

Research Article

The Impact of Palliative Care on Health Status in HIV-Positive Children in an Outpatient Centre in Kenya

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ABSTRACT

HIV-positive children in sub-Saharan Africa have numerous challenges to overcome. These challenges increase psychosocial stress as well as symptom burden including fatigue, weight loss, pain, and mental changes. The symptoms may persist even after initiation of antiretroviral therapy, so such children need additional care. Palliative care lays emphasis on holistic patient-centered care, including physical, psychological, social, and spiritual symptoms, alongside antiretroviral therapy. There is limited data on the impact of integrating palliative care with standard HIV care and treatment in children. The purpose of this study was to fill the gap in the literature by investigating the impact of palliative care on health status in HIV-positive children on antiretroviral therapy. The theoretical framework was based on the humanistic nursing theory. Using the Mann Whitney U and logistic regression tests, the health-related quality of

life of 97 children who received palliative care in addition to standard HIV care was compared to 180 HIV-positive children who received standard HIV care only through chart reviews. According to study results, children receiving palliative care alongside antiretroviral therapy have better physical and psychosocial health compared to children receiving only antiretroviral therapy. Increasing age was a contributing factor to better psychosocial and physical health in patients receiving palliative care. Emotional, social, and school functioning are important factors that determine treatment outcomes in children on antiretroviral therapy, and addressing those factors through palliative care will create a positive social change by improving treatment outcomes, quality of life, and longevity.

Keywords: Pediatrics; Child; Palliative care; Hospice care; End of life care; Health status; HIV/AIDS

Introduction

There are more than 33 million people infected with HIV worldwide [1]. Fifty percent of these are women, and 3.3 million are children [1]. The number of new HIV infections worldwide in a year is about 2.5 million in adults and 330,000 in children [1]. The number of global deaths due to HIV is about 1.7 million in adults and children [1]. Greater than 90% of the world's HIV-positive pediatric population lives in sub-Saharan Africa [2].

Despite antiretroviral initiation, people living with HIV and AIDS continue to suffer symptom burden [3-6]. People living with HIV/AIDS have a higher burden of physical problems compared with the HIV-negative population [7,8]. The prevalence of anxiety and depression is higher among HIV-positive people than in the general population as well as populations with other chronic conditions such as renal failure or cancers [9]. While this compromises quality of life of individuals living with HIV/AIDS, it also threatens the continued success of the roll out of antiretroviral therapy due to the association of depression and distress arising as a result of antiretroviral toxicity and poorer treatment outcomes [10].

Palliative care lays emphasis on holistic patient-centered care, including the impact of illness on the family and recognition of the importance and interdependence of physical, psychological, social, and spiritual symptoms alongside antiretroviral therapy [11]. There is a paucity of evidence from low and middle-income countries and a lack of research evidence of the impact

of integrating palliative care into standard HIV care alongside treatment since the advent of antiretroviral therapy [12]. Integrating palliative care could have positive pain reduction outcomes in people living with HIV/AIDS [13]. Lowther et al. used a mixed methods approach to show the positive impact of palliative care on treatment outcomes in Kenya and South Africa. While these isolated studies have been conducted on adult patients, there is little or no evidence to demonstrate treatment outcomes for children receiving palliative care alongside antiretroviral therapy [14,15].

The purpose of this study was to fill the gap in the existing literature by demonstrating the impact of palliative care on health status in HIV-positive children on antiretroviral therapy. We conducted the study in Mombasa, Kenya, which is a low-income setting [16]. The research approach was that of a quantitative mode. We conducted a chart review of children who had been initiated on palliative care and compared their health scores to those children who received standard HIV care and treatment but without palliative care.

Methods and Materials

We conducted this study at a single outpatient HIV center providing care and treatment services to HIV-positive children. All pediatric patients aged between 5 and 15 years and receiving antiretroviral therapy at the hospital were eligible for chart review. There were no direct patient interviews. We collected all data through chart reviews. The hospital offers palliative care to

all children receiving antiretroviral therapy. However, children and parents have the option of opting out of this service. Hence, there is a group that receives palliative care and there is a group that receives standard HIV care and treatment. The inclusion criteria for the study was HIV-positive children receiving antiretroviral therapy for at least 3 months, of any race and ethnicity, aged between 5 and 15 years and receiving palliative care and standard care or standard care alone for a period of at least 3 months.

The dimensions of health tested using the PEDSQL have been derived from WHO [17]. The scale has 23 items grouped into four major categories (multidimensional scales): physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five items). Scores are divided into two categories (summary scores): physical health summary score (eight items) and psychosocial health summary score (15 items). The total score is 23 items.

