Emotional Energy: The ASPIRE Adherence Workshops

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PREMISE

- The MTN
  - It's a well oiled machine where protocol implementation is concerned
  - Not much worry about our ability to recruit, retain, follow protocol & produce quality data
  - BUT in DC, we had no applause when Jeanne was presenting VOICE results
  - Instead, we had dented faces
    - Seems our women will lie just about anything

The MTN, like all research groups involved in past prevention studies always executes protocols with best possible scientific rigor…….

- YET
  - Most of what we do routinely is hardly enough to achieve near desired adherence (>80%)
  - Seems however good a job with do, enrolling participants for whom the study is the right fit:
    - Motivations towards non-adherence once enrolled are far too strong

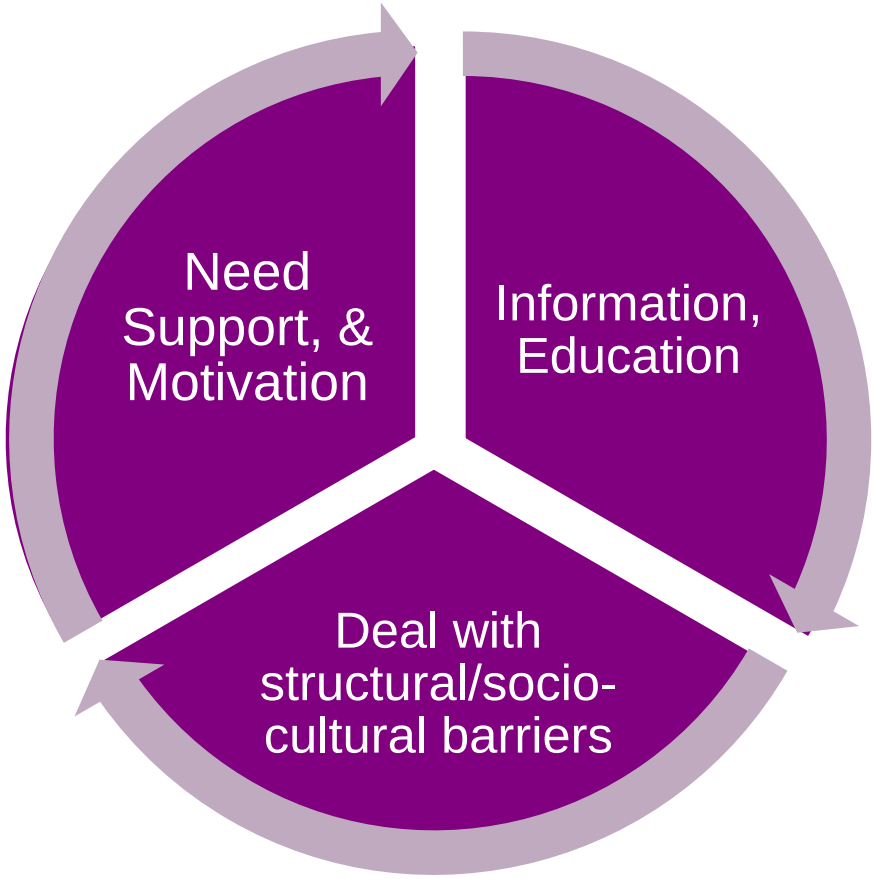
The emotional energy path

- **Participant adherence discussions/Meetings/workshops**

- ***Applaud to the Kampala site***
  - ***For being open to new approaches***
  - ***These meetings pioneered at the site***

- Applaud all sites for innovations, creativity in this area
  - Social clubs (eThekwini)
  - Participant discussion workshops (Kampala)
  - Waiting room participant discussions (MRC)
  - Participant discussion meetings (Zim CTU)
- ***I will highlight 4 valuable lessons learned in ASPIRE guiding current thinking around adherence***

1. Adherence or non-adherence is a behavior



Like all behaviors, knowing what is right doesn't always equal ***Doing right***

We struggle driving up support and motivation for product use

- ***This will be my focus***

Inner motivation is the most abstract of all 3 blocks shaping human behavior

- Society to a large degree shapes how we behave
- But the greatest impact on behavior is shaped by the sense of identity
  - we exploit the power of peer group dynamics to deliver individually focused messages

Adherence or non-adherence as a behavior

- Changing behavior takes time, yet studies are run on a short time frame
  - We can't keep doing the same things @ time & expecting a different result
- We do not have the luxury for missed opportunities
  - Seroconversions are occurring
  - The Peer-adherence model is the best we've got
  - The quickest & easiest way to launch the peer-adherence model is thru Participant Group Discussion Meetings

2. Perpetuating a lie about product use requires motivation

- If we did a poor job at enhancing adherence with VASP, then motivation to lie about product use was greater than the motivation we built for use of product
  - Where do participants derive their motivation to lie?
    - ***That's where our answer lies***

The Kampala participant verbatim...

