

Original Article

An Educational Intervention to Reduce Pain and Improve Pain Management for Malawian People Living With HIV/AIDS and Their Family Carers: A Randomized Controlled Trial

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Abstract

Context. Advances being made in improving access to HIV drugs in resource-poor countries mean HIV patients are living longer, and, therefore, experiencing pain over a longer period of time. There is a need to provide effective interventions for alleviating and managing pain.

Objectives. To assess whether a pain educational intervention compared with usual care reduces pain severity and improves pain management in patients with HIV/AIDS and their family carers.

Methods. This was a randomized, parallel group, superiority trial conducted at HIV and palliative care clinics of two public hospitals in Malawi. A total of 182 adults with HIV/AIDS (Stage III or IV) and their family carers participated; carer participants were those individuals most involved in the patient's unpaid care. The educational intervention comprised a 30 minute face-to-face meeting, a leaflet, and a follow-up telephone call at two weeks. The content of the educational intervention covered definition, causes, and characteristics of pain in HIV/AIDS; beliefs and myths about pain and pain medication; assessment of pain; and pharmacological and nonpharmacological management. The primary outcome was average pain severity measured by the Brief Pain Inventory-Pain Severity subscale. Assessments were recorded at baseline before randomization and at eight weeks after randomization.

Results. Of the 182 patient/carer dyads randomly allocated, 157 patient/carer dyads completed the trial. Patients in the intervention group experienced a greater decrease in pain severity (mean difference = 21.09 points, 95% confidence interval = 16.56–25.63; $P < 0.001$).

Conclusion. A short pain education intervention is effective in reducing pain and improving pain management for Malawian people living with HIV/AIDS and their family carers. *J Pain Symptom Manage* 2015;50:80–90. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

HIV/AIDS, trial, pain, carers, educational intervention, palliative care

Introduction

Advanced HIV infection and its treatment with anti-retroviral therapy are associated with physical and psychological symptoms.^{1,2} These require focused assessment and management using locally available resources and interventions to optimize quality of life for patients and their carers.^{1,3} The negative impact of pain on quality of life has been documented in

many studies.^{4,5} Pain is a major problem for people living with HIV/AIDS.^{6–8} Pain is the most frequent and main cause of psychological distress.^{9,10} Experiencing pain can reduce adherence to drug regimens and quality of life for HIV/AIDS patients.^{11–15}

It is estimated that 35.3 million people were living with HIV/AIDS at the end of 2012.^{16,17} In the same year, there were 1.6 million deaths from AIDS, a

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reduction from 2.3 million deaths in 2005. In 2010, 1.4 million people began HIV medication, an increase in the number of people receiving treatment from the previous year of 27%. Greater access to effective treatment largely explains some of this decline in HIV/AIDS mortality.¹⁸

Sub-Saharan Africa has 10% of the world's population, but it is home to 69% of all people living with HIV/AIDS, making it the worst affected region.^{16,17} Antiretroviral therapy can dramatically increase survival and years of healthy life, but is unavailable in many parts of the region.¹⁸ In 2010 in sub-Saharan Africa, the number of individuals treated with antiretroviral medication increased from 37% in 2009¹⁹ to 49% of the population eligible for treatment.²⁰

In Malawi, the prevalence of HIV/AIDS is estimated at 11% of the population aged 15–49 years, with around 910,000 people living with HIV/AIDS at the end of 2011.¹⁷ Approximately, 250 people are newly infected each day,²⁰ and at least 70% of Malawi's hospital beds are occupied by HIV/AIDS patients,²¹ making Malawi the 12th worst affected country with HIV/AIDS worldwide.²² However, there was a decline in HIV/AIDS prevalence from 14% in 2003 to 10% in 2011, predominantly because of increased access to antiretroviral therapy and preventive strategies.²³ Substantial progress has been made in the provision of HIV medication.²⁴ The involvement of nurses in the prescription and administration of medications and training health assistants to provide HIV counseling services have resulted in a greater proportion of patients starting HIV treatment within three weeks of diagnosis.²⁵ This has resulted in increased antiretroviral coverage to 67% in 2011.^{23,24}

Adequate pain control remains a challenge for HIV/AIDS patients and has an impact on their quality of life.^{13,14} Pain is experienced throughout the disease trajectory, severity being associated with later World Health Organization (WHO) clinical stage,^{2,26–28} with an estimated 80% of people with advanced HIV infection experiencing severe pain.²⁹ Pain is also experienced as an effect of HIV medication.^{30,31} With advances being made in improving access to HIV drugs in resource-poor countries, HIV patients are living longer and, therefore, experiencing pain over a longer period.^{32,33} There is a need to provide effective interventions to HIV/AIDS patients in alleviating and managing pain. A systematic review³⁴ reported that self-management education programs for people living with HIV/AIDS results in short-term improvements in physical and psychosocial health and knowledge. However, all the trials reviewed were conducted in the U.S. and China where the health context is very different and none of these trials directly involved unpaid carers, a group likely to

play a key role in the management of pain of those they care for.

Methods

Study Design

The pain education intervention study was a two-center, randomized, parallel group, wait-list controlled superiority trial. A detailed study protocol has been published.³⁵

Setting and Participants

From October 2012 to June 2013, we recruited participants at HIV and palliative care clinics within two public hospitals (Ekwendeni and Mzuzu Central) in northern Malawi. Both hospitals provide inpatient, clinic-based and home-based care for people with HIV/AIDS that includes active treatment and palliative care. Participants were people living with HIV/AIDS who had a primary carer, who was identified as the individual most involved in their care. They were adults aged 18 years or older. All participants were able to read and write in English or Tumbuka (the vernacular language used in the northern part of Malawi). Participants were at WHO clinical stages III or IV of HIV/AIDS, or with a CD4 cell count of less than 350 cells, when the presence of pain and other symptoms is more likely because of opportunistic infections or side effects of HIV treatment. We excluded people living with HIV/AIDS if they had health problems that hindered cognition and communication such as HIV-associated dementia.

Recruitment

People living with HIV/AIDS in Malawi typically visit the hospital (palliative care and HIV clinics) with their family members. Posters about the study entitled "Pain Education Study" were prominently displayed in the clinics. Additionally, the first author (K. N.) or staff in these clinics informed patients about the study and provided them with information sheets. Potential participants were encouraged to discuss the study with family members before making a decision to take part. Those interested in taking part in the study were asked by K. N. to provide written informed consent. A checklist was used to confirm that all criteria for study eligibility were met.

Randomization, Concealment of Allocation, and Blinding

Baseline assessments were conducted by K. N. before randomization. Randomization was implemented by K. N. using opaque, sealed, and consecutively numbered envelopes. The envelope was opened in the presence of the participant. Participants had a 50% chance of

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