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Identifying self-perceived HIV-related stigma in a population accessing antiretroviral therapy

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Abstract

This study identifies factors associated with self-perceived HIV-related stigma (stigma) among a cohort of individuals accessing antiretroviral therapy (ART) in British Columbia, Canada. Data were drawn from the Longitudinal Investigations into Supportive and Ancillary Health Services study, which collects social, clinical, and quality of life (QoL) information through an interviewer-administered survey. Clinical variables (i.e. CD4 count) were obtained through linkages with the British Columbia HIV/AIDS Drug Treatment Program. Multivariable linear regression was performed to determine the independent predictors of stigma. Our results indicate that among participants with high school education or greater the outcome stigma, was associated with a 3.05 stigma unit decrease (95% CI: -5.16, -0.93). Having higher relative standard of living and perceiving greater neighborhood cohesion were also associated with a decrease in stigma (-5.30 95% CI: -8.16, -2.44; -0.80 95% CI: -1.39, -0.21, respectively). Lower levels of stigma were found to be associated with better QoL measures, including perceiving better overall function (-0.90 95% CI: -1.47, -0.34), having fewer health worries (-2.11 95% CI: -2.65, -1.57), having fewer financial worries (-0.67 95% CI: -1.12, -0.23), and having less HIV disclosure concerns (-4.12 95% CI: -4.63, -3.62). The results of this study show that participants with higher education level, better QoL measures, and higher self-reported standards of living are less likely to perceive HIV-related stigma.

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Author Contributions DT, and JF developed the study concept and design. WZ and KAF performed all statistical analyses. DT, CP, TRO, and CWM contributed to descriptive analysis and write-up. AP was responsible for data collection and program management. RSH and JSGM provided strategic guidance and supervision of the study. All authors contributed to the manuscript and approved the final version for publication.

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Keywords

stigma; ART; quality of life; HIV

Introduction

HIV/AIDS is among the most stigmatizing diseases in the world (Simbayi et al., 2007). HIV-related stigma not only limits people's social interactions and future opportunities, it also contributes to poorer clinical outcomes, depression, fear of disclosure, and reduced quality of life (Fife & Wright, 2000; Heckman et al., 2004; Kang et al., 2006; Sayles et al., 2007). Self-perceived HIV-related stigma (stigma) includes an individual's perception of societal attitudes towards people living with HIV and his or her personal knowledge of being infected with HIV (Berger, Ferrans, & Lashley, 2001; Goffman, 1963; Wright et al., 2007).

Recent literature also finds that stigma hinders quality of life (QoL) among HIV-positive persons on antiretroviral therapy (ART), despite improvements in pill burdens and negative side effects with the introduction of highly active antiretroviral therapy (Burgoyne & Tan, 2009; Holmes & Shea, 1998; Holzmer et al. 2009; Kang, Rapkin, & DeAlmeida, 2006). This finding has been quantified in one study (Holzmer et al. 2009), but did not include a population, like the cohort in this study from British Columbia (BC), Canada, who have access to ART and other medically necessary services free of charge through a universal publicly funded health care system.

Currently in BC there are approximately 5,500 patients with access to ART (Drug Treatment Program). This number is likely to increase with an initiative which began in 2010 called Seek and Treat for Optimal Prevention (STOP) of HIV/AIDS. This pilot project seeks to expand HIV testing, treatment, and support services to clinically eligible British Columbians. One of the five goals of this project is to improve patient experiences in every step of the HIV/AIDS journey (Pollock, 2010). Understanding how stigma affects people on ART in BC may help such an initiative identify and improve the experience of patients on ART who perceive higher levels of stigma and is thus timely research.

The objective of this study is to identify the prevalence and factors associated with self-perceived HIV-related stigma, using quantitative methods, through a cross-sectional study of individuals accessing ART in British Columbia. Identifying and addressing social, clinical and QoL issues may reduce depression and psychological distress, while improving clinical health outcomes and QoL for people living with HIV/AIDS.

Methods

Participants and Recruitment

The Drug Treatment Program (DTP) at the BC Centre for Excellence in HIV/AIDS is mandated by the BC provincial government to distribute antiretroviral medications free of charge, to all clinically eligible HIV-positive individuals. The DTP distributes medications in accordance with the BC Therapeutic Guideline Committee, which remained consistent with those from the International AIDS Society-USA (Thomas et al., 2010). Details regarding the distribution of ART through the DTP have been previously described (Hogg, 2001). In brief, physicians enter individuals into the DTP when they are first prescribed ART by completing a drug request form. The request form acts as a legal prescription and is used to compile baseline information including CD4 cell counts, pVL, and enrolling-physician data.

