

# **WOMEN, HIV and STIGMA**

## **Challenge or Opportunity?**



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## Presentation Goals

- To define stigma and its protean manifestations.
- To identify types and sources of stigma.
- To demonstrate strategies to decreasing stigma impact.
- To increase awareness of the pervasive impact of stigma.



## DEFINING STIGMA

**Webster: A mark of shame or discredit: an identifying mark or characteristic.**

**In the case of HIV, stigma is:**

**An undesirable attribute; extremely discrediting; reducing the person from whole to a 'tainted, discounted one'.**

**(Goffman, 1963)**

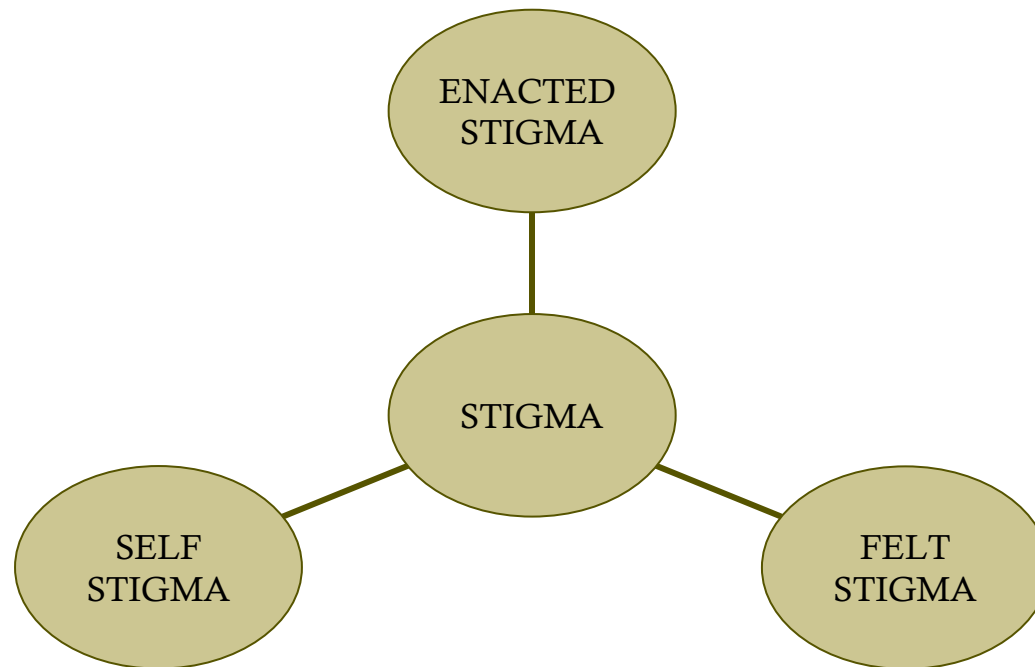


## HIV Related Stigma

- Is a social phenomenon
- Is a powerful and discrediting label
- Negatively changes how individuals are viewed
- Elicits fears that can translate into counterproductive and UNSAFE behaviors
- Can fuel powerful reactions, even violence



# STIGMA Interactions





## NOT ALL STIGMA IS THE SAME...

- Enacted Stigma – changes how people are viewed and treated by others
- Self Stigma – changes how people view themselves
- Felt Stigma – drives fears of reaction – abandonment, isolation, ostracism, IPV



## Case 1. TJ – My Mother's Hope

- 36 yo AA female financial planner
- Presented to Ob-Gyn with recurrent vaginal yeast
- HIV testing is offered and the result is +
- TJ refuses to confront fiancé
- TJ will not disclose to her mother
- She loses interest in work
- Ultimately is fired



## Case 1. TJ – My Mother’s Hope - 2

- **FOUR YEARS LATER**
    - **TJ has moved to DC**
    - **She has been unable to keep a job**
    - **Has not had another relationship**
    - **Lives on welfare and in the projects**
    - **Refuses to take HIV medications**
- “I was my mother’s hope and I blew it all away.”**



What type of stigma does TJ *express*?

- A) Enacted Stigma
- B) Felt Stigma
- C) Self Stigma
- D) None this is all simply depression



## What type of stigma does TJ *express*?

- A) Enacted Stigma
- B) Felt Stigma
- **C) Self Stigma**
  - **She perceives herself as having blown her opportunities, she is ‘unworthy’**
- D) None this is all simply depression



**What type of stigma prevents TJ from disclosing to her mother?**

- A) Enacted Stigma
- B) Self Stigma
- C) Felt Stigma
- D) Other – she is too depressed to tell her mother



What type of stigma prevents TJ from disclosing to her mother?

