prophylaxis (PrEP)

Design an educational initiative to assist with addressing patient care dilemmas in an online environment

Construct a multi-disciplinary task force to monitor and intervene, when appropriate on misleading and/or inaccurate comments provided in cyber world
Discouragement of Product Sharing/Interchange

Ongoing Participation in Educational Platforms

Medication Adherence & Compliance

Comprehensive Assessment of Medicinal Use

Balanced Marketing / Advocacy Strategies
Social media outlets
What is PrEP?

- Provision of a fixed – dose combination product (TDF/FTC) in single daily dose to healthy adults at risk of acquiring HIV (HIV – negative individuals)
  - Recommended in these populations:
    - Men that have sex with men (MSM)
    - Transgender population
    - Heterosexually active men and women
    - Injection drug users (IDU)

Excerpts from social media posts:

I need some advice! I've hardly missed a dose of PrEP the last year I've been on the medication, but I forgot to take it this past Saturday and Sunday (two doses). I had sex on Saturday night and now I'm experiencing some anxiety. I took the pill this morning. Should I be worried? PreP stays in your system right? And how many doses can you miss and have the medication still be effective?

So of course my fear happen. New doctor new insurance and my doctor had no clue on what prep was. And of course I had to educate my doctor on prep so getting tired of explaining this medication

Just filled my first PrEP RX for a 16 y/o patient.

https://www.facebook.com/search/top/?q=prep%20facts%3A%20rethinking%20hiv%20prevention%20and%20sex
I need some advice! I've **hardly** missed a dose of PrEP the last year I've been on the medication, but I **forgot to take it this past Saturday and Sunday (two doses)**. I had **sex on Saturday night** and now I'm experiencing some anxiety. I took the pill this morning. Should I be worried? **PreP stays in your system right?** And **how many doses can you miss** and have the medication still be effective?

- “Hardly” reconciled with “two doses” within past two days
- How many sex acts occurred on Saturday night? How many people?
- Confirm medication history to determine exact number of doses missed

https://www.facebook.com/search/top/?q=prep%20facts%3A%20rethinking%20hiv%20prevention%20and%20sex
So of course my fear happen. **New doctor new insurance** and my doctor had no clue on what prep was. And of course I had to **educate** my doctor on prep so getting tired of explaining this medication

- Continuity with patient
- Coverage options
- Patient’s current educational level about PrEP

https://www.facebook.com/search/top/?q=prep%20facts%3A%20rethinking%20hiv%20prevention%20and%20sex
Conversations analysis

- Just filled my first PrEP RX for a 16 y/o patient
  - Clinical trials surrounding targeted age indications
  - Sexual orientation of the patient
  - Number of reported sexual partners
  - Consistent insurance coverage long term

https://www.facebook.com/search/top/?q=prep%20facts%3A%20rethinking%20hiv%20prevention%20and%20sex
Confidentiality concerns

• Level of confidence that the people interacting and providing healthcare advice are the real representations of themselves?
• Assurance of any medical training???
• Meet Susie Black and James Bond who provide PrEP advice
  – Are we sure these people are actually James Bond and Susie Black?
  – How can we prove it?
  – Should we trust the “advice” received?
Appeal of social media “avatars”

- Reduced perceptions of external judgement
- Less constraints on questions posed
- Opportunities to identify as preferred gender
- Limited accountability for suggested claims
  - Informal exchanges
    - Unintended consequences
      - Therapy interruptions
      - Unanticipated adverse events
      - Furtherance of false claims

*DISCLAIMER*

- The medications included in this presentation that are retrievable via online mediums are for discussion points only.
- Patients report increased use of these products which can merit greater awareness of their existence.
- Drug interaction assessments or chronic monitoring of patients using these products does not appear to be uniform.
- Online transactional features may request varying levels of personal information that may compromise one’s identity.
- **The presenter does not endorse the use of these products** as their utility is not closely supported by clinical evidence.
Other TDF-FTC (Besides Truvada®)

- Tenvir-EM
- Ricovir-EM
- Tavin - EM

⚠️ CAUTION!

- These medications are currently UNAVAILABLE in the United States.
- We as practitioners do NOT support individuals ordering these medications as they are NOT FDA approved in the United States.
## Cost Comparisons

<table>
<thead>
<tr>
<th></th>
<th>Truvada ®</th>
<th>Tenvir – EM</th>
<th>Ricovir - EM</th>
<th>Tavin – EM</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>~$2,010.90 for 30 tabs</td>
<td>~$62.29 for 30 tabs</td>
<td>~$144.00 for 90 tabs</td>
<td>~$240.00 for 90 tabs</td>
</tr>
<tr>
<td></td>
<td>~$168.17 for 90 tabs</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### CAUTION!

