Client perspectives: preferences and stigma

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Background

- Integrated care is assumed to be preferred by clients over more separate or stand-alone models of care, due to reduced need for referrals and clinic visits.

- Integrated care is also assumed to be less stigmatising to HIV+ clients, who may fear being labelled as they walk through the door of an HIV-only clinic.
Pathways to client stigmatisation in health care settings

Medical processes
- Overuse of universal precautions
- Unnecessary tests

Social factors
- Discriminatory provider behaviours:
  - Denial of care
  - Gossiping
  - Verbal abuse
  - Additional fees
- Behaviours of other clients

Structural factors
- Integration/specialisation
- Layout of rooms & buildings
- Administrative procedures

Labelling & breach of confidentiality
- Status exposed
  - Enacted stigma
  - Felt stigma

Ref: Church 2011, PhD Thesis
Data sources

- Investigate preferences for integrated care and stigma using:
  - FP cohort round 3 data
  - Linked qualitative studies (WLHIV)
  - HIV clinic sub-study
Methods: Cohort & linked qualitative

- Cross-sectional analysis of preferences and stigma using Round 3 data from Kenya FP cohort
- Study population: those who used same clinic at baseline and endline:
  - n=662/1215 round 3 respondents (54%)
  - n=662/1959 whole cohort (34%)
- Comparisons in preference scores across integration index using Analysis of Variance (ANOVA)
- Test association between endline clinic index score (low/medium/high) and mean stigma score using conditional multivariable logistic regression modelling
- In-depth interviews with sub-sample WLHIV in cohort (n=73), analysed thematically
Methods: Comparative case study of HIV clinics in Swaziland

- Cross-sectional study design to evaluate 4 different models of HIV care in one town
- Mixed methods:
  - Exit survey of HIV clients (n=611) (m&f)
  - In-depth interviews with clients (n=22)
1. Preferences for integrated care
Preferences for integrated vs separated care (cohorts)

- % clients who disagree or strongly disagree that HIV services should be separated from other health services:
  - 61% of FP clients
  - 78% of PNC Kenya
  - 56% PNC Swaziland (round 3 cohorts)

- No clear association with level of integrated care accessed in FP cohort (Round 3), though those in most integrated sites less likely to want separated services

*among those who attend same facility at round 3 (75%)
Preferences for integration (WLHIV)

- **Desires for ‘same-day’ services:** for financial reasons, distance, lack of transportation; lack of integration led to missed appointments
  “I would have loved to get them all in a single visit, because I usually have transport problems (fare money) since there is a different date for me to take the baby for immunizations, and a different date for my family planning and another date for me to take the child to the VCT. [...] I have tried talking to the nurses, but I encountered a problem”. [PNC female client Swaziland]

- **Benefits of ‘continuity of care’:** the importance of trust in providers:
  “I want to use [FP] but it’s not ok that I have to go [...] to the other side [of the building] because [...] you might find nurses who aren’t like the ones we have this side, and also you have to explain to them and you might find someone who’s not easy to talk to, and that’s a problem” [Female, HIV treatment client Swaziland]

- **But:** importance of reducing **waiting times.** HIV-only models seen to be more efficient by some:
  “I think it’s better to be in a place that deals with just HIV. The waiting time is actually very short here. But if you are in a hospital or clinic that has many services available, with the little staff they have, you end up waiting longer.” [Female, HIV treatment client Swaziland]
Preferences for separated HIV care among HIV treatment clients, Swaziland

- Clients attending HIV-only services strongly favour keeping HIV services separate

Mean score of agreement “HIV services should be separated from other health services”

- Most "specialist" clinic

- Most integrated clinic

Mean score of agreement:
- Clinic A: 2.07
- Clinic B: 2.84
- Clinic C: 4.43
- Clinic D: 4.09

P <0.001 for differences between all clinics except C & D
But important to disentangle the complexity of client preferences

- Qualitative analysis of HIV client IDIs in Swaziland suggests clients value many different dimensions of medical care:

  - Access to medical care
  - Costs of care
  - Access to multiple services
  - Continuity of care
  - Technical competence
  - Interpersonal care
  - Efficiency (fast care)
  - Physical environment (cleanliness, crowding)
  - Equity
  - Confidentiality
  - Respect as a person living with HIV
Attributes of integrated and specialist care impact differentially on satisfaction.

### Integrated care attributes
- Fees for additional services
- Provider knowledge of multiple health areas
- Co-location
- Provider knowledge of client medical history
- See fewer providers
- Multiple needs met in 1 consultation
- Longer waiting times
- Attract different (more) clients
- Any client can attend any service

### Dimensions of satisfaction/dissatisfaction:
- Access to medical care (drugs)
- Costs of care
- Access to multiple services
- Continuity of care
- Technical competence
- Interpersonal care
- Efficiency (fast care)
- Physical environment
- Equity
- Confidentiality
- Respect as a PLWH (stigma)

### Specialist care attributes
- Fees for referral services
- Costs to reach referral sites
- Referral to other sites
- Specialist expertise in HIV
- Focus on one illness
- Shorter waiting times
- Role specialisation
- Only HIV clients
- Encourage openness

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Ref: Church et al (2012), AIDS Patient Care and STDS, 26 (11)
2. Stigma and integrated care
Actions by providers can be highly stigmatising

“[the nurses] announced that those who were there to get pills needed to go to Room 3…that was really bad because everyone was just sitting in the waiting room, and nobody was paying attention to what others were there for...then all of a sudden we have to get up because we’re the ones that’ve been called. People didn’t need to know...”

