#### DISCOURSING

# HEALTH LITERACIES

## FOR HIV/AIDS EDUCATION

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Health literacies are an important tool for HIV/AIDS education which provides a space for students to use local literacy tools such as films, literature, and arts to explore ways of managing the HIV/AIDS virus in communities ravaged by the disease. HIV/AIDS affects the lives of millions of people in many African countries and requires a robust strategy by educators to tackle the epidemic and create safe spaces for students in schools and communities where young people face stigma and discrimination for having the virus or living with people who have the virus. In this paper, I will discuss how students in some African countries respond to locally manufactured HIV literacy educational tools produced by members of the community. I will make the case that it is important for schools to incorporate locally manufactured HIV/AIDS health literacy instruction into the curriculum; this would allow young people to engage with health literacies that are resonant of their embodied experiences.

Keywords: Africa, discrimination, health literacies, HIV/AIDS, school programs

Les littéracies en matière de santé constituent une ressource importante pour l'éducation relative au VIH/SIDA. Plus précisément, elles correspondent aux outils

litéraciques, comme les films, la documentation et les arts, qui permettent de se familiariser avec la façon de gérer l'épidémie de virus HIV/SIDA dans les communautés touchées par la maladie. Le VIH/SIDA affecte la vie de millions de personnes réparties dans un grand nombre de pays africains. Les éducateurs ont besoin d'une stratégie solide pour lutter contre l'épidémie et créer pour les étudiants des espaces sécuritaires dans les écoles et dans les communautés, où les jeunes atteints du virus ou qui vivent avec des personnes atteintes du virus sont victimes de stigmatisation et de discrimination. Dans le cadre de cet article, nous traiterons de la façon dont des étudiants de certains pays africains réagissent à l'offre de ressources éducationnelles sur les litéracies en matière de santé produites par des membres de leur communauté et offertes sur le marché local. Nous soulignerons qu'il est important pour les écoles d'inscrire le contenu de ces ressources dans le programme scolaire. Disposant de ces informations, les jeunes sont à même de se familiariser avec les litéracies en matière de santé, qui reflètent les expériences vécues dans leur contexte.

Mots-clés : Afrique, discrimination, HIV/SIDA, littéracies en matière de santé, programmes scolaires

HIV/AIDS literacies are an emerging public health and research field (Castro-Sánchez, Chang, Vila-Candel, Escobedo & Holmes, 2016). They perform an important role in the "rapidly developing multi-sectoral, global and national, strategies and programs aimed at reversing the current trends of the HIV pandemic" (Schenker, 2005, p. 1). HIV literacies play an important function in reducing HIV-related stigma and discrimination that prevents people living with

<u>HIV/AIDS</u> (PLWHA) from coming forward to be tested and to receive medicines for the management and treatment of the disease (Grossman & Stangl, 2013). The human immunodeficiency virus (HIV) is a disease that infects the cells of the human body, destroying the immune system and damaging its function. It is contagious, yet avoidable if the right precautionary steps are taken. Acquired immunodeficiency syndrome (AIDS) is the term applied to the most advanced stages of the HIV virus infection. According to the World Health Organization (WHO, 2016), it is the final stage of the lethal infectious disease and it is characterized by occurrences of more than 20 opportunistic infections or HIV-related cancers.

HIV/AIDS was first identified in 1981 when some young gay men in the U.S. succumbed to a rare form of opportunistic infection. It rapidly became one of the deadliest communicable diseases in recent history (Sharp & Hahn, 2011). Since its been identified, HIV/AIDS has infected more than 70 million people worldwide, and approximately 35 million people have died from the disease (WHO, 2017). WHO statistics point to the fact that Africa has the highest number of PLWHA. In 2016, 25.6 million people were living with HIV in Africa (WHO, 2016). In South Africa, 7.1 million people are currently living with HIV (AVERT, 2016). Locally generated health literacies are an important tool for curtailing the spread of HIV/AIDS epidemic in Africa, and they have been used to educate various groups of societies on how to manage and contain the disease (Mitchell, 2015; Mitchell & Smith, 2003). The following section shows how locally generated literacy tools such as songs, poetry, and storytelling can be used to teach students about the HIV/AIDS epidemic and reduce the stigma and discrimination that comes with living with the disease.

