

Checklist for Change

HIV & Hepatitis C Stigma in Health Care

Selected research, observations and experiences of HIV/HCV stigma within health care

“Building non-stigmatizing relationships between clients and health care professionals requires “trust, flexibility, non-judgmental care, warmth, being able to speak in the client’s language, and seeing the client as a ‘whole person’ as opposed to a person with a disease.”¹

Based on interviews with service providers, individuals living with HIV or Hepatitis C (HCV) and selected research reports on HIV and HCV stigma in health care

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Checklist for Change is available on the DABC website <http://www.disabilityalliancebc.org> or by calling the DABC office at 604-875-0188

DABC is grateful to the individuals who agreed to be interviewed and generously shared their time and perspectives. Your experience and insight nurtures hope and potential solutions for addressing HIV/HCV stigma in health care.

“Stigma is going to be there ... whether it’s about your Hepatitis C, religion or whatever.”

Stigma

Stigma is defined as “a mark of disgrace associated with a particular circumstance, quality or person.” (Oxford Dictionaries. <http://tinyurl.com/l28w9fj>) Discrimination is behaviour resulting from stigmatizing judgments, e.g. barriers to employment, housing, education or health care. Sources of stigma are plentiful and most of us have characteristics that are stigmatized by some members of society. Some examples include ethnic or racial heritage, socioeconomic status, gender, sexual orientation, drug use/addiction, commercial sex work and disability or chronic illness. The focus of this checklist is stigma within health care related to HIV and hepatitis C (HCV).

The purpose of *Checklist for Change* is to provide an overview of policies and service provider attitudes and behaviours that stigmatize, sometimes intentionally and often unintentionally. In presenting the following research results and service provider observations, Disability Alliance BC (DABC) encourages everyone working with people living with HIV or hepatitis C (HCV) to reflect on their assumptions, judgments and communication skills. Consider your organization’s policies and physical layout, signage and other features that may serve health care providers but present barriers and alienate people with HIV or HCV and their family members.

In the words of one care provider interviewed: “I think that what happens is that people forget that every person who walks through the door is somebody’s brother, mother, sister, uncle or aunt and doing the best that they can in that moment.” If you were speaking to your loved one with a health care need “how would you approach them and can you offer the same level of respect for the person who is sitting in front of you?”

The contents below include selected research and reports on HIV/HCV stigma in health care environments in Canada primarily. In addition, 10 interviews were conducted with service providers (educators and health care providers) and individuals living with HIV or HCV. We hope that this checklist ignites a discussion in your organization, sparks a conversation among co-workers or encourages you to contemplate the ways that stigma affects every one of us.

“People who have Hep C also often have internalized stigma. Some people don’t tell families, healthcare providers, etc. and so don’t get treatment.”

Interview Quotes
There are several quotes included throughout this report, displayed in this text style. All quotes are taken from interviews with health care providers, educators, or people living with HIV or HCV from 2014-2015.

Terminology

Stigma: “exclusion, rejection, blame or evaluation ... of a person or group” based on assumptions or judgments regarding their health issue, culture or sexual orientation. Discrimination refers to the behaviour resulting from the stigmatizing assumptions or judgments.¹

Layering or the “double burden of stigma:” occurs when a person experiences stigma from multiple sources or labels. For example, association with one or more cultural or ethnic group, socioeconomic class, gender, sexual orientation, injection drug use or commercial sex work is frequently stigmatizing and compounds the stigma of HIV and HCV. “Health care providers have also identified the following as potentially stigmatizing issues: ... homelessness, having lice or abscesses, being unreliable, disruptive and/or violent, being deaf, being an immigrant ... [or] being non-Caucasian.”¹

Primary stigma: experienced by the person living with the stigmatizing condition

Secondary stigma: experienced by partners, family members, friends and other associates of the stigmatized person. Also known as “courtesy stigma” or “stigma by association.”¹⁰

Perceived stigma: a perception of stigma regardless of whether or not it is present

Self-stigma/internalized stigma: feelings of despair and self-loathing related to stigma in the surrounding environment/society

Symbolic stigma: the meanings and blame attached to the labels of HIV or hepatitis C, such as drug use or sexual behaviour (sex work, gay male sex, etc.) perceived as “immoral”

“The assumption is always that if I have HIV or Hepatitis C then I’m a drug user. And then the stigma, the shame, the walls go up.”

Levels of stigma and discrimination

Micro level: individual beliefs and close relationships

Meso level: stigma at the community level

Macro level: stigma experienced in health and social service systems¹¹

“Most of the shaming happens in the health care environment. The emergency room is a huge problem. Another place that’s a problem is the lab. People don’t do regular blood work because of the shame they experience. People feel judged, shamed and embarrassed.”

