

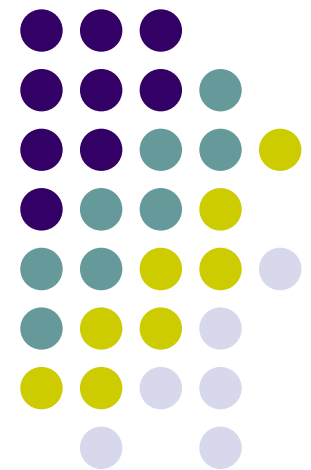
Issues surrounding disclosure for HIV-infected women

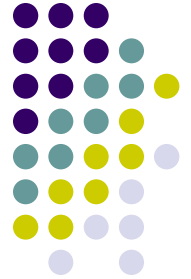
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2008 Women & HIV International Clinical Conference





The work featured here was supported by:

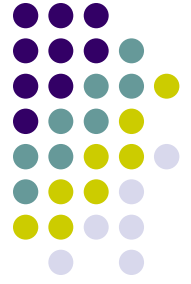
(a) a grant from the University of North Carolina at Chapel Hill School of Nursing, Center for Research on Chronic Illness in Vulnerable Populations (P30 NR03962), National Institute of Nursing Research, National Institutes of Health, awarded to Elizabeth Woodard (Principal Investigator) and Margarete Sandelowski & Julie Barroso (Co-Investigators)

(b) a grant from the National Institute of Nursing Research, National Institutes of Health (R01 NR04907), awarded to Margarete Sandelowski (Principal Investigator) & Julie Barroso (Co-Principal Investigator)

(c) funds from the Cary C. Boshamer Professorship at the University of North Carolina at Chapel Hill, awarded to Margarete Sandelowski.

We thank the New Hanover Regional Medical Center HIV Care Team for their consultation in this project.

Stigma

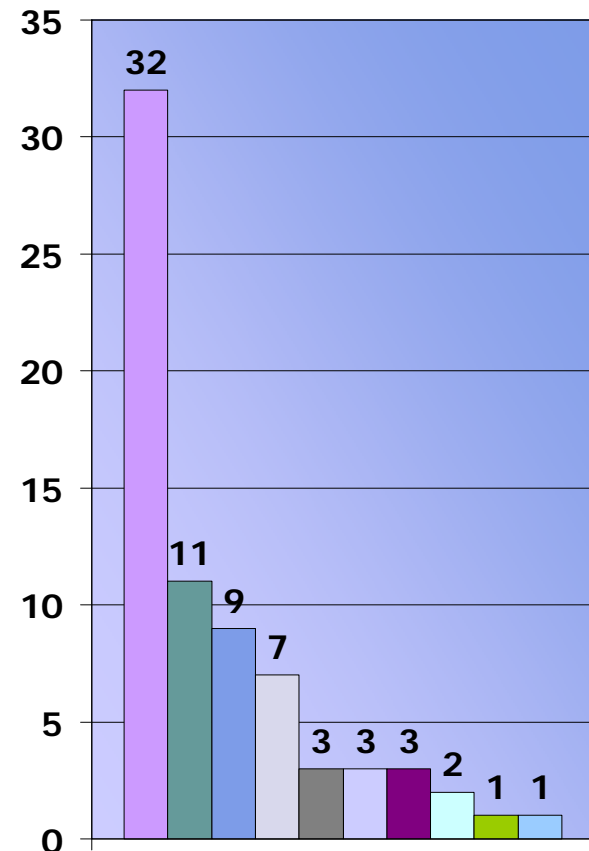


- Goffman's *Stigma* (1963) a major influence in studies of chronic illness
- Stigma is an integral part of the individual experience and social treatment of HIV/AIDS
- Women, historically all-purpose deviants, have been presumed to have a distinctive experience of the stigma of HIV



