Telling the truth:
issues around disclosure of sexually transmitted infections

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I am afraid that…
When patients have just received the diagnosis they report:
• deep sense of grief and loss
• lives threatened or functioning impaired
• personal confusion
• distress
• suicidal ideation
• Men more frequently than women report loss of sexual confidence
• Women more frequently than men report feeling dirty and undesirable

A host of negative consequences following diagnosis
• stigma / discrimination
• estrangement from family/friends, coworkers, community
• other people’s fear of contagion
• fear of complications and death
• severe feelings of guilt, shame
• loss of autonomy and dignity, feeling like a burden

HIV and mental health
• Depression > 2 fold increase (Ciesla & Roberts, 2001)
• 20-35% lifetime prevalence (5-10% normal population)
  - negatively affects ART adherence, QoL, treatment outcomes, disease progression
• elevated suicide rates (time of diagnosis and later)
HIV and mental health

- Anxiety disorders (panic disorder, PTSD, adjustment disorder): up to 38% of patients (depending on stage)
- Over 20% of HIV+ women have PTSD (Cottler, 2001)

Anxiety disorders are
- Positively associated with pain
- Negatively associated with CD4 count

HIV and mental health

Patients with HIV worry about...
- Who will stand by me?
- What effect will it have on my current relationship?
- Can I still date other people?
- Will I be disowned by my family or treated differently?
- What will my friends say?

HIV and mental health

HIV-related events that may trigger suicidal thoughts:
- Learning about positive HIV status
- Fear of disclosing to family & friends
- Losing a significant relationship (e.g., partner)
- Noticing the 1st symptoms
- Undergoing major illness or hospitalization
- Losing a job
- Experiencing major changes in lifestyle
- Requiring evaluation for dementia

In a nutshell

People living with HIV face three key decisions:
1. Decisions about adherence to treatments
2. Decisions about sexual activity and desires about parenthood
3. Whether or not to disclose their diagnosis to others

(Bravo et al, 2010)
Adherence to treatments

Important predictors of adherence:

- Conscientiousness +
- Introversion +
- Neuroticism -
- Openness to experiences -

Psychosocial decision needs

Stigma —> discrimination —> isolation

“One of the first decisions that PLHIV must make is whether or not to disclose, and if so, to whom, when, why, and how. How others handle this is also important. It is unknown how many PLHIV do not disclose and therefore how many may not receive the required support.”

Isolation

Isolation and loneliness likely most salient emotional consequences of being HIV+

Serostatus disclosure predominantly leads to social and community support and acceptance of the disease

Yet, the stigma and uncertain reactions……….
Serostatus disclosure

<table>
<thead>
<tr>
<th>To whom</th>
<th>Advantages of disclosure</th>
<th>Disadvantages of disclosure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner</td>
<td>Possible support from partner</td>
<td>Possible loss of the relationship</td>
</tr>
<tr>
<td>Siblings</td>
<td>Potential support of brothers and sisters</td>
<td>Judgment and exclusion from social contact and support</td>
</tr>
<tr>
<td>Parents</td>
<td>Support of family members</td>
<td>Discrimination, rejection by family and isolation</td>
</tr>
<tr>
<td>Children</td>
<td>Children's right to know</td>
<td>Disrupted relationship with children</td>
</tr>
<tr>
<td></td>
<td>Better to find out from their parents</td>
<td>Rejection by children</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disturbance of the child’s emotional and social well-being</td>
</tr>
<tr>
<td>Friends</td>
<td>Support</td>
<td>Judgment and exclusion from social contact and support</td>
</tr>
<tr>
<td>Healthcare providers</td>
<td>Access to healthcare</td>
<td>Stigma and discrimination</td>
</tr>
</tbody>
</table>

Bravo et al., 2016

Who to tell?

371
339
missing values
32
9%
age mean 44yrs (sd=10.2yrs) range 18-75yrs

yrs since HIV diagnosis mean 6.7yrs (sd=6.2yrs)

marital status 64% married/cohabiting 27.1% single

education 29% higher education 61% secondary school

Personality | Type D personality
DS-14 (Denollet, 2005)
- Negative Affectivity $(\lambda^2=.89)$
- Social Inhibition $(\lambda^2=.87)$

Personality | Self-concealment
Self-Concealment Scale (SCS) (Larson & Chastain, 1990)
- Self-Concealment $(\lambda^2=.91)$

Disclosure to potential confidants
- Did you disclose your positive serostatus to…?
  partner
  mother
  father

Answering categories
No
Yes
Not applicable
Disclosure to potential confidants

- Did you disclose your positive serostatus to...?

Answering categories:
- other family members
- friends
- acquaintances
- colleagues from work

- Disclosure frequencies

1. Dichotomization
   - NO = almost no one + most people not
   - YES = half yes/half no + most people + almost everyone

2. Overall % of disclosure for each participant computed

3. Cochran Q test and posthoc McNemar test to test for differences in disclosure rates across groups of confidants

- Predicting disclosure

1. Logistic regression analysis
   - partner / mother / father

   IV
   - gender
   - time since (known) infection
   - self-concealment
   - negative affectivity
   - social inhibition

   DV
   - YES
   - NO

- Predicting disclosure

2. Linear regression analysis
   - other family members / friends / acquaintances / colleagues

   IV
   - gender
   - time since (known) infection
   - self-concealment
   - negative affectivity
   - social inhibition

   DV
   - almost no one
   - most people not
   - half yes/half no
   - most people
   - almost everyone
Results

Disclosure

- full disclosure: n=49 (15%)
- full concealment: n=37 (11%)

Average disclosure across all confidants: 46.5% (no gender difference)

Rankorder of disclosure frequencies

Cochran $Q = 317.75$, $p < .001$

One-tailed post hoc pair-wise McNemar tests

- partner: 93% (n=234) $p < .001$ (all other following groups)
- mother: 56% (n=147) $p < .036$ (all other following groups)
- father: 50% (n=110)
- other family: 48% (n=151)
- friends: 47% (n=152)
- acquaintances: 23% (n=73) $p < .036$ (all other following groups)
- colleagues: 16% (n=44)

Logistic regression analysis

1. SC (-)
2. Infection Time (+)
3. Neg. Affectivity (+)
**Linear regression analysis**

1. SC (-)
2. Infection Time (+)
3. Neg. Affectivity (+)

**Discussion**

Positive serostatus associated with a host of psychosocial problems

Serostatus disclosure important solution to these psychosocial issues

Yet the stigma and laypersons belief about HIV important barrier

Health care professionals must aim to coach the disclosure process

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**Thank you!**

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