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Zamri Hassan, Zaimuariffudin Shukri Nordin, Collin Jerome

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Buttoned the Unbuttoned: Brief Insights from People Living with HIV/AIDS and Their Caregivers

Zamri Hassan

Faculty of Social Sciences, Universiti Malaysia Sarawak, Malaysia

Zaimuariffudin Shukri Nordin

Faculty of Cognitive Science and Human Development, Universiti Malaysia Sarawak, Malaysia

Collin Jerome

Faculty of Language and Communication, Universiti Malaysia Sarawak, Malaysia

Abstract

The number of people infected with HIV continues to increase globally, despite recent advances in treatment and prevention. Statistics show that an estimated 36.9 million people around the world were living with HIV in 2014, with 2 million people became infected with the illness (UNAIDS, 2014). To aggravate matters, people living with HIV/AIDS (PLWHAs) continue to face many forms of stigmatization throughout their lives, despite the various measures or initiatives taken by themselves and others to minimize them. However, little has been done on examining the creation of newly invented identities as an equally important measure/initiative taken by PLWHA and caregivers, to lessen stigmatization and to gain the support that they direly needed. Moreover, little is known about the awareness of human rights among PLWHA and their caregivers. Using ethnographic methods to collect data in the form of face-to-face interviews and participant observations, the proposed study explores the newly invented identities created by PLWHAs and their caregivers, how they develop and express them, and the ways in which they integrate human rights awareness into the creation of these identities. Approximately 13 (N13) PLWHAs and caregivers mainly from the Kuching area were purposively selected. Findings revealed that, participants developed certain initiatives to reduce stigma; and they also portrayed low level of knowledge related to their rights. The outcomes were then translated into stigma reduction initiatives in which these initiatives can be deployed to minimize stigmatization and gain social support that are direly needed. This indirectly, tightened their rights for better living. The study also suggests some modifications in existing policies and programs both at local and national level so that to improve their quality of life in general.

Keywords: HIV, AIDS, Caregivers, Stigma