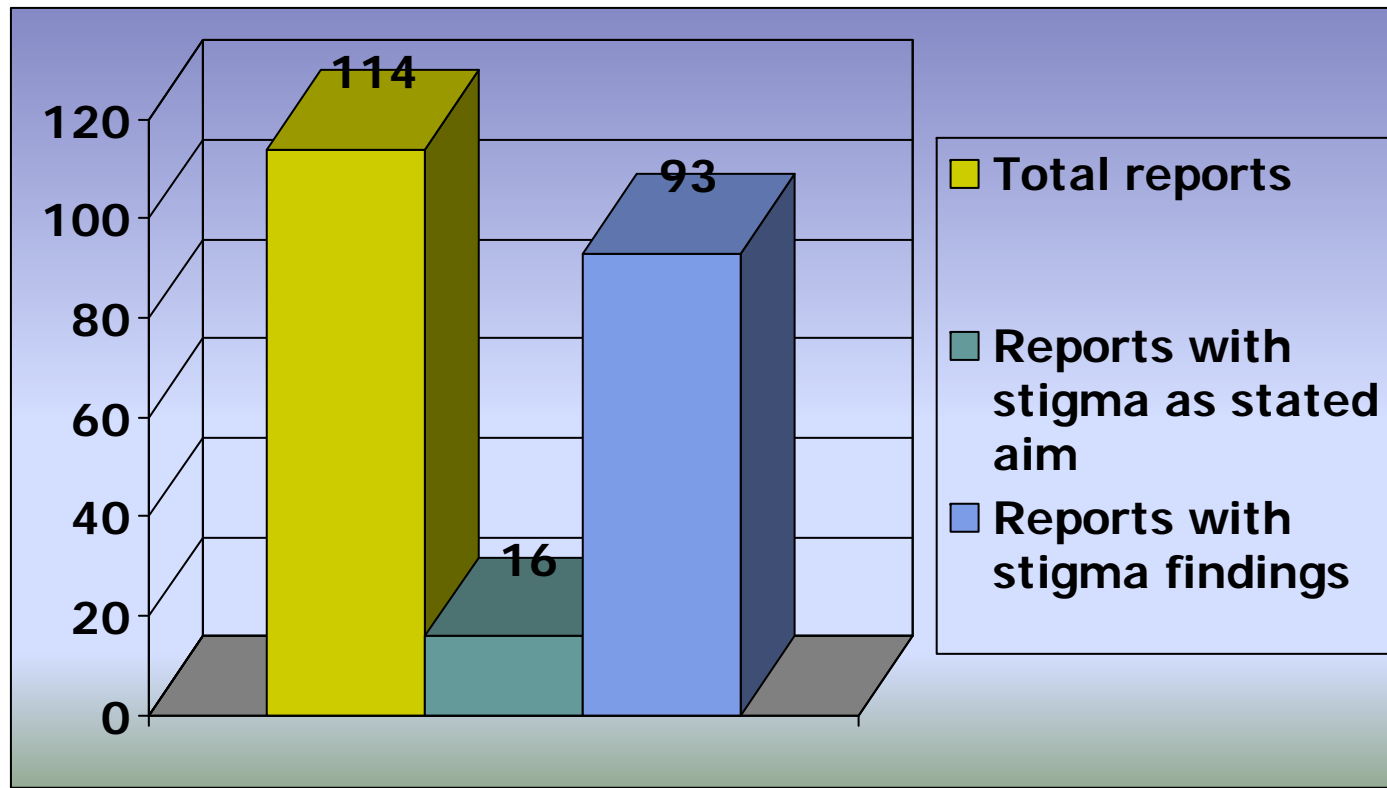
Disciplinary Affiliations of the 93 Reports

- Nursing – 32 reports
- Psychology & Counseling – 11
- Social work and Social Service Administration – 9
- Public Health – 7
- Anthropology – 3
- Sociology – 3
- Behavioral Medicine – 3
- Marriage and Family – 2
- Education – 1
- Political Science – 1

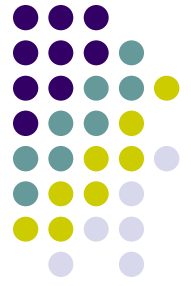




Magnitude of Stigma in HIV Sample



Working Definition of Stigma Finding



- Any conclusion concerning the prejudice, discounting, discrediting and discrimination HIV-positive women perceived to be directed toward themselves or others by virtue of their being HIV-positive, and to how HIV-positive women experienced and managed HIV-related stigma

Qualitative metasummary of findings



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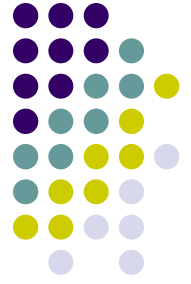
Statements

Abstracted findings

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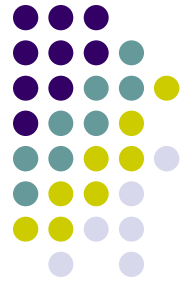
Statements



