Anonymous HIV Testing: What Does it Mean in Policy and Practice? A Case Study in Newfoundland and Labrador, Canada

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HIV infection is not a legally notifiable disease at the national level in Canada; however, provincial and territorial officials voluntarily undertake notification to the Public Health Agency of Canada. A case study involving four community-based sites in Newfoundland and Labrador found that the absence of clear legislation concerning HIV testing presented challenges for nurses who had to interpret and comply with provincial legislation and agency policy while meeting the needs of test-seekers. This ambiguous messaging is part of other conflicting information about the availability of anonymous HIV testing that, along with other factors, may contribute to under-testing and under-diagnosis in the province. From a social justice perspective, developing a national HIV strategy and amending legislation to facilitate anonymous HIV testing might provide clearer direction to nurses and agencies, and promote public health by improving service delivery and increasing testing in under-tested, higher-risk-taking populations.

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HIV is a preventable, sexually transmitted infection that causes immune dysfunction and for which there is currently no known cure. The United Nations Working Group on AIDS and the World Health Organization advanced a voluntary counseling and testing (VCT) model that was adopted in 2006 by the Public Health Agency of Canada (PHAC, 2006b). The goals of VCT are to prevent disease transmission and promote health in HIV-infected and higher-risk-taking populations through improved access to counseling and safe, informed, and confidential testing. There are three VCT options: (a) nominal/name-based, (b) non-nominal/nonidentifying, and (c) anonymous (PHAC, 2007; 2010). These options are differentiated by the type of personal information collected, the coding system used to label the specimen sent to the laboratory for testing, and the options for recording and reporting test results (PHAC, 2010).

Our initial observations in 2008 suggested that there were inconsistencies among government reports, academic literature, and public information about the availability of HIV testing options in a small urban center in Newfoundland and Labrador (NL). We suspected that test-seekers might experience similar confusion. We coined the more inclusive term, test-seeker, to avoid labels such as patient or client to describe individuals looking for HIV information and services, similar to the way in which Kodner and Spreeuwenberg (2002) referred to care-seekers in a community health services context.

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To explore ambiguous messaging about HIV testing options, we designed a case study to compare provincial legislation and agency policy documents with reported practices described by front-line workers and administrative leads at four community-based sites. We wanted to know if anonymous HIV testing was permitted by legislation and available in NL, and how agency employees were negotiating the apparent contradictions between offering anonymous testing services and legislation that required name-based reporting. We adhered to the social constructivist tradition that is characterized by an emergent design, context-specific inquiry, and inductive data analysis. Our thematic content analysis of 63 documents and semi-structured interviews with seven agency employees revealed some of the practical challenges facing nurses and others who must comply with provincial legislation while meeting the needs of test-seekers. We used a social justice lens to explore this “legal-regulatory limbo” (Walsh, 2007, p. 1) and the adequacy of policies under which HIV testing was being conducted. Our study highlights the need for a national HIV response strategy to address local variations across Canadian jurisdictions. Actionable messages for improving service delivery and increasing testing will be helpful to nurses and decision-makers in Canada and the United States, where under-testing among higher-risk-taking populations remains a serious public health concern.

HIV Testing Options and Name-Based Reporting

Constitutional responsibility for the design, management, and delivery of health care and health services in Canada has historically been considered a matter of local rather than national concern (Wilson, 2004). Therefore, the regulation of public health services falls under provincial jurisdiction. This means that each province and territory is responsible for developing and enacting legislation to prevent the spread of communicable diseases including HIV.

The PHAC adopted the VCT model in 2006 and defined three HIV testing options: nominal/name-based, non-nominal/nonidentifying, and anonymous (PHAC, 2007; 2010). Nominal/name-based testing requires test-seekers to provide personal information when requested by the care provider, such as name and provincial medical care plan number (PHAC, 2010). The amount of information collected varies by Canadian jurisdiction. This information is then used to label specimens sent to the laboratory for testing. Test results are recorded on the test-seeker’s health care record. In NL, if the test result is positive, the care provider is obligated by law to notify public health officials and report other information including name, age, sex, and address of the test-seeker (Communicable Diseases Act, Chapter C-26, 1990).

The procedure for non-nominal/nonidentifying testing also varies by jurisdiction and, like the nominal option, may require collection of the test-seeker’s name and medical care plan number, among other information. The provider uses an alphanumeric code or other identifier to label the specimens sent to the laboratory (PHAC, 2010). Test results are recorded in the test-seeker’s health care record. As with the nominal testing option, the care provider is legally required to notify public health officials if the test result is positive.

In the case of anonymous testing, information such as the test-seeker’s age, gender, HIV-related risk factors, and ethnicity may be requested depending on the province or territory or particular test site in which the test is ordered and/or collected (PHAC, 2010). The test is ordered and recorded using a code as the identifier, as the care provider does not request the identity of the test seeker. This means that the care provider may visually identify the person who was tested but would be unable to link the test result to that person. Consequently, test results could not be recorded on the test-seeker’s health care record.

There is notable variation in how Canadian provinces and territories approach anonymous testing, name-based reporting, partner notification, and contact tracing (Jurgens, 2001). Although HIV infection is not legally notifiable at the national level, notification to the PHAC is voluntarily undertaken at the provincial and territorial level on a non-nominal basis (PHAC, 2007; 2010). Thus, the interpretation and application of name-based reporting legislation and the decision to offer anonymous testing is determined in each province and territory. As O’Byrne (2011) pointed out, this has ethico-legal implications for nurses and other health care professionals in fulfilling