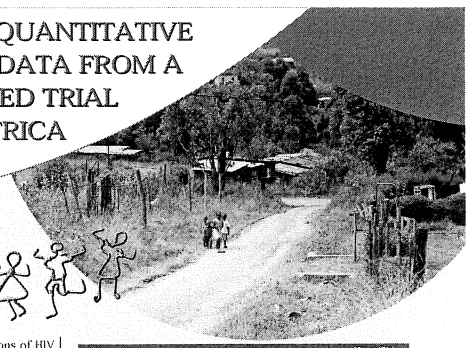
A COMPARATIVE ANALYSIS OF QUANTITATIVE AND QUALITATIVE HIV STIGMA DATA FROM A COMMUNITY BASED RANDOMIZED TRIAL IN KWA-ZULU NATAL, SOUTH AFRICA (PROJECT ACCEPT HPTN 043)



Admire Chirowodza, Nuala McGrath, Heidi van Rooyen, Linda Richter and Tom Coates
Human Sciences Research Council, South Africa

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BACKGROUND

- Methods to accurately measure context-specific dimensions of HIV stigma and how it affects health-seeking behavior are poorly established.
- Understanding the contextual dimensions of stigma remains a priority in addressing challenges to HIV prevention in a variety of settings.
- Both quantitative and qualitative methods are useful for describing stigma in various contexts.
- A mixed method approach is particularly valuable in stigma analysis as the limitations for using only one approach are reduced.

STUDY OVERVIEW

- NIMH Project Accept (HPTN 043) is a multi-site community-level randomized controlled study.
- The primary objective of this study is to test the hypothesis that communities receiving 2-1/2 years of CBVCT, relative to communities receiving 2-1/2 years of SVCT, will have significantly lower prevalence of recent HIV infection.
- Communities are randomized to receive either a community-based voluntary counselling or testing (CBVCT) intervention plus standard clinic-based VCT (SVCT), or SVCT alone.
- CBVCT has three major strategies:
  (1) to make VCT more available in community settings;
  (2) to engage the community through outreach and to make testing normative; and
  (3) to provide post-test support.

METHODS

BASELINE SURVEY

- A baseline behavioral assessment was conducted amongst 2628 adults in the Vulindlela area
- The survey included a stigma component measuring dimensions of stigma viz. Shame, Blame and Equity

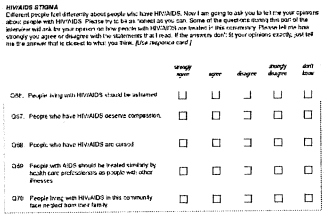
ETHNOGRAPHIC COHORT

- 126 participants were randomly selected from the survey population for the ethnographic cohort
- Cohort participants are interviewed in four separate waves over the intervention period.
- The cohort interviews - explored amongst other things - participants' perceptions and experience of stigma and discrimination.

AIM OF THIS POSTER

To compare how the dimensions of stigma measured in the baseline survey compare to descriptions of stigma from the baseline ethnographic cohort in a rural South African community in Project Accept (HPTN 043)

Figure 1: Stigma questions from Baseline Survey



HIV/AIDS STIGMA

Different people feel differently about people who have HIV/AIDS. Now I am going to ask you to tell me your opinions about people with HIV/AIDS. Please try to be as honest as you can. Some of the questions may sound like part of the interview but I will ask for your opinion on how people with HIV/AIDS are treated in this community. Please tell me how strongly you agree or disagree with the statements that I read. If the answers don't fit your opinions exactly, just tell me the answer that is closest to what you think. (Use response card)

	strongly agree	agree	disagree	strongly disagree	don't know
Q56. People living with HIV/AIDS should be ashamed	☐	☐	☐	☐	☐
Q57. People who have HIV/AIDS deserve compassion	☐	☐	☐	☐	☐
Q58. People who have HIV/AIDS are cursed	☐	☐	☐	☐	☐
Q59. People with AIDS should be treated similarly by health care professionals as people with other illnesses	☐	☐	☐	☐	☐
Q76. People living with HIV/AIDS in this community face rejection from their family	☐	☐	☐	☐	☐

STIGMA QUESTIONS USED IN THE ETHNOGRAPHIC COHORT

- How do people feel about HIV/AIDS in this community?
- Do you know people in your community who are infected with HIV?
  - How do you feel about these people?
- If someone you know told you that they were infected with HIV, how would you react to them?
  - How are these people (you know who are HIV +) treated by others in this community?