Individuals enrolled in the DTP were eligible to participate in the Longitudinal Investigations into Supportive and Ancillary health services (LISA) study. To be eligible, participants were at least 19 years of age, had initiated ART and provided informed consent. Participants for this study were actively recruited from July 2007 to February 2010 through letters distributed by their physician (identified from the DTP), by word-of-mouth, and advertisements at: pharmacies, HIV/AIDS clinics, and service organizations across the province. As of February 2010 there were 917 LISA participants. Only participants currently on ART at time of interview and who had completed the questionnaire section on stigma were included in our sample (n=775). The geographic distribution of LISA study participants across all health authorities in the province of BC is proportionately similar to the geographic distribution of individuals accessing treatment. However, particular sub-populations were deliberately over-sampled in order to sufficiently power sub-analyses. Consequently, women, people with a history of injecting drugs, and people identifying as Aboriginal are over-represented in the LISA cohort.

Study instrument and ethical approval

Information from LISA study participants was collected through a comprehensive interviewer-administered survey, which captured a range of variables including: demographic data, mental health disorders, and QoL measures. Clinical variables, such as CD4 count, pVL, and adherence, were obtained through a linkage with the DTP. Interviews lasted approximately 60 minutes and participants were offered a \$20 honorarium as a gift to compensate them for the time they spent interviewing. All participants accepted the gift. Ethical approval for the LISA study was obtained from the University of British Columbia/ Providence Health Care Research Institute, Vancouver Coastal Health, University of Victoria and Simon Fraser University Research Ethics Boards. The LISA project was funded by the Canadian Institutes of Health Research.

Outcome variable

The main outcome variable for this sub-study of the LISA cohort is self-perceived HIV-related stigma (stigma). This variable is assessed using the HIV Stigma Scale developed by Berger et al. (2001) and modified by Wright et al. (2007). The Wright et al. (2007) scale was developed for HIV-positive youth, with the reduction to ten items intended to reduce instrument burden on respondents. The ten-item scale was deemed more appropriate for use with the LISA study as it was only one component of a lengthy questionnaire. Both scales have been shown to have good internal consistency, reliability and construct validity (Berger et al., 2001; Wright et al., 2007).

Since there is no clinical cutoff for stigma, and the score for our study group has a normal distribution, the variable was kept as continuous. The scale ranges from 0 to 100, such that higher scores designated higher levels of stigma.

Explanatory variables

Socioeconomic and clinical variables were chosen based on prior research and clinical reasoning. These included age, gender, Aboriginal ancestry, sexual identity, education, current employment, current annual income less than \$15,000 (low income cutoff in BC), current smoking, current alcohol use, current illicit drug use (defined as using cocaine, crack cocaine, heroin, speedball (cocaine and heroin), or methamphetamines), depressive symptoms, perception of neighborhood problems, neighborhood cohesion, perceived standard of living relative to neighbors, QoL measures, years living with HIV, years on ART, adherence to ART (defined as the number of days for which treatment is dispensed divided by the number of days which medication is prescribed in the 12 months prior to the interview, 95% adherence being optimal), HIV viral suppression (defined as having two

consecutive pVL measures of <50 copies/mL within six months prior to interview date), and most recent CD4 cell count.

Perception of neighborhood and depression—Perception of neighborhood problems, such as vandalism, and perception of neighborhood cohesion are assessed using scales developed by Ellaway, Macintyre, Kearns (2001). Scales were re-measured from 0 to 100, where higher scores indicate lower levels of perceived neighborhood problems and greater neighborhood cohesion. Perceptions of relative standard of living were also measured by a scale developed by Ellaway, Macintyre, Kearns (2001), which asked about relative standard of living from ‘better off’ to ‘worse off’.

Depressive symptoms are measured using the 10-item Center for Epidemiological Studies Depression (CES-D 10) Scale. Participants with scores of 10 or higher are identified as having depressive symptoms. This scale has been shown to have specificity and sensitivity comparable to the 20-item scale (Anderson et al., 1994).

