

Psychosocial Profile and Lived Experience of HIV-infected Long-term Nonprogressors: A Mixed Method Study

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The goal of this mixed method study was to describe the psychosocial profile of HIV-infected persons identified as long-term nonprogressors (LTNP), and their experiences of nonprogression. Data were collected from 24 participants with a mean age of 48 years and a mean duration of infection of 14 years. Results show rather moderate levels of anxiety and depression symptoms and a modest mean score of social support. Participants adapted by using acceptance, positive restructuring, and active coping strategies. Seven themes marked the experience: (a) reacting to announcement and dealing with diagnosis, (b) valuing interpersonal relations and well-being, (c) making changes in life, (d) coping with stress, (e) dealing with health care, (f) beliefs about reasons for nonprogression, and (g) living positively while dreading progression. The findings enrich a field of knowledge that has had little attention so far and shed light on the psychosocial profile of LTNP and their experiences of nonprogression.

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There have been major advances in our knowledge of the mechanisms of HIV infection over the years. It has been recognized that the virus has no biological

latency period during infection (Cohen, 2011). Moreover, the advent of antiretroviral therapy (ART) has contributed to slowing down the progression of the disease significantly, improving life expectancy and quality of life of persons living with HIV (PLWH; Wood et al., 2006). Although the therapeutic effects of treatment are appreciable, the progression of the infection is still highly variable from one individual to the next as a function of a multitude of factors that can act independently or synergistically (Chatterjee,

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2010; Valcke, 2009). It is important to point out that, without treatment, the progression to AIDS for PLWH occurs, on average, within 8–10 years of infection. However, approximately 5% to 10% of those infected will not progress to AIDS even after 10 years despite the complete absence of ART (Cruz, Amorim, Oliveira, Speranza, & Costa, 2013; Grabar et al., 2009). Individuals who maintain a normal spectrum of clinical profiles (immunologic and virologic) over time despite HIV infection can be categorized as a function of these clinical parameters as slow progressors, long-term nonprogressors (LTNPs), HIV controllers, and elite controllers.

To date, studies conducted on these groups have sought to understand the biological factors that might account for the apparent lack of progression. Most studies have thus focused on examining their immunologic (O'Connor, Holmes, Mulcahy, & Gardiner, 2007), genetic (Pereyra et al., 2008), and virologic (Oette et al., 2006; Rangel et al., 2009) characteristics with the aim of improving treatments and developing a vaccine (Migueles & Connors, 2010). However, little is known about the psychosocial profile and experience of individuals who live with a virus that can at any time progress to full-blown disease. There is, at present, a void of information on the matter, as the few existing studies in this regard are outdated.

To our knowledge, only two studies have explored the lived experience of these individuals in connection with the behavioral and psychosocial factors that contribute to their nonprogression. In a study by Troop et al. (1997), nonprogressors ($n = 62$) pointed to positive thinking, a sense of control, and lifestyle as reasons/beliefs contributing to their good prognosis. In the other study, Barroso (1999) reported that, according to a sample of 25 persons identified as LTNPs who considered the infection as a chronic disease, looking after one's physical and mental health while turning to spirituality influenced the atypical course of their infections. This is virtually all that is known about the psychosocial factors and lived experience of nonprogressing PLWH.

More up-to-date knowledge of the reality and challenges faced by nonprogressors would allow health professionals to target interventions more precisely and to accompany these people more effectively over the course of their health experi-

ences. Against this background, we undertook a study aimed at describing the psychosocial profile of these individuals and their lived experience of HIV nonprogression. To this end, we assessed the level of anxiety and depression, coping strategies used, and perceived social support. These variables are of interest to nursing from the perspective of clinical intervention.

Methods

Design

We collected quantitative and qualitative data from participants in a cohort study of HIV-infected LTNP over a 5-year period (Kamya et al., 2011). For the purposes of our study, we analyzed the data collected at one point in time, namely, the initial measurement, in order to describe the psychosocial profile and the lived experience of a population about which very little is known. A mixed method was used in order to gain a deeper understanding of the profile of this sample by establishing relationships between quantitative and qualitative results (Miles & Huberman, 2003). The study was approved by the Research Ethics Board of the Research Center of the Centre Hospitalier de l'Université de Montréal, and informed consent was obtained from each participant at cohort entry.

Sample

The sample consisted of 24 HIV-infected persons identified as LTNP, derived from six medical centers across Quebec. LTNPs are able to maintain stable CD4+ T-cell levels within the normal healthy range (500–1650 cells/mm³) for a prolonged length of time (7 to 15 years) and remain asymptomatic in the absence of ART (Kemal et al., 2008; Madec et al., 2009; Okulicz et al., 2009). Participants met the following inclusion criteria: HIV infected as determined by enzyme-linked immunosorbent assay and confirmed by Western blot, CD4+ T cell count above 500 cells/mm³ for at least 7 years following diagnosis without ART, and at least 16 years of age. The following exclusion criteria were applied: pregnant and presently or previously on ART.

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