HIV TESTING – A Psychological perspective

Professor Lorraine Sherr, UCL, London
Over 20 years of HIV testing

- Components:
  - Pre test counselling
  - HIV testing
  - Results
  - Post test counselling
Phases of testing
Psychological role in HIV testing

TEST

Psychological adjustment

Treatment decisions

Behavioural response
DECISION MAKING

• INDIVIDUAL

• To test
  – Cost benefit
  – Risks
  – Hurdles
  – Decline
  – Repeat testing
  – Risk behaviour
  – Negotiations
  – Partnerships
    (serosorting, seeking sex, barebacking)

• After test
  – Behaviour change
  – Disclosure
  – Repeat testing

• SETTING
  – Availability
  – Prevalence
  – Treatment access
Decision making theory

- What factors affect decisions?
Perception of Risk

• Absolute vs levels
• Dangerous versus safe (see harm reduction models for examples)
• All or nothing (zero reigns supreme) Elimination more appealing than reduction
• Partial versus total elimination of risk
• Difficulty in understanding probability
• Dosage insensitivity
  – Too many vitamins
  – small amounts of worry
  – dieting
• Framing - Negative versus positive
  – Marteau et al re termination of pregnancy, Sherr et al HIV, Edwards et al 2001)
  – Largest effect when relative risk vs absolute risk
  – Loss framing is more effective than gain framing
  – More information, more understandable associated with improved knowledge and greater wariness

• Hindsight Bias
  – Knowledge of ultimate outcome distorts outcome
  – Highlight data consistent with outcome

• Absolute vs Levels
  • What has more calories? Teaspoon ice cream or a pint of cottage cheese (Markwith 92)
  – Overdosing on vitamins
  – Over worry about small doses
  – Overdo it on amounts (baby formula)
  – Nothing - no cigarette = safe
  – no HIV from unsafe sex = safe
• **Emotions**
  – Real vs illusory loss
  – Loss > gain
  – normal = status quo
  – affected by order, presentation

• **Feelings**
  – Cannot anticipate
  – chronic vs acute
  – adaptation variations

• **Memories**
  – Negative experience
  – Intensity
• Irrational concerns
  – Work of worry \textit{(Janis etc)}

• Sensation vs perception
  – Sensory information can be confusing
  – Many factors contribute to interpretation
  – Human mind mediates input

• Differences between thoughts and actions
• Effects of groups
  – Normative and social influence, Groupthink
  – Polarisation/Risky shift (Moscovici and Doise)
  – Majority influence/Minority influence

• Information
  – How much information do we need to make a decision?
Contexts of coverage

• Pregnancy
• Gay Men
• Zimbabwe
• Legal Considerations
Gay men

- HIV testing
- Repeat testers
- HIV testing and risk
HIV risk behaviours rising
1998-2003, n=4264 gay men


International AIDS Conference 2004 Bangkok WePeC6049

HIV positive, (n=654)
HIV negative (n= 2,652) never-tested (n=958) all reported an increase in non-concordant UAI with a casual partner regardless of age (p<0.05)

J Elford, G Bolding, M Davis, L Sherr, G Hart
International AIDS Conference 2004 Bangkok WePeC6049
Mean optimism score by HIV status

- London (n=690): p=0.5
- Paris (n=1715): <0.001
- Syd/Melb (n=3120): 0.02
- Vancouver (n=357): 0.5

- HIV positive
- HIV negative
- Never-tested
Repeat Testers

• All HIV testing clinic attenders interviewed (n=1446)
• 50.6% repeat testers (721/1446)
• Significantly more gay men (71.7% vs 42.1% het men, 38.6% women)
• No sig differences in frequency Unprotected sex.
• Gay men with 3+ tests significantly more risk.
HIV +ve, HIV -ve, Untested

• Numerous studies looking at groups according to their HIV status.
• Risk behaviours vary
• UK untested often tend to be safer on a variety of parameters
• HIV negative - include previous tested but may be dated
Do new inventions create, confound or confirm risk?

