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# The health literacy needs of women living with HIV/AIDS

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## ABSTRACT

Women in Sub-Saharan Africa are disproportionately affected by the virus and constitute 60% of the total HIV/AIDS infections in this region. Current recommendations endorse the involvement of people living with HIV in the development of programmes for people living with the virus. The purpose of the study was to explore and describe the health literacy needs of women living with HIV. The research design was qualitative, explorative, descriptive and contextual. After women living with HIV/AIDS were sampled purposively, semi-structured interviews were conducted with eight women and qualitative content analysis done. The findings revealed that the women expressed a need to increase their knowledge about HIV/AIDS. The knowledge they needed ranged from basic pathophysiology about HIV/AIDS, to the impact of HIV/AIDS on their health, to an awareness of the modes of HIV transmission and methods of protecting others from being infected. Other important health literacy needs related to self-care and correct antiretroviral use. A need for psychosocial skills was also identified in order for women to build and maintain their relationships. Recommendations were made for nursing practice, education and further research, based on these findings.

## ABSTRACT

Vroue in Sub-Sahara-Afrika word buite verhouding geraak deur die virus en vorm 60% van die totale MIV/VIGS - infeksies in hierdie streek. Huidige aanbevelings onderskryf die betrokkenheid van mense met MIV/VIGS in die ontwikkeling van MIV/VIGS programme vir mense met die siekte. Die doel van hierdie studie was om die gesondheid geletterdheid behoeftes van vroue met MIV te verken en te beskryf. Die navorsing was kwalitatief, verkennend, beskrywend en kontekstueel. Vroue met MIV/VIGS is doelgerig geïdentifiseer en semi-gestruktureerde onderhouds is met agt vroue gevoer waarna kwalitatiewe inhoudsanalise gedoen is. Die bevindinge het getoon dat die vroue 'n behoefte het om hul kennis oor MIV/VIGS uit te brei. Die kennis wat hulle benodig wissel van basiese patofisiologie oor MIV/VIGS, die impak van MIV/VIGS op hul gesondheid, 'n bewustheid van MIV-oordrag en maniere om naasbestaendes teen besmetting te beskerm. Ander belangrike gesondheid

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geletterdheid behoeftes het betrekking tot self-sorg en korrekte antiretrovirale gebruik. 'n Behoefte aan psigososiale vaardighede is ook geïdentifiseer sodat vroue verhoudinge kan behou en bou. Aanbevelings gebaseer op hierdie bevindinge is vir die verpleegpraktyk, verpleegonderwys en verdere navorsing gemaak.

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## 1. Introduction

Women can play a key role in the response to HIV/AIDS; in sub-Saharan Africa, they are disproportionately infected and affected by HIV/AIDS (Joint United Nations Programme on HIV/AIDS [UNAIDS., 2012a, p. 66). Women play a pivotal role in the prevention of mother-to-child transmission and are, more often than men, the caregivers for those living with HIV/AIDS (Erhardt, Sawires, McGovern, Peacock, & Weston, 2009, p. 99). It is therefore crucial that women be involved in the response to HIV/AIDS as has been pointed out: “When women speak out, we must listen carefully, and act with solidarity and commitment to transform words into action” (Bachelet, Gatdi-Mallet, & Sidebé, 2012, p. 6). This article gives voice to a small group of women living with HIV/AIDS on the health literacy needs they see as necessary for themselves and others living with HIV/AIDS to know.

### 1.1. Background

Globally, for women of reproductive age, HIV/AIDS is the leading cause of death (World Health Organisation [WHO], 2009, p. 27). Worldwide almost half (49%) of all people living with HIV are women (UNAIDS., 2012b, p. 10). In sub-Saharan Africa, however, women constitute nearly 60% of all people living with HIV (UNAIDS., 2012a, p. 66). In the case of young women (between the ages of 15 and 24 years) in sub-Saharan Africa, 3.1% are living with HIV versus 1.3% of young men (UNAIDS., 2012a, p. 89). Of all HIV-positive pregnant women, 92% live in sub-Saharan Africa (UNAIDS., 2012a, p. 41). These statistics point to the disproportionate HIV infection of women (especially young women) in sub-Saharan Africa, which is a serious concern for women's health and the health of their children (UNAIDS., 2012a, p. 41), families, and the community.

This disproportionate infection of women is due to gender inequality and women's physiological vulnerability during sexual intercourse (UNAIDS & WHO, 2009, p. 21). In addition to their vulnerability to HIV infection, women bear the greatest proportion of caregiver responsibilities for people living with HIV/AIDS due to their traditional roles of caring for sick family members and making health-related decisions for their families (Erhardt et al., 2009, p. 99). In spite of the significant impact that HIV/AIDS has on the female population, UNAIDS. (2012a, p. 14) reports gaps in young women's basic knowledge of HIV and its transmission. The organisation reports that in their multi-country study, in 26 of the 31 countries that

participated in the national surveys, fewer than 50% of young women had complete and accurate knowledge about HIV.

Health education plays an important role in expanding knowledge, but research shows that a variety of skills and competencies are necessary to understand and utilise health knowledge (Zarcadoolas, Pleasant, & Greer, 2005, p. 196). These skills and competencies include reading and understanding medication labels, calculating medication intervals, and following basic self-care instructions, all of which combine to indicate health literacy.

Health literacy refers to the ability to read health-related material, obtaining and applying information related to health matters (Finset & Lie, 2010, p. 1), and facilitating health and health-related decision-making processes (Baker, 2006, p. 881). Zarcadoolas et al. (2005, p. 197) explain that health literacy is dependent on fundamental literacy aspects such as reading, speaking, writing and interpretation, but it also relies on an awareness of current developments in health, science and public issues. The customs and beliefs of an individual, which influence their ability to interpret and act on health information, are also considered instrumental in health literacy (Zarcadoolas et al., 2005, p. 197).

Competent healthcare providers and health information based on an assessment of the client's needs improve health literacy and the autonomy of the client. Autonomy is reflected in the development of knowledge and skills that allow independent decision-making in healthcare (Zarcadoolas et al., 2005, p. 196). This autonomy is especially vital for women living with HIV/AIDS to improve their health outcomes and consequently the health outcomes of their families and the larger community.

### 1.2. Problem statement

The 2009 AIDS Epidemic Update recommends the involvement of people living with HIV in the development of HIV-related programmes (UNAIDS & WHO, 2009, p. 9). Despite the pivotal role of women in addressing the HIV pandemic, women living with HIV/AIDS have not been fully involved as leaders in designing and implementing HIV prevention programmes (UNAIDS., 2012a, p. 15).

The health education and literacy needs of healthcare workers and caregivers working with people living with HIV/AIDS have been described (Maneesriwongul et al., 2004), but few studies involve people living with HIV/AIDS in describing their own health literacy needs. A study by Nokes, Kendrew, Rappaport, Jordan and Rivera in 1997 assessed the learning needs of HIV-positive persons regarding issues relevant to living with HIV/AIDS. The participants were predominantly

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