[Female, partially integrated site, HIV treatment client, Swaziland]
Stigmatisation fears in FP cohort, Kenya (all clients)

- Generally low levels of agreement with statements of stigmatising behaviours by providers (i.e. clients generally don’t feel stigmatised)
- But those at most integrated facilities more likely to agree with negative statements (i.e. appear more stigmatising)

*among those who attend same clinic at baseline and Round 3 (n=662)
Adjusted analysis: stigmatisation and integration (all clients)

- Association between integration index (endline) and mean stigma score at round 3 (>2.5/5.00)

- Adjusted odds show higher stigmatisation in most integrated facilities at endline, though no difference between medium and low

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<tr>
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<th>cOR (95%CI)</th>
<th>aOR* (95%CI)</th>
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<tbody>
<tr>
<td>Low integration index</td>
<td>1.00</td>
<td>1.00</td>
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<tr>
<td>Medium integration index</td>
<td>0.98 (0.66-1.44)</td>
<td>0.66 (0.78-2.14)</td>
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<tr>
<td>High integration index</td>
<td>2.24 (1.43-3.53)</td>
<td>1.43 (1.54-5.20)</td>
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*adjusted for: age, marital status, education, SES score, HIV status (across cohort), time taken to reach clinic, becoming pregnant over cohort
Do HIV+ clients fear exposure of HIV status less in integrated sites?

- After controlling for other factors*, those most likely to fear status exposure were at partially integrated/stand-alone sites:

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<tbody>
<tr>
<td>Clinic A</td>
<td>1.13 (0.58-2.18)</td>
<td>0.92 (0.45-1.89)</td>
</tr>
<tr>
<td>Clinic B</td>
<td>3.22 (2.02-5.14)</td>
<td>3.33 (1.98-5.60)</td>
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<tr>
<td>Clinic C</td>
<td>12.16 (7.43-19.87)</td>
<td>11.84 (6.89-20.36)</td>
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<td>Clinic D</td>
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- There was no difference between the fully stand-alone and the fully integrated clinic.

*Age, Distance from clinic, time enrolled at clinic, being on ARVs, and taking TB treatment

Ref: Church et al (2013) JIAS, 16:17981
Mutual support in HIV-only settings

“I haven’t told anyone [about my status] I only tell those that I find at the clinic when I go collect my pills, they talk about their situations and I also find myself sharing mine” [Female, HIV treatment client, Swaziland]

“I feel very comfortable because I know that I’m not the only one who has the virus, and it shows that taking the medication is also healthy.[...] I feel that it is very good that I have to [collect ARVs] alone, that we take them separately because people, since people who don’t have HIV, or who don’t know people who have HIV, they tend to treat you like you’re no longer a human being”. [Female, PNC cohort study, Kenya]
Kenya IDI data among PLHIV also indicate desire for services to be integrated into separated HIV clinics

“It’s good to get everything at the CCC [...] in one place on the same day and then you go home. [...] At the CCC, everybody likes me and people don’t discriminate against us, there’s no hatred”. [FP cohort study, Kenya]

“most people, when they come here to the CCC, most of them are afraid to go to the FP clinic. So it’s better if they’re all brought here at the CCC” [PNC cohort study, Kenya]

- Integrated services offered at CCC (FP, drugs, ANC) may reduce stigma:
  - Physical separation of CCC (far away) helped reduce fear of stigma
  - Low trust in HP, respect for confidentiality.
  - Familiarity with other clients
  - Continuity of care, less disclosure to providers
Data indicate that all types of clinic can reduce stigma through:

- Careful room labelling
- Naming of clinic
- Ensuring client HIV records are unidentifiable
- Dispensing ART drugs either in private or without easy identification
- Separating waiting areas of VCT and ART clients at HIV-only clinics
Key limitations

- Cross-sectional approaches limit determination of causality between model and outcomes (preference/stigma), although mixed methods approach attempted to compensate for this weakness.
- Selection bias in cohort - loss to follow up/matching problems; and only those using same clinic assessed.
- Cohort analysis applies to round 3 only.
- Potential response bias in HIV survey (refusal rates higher at Clinics A and B (22 & 28%) vs C and D(6 & 5%)
- Small number of HIV clinics studied - compensated for by case study approach.
Conclusions

- Clients generally prefer getting everything under one roof, but many PLHIV also have preferences to get care in an ‘HIV-only’ environment. (Integrating SRH into specialist HIV sites may be beneficial)

- In the FP cohort, there was no clear association between preferences for integration and level of integrated service attended. HIV clients, however, were more likely to favour separated services if already attending an HIV-only clinic.

- Preferences for ‘types of care’ are complex, and relate to many dimensions of care; some are impacted positively by integration, but some also positively by stand-alone HIV clinics. Choice of model is important for different types of clients.

- Integrated clinics have the capacity to reduce HIV-related stigma, but need to pay attention to ensure clients are not ‘labelled’ unintentionally. Stand-alone sites can also ensure confidentiality, and may offer a source of mutual support unobtainable in an integrated environment.
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