

Disclosure of HIV Status to Partners
Perinatal HIV Working Group
February 15, 2017
CROI 2017 Seattle, WA

Facilitators: Judy Levison MD, Baylor College of Medicine, Houston and Lealah Pollock MD, University of California, San Francisco

Guest: Neal Friedman JD, attorney and public defender, Everett, WA

The National Perinatal HIV Hotline, a program of the Clinician Consultation Center (www.nccc.ucsf.edu), hosts roundtable discussions annually at CROI to promote dialogue around challenging topics and build community among providers. The following is a summary of the 2017 discussion on *Disclosure of HIV Status to Partners*.

Introduction

Women living with HIV have sometimes kept their HIV diagnoses private from friends, family, and sexual partners. During pregnancy and childbirth, providers often experience internal and interpersonal conflicts around their ethical and legal obligations to the privacy of the patient with HIV, the health of the patient's partner, and the treatment needs of the infant. Providers exist within the structural framework of their medical institutions, the cultural framework of their communities, and their personal ethical and moral frameworks. This discussion focused on these conflicting obligations and differing perspectives on the family unit's care and needs.

Summary

In order to tease out a few of the many factors involved in HIV disclosure, we assembled a panel of two providers and a legal expert familiar with HIV disclosure cases. We framed the discussion around two real-life cases, which were presented to elicit discussion on a variety of topics. Questions posed and discussed included:

- What are our beliefs regarding a patient's responsibility to disclose to her partner?
- What is the health care team's responsibility to disclose to a partner?
- Do providers routinely assist patients with disclosure? If so, how? If not, why?
- What resources do providers use to assist with disclosure? Partner services? Protocols? Toolkits?
- What are the laws in your state?
- Do providers discuss HIV disclosure laws with patients?
- How do the laws impact our patients?

Clinician Responsibility

Panelists and participants discussed that a clinician's responsibility to disclose a patient's HIV status involves a complex and often-contradictory mix of legal, medical, and ethical decisions.

Legal obligation

A clinician's legal responsibility varies from state to state. Additionally, laws are sometimes written in such a way that it is not clear what actions are mandated. Some laws indicate that a clinician has a "duty to notify" vs. being "encouraged to notify". What is the difference for the treating clinician between these two mandates? The person(s) or entities who must be notified also differ from state to state. There is the added concern that mandated notification could be in violation of other laws such as HIPAA. In these instances, which law takes precedence?

Examples of persons and entities that must or may be required or encouraged to *provide* notification of a patient's HIV status include:

- Physicians, nurses, pharmacists, dentists, medical examiners, hospital administrators, and laboratory directors
- Clinical laboratories
- Individuals convicted of sexual offense
- Department of Corrections
- State Health Officers

- State and local health departments
- AIDS Drug Assistance Programs (ADAP)

Examples of persons and entities that must or may be required or encouraged to *receive* notification of a patient's HIV status include:

- Local, state, and/or federal health departments and agencies
- Spouses, Sex partner(s) and/or needle-sharing partner(s)
- Pre-hospital or emergency medical personnel, health care providers
- Victims of sexual offense
- Social services: ADAP, local public health agencies, care coordinators, patient navigators
- Health Plans

As an example of the challenges of simply understanding and interpreting the law as well as deciding how to apply it, participants discussed the laws in Texas and in California. [NB California HIV disclosure law was in the process of amendment at the time of this meeting.] Given the many challenges of navigating the legal responsibilities of HIV disclosure, clinicians are encouraged to familiarize themselves with the statutes of their institution, city or county, and state. The CDC maintains a list of HIV criminal laws here:

<https://www.cdc.gov/hiv/policies/law/states/exposure.html>

Professional obligation

One could argue that a clinician's first and primary responsibility is to their patient. This can include a series of needs beyond medical needs. Added to that are the goals of the care team. The obstetrics care team may make decisions that impact the pediatric care team's decisions and vice versa. It is one critical reason that National Perinatal HIV Hotline consultants counsel callers to coordinate closely with all care teams in order to ensure a **decision-making process that supports both patients – woman and infant**. Participants discussed techniques for assuring clear and effective interprofessional communication as well as some of the barriers in the context of HIV disclosure.

Barriers discussed include:

- personal safety outside of the medical setting (e.g., intimate partner violence)
- fear of community or family stigma
- impact on health benefits
- impact on housing
- infant safety and care
- patient fears and desires

Ethical obligation

Panelists and attendees discussed a clinician's ethical obligation, the Hippocratic Oath, and how ethical decisions and legal realities might be in tension with one another.

Tools and Solutions

During the last part of the roundtable, participants discussed how they manage disclosure in their practices and shared resources.

Shared themes:

- Disclosure is a process. Women may decide to disclose to some individuals and not others.