Quality of life (QoL)—Quality of life is measured using the HIV/AIDS-targeted quality of life (HATQoL) instrument developed by Holmes and Shea (1998). The HAT-QoL scale covers nine domains: overall function, sexual dysfunction, disclosure worries, health worries, financial worries, HIV mastery, life satisfaction, medication concerns and provider trust. All domains satisfied Cronbach alphas (>0.70) and were included in our analysis. Measures are re-scaled from 0 to 100, where higher scores indicate better QoL. The instrument has good psychometric properties, including low ceiling/floor effects, good internal consistency and construct validity (Holmes & Shea, 1998).

Statistical analyses

Bivariable analyses were conducted to investigate the association between the outcome variable, stigma, and each explanatory variable, using either the Fisher’s Exact test for categorical variables or the Wilcoxon rank sum test for continuous variables. Multivariable linear regression was used to determine the factors associated with stigma. All instruments used in this analysis have a Cronbach alpha above 0.70, indicating the reliability of instruments in our sample (Streiner & Norman, 1995). Variables were included in the multivariable model if the bivariable test resulted in a p-value < 0.20, indicating a potential association with stigma. Only participants who had complete data for these variables were included in the model. A backward-selection procedure, based on the Akaike Information Criterion (AIC), was used to select the variables included in the multivariable model. The Hosmer-Lemeshow test was used to examine the model goodness-of-fit. All analyses were conducted using SAS version 9.1.3 (SAS, Cary, North Carolina, United States).

Results

As of February 2010 there were 917 LISA participants, of whom 775 were currently on ART and had completed the questionnaire section on stigma. The overall stigma score among participants was 45 (IQR: 30-60). Twenty-five percent of the sample are female, 28% self-reported Aboriginal ancestry, 60% identified as straight, 37% have less than a high school education, and 52% currently use illicit drugs. These overall baseline characteristics of the sample are shown in Table 1. In comparison, the overall stigma score for LISA participants who were not on ART, and not included in this analysis, is 50 (IQR: 35–65, n = 123).

The bivariable analysis (Table 2) shows that lower levels of stigma is associated with age (−0.36 95% confidence interval (CI): −0.51, −0.21), high school graduation or greater (−4.08 95% CI −6.93, −1.24), and current employment (−4.80 95% CI: −7.97, −1.63).

Higher stigma is associated among: females (7.12 95% CI: 3.99, 10.24), participants with an income less than \$15,000 (5.92 95% CI: 3.14, 8.68), and current smokers (4.10 95% CI: 1.25, 6.94). With respect to how the individuals relate to their communities, having a higher perception of neighbourhood cohesion (-2.13 95% CI: -2.92, -1.34), and perceiving higher standards of living (-11.11 95% CI: -14.84, -7.39) were significantly associated with lower levels of stigma, while perceiving higher levels of neighbourhood problems was significantly associated with higher levels of stigma (1.21 95% CI: 0.66, 1.76). A decrease in stigma was associated with years living with HIV (-3.08 95% CI: -5.39, -0.76), years on ART (-0.52 95% CI: -0.92, -0.12), and those with depressive symptoms (14.00 95% CI: 11.40, 16.61). Table 2 also displays the QoL indicators, showing that stigma decreases with better perception of QoL measures.

The multivariable associations between stigma and the explanatory variables included in the final model are presented in Table 3. Participants with high school education or greater had an associated lower stigma score by 3.05 stigma units on average (95% CI: -5.16, -0.93). Reporting higher standards of living was also associated with the perception of lower levels of stigma (-5.30 95% CI: -8.16, -2.44), as well as greater neighbourhood cohesion (-0.80 95% CI: -1.39, -0.21). In terms of QoL measures, lower levels of stigma is significantly associated with perceiving better overall function (-0.90 95% CI: -1.47, -0.34), having fewer health worries (-2.11 95% CI: -2.65, -1.57), having fewer financial worries (-0.67 95% CI: -1.12, -0.23), and having less disclosure concerns (-4.12 95% CI: -4.63, -3.62). The Hosmer-Lemeshow test indicated no evidence of invalid fit for the multivariable model ($p=0.45$).

Discussion

The results of this study indicate that having a high school education or greater and reporting higher relative standard of living are factors that emerge as significant in perceiving lower levels of stigma. In addition, perceiving better overall function, fewer health worries, fewer financial worries, and having less disclosure concerns are also significantly associated with decreased stigma.

There is evidence of a high prevalence of stigma in this cohort, in particular among those who are young, female, lower education level, lower income, report depressive symptoms, and who report residency in poorer neighborhoods. This suggests that individuals experiencing HIV-related stigma may also experience compounded stigma due to additional demographic and socioeconomic factors. These findings are consistent with previous studies (Aranda-Naranjo, 2004; Fife & Wright, 2000; Palmer et al., 2011; Parker & Aggleton, 2003), which suggest that social factors, such as financial insecurity and education level, contribute to stigma because individuals may lack a sense of personal control in their lives and tools that promote resiliency.