#### **Literature Review**

Health literacies can be defined as the degree to which people acquire, process, comprehend, and connect health-related information to their surroundings so as to make informed decisions about their well-being (Mackert, Champlin, Su, & Guadagno, 2015). The term health literacies has evolving meanings. It can be interpreted as the educational tools that people use to make appropriate health related decisions. Health literacies were initially used to signify an individual's possession of specific functional skills, including the ability to read text on food labelling and text on the packets of medicines (Corcoran, 2014). The use of the term is important in representing how health literacies can be reconciled with education, culture, and language to enable and empower people affected by the disease to take control of and manage their health and lives.

Health literacies are an important tool for children to acquire, and this is particularly the case where children live with the stigma of residing with parents or relatives who have HIV/AIDS. In 2015, an estimated 1.8 million children under the age of 15 years were living with HIV, only 49% of them had access to life-saving medicines (UNAIDS, 2016). Evidence from the U.S. has shown that health literacies are important mediators of HIV-related knowledge, behaviors and outcomes (Kalichman, Benotsch, Suarez, Catz, Miller & Rompa, 2000).

Schenker (2005) defines the link between health literacies and the management and prevention of HIV/AIDS as:

the capacity of individuals and/or communities to obtain, interpret and understand basic HIV/AIDS prevention, testing and care information, skills and services and the competence to use such information, skills and services to prevent HIV/AIDS infection and related stigma and discrimination, to know of and understand their HIV status and to enhance the physical, mental and social wellbeing of people living with HIV/AIDS. (p. 2)

Health literacies can be used to combat HIV/AIDS in a variety of ways. It gives people living with the virus a better understanding of the epidemic and provides them with the necessary tools to live longer and healthier lives (Mulwo & Chemai, 2015). The positive link between health literacies and HIV/AIDS management has led to calls for the integration of HIV/AIDS education into the curriculum in primary schools, secondary schools, as well as higher institutions. Between 2006 and 2008, a study was conducted by Mulwo and Chemai (2015) at three South African universities to determine the effective of various media in providing HIV/AIDS information to students. Media types included meetings and lectures, media channels, TV series, talk shows, posters, TV advertisements, articles in magazines and newspapers, leaflets, booklets, television news and radio news, radio advertisements, radio dramas, talk shows, the internet, banners, billboards, and campaigns. The study found that students in South African higher institutions were more likely to accept locally generated literary materials, and that they were suspicious of externally generate HIV/AIDS education materials. Specifically, students felt more comfortable receiving HIV/AIDS knowledge from communication channels created by their fellow students than those that they felt were foreign. Using locally generated literacy materials calls for the use of local songs, poetry and storytelling which are important aspects of many African cultures.

In a HIV/AIDS focused literacy workshop, Mitchell (2015) remembers organizing a project entitled *In my life: Youth stories and poems on HIV/AIDS* in

South Africa. The workshop was aimed at helping young people stay engaged and participate in a literary HIV/AIDS education campaign that emphasized "prevention, treatment and care" for people infected and affected by HIV/AIDS (Mitchell, 2006, p. 355). *In my life* involved a group of 14 young people aged between 14 and 18 from several secondary schools in Western Cape, South Africa. The purpose of the workshop was to launch general writings, a poetry book, and a video documentary about HIV/AIDS effects on students in their communities. The project was aimed at giving the participants a chance to create and reinforce their identity while living in communities affected by HIV/AIDS through visual and printed media. About the project, Mitchell (2006) writes:

it is a particular call to the whole area of language and literacy where issues of self-expression, and of participation and engagement, are already at the heart of what we do. Can we begin to think about a new literacy of AIDS, one that is about keeping young people alive? (p. 355-356)

In another project, Mitchell et al. (2010) organized a literacy project in Swaziland photographing broken doors of school toilets that exposed the vulnerability of girls to the dangers of rape and HIV when using public facilities with no security such as locks on doors or CCTV cameras. Given the high occurrences of gender-based violence and the connections between violence and HIV/AIDS among young girls, Mitchell and Smith (2003) suggest that authors and publishers use literature to confront issues such as "aggressive masculinity, biological vulnerability, negotiating sex, HIV testing, disclosure" (p. 516). Literature and literacies have a major impact on the development of societies and has the power to influence change. Street (2014) suggests that

literacy studies for pedagogy "move beyond teaching children about the technical features of language function" toward "awareness of the socially and ideological constructed nature of specific forms we inhabit" (2014, p. 6). Authors, publishers, and film makers can use locally generated names and geographical locations that students can identify with to pass on knowledge and information about health education in classrooms and communities.