- A) Enacted Stigma
- B) Self Stigma
- **C) Felt Stigma- she feared her mother's reaction**
- D) Other – she is too depressed to tell her mother

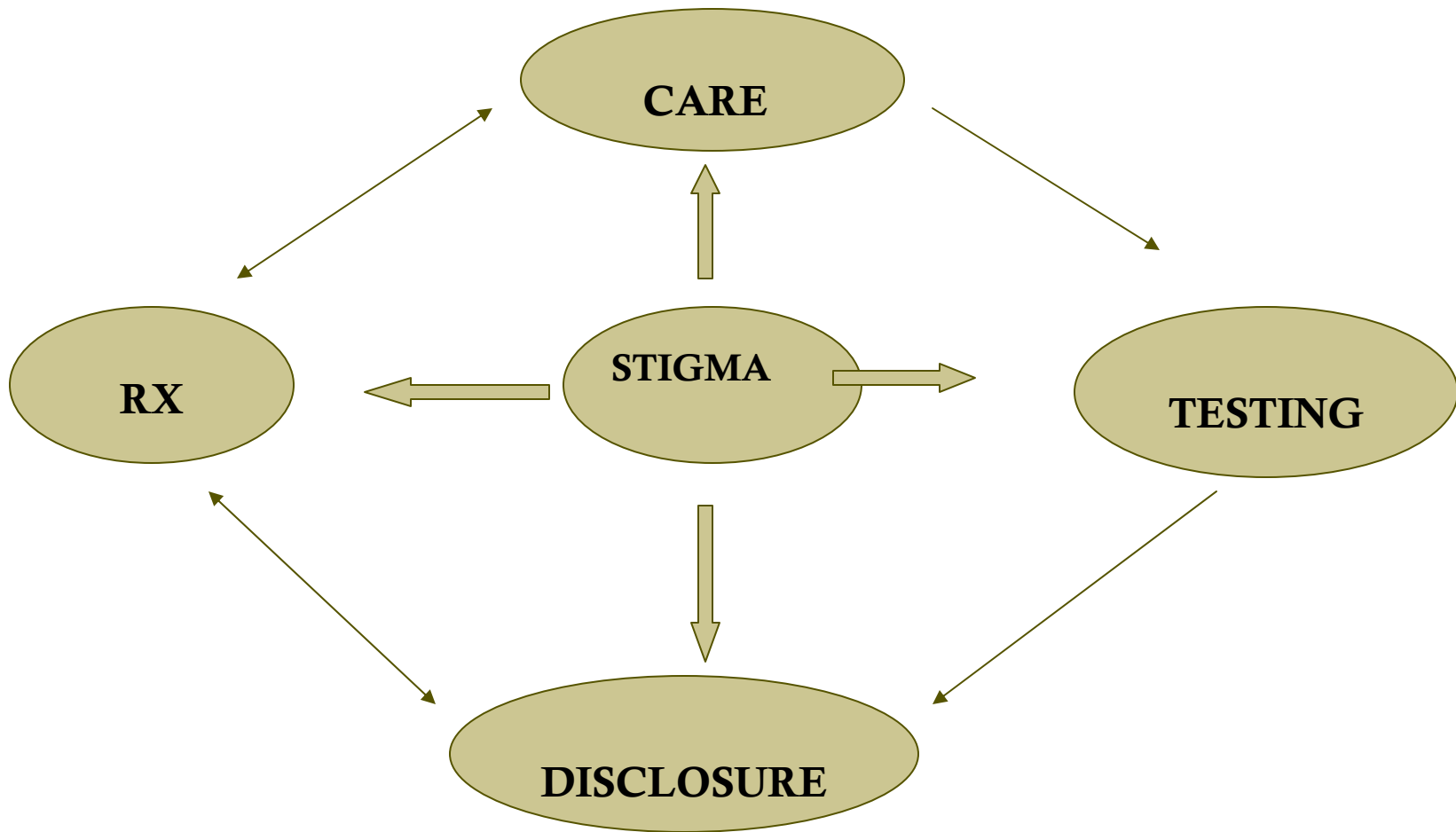


## TJ's Epilogue

- Developed thrush and accepted treatment.
- Refused ART.
- Refused a psychiatric consultation.
- Refused to disclose to her mother
- Developed wasting
- Stated this was her “punishment”
- Finally agreed to contact with a former co-worker
- Co-worker took her back to Virginia where she died.