Our study identified an association between stigma and an individual's perception of their relative standard of living. As expected, participants reporting higher levels of stigma are more likely to have financial worries, and view themselves as worse off than their neighbors. Although our study does not address the direction of this association, our results suggest that one's perception of stigma could affect their experiences in their social environment. These results suggest some connection between social environment and stigma. This relationship warrants further exploration.

As exhibited by the multivariable analysis, stigma continues to affect the QoL of individuals in this cohort. Our results are consistent with the results found in a Holzemer et al. (2009) study, as these authors also observed an association between stigma and QoL. However, by

separating the QoL measures, we were able to further identify which QoL measures were associated with stigma. Moreover, the clinical variables included in our study were obtained from an administrative database, rather than self-report, increasing the reliability of our results.

The QoL measures we found to be associated with stigma are: overall function, health worries, financial worries and disclosure concerns. This finding is consistent with Fife and Wright (2000) and Heckman et al. (2004), who suggest that the higher the severity of an illness, the more likely an individual is to conceal the illness, directly resulting in stigma. In addition, other studies found that the perceived stigma is associated with poorer self assessed physical and mental health, and that perception of stigma is correlated with ones decision to disclose their HIV status (Clark et al., 2008; Wolitski et al., 2008).

It is important to note that in this cohort, a component of the QoL scale that was not associated with stigma in the multivariate model was provider trust. This finding stands in contrast to other studies that are concerned with health care workers' reluctance to care for people with HIV (Sayles et al., 2007; Kopacz et al., 1999; Sadowsky & Kunzel, 1994; UNAIDS, 2000). Our results may be a reflection of the quality of care from primary physicians who service this population. The practice and attitude of health professionals serving the HIV-positive population may thus represent a constructive agent of change for stigma reduction in BC.

Readers should be cautious when interpreting our results since our study draws from baseline interviews, and thus, we cannot infer causality. Our data are also derived from a cohort of individuals with access to a universal, publicly funded health care system where ART is offered free of charge. Our study participants are currently on ART and have been recruited through doctors, clinics, and supportive service organizations. We are aware that the stigma these participants experience may differ from the stigma experienced by people with HIV who are not accessing care or are not on ART. In addition, the moderate financial incentive offered to participants may have led to an over-representation of individuals in need of the financial gain. Despite these limitations, our results have important implications for the delivery of care in this population.

Conclusion

Our study identified several factors: education level, relative standard of living, and QoL, to be associated with self-perceived HIV-related stigma in a cohort of individuals accessing ART in BC. Our results illustrate that stigma continues to affect the most vulnerable populations and ultimately affects a person's mental and physical well-being. Furthermore, this study quantifies the relationship between QoL and stigma. These associations are particularly important as it exemplifies the need for health care workers to address stigma as a holistic health issue, alongside clinical indicators. A multidisciplinary approach that includes physicians, nurses, psychologists, pharmacists, nutritionists, counselors, social workers, and outreach workers are needed to ensure that physical and mental health needs are met. The negative consequences of stigma can be mitigated if identified early and appropriate interventions are applied.

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Table 1

Descriptive summary of LISA study participants on ART with stigma scores (n=775).

Variable	
Stigma Median (IQR)	45(30-60)
Age Median (IQR)	45(40-52)
Gender n (%)	
Female	196(25%)
Male	579(75%)
Ethnicity n (%)	
Aboriginal	216(28%)
Non-aboriginal	559(72%)
Sexual identity n (%)	
Straight	464(60%)
Non-straight	311(40%)
Education n (%)	
Less than high school graduation	286(37%)
Equal of greater than high school graduation (missing =1)	488(63%)
Current alcohol use n (%)	
Yes	402(52%)
No (missing =4)	369(48%)
Current illicit drug use n (%)	
Yes	404(52%)
No (missing =4)	367(48%)
Treatment adherence n (%)	
Equal and greater than 95%	540(78%)
Less than 95% (missing = 79)	156(22%)
HIV viral suppression n (%)	
Yes	568(78%)
No (missing = 45)	162(22%)
Current CD4 cell count n (%)	
Equal or greater than 350 cells/mm ³	391(53%)
Less than 350 cells/mm ³ (missing = 42)	342(47%)
Depressive symptoms n (%)	

Variable	
High	433(56%)
Low (missing=3)	339(44%)

* Participants with incomplete variable data were categorized as 'missing'.