Stigma in health care

Individuals, health care providers and the literature agree that for people living with HIV or HCV, health care is the most common environment for stigma and discrimination to occur.

HIV-related stigma within health care settings is sporadic rather than constant and tends to most often occur outside of HIV-related clinics and services. Examples of high-stigma situations include:

- Urgent or emergency care
- Diagnostic tests
- Surgery
- Medical consultations
- Dental care
- Reproductive, health promotion or mental health services
- Incarceration or hospitalization⁴

People living with HIV and accessing health care in the situations outlined above experience stigma “in moments of heightened vulnerability resulting from their health condition, their health needs, and the power of providers.”⁴

Three major causes of HIV stigma in health care

1. Health care workers lack awareness of stigma and the consequences for patients
2. Insufficient knowledge of HIV transmission and consequent fear
3. Association of HIV with “improper or immoral behaviour”⁵

“There is a large body of evidence indicating that health care workers lack knowledge about hepatitis C.”⁹ This lack of knowledge and consequent discrimination is consistently highlighted in our interviews with people living with HCV.

Consequences of stigma in health care

Stigma and discrimination by health care providers impacts disclosure, testing and treatment through reduced visits, missed appointments, failure to disclose health information, reduced adherence to treatment and poor health care provider-patient relationships. In addition, researchers describe increased patient stress and in some cases an increase in unhealthy activities such as smoking.⁹

People living with HIV or HCV note that stigma and discrimination in health care is considerably more difficult than similar experiences in other environments. The level of disclosure required when discussing personal health issues leaves patients feeling vulnerable. In addition, health care providers are perceived as holding positions of power and any judgment or discrimination within this unequal power dynamic is intensified.⁹

Tips for people living with HIV/HCV: know that in appointments you can “bring someone else along for advocacy, write things down/document, take a list to appointments, make complaints if experiencing negative treatment.”

“Perceived” stigma and discrimination

Perceived stigma and discrimination is difficult to avoid once a person identifies as a member of a stigmatized group or has experienced stigmatizing behaviour from others. The impact of perceived stigma/discrimination can produce negative consequences even when health care provider stigma is not present. For example, simply anticipating stigma can result in a person with HIV or HCV avoiding health care. Alternatively, the individual may change their behaviour toward a health care provider based on anticipated or perceived stigma. Care providers may then react in kind and a self-fulfilling prophecy is created leading to a poor relationship even in the absence of stigma.⁹

“People are reading you so intently that it’s easy to send the wrong message. The people in the front [office] are so important.”

“I think sometimes we label things as one of the ‘isms’ when it may not be because we’re particularly sensitive to it.”

What does stigma within a health care relationship look like?

- staring and watching
- giving judgmental looks
- gossiping
- asking inappropriate questions
- showing signs of discomfort when providing care, distancing themselves
- refusing to touch or enter the room
- using unnecessary precautions
- delaying care, refusing to provide care⁴

- lack of eye contact
- clipped or brusque speech
- blaming patients for their status
- physical abuse
- denial of care, inadequate time spent with patient/needs
- leaving the patient in extreme pain for extended periods of time because of assumption of drug use or drug seeking behaviour
- requiring that the patient sit apart from other patients
- requiring that the patient wear coloured wrist bands signifying HCV status
- speaking loudly with other staff in public wards and unwarranted disclosure of status in front of family and friends.⁹

- exaggeration or adaptation of universal precautions, e.g. wearing gloves when normally not required, wearing two pairs of gloves
- assuming that the patient is addicted based on their physical appearance or presence of scars
- “HIV positive” label written beside patients’ names on the wall in public view¹

“That ability to look at somebody and see the positive ... meeting on common ground. That’s where the magic happens!”

“Organizations need to have very clear value statements about how they treat people. That always has to be the fundamental guiding piece. ... [T]here also has to be a way for staff to work through their own stuff. Like a harm reduction approach with staff.”

“All that the diagnosis of anything does is tells us that the person has a specific challenge that they struggle with in a highly diverse life. If you call someone an ‘addict’ or a ‘schizophrenic’ or a ‘borderline’ ... it’s a short-handed way of closing the chapter on that person. And I think that’s what happens in health care. We get so caught up in their diagnosis—what we have to do, how we have to treat it—that it reduces this complex, multifaceted human being to their diagnosis.”

Rural versus urban

Individuals report difficulty accessing health services in smaller communities and rural areas due to lack of anonymity. A research participant observed “that rural health care often lacks the rigors of knowledge, confidentiality and non-judgment that would allow a person to feel safe seeking treatment or advice around HIV or HCV.”⁹ It is common for people living with HIV or HCV in rural areas to seek treatment elsewhere and in many cases they do not inform their general practitioner or pharmacist in their community.

