

Understanding Pediatric HIV Care Management to Improve the Quality of Care for Children Infected with HIV in Indonesia

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Keywords: Care Management, Children, HIV.

Abstract: The number of children infected with the Human Immunodeficiency Virus (HIV) has cumulatively increased by 68.5% during the period 2010 to 2015 in Indonesia. Due to the need for lifelong treatment to minimize its impact, HIV is considered a chronic disease. With the change to living with a chronic condition, children with HIV may need to receive coordinated care management across the spectrum of their disease from health professionals, and, particularly, nurses. Studies from sub-Saharan countries have shown several programs that have been implemented to manage childhood HIV epidemics. However, gaps in the implementation of programs still exists, due to family contexts, disclosure of HIV status, stigma, discrimination, and health professional capacities. This presentation will describe the programs for the provision of care for HIV infected children in sub-Saharan Africa and their identified barriers and challenges. From the review findings, future research will be proposed for which similar advances can be implemented in Indonesia as part of improving the quality of care for HIV positive children.

1 BACKGROUND

The number of children living with the Human Immunodeficiency Virus (HIV) is becoming more prevalent. In 2013, almost 190,000 children and adolescents, infected with HIV, lived in the Asia region (Saad, Peck-LeongTan, & Subramaniam 2015). Globally, in 2015, the United Nations Program on HIV/AIDS (UNAIDS) estimated 1.8 million children aged under 15 years old were living with HIV, 400 children become newly infected daily, and 110,000 children were died from Acquired Immune Deficiency Syndrome (AIDS)-related diseases (UNAIDS 2016a). The report from Global AIDS in 2014 stated that 4.9 million people were living with HIV, with Indonesia ranked third highest (14%) after India (43%), and China (17%) (WHO 2016). In Indonesia, new infections of HIV among children (10–14 years old) have increased by 63% since 2010 (UNAIDS 2016a). The report by the Ministry of Health stated that the number of children infected with HIV aged below 19 years had cumulatively increased from 1,472 in 2011 to 2,252 in 2015 (MoH 2016).

For children living with HIV (CLWH), their lives are negatively affected, so they may need to receive coordinated care management across the spectrum of their disease from health professionals, nurses, in particular. Rochat, Mitchell and Richter (2008) indicate that CLWH have complex problems related to the biological, psychological, social, economic, and environmental conditions in their lives and have difficulty accessing healthcare services. For example, hospitalized children with HIV are susceptible to discomfort and stressful economic and social circumstances with their disease, stigma regarding HIV, over-burdened hospital facilities, and a lack of specialized staff on the ward (Richter, Chandan & Rochat 2009). On the other hand, numerous studies in a sub-Saharan context have discussed how to manage HIV epidemics for CLWH (Achema & Ncama, 2016; Luyirika et al., 2013; Mbaye et al., 2009). Therefore, this paper aims to describe the provision of care for HIV-infected children and their identified barriers and challenges. Furthermore, potential future research in Indonesia will be outlined to improve the life quality of children who are HIV positive.

2 METHODS

This study utilized an integrative review. This review focused on the provision of care for CLWH manuscripts published between 2009 and 2016. Manuscripts were identified using the following databases: Medline OVID, PsycInfo, Sage Informat, Google Scholar, and Taylor & Francis online. The search options used were Boolean/ phrase and smart text searching with a combination of the following key words: child or children or childhood or pediatric, nurse or nurses or nursing, holistic or psychosocial or social or patient-centered care, HIV, and hospital. Narrower searches resulted in fewer reports. The author then extended the key words: children, HIV, comprehensive care. The author obtained 110 articles, and this was condensed to 11 primary research manuscripts according to the inclusion criteria: written in English and discussed the provision of care for children with HIV. Most manuscripts were found using Google Scholar and Taylor & Francis online. Initially, the author wrote a synopsis of each article onto a table containing the author(s), year and location, research questions and the aim of study, methodological design, and major findings and then continued with the critical appraisal process for quantitative and qualitative manuscripts.

3 RESULTS

Of the 11 included manuscripts, the results were grouped into two over-arching themes: the provision of care for HIV infected children and identified barriers and facilitators to healthcare.

3.1 The Provision of Care for HIV-Infected Children

Children infected with HIV require comprehensive care, which does not only require access to antiretroviral therapy (ART), but also to supportive care to ensure they meet their optimal quality of life.

3.1.1 Access to Antiretroviral Therapy (ART)

Access to ART crucially reduces children's morbidity and mortality. UNAIDS (2016) found that access for children (aged 0–14) to ART increased dramatically from 0% in 2000 to 50% in 2005. However, according to the UNICEF (2016) report, of 1.8 million children under the age of 15 living with

HIV, only half were receiving treatment. A study from the South Asia region comprising Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka argues that the uses of text messaging gateways for medical appointments and ARV pick-ups are alternative strategies implemented to support therapy adherence for CLWH.