ANALYSIS OF BASELINE SURVEY

- Final factor analysis on the baseline survey data includes a total of 1276 participants. This final sample:
  - Includes participants who did not have any missing data on stigma questions
  - Excludes don't know responses from the data

CHARACTERISTICS OF THE SAMPLE IN BASELINE SURVEY

Characteristics		*Number (%)*
Gender	Male	444 (35)
	Female	832 (65)
Age of Participants	18 - 24	702 (55)
	25 - 32	574 (45)
Total		1276

Table 1: Stigma scores (standard deviations) by sub-scale for N = 1276

*Subscale 1: Shame/Blame/Social Isolation	Mean (Standard Deviation)
People living with HIV should be Ashamed	2.94 (0.55)
People with AIDS should be Isolated from other people	3.22 (0.55)
People who have HIV/AIDS are cursed	3.26 (0.52)
People living with HIV/AIDS deserve to be punished	3.32 (0.51)
A person with AIDS should be allowed to work with other people (+)	3.16 (0.56)
Families of people living with HIV/AIDS should be ashamed	3.14 (0.47)
79. It is reasonable for an employer to fire people who have AIDS	3.26 (0.55)
People who have AIDS are disgusting	3.19 (0.62)
People who have HIV/AIDS Deserve compassion (+)	3.02 (0.48)
People with HIV should be allowed to fully participate in social events in this community (+)	3.14 (0.58)

*Measures individual attitudes towards people living with HIV

#Subscale 2: Discrimination	Mean (Std. Deviation)
People living with HIV/AIDS in this community face neglect from their family	2.65 (0.67)
People living with HIV/AIDS Face physical abuse	2.99 (0.58)
People want to be friends with someone who has HIV/AIDS (+)	2.42 (0.66)
People living with HIV/AIDS in this community face ejection from their homes by their families	2.69 (0.64)
Most people would not buy vegetables from a shopkeeper or food seller that they knew had AIDS	2.46 (0.64)
People who have HIV/AIDS in this community face verbal abuse or teasing	2.49 (0.72)
People living with HIV/AIDS in this community face rejection from their peers	2.58 (0.73)
People who are suspected of having HIV/AIDS lose respect in the community	2.45 (0.69)

Measures individual perceptions regarding discrimination of people living with HIV in their community

*Subscale 3: Equity	Mean (Std. Deviation)
People with HIV should be allowed to fully participate in social events in the community (+)	3.14 (0.57)
People with AIDS should be treated similarly by health care professionals as people with other illnesses (+)	3.27 (0.53)
People who have HIV/AIDS should be treated the same as everyone else (+)	3.26 (0.51)
People with HIV/AIDS do not deserve any support	3.07 (0.54)
People with HIV/AIDS should not have the same freedoms as other people	3.10 (0.72)

*Measures individual attitudes towards people living with HIV

MEAN SCORES INTERPRETATION

- Endorsement of stigmatizing views in participants responses yielded a higher score on the 4-point scale ranging from "strongly agree" to "strongly disagree"
- The trend in the mean subscales scores shows lower individual stigma towards people living with HIV (this is measured by the shame, blame, social isolation and equity subscale)
- The scores endorse the existence of high community level stigma as measured by the discrimination subscales.
- Discrimination scores are elevated more than the Shame and Equity subscales.

