Stigma, Isolation, and Discrimination and Their Impact on HIV Serostatus Disclosure: A Global Survey of 2,035 Patients

Presented by Suniti Solomon, MD, Director, Y.R. Gaitonde Center for AIDS Research and Education, Chennai, India

(on behalf of José M. Zuniga, PhD, President/CEO, International Association of Physicians in AIDS Care, Chicago, Illinois, and Washington, DC, United States)
Discussion Overview

• ATLIS 2010
• Methodology
• Stigma, Isolation, and Discrimination
• Key Findings
• Conclusion
• Q&A Session
ATLIS 2010

• Multi-country, comparative, treatment awareness survey of 2,035 people living with HIV/AIDS (PLWHA)
  • Examines global attitudes and perceptions of HIV
• Main survey objectives:
  • Explore different treatment practices and awareness levels to reveal different ways in which people live with HIV/AIDS across the world
  • Explore how different social and cultural factors affect and impact the lives of HIV-positive patients
  • Investigate how patients interact with their primary healthcare provider (HCP), and understand the dialogue that takes place between HCPs and patients
Countries Surveyed

A global review of awareness, attitudes and practices related to long-term HIV treatment

Countries surveyed include:
- United States
- Brazil
- United Kingdom
- Russia
- Germany
- France
- Spain
- Italy
- Cote d'Ivoire
- South Africa
- Australia
- Korea
# Lead Authors

<table>
<thead>
<tr>
<th>Region</th>
<th>Name</th>
<th>Position/Institution</th>
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<tbody>
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Methodology

- Fieldwork conducted January – March 2010
  - Survey vendor: Kantar Health
- Twenty-minute interviews
  - Internet
  - Phone
  - Face-to-face
- Incentives offered where customary
- Respondent qualification:
  - Informed consent to participate in survey
  - Age 18+
  - Diagnosed with HIV/AIDS by a primary HCP
  - Taken ART in the past five years
- Institutional Review Board (IRB) approval
- Task Force review of data
## Survey Methodology & Sample

<table>
<thead>
<tr>
<th>Geographic Markets</th>
<th>Sample Size n=</th>
<th>Methodology</th>
<th>Geographic Spread</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Global Total</strong></td>
<td>2,035</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>North America</strong></td>
<td>201</td>
<td></td>
<td></td>
</tr>
<tr>
<td>U.S.</td>
<td>201</td>
<td>Internet</td>
<td>National</td>
</tr>
<tr>
<td><strong>Europe</strong></td>
<td>1,133</td>
<td></td>
<td></td>
</tr>
<tr>
<td>France</td>
<td>200</td>
<td>Internet</td>
<td>National, spread across five regions</td>
</tr>
<tr>
<td>Germany</td>
<td>200</td>
<td>Internet</td>
<td>National spread of physician offices</td>
</tr>
<tr>
<td>Italy</td>
<td>224</td>
<td>Face-to-Face</td>
<td>Major Cities: Moscow, St. Petersburg, Nizhny Novgorod, Krasnoyarsk, Omsk, Voronezh and Kaliningrad</td>
</tr>
<tr>
<td>Russia</td>
<td>102</td>
<td>Face-to-Face</td>
<td></td>
</tr>
<tr>
<td>Spain</td>
<td>207</td>
<td>Telephone</td>
<td>National</td>
</tr>
<tr>
<td>U.K.</td>
<td>200</td>
<td>Telephone</td>
<td>National, spread across 10 health authority regions</td>
</tr>
<tr>
<td><strong>Asia/Pacific</strong></td>
<td>200</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>100</td>
<td>Internet</td>
<td>National</td>
</tr>
<tr>
<td>South Korea</td>
<td>100</td>
<td>Face-to-Face</td>
<td>Seoul and surrounding vicinity</td>
</tr>
<tr>
<td><strong>Latin America</strong></td>
<td>201</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brazil</td>
<td>201</td>
<td>Face-to-Face</td>
<td>Major Regions: Sao Paulo, Rio de Janeiro, Salvador, Belo Horizonte, Curitiba</td>
</tr>
<tr>
<td><strong>Africa</strong></td>
<td>300</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Côte d’Ivoire</td>
<td>100</td>
<td>Face-to-Face</td>
<td>Major Cities: Abidjan, Bouake, Yamoussoukro and Dalia</td>
</tr>
<tr>
<td>South Africa</td>
<td>200</td>
<td>Face-to-Face</td>
<td>Major Cities: Johannesburg, Tshwane, Durban, Cape Town, East London and Port Elizabeth</td>
</tr>
</tbody>
</table>
Stigma, Isolation and Discrimination – A Global Challenge
Stigma, Isolation and Discrimination

• First among unique obstacles facing PLWHA\textsuperscript{2A}
  – Globally affects HIV prevention, testing, care and treatment\textsuperscript{2B}
• An environment of tolerance in which an individual can take an HIV test and live with an HIV diagnosis is of paramount importance to effective HIV prevention and treatment programs at local and national levels\textsuperscript{2B}
  – HCPs bear the responsibility of ensuring compassionate and non-judgmental care of patients\textsuperscript{2C}
• Society (or all of us) have a responsibility to break down the barriers of stigma, isolation, and discrimination that persist almost 30 years into the global HIV pandemic
According to ATLIS 2010, the emotional toll of HIV/AIDS is still considerable. More than one-third of respondents (37%) report strong feelings of isolation (highest in North America and Asia-Pacific), and depression is prevalent.