## STIGMA IMPACTS...





## STIGMA – The Gift that Keeps on Giving

- **Major obstacle to HIV prevention**
- **Barrier to HIV testing**
- **Interferes with care seeking**
- **Factors in Medication Adherence**
- **Discourages HIV disclosure**
- **Complicit with unsafe behavior**
- **Linked to depression**
- **Factor in IPV**
- **Decreased psychological function**



## STIGMA and HIV Prevention

- HIV stigma closely linked with resistance to HIV testing (self stigma)
- HIV stigma relates to failure to disclose (felt stigma, enacted stigma)
- HIV stigma negatively impacts safe behavior (enacted stigma, felt stigma)



## Case 2. I didn't mean to make her sick

- LA 39 yo AA male with Factor VIIa def, hx of crack and heroin use
- Tested HIV+ in 1995
- **Been sober for 5 years**
- Meets FR an outgoing 36 yo AA female
- A year later she accompanies him to clinic
- He disclosed his status to her 6 months into the relationship
- **Safer sex practices only began then**



## Case 2. What went wrong?

- **LA 39 yo feared telling FR**
- **Planned to only use condoms and ‘stall’ for time**
- **But had multiple episodes of “spontaneous sex” FR initiated**
- **She felt betrayed but chose to stay**
- **She didn’t want him to feel she shunned him due to HIV**
- **She also suspected she was HIV+ and now had no other options....**



## Case 3. I changed because I wouldn't tell

- **CW a 65 yo AA female**
- **Widowed for 7 years, met up with old high school friend**
- **They dated for 3 years then he disappeared**
- **She learned he died of "AIDS pneumonia"**
- **Refused testing for a year**
- **Finally tested and was HIV+**
- **Well controlled on a med regimen her nails darkened**
- **Her hair changed texture**

When she asked me what chemicals I was taking....



**I left the shop – I knew I could never tell her.**



## STIGMA is the invisible opponent

- Interferes with psychological functioning
- Is a source of depression, which is linked to poor Rx adherence
- Has been used to justify behavior like IPV
- Linked to self medication
- Further drives women away from care
- Impacts the entire social and family unit
- **CAN BE AMELIORATED**



## HEART treats STIGMA

- Highly
- Empathic
- AND
- Responsive
- Treatment



## WHAT YOU CAN DO....

- **ASK!!! HIV+ women report feeling more stigma and that did not diminish over time. (Clark, 2003)**
- **LISTEN** to the concerns she shares – ‘lack of support’ may be from self stigma
- **CHECK** on safety. IPV can be fueled by stigma and may not be disclosed.
- **Review** sexual history and practice.  
**EXPLORE** any report of lapses in safety (? Felt stigma, ?enacted stigma)



## SUPPORT BEATS BACK STIGMA

- **Bowleg (NHPC, 2007) reported on a AA women's support group::**
  - Returned to support group weekly
  - Shared concerns and experiences
- **Finding: Women reported the group:**
  - Helped them face HIV
  - Encouraged them to reach out to others
  - Was a weekly source for 'shelter' – they laughed and cried together
  - Would be 'lost' without it



## Support is KEY

- **Run completely by the women and their facilitators**
- **Women shared their stories**
- **Identified barriers and impact of stigma**
- **Developed a shared project – a luncheon**
- **They provided HIV information**
- **AND THEN THEY SHARED THEIR STORIES OPENLY**



## SUMMARY TAKE HOME POINTS

- **Stigma takes many forms**
- **It is a negative (and often unseen) force**
- **Impacts the individual in every domain**
- **Can lead to violence**
- **Support can offset stigma**
- **Providers must PROBE for stigma – you don't ask, you won't find it**
- **Open acceptance is the antidote for stigma**
- **Support is the lifeline**



## ALL I EVER DID...

- “....tell them Dr. Cargill, all I ever did was love a man. Did that make me bad? Does that make me lower than you? Have you ever loved someone and found out they was [sic] bad for them? I hate this disease, sometimes I hate to see **you**. It all comes back every time. All I ever did was love a man....”

*FR at the end of a visit*

I have learned that the medicines treat  
my virus...



**But it's the support group that heals my heart.**



# QUESTIONS?

