

Improving Medical Care and Medical Education: Suggestions from People Living with HIV/AIDS



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For the CHIME Study Group

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Outline



- Background
- Methods
- Results
- Future directions

The Issue



- Prejudice and stigma towards People Living with HIV/AIDS (PHAs) exists among healthcare practitioners¹
- A national survey in the UK confirmed more education on HIV/AIDS is needed in medical and dental schools
 - Focus on attitudes towards patients and ethical issues
- In Ontario, HIV-related stigma prevents HIV-positive individuals from receiving adequate preventative and prophylactic HIV care³

The Issue



- More effective medical education is required to reduce stigma
 - This should begin with PHA engagement:
 - ✦ What stigma is there?
 - ✦ What is lacking in the therapeutic relationship?
 - ✦ What would be important to include in medical education?

Description



- This study is in support of the Collaboration for HIV Medical Education (CHIME)
 - Involving PHAs as Patient Instructors in Simulated Medical Encounters
- Goals:
 - Identify PHA past and current experiences within the healthcare system
 - Identify ongoing gaps in HIV care
 - Identify strategies to improve HIV care
 - *all from a diverse PHA perspective

Methods

Recruitment



Focus
Groups

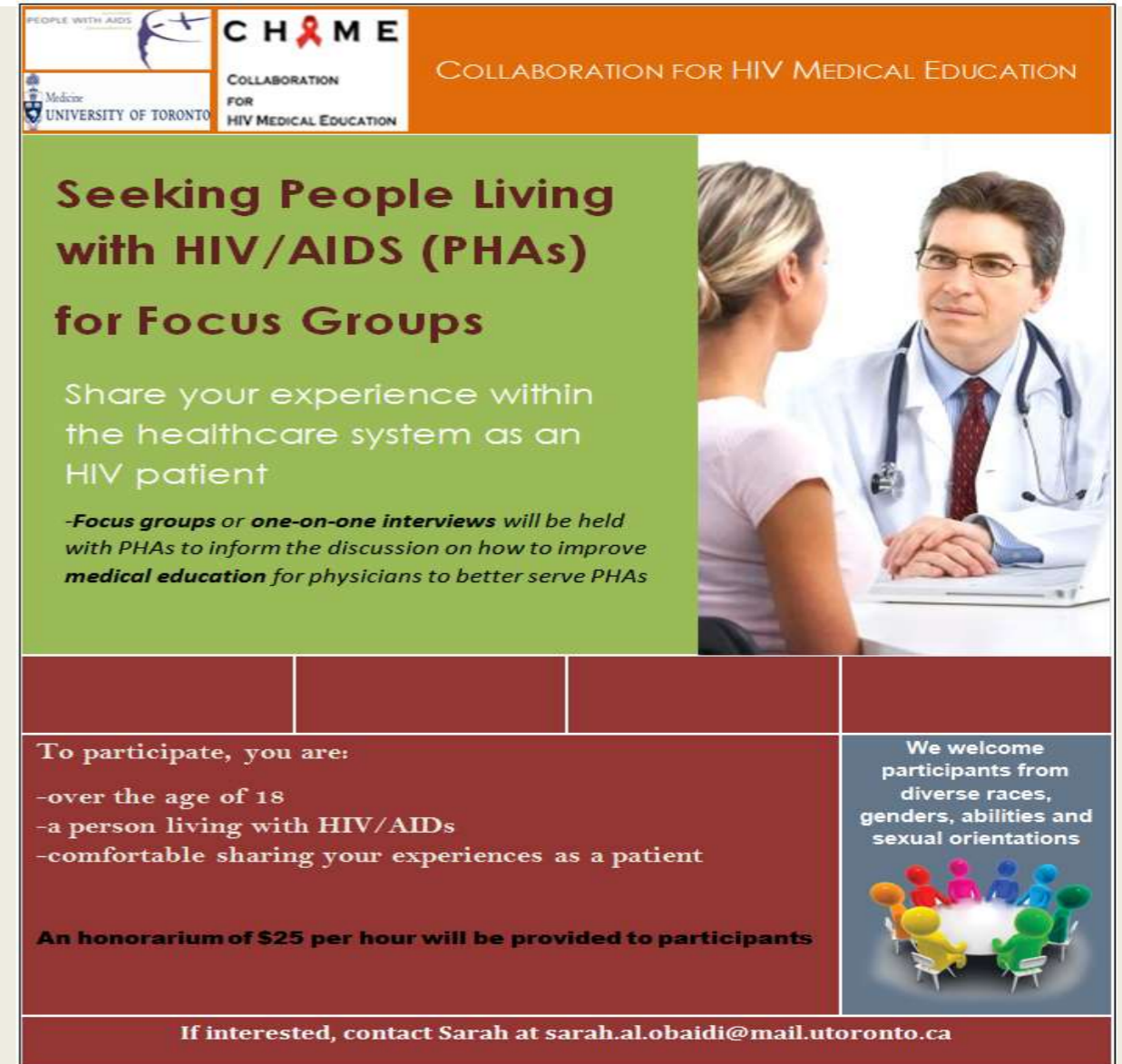


Qualitative
Analysis



Methods

- Inclusion criteria:
 - Living with HIV
 - Age ≥ 18
 - English-speaking
- Aimed for diversity in race, gender, sexual orientation
- Poster recruitment



The poster features logos for 'PEOPLE WITH AIDS', 'CHME' (Collaboration for HIV Medical Education), and 'UNIVERSITY OF TORONTO'. It includes a photograph of a doctor and a patient, and a group of diverse people sitting around a table. The text is organized into sections: a main title, a description of the role, a list of requirements, a statement of inclusivity, and contact information.