The following variables were of interest in the study: type of care (palliative vs. standard), age, gender, duration on antiretroviral therapy, CD4 count, psychosocial health summary score, and physical health score. A cross-sectional study design was used to study the impact of the independent variable (the type of care) on the dependent variable (psychosocial health and physical health). Variables that were controlled were age, gender, and duration on antiretroviral therapy.

Ethical procedures

Before any charts were reviewed and information retrieved, ethical approval for the study was sought from the Walden University Institutional Review Board (IRB). The IRB approval number for this study was 07-26-16-0395061. Regulations for conducting a study in Kenya require a local IRB approval which was sought from the Ethics Review Committee in Kenya. The ERC approval number from KNH-UON-ERC was P268/03/2016. Once all approvals were in place, data collection began.

All patient charts are stored in the medical records department. Each child has a unique identifier which is recorded on the patient chart. Study numbers were assigned to each patient chart by the medical records staff. Names of patients were not revealed to the researchers. The study numbers of eligible patients and the relevant information were extracted from the patient chart. All information was thus de-identified from the patient and is not traceable to the individual patient.

The information collected was at a single point in time. There was no follow-up information collected. The information collected was entered into an Excel sheet and the chart returned to the medical records department. No additional information was retrieved from the chart. There was no direct communication with the children or their guardians. All information collected was stored in an Excel/SPSS worksheet, and will be destroyed after a period of 5 years.

Results

We conducted a pilot study prior to the initiation of data collection proper. In the pilot study, charts for children

receiving palliative care and those receiving standard care were randomly assigned for data extraction. Ten charts were randomly selected for the pilot. We recorded the data in an Excel spreadsheet. Interrater reliability was tested by asking at least two data abstractors to abstract data from the same chart. There was no difference in the data extracted by the two data abstractors (Cohen's kappa agreement > 0.90) [18]. Intrarater reliability was tested by getting a data abstractor to abstract data from the same chart on two different occasions. Again, the data abstracted on both occasions were the same (Cohen's kappa agreement > 0.90). The pilot study showed that data collection from the charts of patients would be a fairly simple exercise as all information was directly available in the chart. The pilot study had no impact on the main study, and there were no changes required in data analysis strategy.

At the time of the study, 949 children were receiving antiretroviral therapy at the center. Based on the eligibility criteria, 277 children were eligible for the study. Of these, 180 had received standard care and 97 had received palliative care. All eligible charts were included in the analysis. We conducted data collection from August 1st, 2016 to August 31st, 2016.

Descriptive and demographic characteristics

A total of 277 charts were eligible for review and we extracted data from these charts. Forty-eight percent (n=134) of the children were female. The mean age of all children was 11.6 (SD=3.19). The mean duration on antiretroviral therapy was 73 months (SD=35.64). Thirty-five percent (n=97) of the children had received palliative care in the last 3 months. Mean nadir CD4 was 847.1 (SD=506.01) and the mean last CD4 for all children was 840 (SD=541.25).

Characteristics by type of care

Standard care: One hundred and eighty children (65%) of all children had received standard HIV care and treatment in the last 3 months. Forty-five percent (n=81) of children who received standard care were female, and the mean age was 12 years (SD=3.26). The mean duration on antiretroviral therapy of this group was 79.2 months (SD=34.586). Mean nadir CD4 was 798.43 (SD=487.03) and the mean last CD4 was 784.665 (SD=543.6355).

Palliative care: Ninety seven (35%) of all children had received standard HIV care and treatment in the last 3 months. Fifty four point six percent (n=53) of children who received standard care were female, and the mean age was 10.823 years (SD=2.87). The mean duration on antiretroviral therapy of this group was 63.2 months (SD=35.41). Mean nadir CD4 was 935.1 (SD=529.97) and the mean last CD4 was 946.398 (SD=523.38).

The Kolmogorov-Smirnov and Shapiro-Wilk tests for normality revealed p values of 0.0 for each variable. The p value of 0.0 (<0.05) demonstrated that the data significantly deviates from a normal distribution. Thus, the assumptions of the independent t test and linear regression were not met. We used a Mann-Whitney Test as a nonparametric test instead of the independent t test and logistic regression instead of linear regression.

The PEDSQL has two major components: The psychosocial health summary score and the physical health summary score.

The psychosocial health summary score is a summation of the emotional, social, and school functioning score.

