



Association of disclosure of HIV status with medication adherence



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ABSTRACT

Objective: Disclosure may affect adherence to antiretroviral treatment. In a medication adherence program, this cross-sectional study describes disclosure, perceived reaction after disclosure, living situations, and the relationship of disclosure with antiretroviral adherence.

Methods: A combination of a questionnaire to measure disclosure and longitudinal electronic monitoring of medication adherence was used.

Results: A total of 103 out of 159 eligible patients gave informed consent. The characteristics differed between participants and nonparticipants (race, education, sexual orientation, medication adherence). Thirteen participants did not disclose their HIV status. Seventy-three (81%) participants judged the reaction after disclosure positive. Among the 62 participants cohabiting, 52% disclosed to all co-residents. Adherence was high (median 100%). HIV disclosure was negatively associated with adherence, when disclosing to the mother (OR=2.46, p-value=0.086) and to siblings (OR=2.89, p-value=0.029). Living alone was associated to a lower adherence than cohabitation (Rate Ratio=1.42, p-value=0.007).

Conclusion: HIV disclosure and adherence are sensitive issues, which may explain the reason for refusal. Nonparticipants may be those with the most difficulties disclosing.

Practice implications: An unbiased collection of sensitive information, as HIV disclosure, is a difficult task. A cohort design, with research data collected systematically by a trusted healthcare provider, may better describe the association between adherence and disclosure.

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1. Introduction

Disclosure of HIV diagnosis is a complex and emotionally charged decision involving numerous factors, including the length of time since the HIV diagnosis and the patient's social network. Sex partners are often the first to receive disclosure, before friends and family members. Full disclosure to children often occurs slowly as the children age [1–3]. However, not everyone will eventually disclose their HIV status; approximately 10% of patients will never talk about their medical condition [4].

Prior to disclosure, patients must first balance the positive and negative consequences of this action. These consequences depend on the patient's support system and own emotional goals [5,6]. For example, because HIV is still largely stigmatized, disclosure of an

HIV-positive status could lead to rejection and stigmatization of a patient, sometimes even by his or her family. In contrast, the patient might desire the honesty and support that may accompany disclosure. Studies in American women have shown that patients who choose to disclose have more social support, less depression, better coping strategies and no regrets regarding the disclosure [7,8]. The desire to disclose is not solely for personal reasons because the patient is compelled to disclose to protect close relatives and sex partner(s) [1,2,8].

The association between disclosure and medication adherence is not well established in the literature. It is complex and probably mediated by psychological and emotional processes [9–11]. Positive social support and consequently disclosure are both needed to positively impact medication adherence [9]. Indeed, poor social support may negatively impact medication adherence [6]. Likewise if disclosure increases social support, outcomes of HIV infection tend to improve whereas they worsen when support decreases [5]. Similarly, adherence may be more difficult when patients want to hide their status from others, making it difficult at

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times to take the medications as prescribed [12]. Hiding medication or hiding medication intake contribute to treatment interruptions [12].

Taking medication daily is a real challenge for patients on chronic treatments, but it is crucial to reach therapeutic goals. In HIV-positive patients, the daily medication regime entails taking oral combination antiretroviral drugs to suppress the viral load, avoid resistance and prevent the spread of the virus in the community [13–18]. Medication adherence behavior is influenced by a multitude of factors, which are classified by the WHO into 5 different dimensions: patient-related, condition-related, therapy-related, socio-economic and health system-related factors [19,20]. Disclosure (defined as the process of revealing one's condition) is a patient-related dimension (e.g., influenced by the patient's perception of stigma and mental health), but it is also a condition-related dimension (e.g., disclosing HIV is more complex than disclosing chronic diseases such as hypertension or diabetes). Disclosure is also linked to social factors (e.g., race and society).

To support chronic patients' medication adherence across all 5 WHO dimensions, the pharmacy of the Department of Ambulatory Care & Community Medicine in Lausanne, Switzerland, implemented a medication adherence program in HIV in collaboration with physicians and nurses in 2004 [21,22]. In the program, a large number of patients mentioned (among other factors) both the presence or absence of social support and disclosure as a facilitator or barrier to medication adherence. Some patients described taking their antiretroviral treatment only when alone and hiding their treatment in a strategic place (e.g., under a pile of clothes in the rear of a closet, in a locked suitcase under the bed, or in the cellar). Patients also expressed different attitudes regarding disclosure of their HIV condition.