PEOPLE WITH AIDS
CHME
COLLABORATION FOR HIV MEDICAL EDUCATION
UNIVERSITY OF TORONTO

COLLABORATION FOR HIV MEDICAL EDUCATION

Seeking People Living with HIV/AIDS (PHAs) for Focus Groups

Share your experience within the healthcare system as an HIV patient

-Focus groups or one-on-one interviews will be held with PHAs to inform the discussion on how to improve medical education for physicians to better serve PHAs

To participate, you are:

- over the age of 18
- a person living with HIV/AIDS
- comfortable sharing your experiences as a patient

An honorarium of \$25 per hour will be provided to participants

We welcome participants from diverse races, genders, abilities and sexual orientations

If interested, contact Sarah at sarah.al.obaidi@mail.utoronto.ca

Methods

- Three focus groups of approximately two hours
 - 5-8 participants per group
 - total sample size: 20 PHAs
- Demographics:
 - Age: between 40 and 60 years
 - Sex: ~80% male, 20% female
 - Ethnicity: ~60% Caucasian, 25% African-American, 15% Hispanic, Asian or other



Results



- 5 major themes were identified:
 - Stigma and discrimination
 - Power imbalance inhibiting care
 - Communication
 - Holistic medicine
 - Empowerment through teaching

1) Stigma and Discrimination



- Societal attitudes
- Within healthcare:
 - ✦ “Even though they [dentists] were wearing their rubber gloves and their masks....the fear that they did not want me as a patient became very very obvious.”
 - ✦ True vs. perceived discrimination
 - A PHA felt they received better care once he was perceived as “high functioning”
 - Standardized precautions i.e. for pneumonia perceived as discriminatory
- Internalized-guilt or self-blame

2) Power imbalance



*“Something that needs to be addressed in the education of medical students is the **power dynamic** that goes on between the doctor and the patient. This is reinforced by the “God Complex” that many physicians seem to have. So being able to point out [to medical students] that power distribution so that they don’t have much of an authority in telling us what to do but more **listening to what we need** and decreasing the power imbalance would go a long way to making patients feel more comfortable.”*

2) Power Imbalance



Need to improve PHA engagement via:

- Self-advocacy (being proactive)
- Patient-centered care: physician engaging patients in their own care

“We need to become negotiators with our doctors and see them as equals that are providing us with a service.”

3) Communication



- Respect
- PHAs feel the need to be treated as people, not “animals”
- Dichotomy between scientific knowledge and ability to build a good patient-physician relationship
 - “One of the physicians here—his bedside manners are awful, but his knowledge is top class.”*
- Need to create a welcoming office environment

4) Holistic Medicine



- PHAs would appreciate to be viewed as a whole person

“I tell him about the nausea I’m experiencing very frequently and his response is my ‘CD4 is 1000’ as if that was the end-all and be all of treating somebody with HIV.”

“Something else that might be helpful for a doctor is...to acknowledge that HIV affects more than just our physical selves and enquire about how HIV is affecting you social self, your emotional self.”

- Holistic care received from generalists, specialists, allied healthcare professionals

5) Empowerment through Teaching



*“The books, the materials, do not tell as much as someone who has had the **lived experience**.”*

- PHAs in role-playing for students, evaluating students, teaching communication
- PHAs view themselves as teachers even when in clinic as patients
- PHAs feel valued as experts when teaching in medicine

*“It was **great** being able to share the story and illuminate them a little bit more.”*

Recommendations and Conclusions



- Despite movements towards patient-centred care, PHAs still feel **disempowered** and experience **discrimination** in our healthcare system
- Improving **communication skills** and HIV **knowledge** in healthcare providers is paramount
- Involving PHAs as **educators** may not only improve HIV care but enable **self-empowerment**

Recommendations and Conclusions



- One meaningful way to involve PHAs in healthcare improvement is by engaging them as teachers in undergraduate medical education.
- The CHIME Study
 - Data analysis is in process
- The University of Toronto is working to incorporate this model into their practical skills teaching
 - Stay tuned!

References



- ¹Pearce L. (2010). Prejudice in practice. *Nursing Standard*, 25(13), 18-9. Retrieved from <http://ovidsp.ovid.com.myaccess.library.utoronto.ca/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=21207818>.
- ²Carter YH, Greenfield SM, Kenkre JE. (1997). A national survey to medical and dental schools to assess the level of undergraduate teaching and research about HIV/AIDS in the UK. *Int J STD AIDS*. 8:88–94.
- ³Lawson E, Gardezi F, Calzavara L et al. (2006). HIV/AIDS stigma, denial, fear and discrimination, experiences and responses of people from African and Caribbean communities in Toronto. Toronto (ON): African and Caribbean Council on HIV/AIDS in Ontario and University of Toronto, HIV Social, Behavioural and Epidemiological Studies Unit.



CHIME study participants

CHIME Research Group

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Medicine
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