Honestly, if I had not been a part of these group discussions, I would not have used the product myself

With what was being said, it was way too much, anyone would be scared from using the product

But here, we freely discuss our concerns & ask questions without fear or intimidation

With the one-to-one sessions, you cannot be free, you fear the staff and it feels disappointing to say when you're not using product

3. We make too many assumptions

- That participants clearly articulate the value of HIV prevention & that should transcend their concerns or the lack thereof
- That they surely should appreciate their HIV infection risk levels
- Through the participant discussion meetings, we've learned that:
  - *Local HIV statistics matter (New HIV infections per day)*
    - *"Knowledge is Power"*
  - *A more intimate sharing of personal experiences of impact of the HIV epidemic in each persons family speaks louder*
  - *A call to action from one participant transcends many staffs' voices*
    - *Verulam's Sero-converter message*

Verulam Participant

- *1st met her in July 2013*
- *She seemed withdrawn during the discussions*
- *Only learnt she was a sero-converter after the discussions*
- *She was so touched incidentally, she felt it was only honorable for her to educate others what an opportunity they still had to make a difference, since she always removed the ring right at the clinic*
- *Sept check-in showed she's now an active peer*

4. WE (STUDY STAFF) ARE THE LEAST EMPOWERED TO IMPACT POSITIVELY ON ANY PARTICIPANT

- Fellow participants' & other community members opinions matter more
  - We're often viewed as product advocates regardless…
  - We have no clue what wearing the ring feels like
  - We have not been good at highlighting if we're part of the community we serve
    - These women do not identify with staff
    - Often, we still relate to our participants as a vulnerable group

Group of five at Chatsworth in July discussion

- ***Great enthusiasm generated, after a staff & ppt shared of a niece/daughter raped & infected (respectively)***
- ***So touched, they decided the ring's success was their fight.***
- ***Resolved to become ring use advocates (one elected chairperson)***
- ***Decided they need to actively be talking to other participants on daily basis***
  - ***divided themselves into groups of 2 based on location for easy pick up by the site & at a no re-imbursement basis***
  - ***Required update on improvements based on PK***
- ***Checked in with site in Sep't & group still active***

Bothas Hill Participant

- *Met at the September meeting 2013*
- *She finally, after 9 months of non-adherence to ring, was touched by discussions/emotions & she was to start adhering*
- *I think a peer educator's story in our discussion was all she needed*

Participant adherence meetings; What are they?

- They are NOT:
  - Informational sessions
  - Educational sessions (but rather sharing sessions)
- They should be:
  - Highly emotionally charged, (not from a rehearsal session, but from the heart).
    - Participants too read beyond what you say
  - They should be REAL
  - Focused & person-centered (you elicit individual stories & messages)
    - It's the individualized stories a moderator uses to elicit true emotions & guide ppts on the bigger picture

Real emotions at Ispingo

- *A lot of sobbing, sparked by a participant who could hardly hold her emotions when I asked her to share her story*
- *One participant sobbed all thru our discussion*
- *Another, reported she was part of a group that had been previously simply fooling around, only interested in the R150*
    - *Had not figured her actions were somewhat related to 4 people in her life infected & on ART*

If you want a story, you've got to tell one

- The way you share your story provides:
  - the detail you want in one told back to you
  - the emotions to be involved
  - you need to have an eye out for one likely to have a compelling as an initiator
- It shows you belong & you care beyond your job

ASPIRE workshop

- Wednesday, Grand Ballroom 1:30-5:00pm
- Skills building workshop in conducting these adherence meetings/discussions
  - Presentations from Kampala site & Botha's Hill on their experiences with these so far
  - Most importantly, an opportunity to share:

Thank you very much

ASPIRE
A Study to Prevent Infection with a Ring for Extended Use

MTN
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