- **Tenvir – EM, Ricovir – EM, and Tavin - EM** are currently **UNAVAILABLE** in the United States.
- We as practitioners do **NOT** support individuals ordering these medications as they are **NOT** FDA approved in the United States.
### Dose Comparisons

<table>
<thead>
<tr>
<th>Truvada ®</th>
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<th>Ricovir - EM</th>
<th>Tavin – EM</th>
</tr>
</thead>
<tbody>
<tr>
<td>FTC 200mg TDF 300 mg</td>
<td>FTC 200mg TDF 300 mg</td>
<td>FTC 200mg TDF 300 mg</td>
<td>FTC 200mg TDF 300 mg</td>
</tr>
</tbody>
</table>

**CAUTION!**

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Participating countries (PrEP via postal mail)

- Australia
- Canada
- France
- Germany
- Italy
- Mexico
- Netherlands
- Peru
- Thailand
- United Kingdom
- Portugal
"I am a social worker and usually visit an orphanage that has children with HIV. Some of these children are being treated using the Tenvir EM tablet. One can buy Tenvir online from ADC, so I usually donate this medicine to the orphanage. This adds to my convenience as I don’t have to visit the medical store to buy such medicines. I have heard that it is really effective in improving the immunity of the patient."
Mr. Justin Times is initiated on Truvada by his physician for PrEP. He later learns from an internet forum that he can purchase cheaper generic versions of Truvada online. Mr. Times then decides to order both Tenvir-EM and Ricovir-EM products since the forum claims that they are equally effective.
Proposed context for internet-based PrEP retrieval

- Lack of Insurance
- Concern about insurance discontinuation
- Resale of shipped products
- Implications
  - Possession of Multiple PrEP products
  - Uncertainty of product quality
  - Potential Resistance

Initiation Purchase of PrEP through online sales (Send to USA)
Community Outreach

PREVENTION YOU CAN GET BEHIND!
PrEP Social Night

Questions about PrEP? Want to meet guys on PrEP?
Meet Damon L. Jacobs, Therapist and PrEP Advocate

Alibi, Manchester Room
February 10th 2017 6pm-8pm

www.PrEPwithPRIDE.com
prep@pridecenterflorida.org • (954) 453-9000, Ext. 210

UCLA CARE CENTER & BASH LA INVITES YOU TO
SUNDAY, FEBRUARY 5TH

G.P.S.
"GIVE PrEP A SHOT"
Social Mixer!

"COME AND LEARN ABOUT AN HIV PREVENTION STUDY!"

-FOOD & DRINKS WILL BE SERVED-
COMPLIMENTARY RSVP AT GIVEPREPSHOT.EVENTBRITE.COM
Perceptions around PrEP
Perceptions around PrEP
Group chat around PrEP

*The comments provided below were lifted directly from social media posts and were not edited by the presenter for content or grammatical considerations.*

Had an amazing time on a gay cruise and I truly able to enjoy sex thanks to prep

Great post! Thanks for sharing. #Pleasure

Sounds hot!

I'm looking on going on a (gay)cruise Which did you go on? Thank you in advance

It was last week. Atlantis

Around the Caribbean? My friends went on that and took PrEP with them ;-)
*The comments provided below were lifted directly from social media posts and were not edited by the presenter for content or grammatical considerations.*

**Yes and prep is a must**

I must get in touch and hear how they got on. Looks like I maybe booking a cruise 😊

is there a lot of sex on these cruises?

Loi a huge boat full of men who like men?
Noooo very little sex 😅

Done Atlantis (and other gay cruises) a few times. You can have as much or as little sex as you want. Take PrEP with you. Just like the boy scouts, you'll always be prepared :) id be hosting orgies lol

I don’t believe you. We need to know the story in graphic detail.

https://www.facebook.com/search/top/?q=prep%20facts%3A%20rethinking%20hiv%20prevention%20and%20sex
*The comments provided below were lifted directly from social media posts and were not edited by the presenter for content or grammatical considerations.*

How many men go? I would need ten bottles of prep 😊😊

Number of men = depends on the particular cruise ship's capacity
darn! i wanna go to one that has a lot!!!

Royal Caribbean's Harmony of the Seas, currently the world's largest cruise ship has a maximum passenger capacity of 6,360. Atlantis used it recently :)

6k men? that's almost enough for me!

that's what the Royal Caribbean's website says the ships passenger max is :)

I went with Atlantis on a smaller Royal Caribbean ship.....3,000+ men. That was more than enough :)
Points of Consideration:
- Recent evidence has further explored effectiveness of 4 tablets/week
- Dosing schedule of 2:1:1
  - Sample regimen:
    - 2 tabs of TDF/FTC 2 – 24 hours before sex on Day 1
    - 1 tab of TDF/FTC 24 hours after sexual event on Day 2
    - 1 tab of TDF/FTC 48 hours after sexual event on Day 3

Implications of PrEP portrayal

- Perceptions of “party – drug”
- Prompting of promiscuous behavior
- Concern for STI acquisition(s)
- Medication sharing
- Indiscriminate use
Suggestions moving forward...

- Restructure healthcare curricula to increase formal orientations to social media messaging
- Remind patients not to share personal medical information on social media sites
- Restrict or prevent healthcare personnel from responding to individual medical queries
- Recommend or revitalize social media – inclined healthcare task forces to further explore online exchanges
Questions / Answers
Thank You

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