ETHNOGRAPHIC COHORTANALYSIS

CHARACTERISTICS OF THE BASELINE COHORT SAMPLE

Characteristics of Sample		*Number (%)*
Gender	Female	64 (50.8)
	Male	62 (49.2)
Age	Younger (18 - 24)	64 (50.8)
	Older (25 - 32)	62 (49.2)

QUALITATIVE DATA ANALYSIS PROCESS

- Interviews were transcribed and translated
- The site team applied topical codes to the transcripts (50 codes in all) using Atlas.ti software.
- The codes that were applied to the data covered testing, stigma, discussions, risk, ARVs
- We reviewed, 287 quotations coded as community level attitudes about HIV and 249 quotations coded as personal attitudes of people living with HIV for the analysis

MAJOR THEMES

- Personal level attitudes towards People Living with HIV/AIDS (PLHA)
  - Many participants expressed a feeling of "sadness" and sense of feeling "bad" when they thought of those who may be HIV positive in their community.
  - Participants associated being HIV positive with a loss of life, sickness and ill health; that it could result in possible isolation from neighbours and feeling of hopelessness resulting from "knowing that you are going to die at any time".
  - Participant descriptions of their personal attitudes towards people living with HIV did not display any endorsement of stigmatising attitudes towards people living with HIV/AIDS. Instead, many participants expressed sympathy for PLHA and showed a willingness to "advise them on health matters" and treat them "just like other people".
- Community level attitudes
  - Contrary to their personal attitudes towards people living with HIV, many participants expressed that community level attitudes towards PLHA were not favourable and were quite hostile towards people living with HIV/AIDS.
  - Narrative descriptions of how other community members treat people with HIV revealed various forms of discrimination towards PLHA. Forms of discrimination in the community included gossiping, scolding, ridiculing and isolation of people living with HIV.
  - Gossiping and social isolation from neighbours was an overarching theme in most participants descriptions of community level attitudes towards those living with HIV/AIDS
- Example: Community talk about people with HIV
  I: *But may be if you look at other people, how do they treat them (people with HIV)?*
  P: *Hey, you find that a person is now sick; he is on someone's back and is taken to the hospital. The people then, with their curiosity then come out (to look at the person taken to the hospital), there also others peep through the windows that a person has now been put on the wheelbarrow (on his way to the hospital). This disease (HIV), aunties even the elderly people talk.*
  I: *Do they talk?*
  P: *Yes, yes, yes (laughter). You become the talk of the town* (Male, 25years old)
- Low levels of HIV disclosure in the Community:
  - Participants reported that disclosure by HIV positive people was generally low in the community. This could be that the unfavourable community attitudes – i.e. the high levels of negative "community talk" and gossip – could deter people from disclosing
  - As with other studies, this study shows a difference between perceptions of stigma and discrimination and actual discrimination.
  - As disclosure is low in this community, respondents' reports of discrimination of PLHA appear to be based more on perception or suspicions of disclosure rather than first hand knowledge of negative consequences to PLHA following disclosure.

CONCLUSIONS

- Both sets of data reveal low endorsements of individual level stigma towards people living with HIV/AIDS, while endorsing the existence of high community level stigma
- The qualitative data provided detailed descriptions of both individual and community level expressions of stigma. For example, the sympathy and sadness expressed for PLHA may explain the low levels of personal stigma identified on the stigma scale
- In addition, the qualitative data also showed what forms community level stigma takes in this rural community. Rural societies are often traditional, conservative and intimate. As such, rigid rules, monitoring and suspicion often govern interpersonal and especially sexual behaviour of the individual and others. It is in this context, that the gossiping scolding, ridiculing and fears of social isolation of PLHA needs to be understood.
- Of interest is the way that individuals portray themselves positively and see "others" in the community as capable of discriminating behaviour. This may be an indication of a social desirability bias in the data.

Contact e-mail address: achirowodza@hsrc.ac.za

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