Electronic Dose Monitoring Feedback (EMF) with Youth: Qualitative exploration of reactions to viewing their dosing calendars

Presented by: Eamonn McGonigle

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The TERA study evaluated a 3-session, 12-week virtual coaching intervention among YLWH (Youth Living with HIV) in the US within the Adolescent Medicine Trials Network.

EDM Electronic Dose Monitoring was used in TERA as the measure of adherence for all participants. For intervention participants…
- To monitor daily dosing with outreach from coaches in the event of late dosing
- To generate a calendar of daily dosing for youth to review with their coach at their 4- and 12-week coaching sessions.

EMF
- Electronic Dose Monitoring Feedback (EMF) offers “objective” data (vs discussing adherence in aggregate or in general)
- EMF shows granular data that can be otherwise ‘unknown’ to participants such as patterns of dosing
- EMF provides opportunities for visual learners
Background: TERA study, EDM and EMF

- Adherence calendars have been used in a number of health interventions\(^1\mbox{--}^2\) and with adults living with HIV\(^3\)
  - LITTLE information available about how YLWH experience EMF.

- With the rise in tracking apps and electronic dose monitoring (EDM), reactions to viewing daily dosing data can help to guide interventions and program features.

- We evaluated transcripts of the TERA coaching sessions to characterize how youth reacted to receiving their EMF in the form of dosing calendars.

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\(^1\) Bell & Haberer, 2017 \(^2\) Seng, 2018 \(^3\) van Heuckelum, 2017
METHODS

- Coaching sessions that included EMF were recorded and transcribed
- 39 participants (36 from week 4 and 36 from week 12)
- Iterative review of discourse around the EMF
- Thematic coding
- 10% of excerpts reviewed for inter-coder reliability

RESULTS

- Youth were 14-25 years old
- 46% acquired HIV vertically
- Majority African American/Black
- All on a dosed once a day regimen (per enrollment criteria)
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## RESULTS: 6 Primary Themes (not mutually exclusive)

<table>
<thead>
<tr>
<th>Feeling of Pride/Satisfaction</th>
<th>Feeling of Positive Surprise</th>
<th>Feeling of Empowerment or Motivation</th>
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</thead>
<tbody>
<tr>
<td>Participants described feeling proud of their dosing results. They are <strong>satisfied with the calendar and happy with themselves.</strong> Continue with their current adherence plan due to a satisfactory calendar.</td>
<td>The reaction of surprise was positive, and the results of the dosing data were <strong>better than expected.</strong></td>
<td>Dosing data results either <strong>encouraged them to improve or set goals</strong> for their drug adherence due to an unsatisfactory calendar or continue with their current adherence plan due to a satisfactory calendar.</td>
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<table>
<thead>
<tr>
<th>Feeling of Guilt or Shame</th>
<th>Neutral Reaction</th>
<th>Feeling of Negative Surprise</th>
</tr>
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<tbody>
<tr>
<td>Participants felt shameful or guilty over the results from their dosing data calendar. They are <strong>unsatisfied and/or upset with how the results turned out.</strong></td>
<td>The participants gave no particular emotion or reaction to being presented with the dosing data results. Results were <strong>unexciting, as expected, or uninteresting.</strong></td>
<td>The reaction of surprise was negative, and the results of the dosing data were <strong>worse than expected.</strong></td>
</tr>
</tbody>
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RESULTS

- Satisfaction/Pride (64%, 69%)
- Over half of participants (58%) verbalized surprise
  - Positive (31%, 33%)
  - Negative (11%, 8%)
- Shame/guilt identified (22%, 19%)
  - 67% in reaction to EMF calendars showing **under 80% adherence**
  - Preliminary findings suggest coach reflections and reframing were able to shift conversations towards a focus on strengths/change
Summary and Discussion

- EMF as calendars provided an opportunity for reflection and conversation about adherence patterns.
- The majority of participants appeared to have positive reactions to viewing their calendar.
  - Negative reactions appeared to allow for insight into the wide range of experiences with coach facilitation.
- Frequent reactions of surprise suggest seeing patterns of dosing offered the possibility for seeing adherence in new or different ways.
Next Steps

- Additional work is needed to determine if different types of EMF visualization might offer different levels of insights, change, or impact among YLWH. We worked exclusively with calendars as EMF.

- We currently working on identifying coaching strategies around reframing and reflections to create strength-based conversations regarding adherence for YLWH.
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