In the novel *Stronger Than the Storm* by Van Dijk (2000), the author uses Thinasonk, a metropolitan municipality in South Africa, as the forename of the protagonist in the book. In the South African novels, *Blue Train to the Moon* (1993) by Dianne Hofmeyr and *The Sound of New Wings* (1999) by Robin Malan, the authors use local contents and issues in their books to discuss the topics of desire, safe sex, and the benefits of HIV testing (Mitchell & Smith, 2003). In the graphic photonovella entitled, *Roxy: Life, Love and Sex in the Nineties: Picture thriller*, the Medical Research Council in Cape Town, South Africa uses local content as tools for promoting HIV/AIDS literacies to the public. In the graphic novel, *Pedro and Me: Friendship, Loss and What I Learned,* Judd Winick (2000) writes an autobiographical novel about the human drama of living with AIDS, and his friendship with the AIDS educator, Pedro Zamora.

Using local names in novels are important ways of delivering health information about HIV/AIDS prevention, care and management and teaching health literacies in the classroom. It also reinforces the community's sense of identity when dealing with HIV/AIDS health literacies. Using local content in films is also an important way of integrating HIV/AIDS education into the curriculum. Crawford and Rossiter (2006) write that "the capacity to make sense of stories (in films as well as in novels) is a basic human ability that quickly and almost unconsciously builds up an impression of the values out of

which the characters operate" (p. 341). Many young people are drawn to films, particularly when they can relate to the characters in the story.

Films have a capacity to incline young people to a way of thinking and being. Some South African films and documentaries have been using storytelling in films as a tool for HIV/AIDS education and as an avenue for opening conversations about HIV/AIDS; they include Yesterday (2004), directed by Darrell Roodt; Life Above All (2010) by Oliver Schmitz; Angels in the Dust (2007) by Louise Hogarth and the HBO documentary, *The Lazarus Effect* (2010). HIV/AIDS health literacies are also disseminated through videos, cassettes, and CDs. For example, the UNESCO Bangkok Culture Unit began distributing audio materials in ethnic radio soap operas to inform the community about the prevention of HIV/AIDS (UNESCO, 2005a as cited in Schenker, 2006). In Guyana, a special radio show to educate adolescents about HIV/AIDS was produced (Inter-American Development Bank, 2004). Some community schools have successfully educated communities about HIV/AIDS prevention through art using media, as well as visual and auditory perceptions (Peltzer et al., 2012). The impact of the literacies is greater when students and communities identify directly with the HIV/AIDS health literacy content. The next section discusses the stigma and discrimination that come with living with HIV/AIDS and how safe spaces can be created for students living with the disease.

## HIV/AIDs Stigma, communities, classrooms and safe spaces

The word stigma originates from the Greek word that means a tattooed mark branded on the skin to identify an individual as someone who has committed a crime and who should be avoided (Visser & Sipsma,

2013). HIV/AIDS stigma in many parts of the African region is based on the belief that a person has committed an immoral act, is promiscuous, or that the disease is a punishment from God (Visser, Makin, Vandormael, Sikkema & Forsyth, 2009). In fact, HIV can be transmitted in a variety of ways that include sharing needles or syringes, blood transfusion, mother to child during pregnancy, birth or breastfeeding, and contact with open wounds, not just anal and vaginal sex (HIVgov, 2017). Stigmatization and discrimination against people with HIV/AIDS is based on ignorance and misrepresentation. A study carried out by Visser and Sipsma (2013) showed that:

| 14.50% | Would not like someone with HIV to live next door                  |
|--------|--|
| 16.00% | Would not like to be friends with someone who is HIV positive      |
| 20.00% | Would not like to sit next to someone with HIV in public transport |
| 29.50% | Would not employ someone with HIV                                  |
| 20.00% | Would not drink from a tap if someone with HIV had drunk from it   |

In reality, people cannot contact HIV/AIDS by hugging, shaking, or sharing a toilet or a tap with PLWHA (HIVgov, 2017).