Sample profile

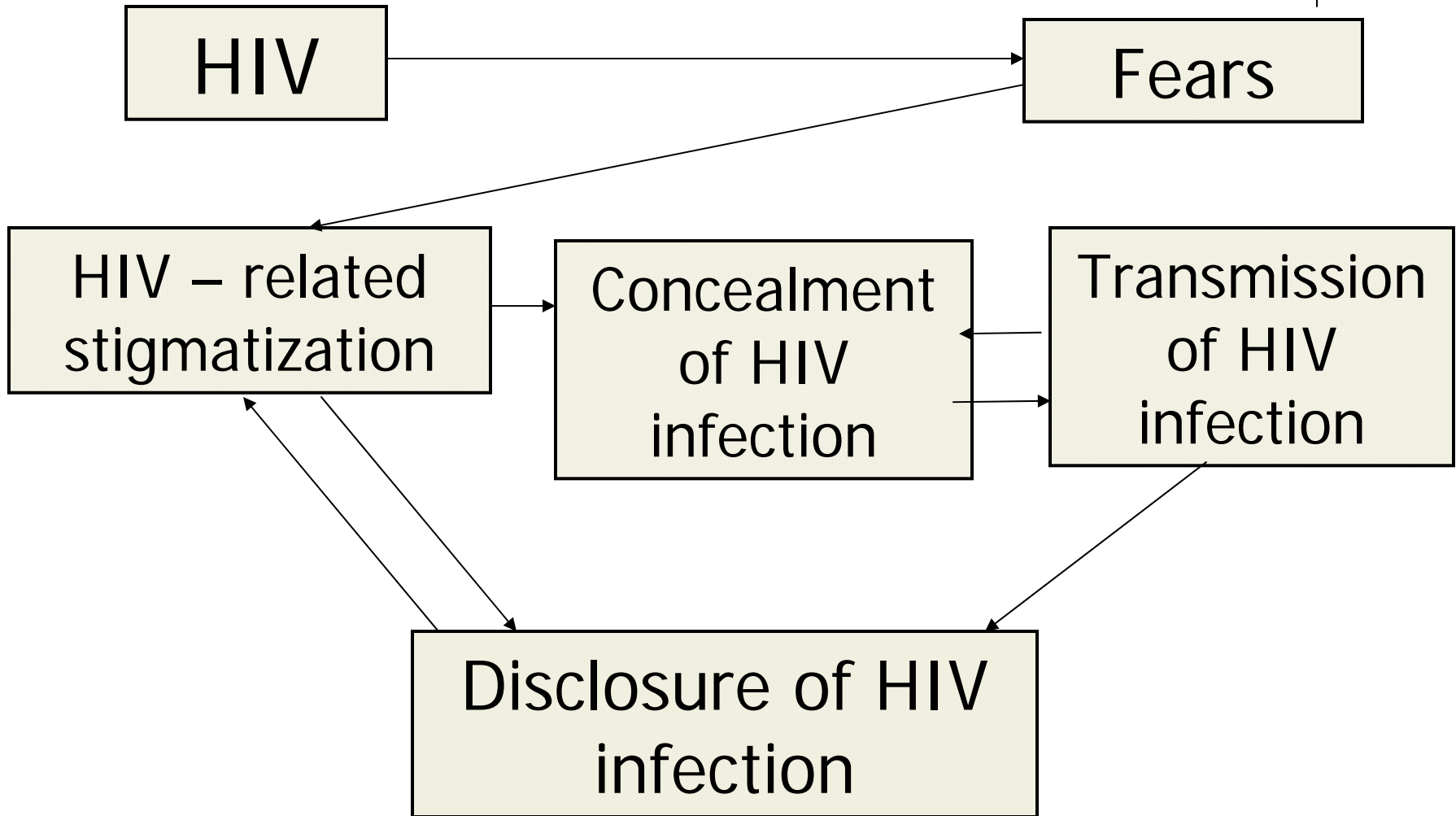
- Of the 93 reports:
 - Sample sizes ranged from 1-264 women
 - Total women across the 93 reports -1,780
 - Mean sample size - 25
 - Median sample size - 15
 - Modal sample size - 12 (counting reports with identical samples only once and counting only the largest n in reports with overlapping samples)
 - Most of the women (71%) were minorities (56% African American)

Key Findings

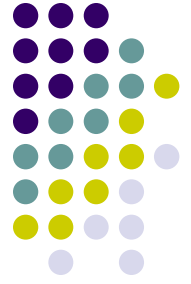


- Pervasiveness of both felt and enacted stigma
- Gender-linked intensification of HIV-related stigma
- Unending work and care of stigma management