- Healthcare providers working with women living with HIV need to develop the skill of assisting their patients in disclosing and managing the process (ideally in collaboration with psychosocial care providers who possess this skill).
- Ask about a woman's circumstances.
- Encourage safe disclosure.
- Make no assumptions about relationships.
- Develop a contingency plan for unintentional disclosure.
- Potential for violence is critical to keep in mind.
- Father of the baby also has rights and can access the baby's medical information. Information about medications and treatments may reveal a mother's status. This situation needs to be anticipated and managed.
- Help women develop strategies for safe and comfortable disclosure. Plan timing of disclosure; develop reasons why patients can't breastfeed and need to use condoms that are unrelated to HIV status.

Some tools and management strategies:

- One participant provided a laminated card labeled "privacy" for patients to give their healthcare providers. Allowing a woman to display the card in her room can help avoid unintentional disclosure to family, friends, and partners by allowing the patient or provider to request that all visitors leave the room prior to any medical discussion. The card makes the request seem more "official" as though it is hospital policy.
- Several attendees requested disclosure toolkits, policies or procedures (see **Resources** below).
- Some clinical settings encourage couples testing. This allows partners to test together which can enable a woman to appear to learn her HIV status for the first time which may ease the disclosure process and lessen the possibility of negative reactions from her partner.
- Some clinicians advocated assisting a woman to disclose in the clinical setting, with or without a provider present, as desired by the patient. This strategy can lessen the possibility of negative reactions and also allow the partner, friend, or family member to ask questions and get tested immediately if desired.

Resources

HIV disclosure laws

The CDC maintains a list of HIV criminal laws here: <https://www.cdc.gov/hiv/policies/law/states/exposure.html>

The Center for HIV Law and Policy, <https://www.hivlawandpolicy.org/>

The Center for HIV Law and Policy is a US resource and advocacy organization working to advance the rights of people affected by HIV. They combine an online HIV Policy Resource Bank, a creative national advocacy agenda, and case assistance focused on systems and institutions with significant impact on marginalized communities

Toolkits

NEGOTIATING DISCLOSURE. THE HIV SERO-STATUS DISCLOSURE TOOLKIT

HIV disclosure is complex. It is so much more than sharing a status. This resource aims to humanize this complex, emotional, and personal process; give context to the experience of persons living with HIV/AIDS; and engage professionals looking to provide support.

<http://hivdisclosure.ca/>. Accessed 2/6/18.

Policy & Practice Toolkit for Ontario AIDS Service Organizations on Clients' HIV Disclosure Decisions and Process

<http://www.catie.ca/en/pc/program/oodp?tab=materials>. Accessed 2/6/18.

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Discussion notes are distributed via the ReproID HIV listserv. The ReproIDHIV Listserv is a dynamic forum for clinicians and other healthcare professionals who specialize in reproductive infectious diseases. Participants use the forum to discuss clinical cases, share clinical approaches and protocols, network with colleagues, and arrange patient referrals. For more information, or to join the listserv, please contact marliese.warren@ucsf.edu.

Acknowledgements

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Attendees – CROI 2017 Perinatal HIV Roundtable

Adams, Mary Ellen	Albany Medical Center
Anders, Jean	Johns Hopkins
Atrio, Jessica	Einstein Montefiore
Barton, Tess	Baylor College of Medicine
Beckerman, Karen	Bronx-Lebanon Hospital Center
Bell, Tanvir	University of Texas
Chappell, Catherine	Magee-Womens Hospital of UPMC
Chu, Carolyn	Clinician Consultation Center, University of California, San Francisco
Cohn, Susan Ellen	Northwestern University Feinberg School of Medicine
Dionne-Odom, Jodie	University of Alabama at Birmingham
Dong, Betty	Clinician Consultation Center, University of California, San Francisco
Elwood, Chelsea	University of British Columbia
Goldschmidt, Ron	Clinician Consultation Center, University of California, San Francisco
Hahn, Monica	University of California, San Francisco
Havens, Peter	Medical College of Wisconsin
Hoyt, Laura	Children's Hospitals and Clinics of Minnesota
Kacanek, Deb	Harvard School of Public Health
Levison, Judy	Northwest Health Center, Baylor College of Medicine
Loutfy, Mona	Women's College Research Institute, Women's College Hospital, University of Toronto & Maple Leaf Medical Clinic
Momplaisir, Florence	Drexel University
Pollock, Lealah	Clinician Consultation Center, University of California, San Francisco
Rana, Jesleen	Women's Health
Santos, Roberto	Albany Medical Center
Short, William	University of Pennsylvania
Slome, Sally	Kaiser Permanente Oakland
Stek, Alice Marie	Keck School of Medicine, University of Southern California
Tedaldi, Ellen	Temple University
Warren, Marliese	Clinician Consultation Center, University of California, San Francisco
Weinberg, Adriana	University of Colorado Denver
White, Vanessa	NIH - Office of AIDS Research
Yee, Lynn M.	Northwestern University Feinberg School of Medicine