To better comprehend whether our HIV+ cohort population taking part in the adherence program has to hide antiretroviral treatment from others, we systematically describe the extent of participant disclosure, including their demographics, living arrangements and perceived reaction towards disclosure, and investigate whether an association exists between medication adherence and HIV disclosure.

2. Methods

2.1. Study design and participants

We administered a cross-sectional questionnaire among participants of an interdisciplinary medication adherence enhancement program. This program is described elsewhere and explores daily medication adherence through electronic monitoring and brief repeated motivational interviews. It is run by community pharmacists in collaboration with the medical team [23].

All HIV patients who were 18 years and older, fluent in French and had participated for more than 30 days in this interdisciplinary adherence enhancement program between October 2012 and June 2013 were invited to participate.

The protocol was approved by the Ethics committee of Canton de Vaud, Switzerland. Informed consent was obtained from all participants.

2.2. Procedures

After each consecutive routine adherence program visit, a research assistant independent from the clinical staff presented the study to the patient and asked for informed consent. Then, he administered the questionnaire. Reasons for refusing or postponing participation in the study were systematically recorded. Electronic adherence data were extracted from the adherence

program database. Socio-demographic and clinical data were extracted from the Swiss HIV Cohort Study (SHCS) database.

2.3. Measurement

2.3.1. Questionnaire

The questionnaire was a 10-item survey developed for the purpose of this study because no existing instrument with established psychometric properties was available at the time of the study. The different groups of interest for disclosure were established according to the literature and the SHCS [5,8,24–26]. A question was added to explore specifically whether patients had to hide to take their antiretroviral treatment. Eventually, our questionnaire contained 3 dimensions of interest: the extent of disclosure, the attitudes of disclosure recipients and the patient's living situation. For each question, participants had the alternative option of not responding, marking the question as inapplicable, or marking that they did not know. The questionnaire took approximately 10 min to complete.

The extent of disclosure was explored through two questions. The first asked "How many people did you disclose to (healthcare professionals excluded)?" (possible answers were 0, 1, 2, 3–5, 6–10 or >10). The second question reviewed 14 different groups of people to whom participants could have disclosed. For each group, participants indicated if such a group existed within their social environment and then whether they had disclosed to one or more members of the group. The groups included spouses, stable sex partners (>6 months), occasional sex partners, mothers, fathers, siblings, children, other relatives, close friends, religious leaders, colleagues, bosses, acquaintances, and HIV support groups.

Two questions assessed the attitudes of the disclosure recipients. The first was a general question: "Did people you disclosed to react: always negatively, negatively most of the time, positively most of the time, or always positively?" The second question asked whether the participants' significant others were disclosed to and their current attitude (positive, neutral, or negative).

The living situation included the number and groups of people the participant lived with as well as the percentage of people among those to whom the patient had disclosed his/her HIV status. Possible responses were living alone, with spouse, with sex partner, with children <18 years, with relatives, with friends or roommates, or in an institution (e.g., clinic or jail). Participants were permitted to choose more than one answer. Then, the participants were asked about the total number of people living at home and the total number among those people to whom the patient had disclosed.

Because the reaction to disclosure evolves with time, we added a question evaluating the time of first disclosure (<1 month, 1–3 months, 3–6 months, 6–12 months or >12 months) to analyze whether the first disclosure occurred recently or in the past and whether the time line differentially impacted adherence. The questionnaire was reviewed by all of the pharmacists of the adherence enhancement program, and changes were made until a consensus was reached. Then, the questionnaire was tested by 3HIV-positive patients who were not participating in the medication adherence program to verify the comprehension of each item and the time needed for survey administration. Minor changes were made based on the results of this testing.

2.3.2. Adherence data

Because participants were taking part in the adherence enhancement program, adherence data were measured from all of them using electronic monitors (MEMS SmartCap™, Medication Event Monitoring System, AARDEX, MWV Healthcare, Switzerland) [27]. Each drug of the antiretroviral therapy was

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