Rethinking HIV-Related Stigma in Health Care Settings: :

A Research Brief

BACKGROUND

Research conducted in Canada indicates that people living with HIV (PLWH) continue to endure stigma and discrimination in the context of health care[1]. We know that stigma and discrimination in health care settings have a negative impact on people living with HIV and the quality of the care they receive[2]. We also know that HIV-related stigma and discrimination act as barriers to health care access among people living with HIV[2].

Research conducted on this particular topic has been almost exclusively focused on individual experiences of HIV-related stigma. As a result, the structural nature of HIV-related stigma in health care settings has remained largely undocumented and unexplored by researchers. The objective of this study was to explore these two dimensions of stigma in the health context in the province of Quebec.

PROJECT

For this study, individual interviews were completed with 15 men and 6 women. The average participant was born between 1960 and 1969. All participants were Caucasians. Half of the participants had an annual income between $10,000-19,000 (10/21). Nine participants had a high school diploma, 6 had a college degree, and 6 had a university degree. The year of diagnosis was distributed as such within the group:

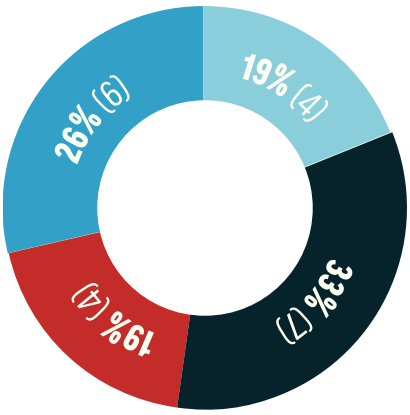
Year of Diagnosis

< 1990

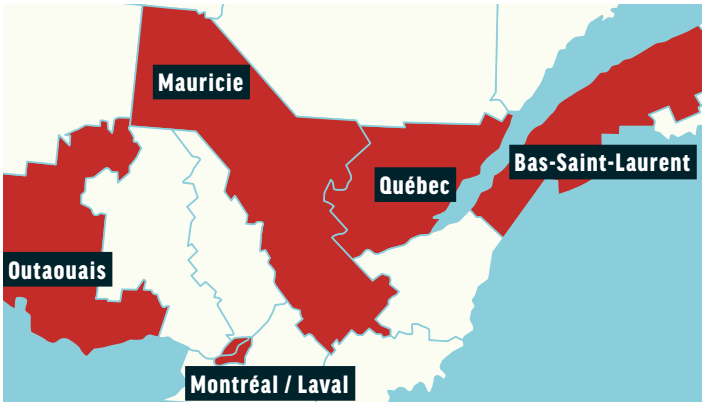
1990-1995

1996-2000

> 2000



Interviews were conducted in home settings and community-based settings in 5 regions of the province of Quebec: Bas-Saint-Laurent, Montréal / Laval, Mauricie, Outaouais, and Québec between April and August 2013.



Participants were asked to describe previous experiences with health care providers and share their feelings about these particular experiences. They were also asked to describe the impact of stigma and discrimination on their lives with a particular focus on health, access to services, quality of life, and well-being. Finally, they were encouraged to share their thoughts around stigma and discrimination in the context of health care in general based on their experiences.

Each interview was audio-recorded using a digital voice recorder, transcribed and reviewed by the researcher. Data analysis followed the basic principles of thematic analysis. During the analysis, three themes were identified and relations between these themes were identified to reflect the experiences of participants. Please refer to the next section and the visual summary for a brief description of these themes.