<table>
<thead>
<tr>
<th></th>
<th>Global Total</th>
<th>North America</th>
<th>Europe</th>
<th>Asia-Pacific</th>
<th>Latin America</th>
<th>Africa</th>
</tr>
</thead>
<tbody>
<tr>
<td>I often feel alone and isolated because I have HIV or AIDS</td>
<td>37%</td>
<td>42%</td>
<td>35%</td>
<td>52%</td>
<td>41%</td>
<td>24%</td>
</tr>
<tr>
<td>My friends and family don’t really understand HIV or AIDS</td>
<td>31%</td>
<td>29%</td>
<td>30%</td>
<td>40%</td>
<td>38%</td>
<td>23%</td>
</tr>
<tr>
<td>I feel like a burden to my family and friends</td>
<td>30%</td>
<td>22%</td>
<td>31%</td>
<td>43%</td>
<td>22%</td>
<td>31%</td>
</tr>
<tr>
<td>There is no one I can count on to help take care of me when I need help</td>
<td>19%</td>
<td>22%</td>
<td>19%</td>
<td>20%</td>
<td>12%</td>
<td>21%</td>
</tr>
</tbody>
</table>
Societal and cultural stigmas continue to impact PLWHA around the world

- 38% of respondents feel they are being judged by others
- Nearly half of respondents had encountered someone who was afraid to have casual contact with them because of their HIV/AIDS
  - 25% reported that someone would not share food or a drink because their HIV/AIDS
  - 24% reported that someone would not kiss them due to their HIV/AIDS

16% of North American and 10% European respondents cited discrimination due to their sexual orientation
Stigmas that respondents reported affected them the most varied across regions

- The person with HIV/AIDS has or does engage in risky behavior (sexual promiscuity, drug use, prostitution)
- People with HIV/AIDS do not live a long time
- People with HIV/AIDS should be avoided
- HIV/AIDS is easily transmitted through normal everyday activities (i.e. holding hands, sharing food or a drink)
- People with HIV/AIDS look different
- None of the above

% of Total Respondents

- Global Total
- North America
- Europe
- Asia-Pacific
- Latin America
- Africa
42% of respondents cited “strong concerns” about others learning their serostatus

Drivers of Concerns About Disclosing Serostatus

- Social Discrimination (79%)
- Impact on Establishing Future Relationships (46%)
- Impact on Current Relationship (42%)
- Reputation (42%)
- Risk of Losing Work/Job (36%)
- Risk of Losing Family/Friends (35%)
96% of respondents reported having disclosed their serostatus to at least one person

- Overall, 17% of respondents in a long-term relationship had not disclosed their HIV/AIDS status to their spouse/partner
- Globally, respondents reported that disclosing their status to family members was most difficult (65%), this was notably high in Europe (68%)
- Disclosure concerns were highest among those respondents who were recently diagnosed: <1 year, 56%; 1-5 years, 47%

16% of respondents in Asia-Pacific and 8% in Latin America had never told anyone about their HIV/AIDS status
Many respondents believe there is a need for more public education around stigmas.
Conclusion

• Despite great strides, 29 years into the HIV pandemic, HIV-associated stigma, isolation, and discrimination persist

• Addressing these challenges can benefit individual, community, and public health
ATLIS 2010 was funded by Merck & Co., Inc., Whitehouse Station, NJ USA, which operates in many countries as Merck Sharp & Dohme
Thank You

South Africa
• Beatit
• Moretele Sunrise Hospice
• Bopheleng MES Impilo Hospice
• Sicelinceba Health Organisation
• Tswaragang
• Hermanus Rainbow Trust
• SAMAREC

Australia
• NAPWA - National Association of People Living with HIV/AIDS
• PLWHA (Vic) Inc- People Living With HIV/AIDS - (In Victoria)
• Queensland Positive People
• Western Australian AIDS Council
• PLWHA (SA) - People Living With HIV/AIDS - (In South Australia)
• Positive Life (NSW) Inc
• Positive Women’s Network

Korea
• KANOS - Korea HIV / AIDS Network of Solidarity
• Love4one

Russia
• Human Action (‘Gumanitarnoye Deystviye’)
• Regional Center for Prophylaxis and Treatment of AIDS and Infectious Diseases
• Social and Psychological Center "Doveriye"
• Center for Prophylaxis and Treatment of HIV of Sverdlovsk Region
• Jasen

U.K.
• Positively Women (local branches)
• Positive Action local branches
• Terence Higgins Trust (local branches)
• AB Plus (local Branches)
• Body Positive (local branches)

Côte d'Ivoire
• Lumiere Action
• Club Des Amis (Association Des Personnes Vivant Avec Le Vih)
• Aibef (Association Pour Le Bien Etre Familial)
• Le Missi
• Cip Cames
• Fsu Com
• Chu De Yopougon
• Hôpital General Yopougon Attie (Port Bouet)
• Fsu Com Abobo Avocatier
• Hôpital Fsu Abobo Baoule
• General D’Anyama
• Centre plus de yopougon
Q&A Session