- Will sex education make youth sexually active - *evidence to the contrary*
- Will compulsory HIV testing for marriage reduce HIV - *evidence to the contrary*
- Will clean needle exchange increase drug use - *evidence to the contrary*
- Will vaccines, microbicides, trials or treatments enhance risk behaviour?
- Will HIV testing change or affect risk?
Viagra use in previous 12 months

- **HIV positive (n=126):**
  - 28% Recreational
  - 9% Prescription only

- **HIV negative (n=477):**
  - 19% Recreational
  - 1% Prescription only

- **Never-tested (n=169):**
  - 7% Recreational
  - 2% Prescription only
Non-concordant UAI according to Viagra use

- HIV positive: 33 used Viagra, 14 didn't use Viagra, $p < 0.001$
- HIV negative: 22 used Viagra, 14 didn't use Viagra, $p < 0.05$
- Never-tested: 33 used Viagra, 21 didn't use Viagra, $p < 0.05$

UAI did not necessarily occur while using Viagra.
Zimbabwe

• Uptake of HIV testing and implications for behaviour change
  • Acknowledge thanks to Simon Gregson, Geoff Garnett, Ben Lopman, and the whole Welcome HIV Group.
AIM

• Examine determinants of uptake of VCT

• To examine gender similarities and differences.

• To examine changes in sexual risk behaviour following VCT

• Compare HIV incidence amongst testers and non testers
METHODS

• A household survey was conducted in 12 rural areas in Manicaland, Zimbabwe (full description ref Gregson 2001).
• Baseline (1998-2000) Follow up 3 years
• Respondents completed confidential standardised survey data reporting on demographics, behaviour, HIV testing experience
• Anonymous HIV dipstick test - referral to named HIV testing on request project provided
Respondents

• Data was available from 8,663 respondents,
  – 3,471 males and
  – 5,192 females

• 8,231 (95%) agreed to provide blood samples for an anonymous HIV dipstick test.

• 1,637 were HIV positive and 6,594 were HIV negative, giving a 19.9% prevalence of HIV of those tested and 18.8% of all respondents.

• Follow up data was available for 5,775 (61%) for behaviour change study
Voluntary Counselling and Testing - VCT

- 1,397 (16.1%) had undertaken VCT.
- Males were significantly more likely to report VCT than females
  - 770 (22.2%) vs 627 (12%) p < .0001.
- VCT increased from 6% at round 1.
• The majority of the respondents wanted to know if they were HIV infected n=7650 (88.3%).
  – Males were more likely to want to know their HIV status than females
  – 3,139 males (90.5%) vs 4,511 (86.9%) females p < .0001.
## Gender differences

<table>
<thead>
<tr>
<th>Variable</th>
<th>Male</th>
<th>Female</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Test for HIV</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>770 (22.2%)</td>
<td>627 (12.1%)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>No</td>
<td>3471</td>
<td>5192</td>
<td></td>
</tr>
<tr>
<td><strong>Received counselling before given result?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>321 (42.3%)</td>
<td>398 (64.7%)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>No</td>
<td>438</td>
<td>217</td>
<td></td>
</tr>
<tr>
<td><strong>Collect result?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>356 (46.9%)</td>
<td>443 (72.2%)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>No</td>
<td>403 (53.1%)</td>
<td>171 (27.9%)</td>
<td></td>
</tr>
<tr>
<td><strong>Collect results (n=799), post test counselling</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>241 (67.7%)</td>
<td>305 (68.9%)</td>
<td>0.7</td>
</tr>
<tr>
<td>No</td>
<td>115 (32.3%)</td>
<td>138 (31.2%)</td>
<td>ns</td>
</tr>
</tbody>
</table>
Counselling

