



Living With Constant Suffering: A Different Life Following the Diagnosis of HIV

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We used grounded theory in semi-structured interviews with 32 persons living with HIV (PLWH) in Barcelona, Spain, and found that PLWH live with constant suffering, a core category combining four realities: I need help; My life is constantly controlled; I have a new imposed life; and I have an uncertain reality. Participants described being constantly controlled by health policies and medications. They thought their lives were in the hands of others and that a new life, characterized by the constant fear of stigma, had been imposed on them. They felt they were losing freedom and vitality, as many questions remained unanswered, causing uncertainty related to health and public life. Emotional help was obtained mainly from peers and social networks. Our emergent theory shows a disruptive experience, with serious consequences to individual and social development. Health care has to focus on the real needs of PLWH to reduce suffering and uncertainty.

(Journal of the Association of Nurses in AIDS Care, 26, 613-624) Copyright © 2015 Association of Nurses in AIDS Care

Key words: *AIDS, care, grounded theory, HIV, nursing, stigma, suffering*

Globally, the number of persons living with HIV (PLWH) has been decreasing, but more than 34 million people are infected (Joint United Nations Programme on HIV/AIDS, 2013). In Spain,

approximately 130,000 people live with HIV, and 30% are unaware that they are infected (Carnicer Pont, Vives Martín, & Casabona Barbarà, 2011). As in most industrialized countries, medical specialists provide HIV clinical monitoring and drug management in hospitals and clinics. Other professionals involved in providing care include nurses, psychologists, nutritionists, and social workers, and an extensive network of associations offer testing, counseling, and community interventions.

An HIV diagnosis generates many societal questions, especially for those who seek to understand their diagnosis and for the families of PLWH. Living with HIV is associated with a wide range of feelings, such as anxiety or emotional stress (Hult, Wrubel, Bränström, Acree, & Moskowitz, 2012), fear (Land & Linsk, 2013), hope (Avornyo, 2014; Walstrom et al., 2013), desperation and despair (Kylmä, Vehviläinen-Julkunen, & Lähdevirta, 2001), uncertainty (Brashers et al., 2003; Penrod, 2007),

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vulnerability (De Santis & Barroso, 2011), and a sense of guilt and internalized stigma (Herek, Saha, & Burack, 2013). In a qualitative meta-synthesis, Barroso and Powell-Cope (2000) reported that the experience of living with HIV was built around six encompassing metaphors: finding meaning in HIV, shattered meaning, human connectedness, focusing on the self, negotiating health care, and dealing with stigma.

Peculiar to HIV, a multitude of “unknowns” add to the stigma associated with the infection and, when attached to the infected, can lead to failed therapies, depression, despair, and other psychosocial challenges (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013; Holmes & Winskell, 2013). Gaining an understanding about individual experiences and interpreting meanings in those experiences could lead to an understanding to fill the knowledge gap related to this phenomenon. Data reported in the literature regarding HIV infection are mostly focused on the biomedical perspective, including epidemiological studies, assessments of virology, control mechanisms to limit the illness and reduce its transmission, effectiveness of treatment, and management of the secondary side effects (Kazanjian, 2014). Many studies (e.g., Hult et al., 2012; Kremer, Ironson, Schneiderman, & Hautzinger, 2006) do not consider people as complex, heterogeneous, and subjective individuals. Therefore, knowledge about structural and conceptual change is needed in order to deeply understand stigma and the unknowns, and thus, offer relevant care.

Study Purpose and Design

The purpose of our study was to better understand the meaning of living with HIV in order to construct a substantive theory explaining the paths that link identified casual factors. Learning about the experience from subjective participant perspectives offers nurses insights into how to provide patient-centered care. Caring for people does not necessarily imply nursing care in the traditional way. Removing the stigma; understanding the denial, anger, and depression; and accepting the general significance of an individual’s own experiences can lead to tailored interventions. For this reason, clinical professionals and service organizations must focus on

providing individualized patient-centered care for HIV-infected clients.

The inductive qualitative methodology, Grounded Theory, was selected for the study. The main objective of this method is to generate theories that can explain studied phenomena through deep understanding of phenomena in a natural social context (Strauss & Corbin, 1990), and the Grounded Theory method best fit our desire to understand the complex social processes and to explore these unknown phenomena (Smith & Biley, 1997). We also chose the Grounded Theory approach because of its well-known descriptive, exploratory, and explicative properties (Strauss & Corbin, 1990), optimal for nursing use to contextualize care and better understand subjective experiences.

Our study was approved by the Ethics Committee of Parc de Salut Mar, Barcelona. Prior to being interviewed, all participants signed an informed consent form. The interviewer also explained the purpose and characteristics of the study and ensured confidentiality. To protect confidentiality and provide anonymity, a de-identified number was used for each transcript and interview report. In addition, participants were informed that interviews could be ended when they considered it appropriate.

We identified participants through theoretical sampling and the snowball method. Theoretical sampling is important for researchers seeking to develop a theory from emerging concepts by a repetitive process of collecting and analyzing data purposed to reach conceptual density (Strauss & Corbin, 1990). Memos were used to record analytics such as codes, intercode relationships, reflexive insights, decisions, and theoretical issues that should be explored in further interviews. Memo notes, as well as constant critical reflection with discussion among group members, helped us to achieve conceptual density, that is, dense, rich, and tightly linked categories (Strauss & Corbin, 1990).

The study was advertised through various HIV organizations. The only inclusion criterion for study participation was being HIV infected. Exclusion criteria included those HIV-infected people with severe deterioration of physical or mental health. Data were collected from March 2011 to February 2012, in Barcelona. A total of 32 semi-structured interviews were conducted, 16 performed online and 16

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