Cycle of HIV infection, stigmatization, disclosure & concealment

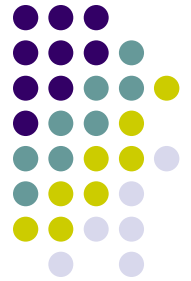


Factors Contributing to Stigmatization of Women



- Association of HIV with promiscuity & substance abuse
- View of women as carriers of infection
- Minority status
- Motherhood

Responses to knowledge of HIV status



| | Responses | |
|--------|---|---|
| Agent | Positive | Negative |
| Self | Self-verifying: Renewed interest in life Positive reframing of self | Self-denigrating: Shame & guilt Self-imposed social isolation & withdrawal Depression |
| Others | Supportive: Urge to protect Caring & concern | Non-supportive: Shame, embarrassment Social rejection & withdrawal Sadness Violence |

Stigma management



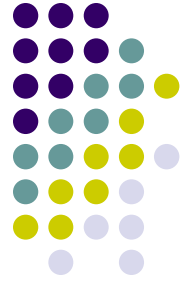
- Activities

- Information control
- Normalization
- Education & advocacy
- Creation of / participation in supportive communities

- Objectives

- Preservation of relationships
- Preservation of social support
- Maintenance of moral identity
- Maintenance of normal life
- Avoidance of rejection & pain
- Protection of self & others from harm

Managed & Mismanaged Disclosure



- Managed disclosure (in control)
 - Full disclosure
 - Partial or selective disclosure or concealment
 - Full concealment
- Mismanaged disclosure (lost control)
 - Disclosure by undesignated agent
 - Discrediting clues & cues
 - Serial disclosures

Framework for decision-making to control information



Who will tell?

Self
designated other

Whom to tell?

Children, family,
partner, providers,
employer & co-
workers, friends &
acquaintances

When to tell?

A good time

Immediately after
diagnosis

When to tell?
Delayed until
adjusted to
diagnosis

Before imminent
disclosure by
others

Any opportune
moment

Necessary
circumstances

Why tell?

What to tell?

Full disclosure
Selective disclosure
Transmission is likely
Concealment

To obtain health & social
services
To secure social support

To prevent transmission of infection

To prevent mismanaged disclosure

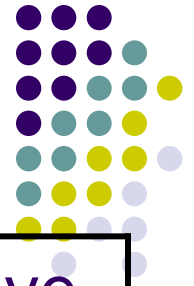
To maintain in-group alignments

To disavow out-group alignments

A need to know exists
The right to know exists
Full disclosure tells
Target is trustworthy
Target can keep a secret
Low risk of rejection or
harm (self and loved ones)
Wishes of family
To preserve social support
To prevent discrimination
To prevent suffering of loved ones
To fulfill wishes of family
To maintain in-group alignments
To disavow out-group alignments

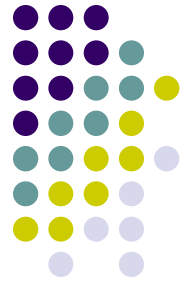
Why not tell?

Benefits, risks, & outcomes of information control



| Information control | Benefits & positive outcomes | Risks & negative outcomes |
|-------------------------------------|---|--|
| Disclosure | <ul style="list-style-type: none"> • Improved self-image & self-healing • Sense of pride & accomplishment • Relationship authenticity • Relief from secrecy & rumor | <ul style="list-style-type: none"> • Discrimination in employment & housing • Violence |
| Concealment | <ul style="list-style-type: none"> • Maintenance of moral identity • Privacy | <ul style="list-style-type: none"> • Burden of secrecy and rumor • Relationship inauthenticity • Transmission of HIV infection |
| Both Disclosure/ Concealment | <ul style="list-style-type: none"> • Social support • Access to health & social services • Sense of control & empowerment | <ul style="list-style-type: none"> • Social isolation • Diminished access to health & social services • Loss of control • Damaged self-image |

How to convey this information to the women who need it?

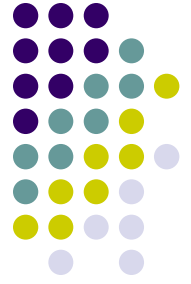


- Developed a DVD which can be watched on a regular TV or a computer
- Performers would portray five composite fictional representations of the research participants, with each character relaying a narrative based on one or two of the most significant research themes as determined by the research synthesis
- Although essential that the viewer be intrigued by the composite characters, empathize with their situations, and connect with the narrator, equally as important was the need to communicate the research themes



Intertext

- HIV-positive women experience and fear the negative social effects of disclosure that come with telling other people about their HIV status. These experiences and fears include rejection, discrimination, and violence. These women often adjust their daily lives to this stigmatization, in both close and distant relationships.