• Of 1,185 who had tested for HIV, 51% received pre test counselling
• Lower for males than females (42% vs 65% p<.001)
• Both Males and Females, pre-test counselling more likely to return for results (M 82% vs 21%; F 80% vs 53% p<.001 for both)
• Females > Males to collect their HIV test results (72.2% vs 46.9%).
## Deterrents from HIV testing

<table>
<thead>
<tr>
<th>Factor</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>1467</td>
<td>1329</td>
</tr>
<tr>
<td></td>
<td>42.3%</td>
<td>25.6%</td>
</tr>
<tr>
<td>Stigma</td>
<td>138</td>
<td>587</td>
</tr>
<tr>
<td></td>
<td>4.0%</td>
<td>11.3%</td>
</tr>
<tr>
<td>Partnership break</td>
<td>56</td>
<td>117</td>
</tr>
<tr>
<td></td>
<td>1.6%</td>
<td>2.3%</td>
</tr>
<tr>
<td>Job loss</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>0.2%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Fatalism no cure</td>
<td>196</td>
<td>190</td>
</tr>
<tr>
<td></td>
<td>5.6%</td>
<td>3.7%</td>
</tr>
<tr>
<td>+ve results=death</td>
<td>201</td>
<td>371</td>
</tr>
<tr>
<td></td>
<td>5.8%</td>
<td>7.1%</td>
</tr>
<tr>
<td>Other</td>
<td>1397</td>
<td>2577</td>
</tr>
<tr>
<td></td>
<td>40.3%</td>
<td>49.6%</td>
</tr>
</tbody>
</table>
Deterrents and promoters

- Psychological factors most common deterrent 32.3%.
- Males more mention of psychological deterrents (42% vs 25% p<.0001).
- Anxiety, general concern, wanting reassurance of uninfected mentioned by 75%
- Stigma was a deterrent for 8.4%—mentioned 3 times more often by females than males.
- Fears of partnership break up and job loss accounted for only a small number of respondents.
FACTORS ASSOCIATED WITH HIV TESTING

• For both sexes, age was strongly associated.

• Multivariate controlling for age shows:-
  – Greater education
  – Men
    • fewer total lifetime partners
    • More casual partners
  – Women
    • Fewer total life partners

• Greater knowledge of HIV
Dipstick results (n=8,231)

- Of those HIV +ve by dipstick, 343 (21%) had VCT in the past.
  - 30% of men who were positive by dipstick had VCT
  - 16.2% of women who were HIV+ve by dipstick had VCT.
- Males who were HIV +ve by dipstick (n=591), 76 (12.9%) had VCT and results.
- Women (1,046) had tested HIV +ve by dipstick, 119 (11.4%) had VCT + results.
- Of those who were HIV -ve by dipstick, 964 (14.6%) had VCT.
MCTC

• At the time of interview, 171 women reported they were pregnant.
  – 24 (14.1%) had VCT.
  – 164 had dipstick tests, and 34 (20.7%) were HIV+ve

• 5,401 respondents had a child
  – 1,041 had VCT (19.3%)
  – 5,065 had dipstick tests and 1435 (28.3%) were HIV +ve
Risk and VCT

• 4.9% of men and 4.5% of women said they knew the HIV status of their regular partner.

• Of the 68 who had exchanged money for sex in the last months,
  – 19 (27.9%) had VCT
  – 61 provided dipstick sample, and 26 (30%) were HIV+ve
HIV+ve by dipstick

• Significantly more likely to have:-
  – More different regular sexual partners in past years
  – More different non-regular sexual partners in the past years
  – More current sexual relationships
  – More likely to meet partner in the beer hall.
  – More likely to have had a child
  – Significantly more likely to have had VCT in past 21% vs 14.6% p<.0001
VCT and subsequent sexual behaviour

• Risk behaviour from followed up individuals who were sexually experienced (n=5,216)