[There are] “huge issues associated with smaller communities... people going up to the counter and having staff talk out loud about diagnoses, staff not knowing a lot about HCV/HIV.”

Organizational Factors contributing to stigma

Physical layout

Signs identifying a clinic or office as serving HIV or HCV patients can create a barrier for people who fear being labeled by others who may see them entering or leaving. “Ability to access HIV care without being labeled ‘HIV positive’ is imperative according to health care professionals.”¹

Cramped office space or physical layout that does not allow for privacy while speaking to reception staff can be concerning for patients¹

Medical files or other documents placed in open view of people in waiting rooms and patients walking past breach patient privacy, especially if they have been “flagged” or marked in some way to identify the patient as HIV- or HCV-positive.¹

“It’s important to have visual cues... like a statement saying we respect ALL people regardless of who they are.”

Organizational policies

Organizational policies are instrumental in guiding staff and implementing practices to protect patient privacy and minimize stigmatizing behaviours. Examples of policies that help to reduce stigma include:

- adopt a harm reduction policy with patients¹

“Harm reduction refers to policies, programs and practices that seek to reduce the adverse health, social and economic harms associated with the use of psychoactive substances and sexual activity. Harm reduction is a pragmatic response that focuses on keeping people safe and minimizing death, disease and injury associated with risky behaviours, while recognizing that the behaviour may continue despite the risks.”¹²

- ensure clearly articulated and monitored policies regarding patient privacy and right to confidentiality, for example, ensure that patient files are not visible with private information open to viewing by others as they pass by, staff should avoid using names when discussing patients in areas where they may be over-heard by other patients or family members, avoid using “caution sheets” in patient files or identifying HIV- or HCV-positive patients with coloured wrist-bands, etc.¹
- minimize barriers by limiting questions asked to those required to deliver care. Provide anonymity (including anonymous HIV testing) if requested.¹
- recognize that newly diagnosed patients may require more assistance navigating the health care system¹
- enable a “flexible approach to care,” allowing staff to be flexible in their application of policies and rules with patients.¹
- create processes to enable patients to evaluate services, including staff behaviour¹

- provide culturally appropriate care and involve individuals in the community to ensure a safe and respectful environment. Hire staff from the communities served.¹
- practice “client-centred care ... working with the client, based on where the client is at in their life and circumstances”¹

“Front line staff are so important in an organization. They have to greet every single person who comes in the door with utmost respect and dignity. Or at least they have to treat everyone the same way.”

“[There should be] information in the waiting room about where people can go for support and resources.”

Staff training

- a supportive work environment where respect is modeled and high staff morale is present has been identified by health care providers as key in providing high quality care for patients¹
- staff training in communication skills and “dealing with aggressive or escalating situations” is important¹
- it’s important that training to prevent stigmatizing practices begin when health care providers are students. It can become more difficult to adopt new approaches as time passes.¹
- research indicated inadequate knowledge of correct procedures in “universal precautions” by health care providers.⁹ Training on stigma and universal precautions is recommended.⁵
- training in patients’ right to privacy is recommended⁹
- patients newly diagnosed with HCV have reported that their care providers exhibited poor communication skills and delivered unclear health information⁹
- evidence indicates that health care providers lack knowledge about hepatitis C and this may be contributing to negative attitudes and stigma⁹
- health care providers should be familiar with and able to refer patients to appropriate and respectful service providers of various types in the community¹
- patient advocacy is expected of health care providers: informing patients of their rights, referral to community services, recommending strategies for navigating the health care system and accessing funding sources for medications¹
- health care providers should be aware of community services beyond health and be informed about income/disability supports and have the skills to advocate for housing or treatment¹
- when providing staff training, it’s important to include all staff members, including doctors, nurses, cleaners and administrative staff. Including people living with HIV and HCV gives a “human face” to the information.⁵
- an opportunity for reflection on stigma and communication skills is highly recommended. Research shows that health care providers were surprised to hear that their actions and statements were considered stigmatizing or discriminatory by patients.⁹

“Watching other staff model behaviour is a great way to learn.”

“Lots of training, teamwork, peer coaching, modeling, humour with co-workers... there’s a lot of support amongst the team.”

“Then I went away and thought, ‘am I doing anything to perpetuate stigma? Are frontline workers doing anything to continue stigma by what we say?’”

Service providers should “know enough about [HCV] to not have preconceived notions. People can tell if you’re feeling apprehensive and uncomfortable around them. ... [K]nowledge is the key!”

“I think that basic respect in a busy clinical environment is the thing that seems to go first. Training programs ... need to be offered regularly and made mandatory because people are not being treated well or with respect.”