Mann-Whitney test results indicated a significant difference in emotional ($U=5975.5$, $p=0.00$), social ($U=7680.5$, $p=0.014$), and school functioning ($U=5333.0$, $p=0.00$) between children receiving palliative care and those receiving standard HIV care with significantly higher scores in the palliative care group. The overall psychosocial health score was also significantly higher in children who had received palliative care ($U=4760.5$, $p=0.00$). Physical functioning was also better in children who had received palliative care compared to those who received only standard HIV care ($U=6806$, $p=0.00$).

In the model for psychosocial health, age ($p=0.001$) added significantly to the model. However, gender ($p=0.261$), duration on antiretroviral ($p=0.874$), nadir CD4 ($p=0.088$), and last CD4 ($p=0.135$) did not add significantly to the model. In the model for physical health, age ($p=0.00$) added significantly to the model. However, gender ($p=0.781$), duration on antiretroviral therapy ($p=0.282$), nadir CD4 ($p=0.058$), and last CD4 ($p=0.53$) did not add significantly to the model.

The results of this study found that emotional functioning, school functioning, and social functioning were better in children who had received palliative care for at least 3 months compared to children who had received standard HIV care in Kenya. Emotional, school, and social functioning are indicators of psychosocial health in PEDSQL [17]. The PEDSQL inventory is a tool designed to assess the HRQOL in children [17]. The tool is a practical, validated, generic measure of the quality of life of children [19].

Discussion

The findings on participants' psychosocial well-being in this study were consistent with findings in similar studies. Psychosocial well-being has been studied in children from various angles. In the study by Xu et al., results revealed that children who had a parent living with HIV/AIDS or who had lost either parent to HIV/AIDS had a lower quality of life scores than children who did not have an HIV confirmed parent [20]. The findings are also consistent with older studies where the association of self-esteem and psychosocial problems were assessed [21,22].

The findings of this study contribute to the comfort plan proposed by Henley; the home-based care model that links hospital, clinics, and home care proposed by Uys; the clinical and palliative day care services model proposed by Knapp et al., and the hospice initiated antiretroviral therapy model proposed by Henley et al. [23]. However, the findings of this study additionally revealed the possibility of an integrated nurse-led out-patient model for HIV-positive children. The study by Lowther et al. had similar findings for the adults' population [24-26].

One major limitation of previous studies that have conducted a needs assessment of palliative care in HIV-positive children is the use of morbidity and mortality data on children [27]. This limits the definition of palliative care to end of life instead of from the time of diagnosis when it should ideally begin [27].

In this study, we did not limit the definition of palliative care to end of life. This is an important strength of the study that separates from previous studies on palliative care in HIV-positive children.

The results of this study also revealed a significant difference in psychosocial health between children who had received palliative care compared to those who had not ($U=4760.5$, $p=0.00$). These findings are similar to those seen in the study by Lyon et al. [28]. In the study by Lyon et al., children who were HIV-positive and were enrolled for palliative care reported that their psychosocial health was well preserved. Children who enrolled in palliative care were those who had a low quality of life score, in general, as well as low health perception and physical and social functioning [28]. These limitations were addressed in our study, where all children regardless of their quality of life were provided an option of palliative care.

Improvements in physical and psychosocial health were also noted in this study. These findings are similar to those shown by Lowther et al. in the randomized study conducted on adults [26]. Lowther et al. used the A-POS, the MOS-HIV, GHQ-12, and the CSRI.

When controlling for variables such as age, gender, duration on antiretroviral therapy, nadir, and last CD4, it was noted that age contributed to the model of psychosocial and physical health. An increase in age contributed to better physical and psychosocial health. Older children receiving antiretroviral therapy are more likely to have better physical and psychosocial health than younger children. One explanation would be that as the child grows older, there is more acceptance of the disease. Wiener et al. demonstrated that young adults are open to even end of life such discussion, and they take it with much interest [29]. Older children often have a better understanding of the disease, and this may contribute to better physical and psychosocial health.

Conclusion

The findings of this study can be used as a basis for integrating palliative care into care and treatment plans for children with HIV/AIDS. Integration can begin at health facility level. Integration of palliative care with standard HIV care can be incorporated in the guidelines set at the county and even national level. Research has shown that emotional, social, and school functioning are important factors that determine treatment outcomes in children on antiretroviral therapy. Addressing them through palliative care will improve treatment outcomes, quality of life, and longevity in children.

This study was carried out in Kenya in sub-Saharan Africa. The needs of children in this region are special and thus need special attention. Addressing such needs together with antiretroviral therapy will improve treatment outcomes in HIV-positive children and improve their quality of life and thus create a positive social change in the lives of such children.

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