



# *HIV as Chronic Illness: Caregiving and Social Networks in a Vulnerable Population*

Javier Mignone, PhD

Paula Migliardi, MA

Carol Harvey, PhD

Jennifer Davis, BA

Lucia Madariaga-Vignudo, MA

Carla Pindera, MA, RN

*We sought to understand the support networks of people living with HIV (PLWH) in the Canadian cities of Winnipeg and Regina, particularly of their network of caregivers and with a focus on people from disadvantaged and/or stigmatized communities. Using a variation of the Photovoice method, 31 study participants took photographs of their everyday realities and were then interviewed. Among the findings was the heavy reliance on institutional caregivers and on nonhuman sources of support. There was evidence of peer-to-peer networks of care, but the strongest connections were with their formal caregivers. HIV as a chronic condition among disadvantaged and/or stigmatized groups requires paying special attention to informal and formal care dynamics and to where social or family networks cannot meet the basic needs. Honing in on and enhancing these features through programs and services can only improve the situation of stigmatized yet hopeful and resilient PLWH.*

(Journal of the Association of Nurses in AIDS Care, 26, 235-245) Copyright © 2015 Association of Nurses in AIDS Care

**Key words:** caregiving, HIV, support network, vulnerable populations

The transition of HIV from an acute to a chronic condition has had implications for public policy. The initial plague model of HIV was, by the mid 1980s, being redefined to a chronic disease model,

where the focus of care shifted to long-term management and living with HIV (Beaudin & Chambré, 1996). As Strug, Grube, and Beckerman (2002) indicated, more than 80% of those diagnosed with HIV during the initial years of the epidemic died within 2 years. What was a terminal illness has become, at least for industrialized countries, a long-term chronic illness (Linsk, 2011). Consequently, there has been a substantial shift in health and social support needs for people living with HIV (PLWH).

In Canada, PLWH have access to highly active antiretroviral therapy and information about healthy

*Javier Mignone, PhD, is an Associate Professor, Department of Family Social Sciences, Faculty of Human Ecology, University of Manitoba, Winnipeg, Manitoba, Canada. Paula Migliardi, MA, was a Community-Based Research (CBR) Facilitator of the Prairie HIV CBR Program (Canadian Institutes of Health Research funded) at the time of this study and is currently a Research and Evaluation Coordinator of the Sexuality Education Resource Centre in Winnipeg, Manitoba, Canada. Carol H. Harvey, PhD, is a Professor and Senior Scholar, Department of Family Social Sciences, Faculty of Human Ecology, University of Manitoba, Winnipeg, Manitoba, Canada. Jennifer Davis, BA, was, at the time of this study, a Research Project Coordinator at Nine Circles Community Health Centre, Winnipeg, Manitoba, Canada. Lucia Madariaga-Vignudo, MA, is a community-based researcher, Winnipeg, Manitoba, Canada. Carla Pindera, MA, RN, is the Manager of Clinical Programs at Nine Circles Community Health Centre, Winnipeg, Manitoba, Canada.*

living with the illness. For the most part, they are living longer and healthier lives, which has implications not only to them but also to those persons who care for them. As [Wight \(2000\)](#) suggested, HIV caregiving has become, in some aspects, similar to that of chronic care for the elderly, in the sense that it involves caregiving over many years and is often provided by caregivers with failing health themselves. A major trend in the treatment of PLWH has been the shifting of their care away from hospitals or clinics into the home ([Wrubel & Folkman, 1997](#)). In this light, [Wrubel and Folkman \(1997\)](#) have argued that the responsibility assigned to informal caregivers such as family members and friends would undoubtedly increase. However, this may not be clearly the case for PLWH who are from vulnerable populations. Our study sought to better understand the support networks of those from disadvantaged communities in the Canadian cities of Regina and Winnipeg.

### Caregiving and Social Support

Key aspects of HIV as a chronic disease relate to social support and caregiving. Social support is generally understood intuitively as the assistance provided by others in a challenging life circumstance ([Swendeman, Ingram, & Rotheram-Borus, 2009](#)). It is a notion related to that of social networks, although more specifically in relation to ties of family members or others of significance, including friends and neighbors. A subjective aspect of social support is the perception of feeling valued and cared for, and having trusted people available if needed. Empirical evidence has suggested that social support is beneficial for health ([Cohen & Janicki-Deverts, 2009](#)). In particular, positive coping by PLWH has been associated with good social support ([Stowers-Johansen & Kohli, 2012](#)).

Caregivers can be significant sources of social support. Caregivers can be defined as those who act as primary and/or significant providers of care to PLWH. A caregiver may or may not also be infected with HIV. Care can include, but may not be limited to, assistance in the emotional, social, physical, and spiritual realms ([Thoits, 2011](#)). Care can consist of social support, food preparation, and hands-on care, such as helping the partner move and preparing comfortable

beds ([Beals, Wight, Aneshensel, Murphy, & Miller-Martinez, 2006](#); [Fiori & Jager, 2012](#)). Caregivers can also spend significant amounts of time advocating on behalf of PLWH, in hospital and other administrative offices.

Much of the literature on caregiving focuses on the tasks of caregivers, for instance, domestic work and personal care. However, solely focusing on the tasks performed by caregivers does not capture particular aspects of the illness, nor does it take into consideration the characteristics of the care recipient and caregiver relationship ([Wrubel & Folkman, 1997](#)). Factors such as the clinical course of the illness, socioeconomic status, and lifestyles of PLWH are often neglected.

A further way of categorizing caregivers is to distinguish between formal and informal caregivers. Some authors define informal caregivers as persons who voluntarily provide assistance during an illness ([Knowlton et al., 2011](#)). Informal care for affected persons can be provided by a friend, a neighbor, a family member, or a partner, for example. The caregiver is considered informal because the relationship between the caregiver and the person in care is not established or regulated by any organization or employer ([Knowlton et al., 2011](#)). Likewise, the parameters for the care relationship may change regularly and indefinitely. In contrast to informal caregiving, formal caregiving is more official in nature. Formal caregivers may be employees or volunteers in organizations that serve PLWH, or they may be employed directly by HIV-infected individuals and/or their family members and friends.

Caregiving research has, for the most part, been centered on caregivers of the elderly and of the middle class ([Fiori & Jager, 2012](#)). Very few studies have examined informal caregiving for low-income PLWH. In many circumstances, informal caregivers come from the same ethnic, cultural, and socioeconomic milieu as the HIV-infected individuals to whom they offer care ([Knowlton, 2003](#)). For instance, a study found that among a group of low-income African Americans living with HIV there were no racial, educational, income, and hospitalization differences of note between the care receivers and the caregivers ([Knowlton, 2003](#)). This suggests that PLWH who belong to disadvantaged communities rely on people with similar backgrounds.

Download English Version:

<https://daneshyari.com/en/article/2659780>

Download Persian Version:

<https://daneshyari.com/article/2659780>

[Daneshyari.com](https://daneshyari.com)