Checklist For Change

The following checklist is intended to encourage reflection on knowledge of stigma within health care environments. Readers are encouraged to complete the checklist independently or to use it as a focus for discussion at a staff meeting or training session.

Individual Checklist

- I have a clear understanding of stigma and ways it may affect communication between health care provider and patient/client.
- I have a clear understanding of discrimination—behaviour resulting from stigma—and the barriers it can create for people living with HIV or Hepatitis C (HCV).
- I understand that HIV and HCV stigma is most commonly experienced within the health care setting.
- I am familiar with the “high stigma health care settings” (urgent/emergency care, labs/diagnostic testing, surgery, medical consultations, dental care, reproductive, health promotion and mental health services, and incarceration or hospitalization).
- I recognize that self-stigma or internalized stigma may inhibit open communication for a person living with HIV or HCV.
- I am aware that my personal attitude towards potentially stigmatizing issues (e.g. HIV/HCV, ethnic/racial heritage, socioeconomic status, gender, sexual orientation, drug use/addiction, commercial sex work, disability/chronic illness, etc.) may be reflected in my communication and behaviour without my knowledge.
- I am aware that many individuals experience stigma from multiple sources (e.g. socioeconomic status, drug use, commercial sex work, sexual orientation, etc. in addition to HIV or HCV).
- I am aware that many people anticipate “perceived stigma” based on previous experience and may assume that my communication and actions are based on stigmatizing attitudes.
- I am knowledgeable about how HIV and HCV are transmitted.
- I am aware that stigma often results from associating HIV or HCV with perceived “immoral behaviour” (e.g. drug use, commercial sex work, etc.).
- I recognize the power imbalance within health care provider-patient/client relationships. Treatment requires patient/clients to disclose personal and possibly embarrassing information and thus concern about judgment can be intensified.

- I am aware of the impact of my communication skills (including nonverbal and body language) in supporting my patient/client and their ability to communicate regarding their health.
- I understand that patient/client concerns about privacy are often greater outside larger, urban centres.
- I know that monitoring my assumptions can be an effective way of identifying stigmatizing beliefs.
- I sometimes assess the fairness and effectiveness of my communication skills/behaviour by asking myself, "Would I treat my family member or close friend in this manner if they were sitting before me with the same symptoms/problem?"
- I am familiar with and recommend community resources and supports available for my patients/clients.
- I participate regularly in training opportunities: interpersonal communication, HIV and HCV, universal precautions, stigma and discrimination, community resources, patient advocacy, etc.

Organizational Checklist

- Our organization utilizes a "harm reduction" approach.
- Our organization has clearly articulated policies regarding patient privacy and right to confidentiality.
- Our organization supports our health care providers in a "flexible approach to care" (staff are allowed a flexible application of policies and rules).
- Patient/client respect is evident in our organization's approach to care.
- Our organization provides regular staff training.
- Our organization incorporates "culturally appropriate care" and training to support it.
- Our organization emphasizes patient/client right to privacy through confidential interaction with reception staff and privacy when files and other documents are made available for health care provider use.
- Our organization provides visual cues (posters, brochures, etc.) to welcome and support patients/clients with HIV/HCV.

References

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11. *Learning Guide: Stigma in Women Living with HIV*. [London, UK]: Women for Positive Action, 2012. <http://tinyurl.com/otajhya>
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Resources

BC Centre for Disease Control

Hepatitis C

<http://www.bccdc.ca/dis-cond/a-z/h/HepatitisC/default.htm>

HIV/AIDS

<http://www.bccdc.ca/dis-cond/a-z/h/HIVAIDS/default.htm>

Canadian Aboriginal AIDS Society

<http://www.caan.ca/>

Canadian AIDS Society

<http://www.cdnaids.ca/>

Canadian Liver Foundation

Hepatitis C

http://www.liver.ca/liver-disease/types/viral_hepatitis/Hepatitis_C.aspx

CATIE

Canada's source for HIV and Hepatitis C Information

<http://tinyurl.com/nz6uk85>

Hepatitis C Education & Prevention Society

<http://hepcbc.ca/>

Pacific Hepatitis C Network

<http://www.pacifichepc.org/>

Positive Living BC

<http://positivelivingbc.org/>

Positive Women's Network

<http://pwn.bc.ca/>

Patients' Bill of Rights

Managing Your Health: A Guide for People Living with HIV: 3. Your Healthcare Team [includes "HIV Patient's Bill of Rights"]. [Toronto, ON]: CATIE, 2009. <http://www.catie.ca/en/practical-guides/managing-your-health/3>

HCV Manifesto. Victoria, BC: Hepatitis C Education and Prevention Society, [n.d.]. <http://hepcbc.ca/hcv-manifesto/>