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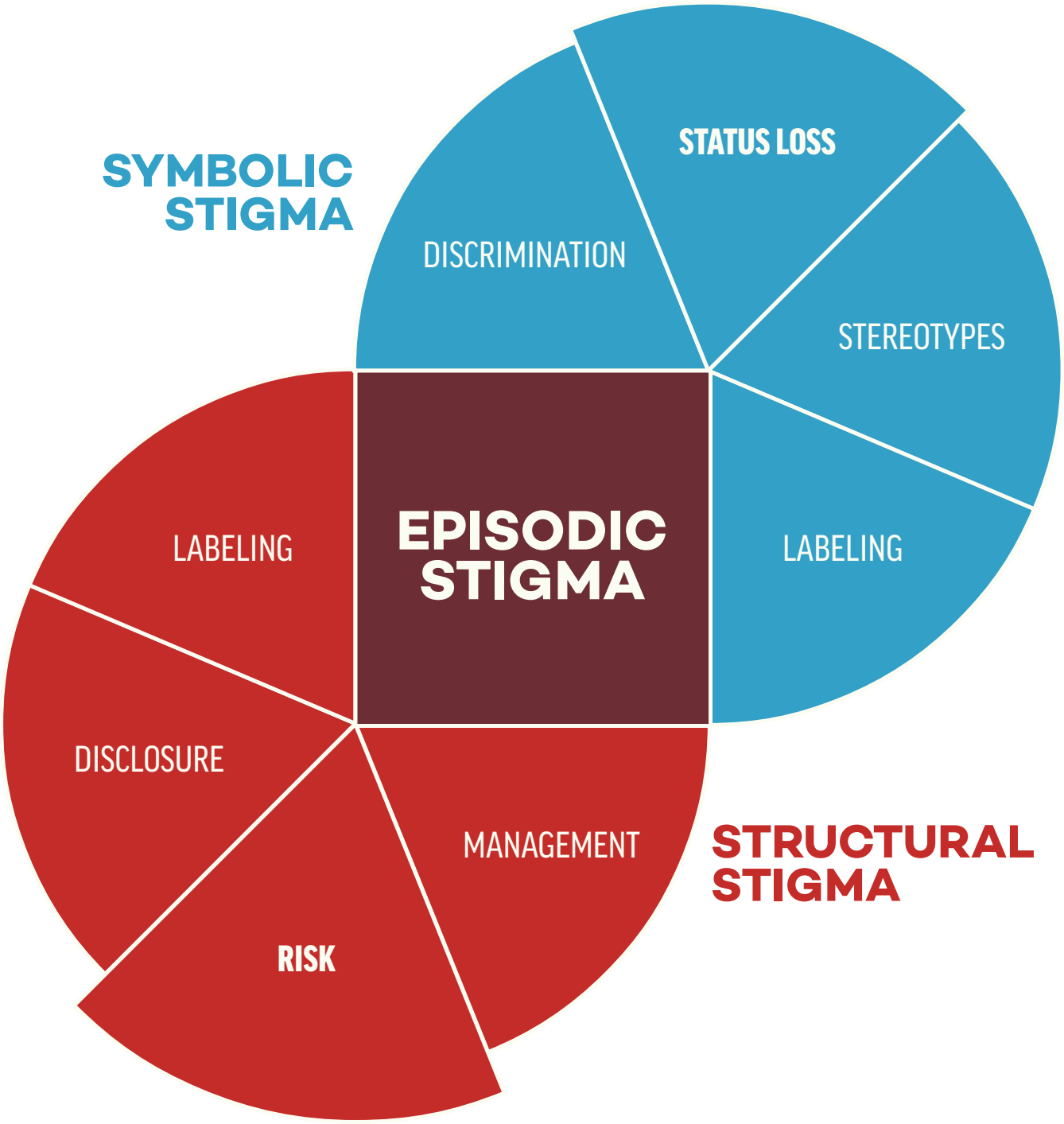
1 Mill et al. (2007). The Influence of Stigma on Access to Health Services by Persons with HIV Illness: A CBR project. Mill et al. (2009). Accessing Health Services While Living With HIV: Intersections of Stigma. Canadian Journal of Nursing Research, 41 (3), 168-185. Mill et al. (2010). Stigmatization as a Social Control Mechanism for Persons Living with HIV and AIDS. Qualitative Health Research, 20 (11), 1469-1483.

2 Nyblade et al. (2009). Combating HIV stigma in health care settings: What works?. Journal of the International AIDS Society, 12, 15.

THEMES AND SUB-THEMES



KEY FINDINGS

THEME 1 | EPISODIC STIGMA

Participants considered that HIV-related stigma in health care settings is EPISODIC rather than present at all times. They made a point of explaining that HIV-related stigma tends to happen outside the "HIV network" – i.e. outside HIV clinics and related services.

For them, this meant that stigma was present at times when they sought care and services for something else than HIV. It also meant that they experienced stigma in moments of heightened vulnerability resulting from their health condition, their health needs, and the power of providers.

Examples of these moments included: 1) requiring urgent care, diagnostic tests, surgical interventions, dental procedures, and medical consultations; 2) seeking reproductive, health promotion, and mental health services, and 3) being incarcerated, hospitalized, and diagnosed.