• Individual behaviour change
  – Men and women who tested negative and received results more likely to become more risky
    • Beer hall attendance
    • Number of concurrent partnerships
    • Number of last month partnerships
    • Women who tested +ve reported reduction in consistent condom use
VCT and Subsequent HIV Incidence

- HIV incidence calculated for those who tested negative at/near baseline and were followed up.
- HIV incidence at f/up did not differ significantly between those who had HIV tested or not.
  - True for crude, gender adjusted and age adjusted models.
Round 3 data (current)

- VCT and collect results 7.8%
- Profile remains of older, married, well educated people
- Most at risk are not going for testing
- HIV Prevalence declined 18%-15% males; 22%-19% females
- Both males and females testing +ve reported less risky behaviour after VCT.
- Those testing negative appear to be changing behaviour to become more risky
PREGNANCY

Uptake of HIV testing in pregnancy in 3 London Hospitals
Sustaining uptake over 2 year period
Methods

- Audit questionnaires
- Immediately after ante natal booking
- 4 months in 2002 in 3 London Hospitals
- Follow up in May 2004 in 3 London Hospitals
Questionnaires

- Demographic information
- Obstetric history
- HIV Risk factors
- Length of time spent discussing HIV testing
- Previous HIV testing
- Uptake of HIV test
- Uptake of other ante-natal Screening
- Reasons for declining were noted and rated
• 2,710 women attending, 401 (15%) declined HIV test
  – 38% HIV test in past
  – 65% accepted all other tests
## RESULTS

<table>
<thead>
<tr>
<th>Variable</th>
<th>2002 (4/12)</th>
<th>2004 (1/12)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>2710</td>
<td>850</td>
</tr>
<tr>
<td><strong>Response rate</strong></td>
<td>76%</td>
<td>59% *</td>
</tr>
<tr>
<td><strong>HIV Test uptake</strong></td>
<td>85%</td>
<td>88.2% *</td>
</tr>
<tr>
<td>% Declines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• consented to all other tests</td>
<td>65%</td>
<td>45.9%</td>
</tr>
<tr>
<td>• from Sub Saharan Africa</td>
<td>ns</td>
<td>sig</td>
</tr>
<tr>
<td>• Older</td>
<td>Sig</td>
<td>sig</td>
</tr>
<tr>
<td>• Parity (Multiparous)</td>
<td>Sig</td>
<td>Sig</td>
</tr>
<tr>
<td>• Weeks at booking (late bookers)</td>
<td>Sig</td>
<td>Sig</td>
</tr>
<tr>
<td>• Marital status</td>
<td>Ns</td>
<td>Ns</td>
</tr>
<tr>
<td>• Religious group</td>
<td>Sig</td>
<td>Sig</td>
</tr>
<tr>
<td>• Previous HIV test</td>
<td>Sig</td>
<td>ns</td>
</tr>
</tbody>
</table>
## Risk factors (2004)

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Accept</th>
<th>Decline</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>39 (5.3)</td>
<td>10 (13.5)</td>
<td>49 (6.1)</td>
</tr>
<tr>
<td>No</td>
<td>696 (94.7)</td>
<td>64 (86.5)</td>
<td>760 (93.9)</td>
</tr>
</tbody>
</table>

Women with at least one risk factor for HIV (n=56; 6%) (i.e. STI, IV drug use, partner HIV positive and coming from endemic country) were significantly more likely to decline an HIV test than those with no reported risk factors (p=.001)
Recent study – HIV

Discussion

No significant difference in appraisal on decline/accept
Uptake over time

• Up by 3%
• Yet Sub Saharan African women significantly less likely to test
• The longer time spent on HIV discussion, less likely to test (under 3 minutes)
• IN 2002 HIV was the most common test declined, by 2005 Down’s syndrome more often declined
HIV testing and women

• Pregnancy but no termination or family planning clinics
• Only 10% of positive pregnant women in Africa are getting interventions
• No HIV testing for children from interventions
• Testing of mothers -
  – first tested=first infected
Consent to test
Pregnant women’s views