PLWHA experience stigma and discrimination in various ways; some PLWHA begin to take a subjective internalized stigma as their health worsens (Visser & Sipsma, 2013). In internalizing the stigma, people living with HIV/AIDS become reluctant to socialize, become reckless with their lifestyle, experience loss of self-confidence, and engage in taking illicit drugs as a way of coping with the trauma that comes with living with the disease (Simbayi et al, 2007). In the case of school children, some drop out of school as they develop a sense of hopelessness (Mulwo & Chemai, 2015).

The lack of health literacies surrounding HIV/AIDS has led to people refusing to shake hands with PLWHA. Unfortunately, this has resulted in the treatment of people living with HIV/AIDS as outcasts and untouchables in society. In a study conducted in Karnataka, India, one participant speaking about the stigma of living with HIV said:

I do not think it is advisable for the people infected with HIV/AIDS to tell others about their [HIV] status because if they do so they will be treated as untouchables. They will not be allowed to mingle with other people ... They will not be allowed to speak to others. The food they prepare will not be touched by anybody; nor will they [community] give them food. They will not be allowed to touch others, sit with others... (Rahangdale et al., 2010, p. 4).

Schools and communities have a role in ensuring that they expose children to HIV/AIDS health literacies. A project carried out by Torstensson and Brundrett (2011) on the impact of HIV/AIDS on children was directed at creating safe spaces for 168 children in primary schools in Botswana. The safe spaces were aimed at providing children with an opportunity to share their personal stories, experiences and fears about HIV/AIDS. The children in the Torstensson and Brundrett (2011) project spoke about the pressures associated with arranging funerals and with being orphaned that result from deaths in their families because of HIV/AIDS. The project was a valuable health literacy tool because it provided a powerful platform for dialogue in the local dialect where linguistic barriers were eradicated. The study noted that HIV/AIDS had a negative effect on children's ability to concentrate on school work and spend time learning or playing with friends. Torstensson and Brundrett (2011) have encouraged educators to create safe spaces by allowing children in communities

affected by HIV/AIDS to share their experience in the classroom through drawing and other art forms.

Mathematics literacies are also a key component of HIV/AIDS education, Ojose (2011) writes that "mathematics is so entwined with today's way of life that we cannot fully comprehend the information that surrounds us without a basic understanding of mathematical ideas" (p. 91). van Laren (2012) contends that the integration of HIV/AIDS into mathematics elevates the status of HIV/AIDS education because mathematics is a high-status subject. Using statistics in pie charts to display HIV statistics in different regions of the world can help students and educators to find ways of interpreting and reflecting on the significance of HIV/AIDS health literacies in the curriculum. Health literacies are a powerful tool in tackling the cultural misinformation surrounding HIV/AIDS in classrooms and communities. Indeed, governments in many African countries have partnered with their local communities to organize health literacy programs that provide health education to people. For example, the South African government invest USD 1.5 billion annually to run HIV/AIDS programs (South African National AIDS Council, 2015). Governments in developed countries, such as the Canadian International Development Agency, has initiated an international development program to support governments in 29 developing countries to provide children with education related to HIV/AIDS health literacies (Oxfam Canada, 2016).

#### **Conclusion**

Health literacies deliver pedagogical well-being to young people in the community. They also require that instructors and educators provide students with safe spaces where locally generated songs, poetry and storytelling can be used as educational tools for teaching literacies around HIV/AIDS. In this paper,

the author demonstrated how health literacies as a tool for confronting HIV/AIDS can be conceptualized to allow educators and students open dialogues about the stigmas of living with the disease. Using local content to teach HIV/AIDS literacies in the curriculum can help students prevent and manage the disease in ways that are beneficial to young people and the community.

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