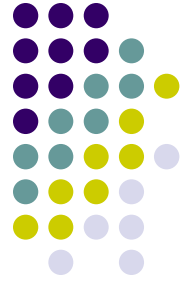
- Like most of the 1,700 women interviewed, it's likely you also struggle with issues of disclosure, and there are many circumstances to consider. Whatever your decisions, talk to your nurse, health care provider, social worker, or case worker, along the way. They can help as you sort through options, make choices, and decide if, when, how, and whom to tell.



- When it comes to disclosure, HIV+ women struggle most with whether or not to tell their children. Will the children understand? Will they be able to handle it? Will their friends find out and be afraid of them? Will their friends' parents find out and forbid their children to play with those of an HIV+ woman? HIV+ women worry that telling their children might endanger them or hurt their relationship with them.



- Keeping HIV a secret can be a burden and may result in a woman leading a double life, having only limited relations, or even lying. Again, no one else's situation is exactly like yours, and your circumstances may change over time. It's important to communicate with your nurses, doctors, and those family members and friends you trust deeply. Discussing your HIV status may be an important part of your care and health.



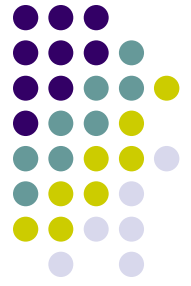
- Disclosure can have positive effects. It can make further disclosure easier, can help “heal” HIV positive women who disclose, can help them once again understand who and what they are, can bring relief, can make them feel important, maybe for the first time. Disclosure can lead to pride, can bring self-respect, and sometimes helps HIV positive women feel they’ve accomplished something important.



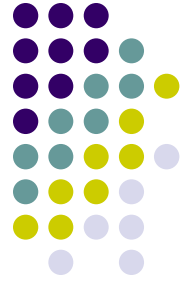
- According to the women in the studies there are some benefits and positive outcomes to disclosing your HIV status. You can gain the support of your friends and family and get needed health and social services. You may also feel a greater sense of control and empowerment, and feel better about yourself. It may also help you feel more true to yourself in your relationships, now that this secret is out. Finally, there is the sense of relief you may feel from the burden of keeping the secret.



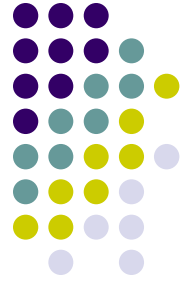
- Some women struggle with issues beyond their HIV status. These include the extra stigma and discrimination connected with being a woman, being a minority woman, and being a mother. Sometimes women are looked down upon because people make assumptions that their illness is related to drug use, prostitution, promiscuity, poverty, or homelessness.



- Women in the studies revealed that being a mother, being a woman of color, being a drug user, a prostitute, being homeless, or even if people just *assume* you fall into any of those categories, can add to the difficult stigma of HIV. If one or more of these circumstances apply to you, then you may, quite naturally, be feeling extra pressure.



- HIV-positive women are ambivalent about disclosing their HIV to potential and actual sex partners, because partners' failure to disclose their own HIV was the reason for their infection and a cause of mistrust. It might also cause partners to reject them.



- As an HIV-positive woman, you can't totally eliminate the stigma that is associated with HIV infection, because stigma is enacted by people without HIV. Unfortunately, there's not much we can do to control that. But there are things that you *can* control about how you respond to stigma and to what extent stigma will or will not affect your health and your life.

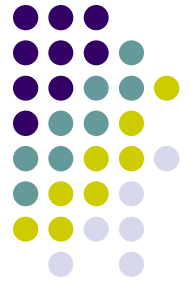


- As you've learned throughout this program, one of the most critical decisions to make because of stigma is deciding whether or not to disclose your status. If you decide to do so, then other decisions follow. From the 1,700 women interviewed in 93 different studies, some common advice is clear:



The calculus of disclosure

- Decide **who** will do the telling: yourself, or someone else that you choose.
- Decide **whom** to tell: children, family, partner, providers, employers and coworkers, friends.
- Decide **when** to tell: immediately after you are diagnosed, after you've had time to adjust, before the person may find out from others, or any time that seems right.
- Decide **under what circumstances** to tell: What are the necessary conditions that would make you feel like you need to tell someone you are HIV-positive?



- Decide **what** to tell: Will you reveal everything about your diagnosis, or just some of it?
- Decide **why** you should tell: To obtain needed services? To have the support of friends? To prevent transmission of infection? To prevent someone else from telling?
- And finally, think about reasons NOT to tell. As you have heard in this program, there are times and circumstances when it is better not to disclose.

Thank you!