- N=697 (79% response rate)
- 22.2% did not believe consent would be asked for HIV testing
- 17.7% thought they could not refuse
- Uptake is lower for those who believe consent will be sought and refusal is possible
- Consent needs urgent attention when it comes to pregnant women and HIV
- Only 1 in 5 units have written consent
- 1 in 4 units do not know their consent policy

## Tested But No RESULTS

<table>
<thead>
<tr>
<th>STUDY</th>
<th>YR</th>
<th>PLACE</th>
<th>N</th>
<th>% NO RESULTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zacharich</td>
<td>03</td>
<td>Malawi</td>
<td>1049</td>
<td>4.5%</td>
</tr>
<tr>
<td>Cartoux</td>
<td>98</td>
<td>Cote d’Ivoire</td>
<td>5766</td>
<td>41.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Burkino Faso</td>
<td>3958</td>
<td>18.2%</td>
</tr>
<tr>
<td>Ladner</td>
<td>96</td>
<td>Rwanda</td>
<td>1233</td>
<td>31.2%</td>
</tr>
<tr>
<td>Ramon</td>
<td>98</td>
<td>Cote d’Ivoire</td>
<td>1401</td>
<td>10.0% return</td>
</tr>
<tr>
<td>Downing</td>
<td>98</td>
<td>Uganda</td>
<td>300,000</td>
<td>13.7% result</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>25.0%</td>
</tr>
<tr>
<td>Study</td>
<td>Setting</td>
<td>Total Number</td>
<td>Description</td>
<td>Positive Rate</td>
</tr>
<tr>
<td>---------------------</td>
<td>--------------------------</td>
<td>--------------</td>
<td>---------------------------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Sherr et al (00)</td>
<td>Obstetric units</td>
<td>288</td>
<td>No written/verbal consent</td>
<td>24%</td>
</tr>
<tr>
<td>Larsson 1990</td>
<td>n=58 refusers</td>
<td>58</td>
<td>“blind analysis”</td>
<td>100%</td>
</tr>
<tr>
<td>Dalzell et al (95)</td>
<td>STD attenders</td>
<td>538</td>
<td>Consent to test and test discrepancy</td>
<td>3.8% +ve</td>
</tr>
<tr>
<td>Hull et al</td>
<td>Women</td>
<td></td>
<td>HIV test of refusers</td>
<td>2% +ve</td>
</tr>
<tr>
<td>Jenum et al</td>
<td>Women</td>
<td></td>
<td>Tested test refusers</td>
<td></td>
</tr>
<tr>
<td>Denayer (90)</td>
<td>Obstetricians</td>
<td>340</td>
<td>HIV testing without informing</td>
<td>34%</td>
</tr>
<tr>
<td>Henry et al (91)</td>
<td>US Hospitals</td>
<td>200</td>
<td>HIV consent not obtained</td>
<td>29.1%</td>
</tr>
<tr>
<td>Rey (98)</td>
<td>Southern France</td>
<td></td>
<td>Consent not requested</td>
<td>(92-96) 62%-35%</td>
</tr>
<tr>
<td>Barbacci (90)</td>
<td>1,564 patients</td>
<td></td>
<td>Test refusers tested</td>
<td>yes</td>
</tr>
<tr>
<td>Simon (96)</td>
<td>20,125 patients</td>
<td></td>
<td>Test refusers tested</td>
<td>yes</td>
</tr>
<tr>
<td>Jones (93)</td>
<td>1,929 patients</td>
<td></td>
<td>Test refusers tested</td>
<td>yes</td>
</tr>
<tr>
<td>Behrendt (94)</td>
<td>2,842 patients</td>
<td></td>
<td>Test refusers tested</td>
<td>yes</td>
</tr>
</tbody>
</table>
Legal considerations
• Discrimination
• Criminalisation
What does the future hold for HIV testing?