

Enlarging the therapeutic space: Using focus groups to determine the wider impact of digital storytelling by women who live with HIV

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Abstract

Altered Lives is a multi-layered digital storytelling project that was undertaken with women who live with HIV. Stage 1 involved the production of the stories as animated films. It explored the therapeutic benefits of ‘telling one’s story’ and having it ‘retold’ within the context of similar experiences. Stage 2, described in this paper, explored, through focus groups and interviews, therapeutic and other benefits for further audiences of the films. Three distinct groups took part: young people, healthcare professionals, and women currently being tested for HIV. The outcomes suggested significant therapeutic and educational benefits from viewing the films, highlighted problems with current health information systems, and indicated areas for further research.

Keywords

Focus groups, human rights, women with HIV, digital storytelling, arts-based qualitative research

If health is about adaptation, understanding and acceptance, then the arts may be more potent than anything medicine has to offer (Smith, 2002).

Introduction

Altered Lives was a digital storytelling project that was undertaken in 2012 with New Zealand women who live with Human Immunodeficiency Virus (HIV). As a practice-based project, it involved the researchers working with women who live with HIV to create short animations that showed what it is like to live with this chronic illness. These animations were then shown to a series of focus groups during 2013 to determine what, if any, value was derived from viewing the animations.

Women account for more than half of the people living with HIV globally, with young women aged 15 to 24 being the most vulnerable to infection (Bruning, Kor & Sango, 2012).

In New Zealand approximately 400 women live with HIV (Positive Women, 2008), and although HIV was once considered to be a gay man’s disease (Brooks, 2004), the majority of new infections throughout the world now occur in women (Squire, 2003).

Studies have revealed that the stigma associated with being HIV-positive has been linked to fear and isolation (Freiden et al., 2006) and also to anxiety and depression (Hazra, Siberry & Molensson, 2010). However, keeping silent about HIV status not only perpetuates cycles of shame, it also has the effect of limiting an individual’s capacity to sustain their heart, mind and soul, a capacity which is seen as essential to the self-care and wellness of women as they grow older with HIV (Plach, Stevens & Keiger, 2005). This is especially true for HIV-positive women living in rural New Zealand. Geographically isolated, many such women keep their status secret, resulting in little or no support from family or friends.