Table 2

Univariate linear regression model between self-perceived HIV-related stigma and the study variables of interest.

Variable	Unadjusted		p-value
	Regression Coefficient	95% CI	
Age (per 10 year increment)	-0.36	(-0.51, -0.21)	<0.001
Gender n (%)			
Female vs. Male	7.21	(3.99, 10.24)	<0.001
Ethnicity n (%)			
Aboriginal vs. Non-Aboriginal	-0.44	(-3.51, 2.64)	0.781
Sexual identity n (%)			
Straight vs. Gay/Lesbian/Bisexual	7.68	(-4.42, 19.78)	0.213
Gay/Lesbian/Bisexual vs. Transgender/other	1.31	(-10.86, 13.48)	0.833
Education n (%)			
Equal or greater than high school graduation vs. Less than high school graduation	-4.08	(-6.93, -1.24)	0.005
Currently employed n (%)			
Yes vs. No	-4.80	(-7.97, -1.63)	0.003
Annual income (\$CAD) n (%)			
Less than \$15 000 vs. Equal or greater than \$15 000	5.92	(3.14, 8.68)	<0.001
Current smoking n (%)			
Yes vs. No	4.10	(1.25, 6.94)	0.005
Current alcohol use n (%)			
Yes vs. No	-0.06	(-3.41, 2.21)	0.674
Current illicit drug use n (%)			
Yes vs. No	1.43	(-3.02, 5.89)	0.528
Years with HIV (per 10 year increment)	-3.08	(-5.39, -0.76)	0.009
Years on ART	-0.52	(-0.92, -0.12)	0.011
Treatment adherence n (%)			
Equal and greater than 95% vs. Less than 95%	-3.37	(-6.89, 0.16)	0.061
HIV viral suppression			
Yes vs. No	-2.53	(-7.11, 2.05)	0.279
Current plasma viral load			
Equal or greater than 10,000 vs. Less than 10,000	1.15	(-5.10, 7.40)	0.718

Variable	Unadjusted		<i>p</i> -value
	Regression Coefficient	95% CI	
Current CD4 cell count <i>n</i> (%) Equal or greater than 350 cells/mm ³ vs. Less than 350 cells/mm ³	-1.70	(-4.56, 1.16)	0.245
Depressive symptoms <i>n</i> (%) High vs. Low	14.00	(11.40, 16.61)	<0.001
Perception of neighborhood problems (per 10 score increment) (higher=worse)	1.21	(0.66, 1.76)	<0.001
Perception of neighborhood cohesion (higher=worse)	-2.13	(-2.92, -1.34)	<0.001
Perception of relative standard of living <i>n</i> (%) About the same vs. Worse off	-7.94	(-11.40, -4.49)	<0.001
Better off vs. Worse off	-11.11	(-14.84, -7.39)	<0.001
Quality of life (per 10 score increment) (higher=better)			
Overall function	-3.35	(-3.91, -2.78)	<0.001
Life satisfaction	-3.53	(-4.19, -2.86)	<0.001
Health worries	-4.36	(-4.85, -3.87)	<0.001
Financial worries	-2.82	(-3.30, -2.33)	<0.001
Disclosure concerns	-5.20	(-5.74, -4.67)	<0.001
Provider trust	-0.89	(-1.73, -0.06)	0.087

Table 3

Multivariable linear regression model between self-perceived HIV-related stigma and the study variables of interest.

Variables	Adjusted		<i>p</i> -value
	Regression Coefficient	95% CI	
Education <i>n</i> (%)			
Equal or greater than high school graduation vs. Less than high school graduation	-3.05	(-5.16, -0.93)	0.005
Quality of life (per 10 score increment) (higher=better)			
Overall function	-0.90	(-1.47, -0.34)	0.002
Health worries	-2.11	(-2.65, -1.57)	<0.001
Financial worries	-0.67	(-1.12, -0.23)	0.003
Disclosure concerns	-4.12	(-4.63, -3.62)	<0.001
Perception of neighborhood cohesion (higher=worse)			
	-0.80	(-1.39, -0.21)	0.008
Perception of relative standard of living <i>n</i> (%)			
About the same vs. Worse off	-3.58	(-6.17, 0.99)	0.007
Better off vs. Worse off	-5.30	(-8.16, -2.44)	<0.001