Impact of Stigma in the Health Care System

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Disclaimer

- All views expressed in this presentation are mine and do not represent the views of any affiliated organizations

Impact of stigma/discrimination by HCWs

Case example 1: Mary

- 35 yo First Nations woman, HIV and HCV positive (not on treatment, high viral load, CD4 150(14%), IDU
- Admitted to our inner city hospital with fever, headache
- Severe headache after lumbar puncture
- Can be relieved in minutes with a "blood patch"
- Specialized procedure, done by anesthesiologists

Case example 1: Mary, cont'

- I consult the Anesthesiologist on call and they come and the resident comes to review her and decline to do LP: "not indicated"

- Phone call to resident and staff to discuss – state that reason is that she is at greater risk of infection from procedure

Case example 1: Mary, cont'

- I do a literature search, pull the relevant medical articles and send to the resident that night. The following day (Friday), both resident and staff have changed over
- I send them the literature showing no greater risk of infection and they indicate that they will review that evening
- Come back on Monday- no procedure done, by now headache improved

Case example 1: Mary, cont'

- Reason for decline?

- Although not explicitly stated, I believe that reason is her HIV status and possible risk of blood and body fluid exposure

- Impact of stigma/discrimination within patient communities on the provision of health services

Case example 2: Jane

- 35 year old black female, born in Sudan, in Canada x 7 years
- Pregnant - ~20 weeks and first prenatal visit – found to be HIV positive
- 3 children- ages 3-5, delivered in Edmonton, HIV negative during pregnancy with 3rd child

Case example 2: Jane cont'

- One of our partner notification nurses (PNN) finds out that she has a new sexual partner (Sean) of several months
- Also determines that he was named as part of an investigation into a 17 year old female newly diagnosed HIV positive a few years ago and is known HIV positive
- Jane declines to come to the clinic for a visit so language line interpreter booked and phone call to Jane – ?informed of HIV status by RN

Case example 3: Jane cont'

- 1st Clinic visit – Jane attends with partner (Sean) and an interpreter
  - She speaks little/no English
  - Interpreter is a patient of mine (also HIV positive, very stable on treatment) and I ask him to excuse himself as I am concerned about potential for confidentiality
  - Sean remains and we mostly discuss the pregnancy (she is not around 20 weeks) and need for urgent OBGYN assessment
    - Ultrasound did not visualize fetal heart well and suggested more detailed follow up

Case example 2: Jane cont'

Patient visit #2

- Jane has had ultrasound which shows severe cardiac and neural tube defects
- Interpreter now present with Jane and Sean
- She asks why she is there in this clinic and I tell her it is for follow up of HIV – she is shocked and states not aware of her status
- Offer referral to support services – all declined

"Well I might as well as go home and kill myself"

"Why?"

"Because I am going to die anyway"

"What about your kids"

She shrugs

"How can I go out now- everyone will know I have HIV"

"How will they know you have HIV?"

We discuss that no one will know – we and interpreter bound by confidentiality

Case example 2: Jane cont'

- Admitted to hospital with vaginal bleeding, discussion about termination (declines), spontaneous labour with delivery of stillborn at 24 weeks

- 3rd Follow up visit with me, this time without Sean:
  - blames MD for CT scan which she insists caused the fetal abnormalities and premature labour
  - We discuss that most likely abnormalities due to seizure medications but it is clear she does not believe me
  - I discuss with her taking ESL classes

"I have been dependent on a man all the time and look where it has got me"

"Now I want to do something for myself – I want to learn English and go back to school"

Meanwhile with Sean

- I manage to speak with him and he initially declines previous knowledge of HIV status and then states that the clinic was supposed to call him for follow up and since they did not, he assumed everything was "OK"
- We learn that warrant out for his arrest from previous charges
- Child and Family Services ban him from going to her home

Many issues for discussion in this case: stigma/discrimination in Afro Caribbean Black communities

- Profound stigma and discrimination within some African communities resulting in silence, reluctance to test and difficulties with disclosure among PHAs[1]
- Stigmatizing attitudes towards PHAs based on assumptions about the infection, e.g. HIV/AIDS is a "Gay disease," promiscuity leads to infection[1]
- Reluctance to engage and remain in care
- Mistrust of the health system/health care providers

[1]Ontario HIV/AIDS Strategy for African, Caribbean and Black Communities, 2013-2018

Stigma/discrimination in ACB communities cont'

- Knowledge gaps around HIV[1], e.g. belief that HIV an "inevitable death sentence"

- Not breast feeding a "sign of HIV"
  - Case reported from Calgary a few years ago a lesson to us providing HIV care

"..just by speaking or working with someone who is a PHA, you are told that you could be infected with them."

Focus Group participant[1]

[1]Ontario HIV/AIDS Strategy for African, Caribbean and Black Communities, 2013-2018

Summary

- Stigma/discrimination can come from the health care side as well as from within patient communities
- Reducing the impact of stigma/discrimination requires varied approaches and is a slow, steady process
- We as HCWs can all do better by learning the necessary skills to reduce stigma/discrimination – hopefully the work the CPHA is doing will help with this

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