THEME 2 | SYMBOLIC STIGMA

During the interviews, participants described HIV-related stigma has something that is experienced during interactions with health care providers. This is known as SYMBOLIC STIGMA. It is the most frequently reported and studied manifestation of HIV-related stigma.

Symbolic stigma starts with the experience of being labeled and stereotyped for being HIV-positive. For example, participants described how they were automatically categorized as "drug seeking patients" by health care providers for being HIV-positive.

This is followed by status loss and discrimination. As such, participants who were stigmatized reported being treated like they had fewer rights than other patients and being treated differently by health care providers because of their serological status.

Examples of stigmatizing and discriminatory actions:

- Staring and watching
- Giving judgemental 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 care

THEME 3 | STRUCTURAL STIGMA

The experiences described by participants revealed another manifestation of HIV-related stigma called STRUCTURAL STIGMA. It presented itself as the exact opposite of symbolic stigma. This particular dimension of stigma has not been studied in great details in the field of HIV.

Structural stigma refers to the strategic use of labeling for "risk management". It relies on the assumption that people living with HIV pose a risk to health care providers and that is necessary to identify patients who are HIV-positive to properly "manage" this perceived risk.

The important attributed to disclosure in health care settings was highlighted by participants. They also provided numerous examples of unethical, arbitrary, and discriminatory strategies that were explained or presented to them as "risk management" strategies.

Examples of "risk management" strategies:

- Using formal and informal policies

  Examples: using forms with questions specific to HIV to screen patients, scheduling appointments last or later in the day, systematically refusing services to patients living with HIV on the basis that they are considered to pose a risk to other patients.

- Breaching confidentiality

  Examples: disclosing the serological status of a patient to "warn" colleagues, "flagging" a patient who is HIV-positive by indicating the serological status on the chart (using a sticker or a red pen) and/or in other work-related documents (ex: care plan).

- Reinterpreting universal (standard) precautions

  Examples: creating new rules for patients who are HIV-positive and making practice decisions based on rationales like "we need to take extra precautions", "we need to be more careful" or "we need to clean more, disinfect more thoroughly, and sterilize the equipment for longer periods of time".

RECOMMENDATIONS

Based on the research findings, the following top 10 recommendations were formulated:

1. Provide accompaniment services in moments of heightened vulnerability especially when the person is unwell, in pain, or hospitalized. Encourage people living with HIV to bring someone along for support when they go to medical appointments, clinic visits, and so forth.

2. Develop a practical guide on the rights of people living with HIV in health care settings. This guide should be specific enough to address the rights of people living with HIV with respect to disclosure, confidentiality, and discrimination in health care settings.

3. Develop a quick reference guide for people living with HIV that details the principles of universal (standard) precautions and what is considered "good practices" in clinical settings with respect to the use of gloves, masks, gowns, and isolation precautions.

4. Encourage people living with HIV to file complaints against providers and institutions in cases of stigma and discrimination. Provide the necessary support (i.e. informational, practical, psychological, and financial) for complaints to be filled and followed through.

5. Ensure that all health care providers have the necessary knowledge and competencies to provide safe, competent, and ethical care to people living with HIV. Hold the educational and health care sectors accountable for meeting current standards of practice in HIV care.

6. Develop key messages targeted at health care providers on the risk of HIV exposure and transmission to ensure that practice is informed by scientific evidence and up-to-date information on this topic.

7. Document current practices in health care settings by conducting surveys and reporting the findings to professional regulatory bodies. The survey of dental offices completed by COCQ-sida throughout the province of Quebec could serve as a model for future initiatives.

8. Produce report cards for health care institutions, departments, clinics, and so forth based on a set of criteria including, but not limited to, adherence to standard (universal) precautions, adherence to transmission-based precautions, confidentiality, and record-keeping.

9. Advocate for the development of internal policies in health care to ensure that current standards of practice in HIV care are clearly delineated and applied in day-to-day operations. Include these policies in the production of report cards as previously described.

10. Develop a campaign for health care providers to reiterate the principles underlying the use of universal (standard) precautions in clinical practice. This campaign should be focused on the underuse, inconsistent use, and overuse of standard (universal) precautions.

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Researcher: Dr. Marilou Gagnon, RN, ACRN, PhD, Associate Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa (ON), CANADA – marilou.gagnon@uottawa.ca

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