3.1.2 Supportive Care

Children with HIV not only need ART, but also require supportive care. This is an important finding and according to Achema and Ncama (2016) holistic supportive care, including nutritional, educational, and psychosocial support given by families, caregivers, and nurses is essential for CLWH to support the achievement of a better quality life. As well as nutritional, educational and psychosocial support, sexual reproductive health and circumcision positively prevent children from HIV transmission.

Children with HIV require education for awareness and reproductive health to prevent themselves from HIV or other sexually transmitted infections (STs) before they become sexually active. A qualitative study in South Africa found that young children aged 10–14 years did not have adequate knowledge about sexual and reproductive health (Vujovic et al., 2014). Vujovic et al. (2014) state that sexual and reproductive programs for adolescents are rare. Within the same literature, children reported that they needed separate clinics to adults, so they can ask about physical development, condom use, pregnancy and how to avoid pregnancy, menstruation, and hygiene (Vujovic et al., 2014). Besides condom and contraceptive injections being available from the health service, children also said that they needed friendly health providers with whom they could talk comfortably (Vujovic et al., 2014).

Male circumcision is another cost-effective form of supportive care, which effectively reduces the risk of sexual transmission from males to females. Modeling studies (2009–2011) from 14 countries: Botswana, Ethiopia, Kenya, Lesoto, Malawi, Mozambique, Namibia, Rwanda, South Africa, Swaziland, Uganda, The United Republic of Tanzania, Zambia, and Zimbabwe found that 80% of males aged 15–49 were circumcised, which prevented the occurrence of new HIV infections by 3.4 million (Sgaier et al., 2014). Within 15 years, male circumcision saved up to US\$ 16.5 billion (Sgaier et al., 2014). Therefore, the voluntary male circumcision program can be part of the HIV prevention strategy. To implement the program, circumcision training for health professionals or

Table 1: The gaps for future implementation of research into the provision of care for CLWH in Indonesia.

Research Findings	Potential Research Topics in Indonesia
Key Performance: Access to ART: comprehensive sexual and reproductive health	
Children have less knowledge on sexual and reproductive health; voluntary male circumcision is an effective program for HIV prevention.	Improving sexual and reproductive health for CLWH (practice, barriers and challenges; strategies to enhance the practice; building knowledge of CLWH; developing strategies to implement the practice for nurses); transition care for young children.
Text messaging for ARV pick-up is effective	How is adherence therapy conducted for CLWH? Strategies to engage children and families to improve ARV.
Key Performance: Caregiving and HIV	
Disclosure model with honest communication from Botswana improves the quality care of CLWH	Evaluate the implementation of disclosure status (e.g. barriers and facilitators); assessing the knowledge and behaviour of health care towards disclosure-status; strategy to improve the readiness of disclosure (e.g. communication, model delivery of care); the role of the government in the support of disclosure due to the implemented decentralization approach.

providing health education for families requires management. For example, nurses in 15 priority countries such as Sudan have been trained to provide voluntary male circumcision services (UNAIDS 2016b).

3.2 Barriers and Facilitators to Healthcare

As well as the provision of care, the implementation of care for HIV positive children have barriers and facilitators, including low socio-economic and parental education, disclosure of HIV status, stigma and discrimination, and health professional capacities.

3.2.1 Low Socio-Economics and Lack of Parental Education

Low socio-economics (LSEs) and lack of parental education are barriers to healthcare seeking behavior. McGrantham-Mc Gregor et al. (2007) cited in Rochat et al. (2008) stated that poverty in sub-Saharan Africa was a platform for HIV and AIDS, which were linked to malnourishment, poorly developed health and education, and a distressed care environment, requiring attention. This information is consistent with known facts from sub-Saharan Africa, where it is reported that adolescent girls face higher risk of HIV infection due to their life circumstances, i.e. living in poverty, malnourishment, LSE problems, and poor-quality education (UNICEF 2016b). Moreover, poverty, economic problems, and large family size contributed to dangerous survival strategies such as transactional sex, and children’s insecurities such as food, shelter, school fees, and other school supplies (Betancourt et al., 2012). Kidman and Heymann (2016) support that aspects of

vulnerability of HIV-experienced caregivers and children infected with HIV are linked to poverty, food insecurity, inability access to school, ill health, and limited access to safety. Therefore, strengthening economic problems and developing family health education are important to ensure adequate care for children with HIV. Betancourt et al. (2012) assert that providing financial assistance positively supports vulnerable children and their families.

3.2.2 Disclosure of HIV Status

Disclosure of HIV status is a big challenge and still exists. In 2016, most people living with HIV (PLWHA) did not know their status (UNAIDS 2016a). As stated in UNAIDS (2016b), 14.5 million out of the 36.7 million people living with HIV do not know their status. Parents or caregivers tend to silence and protect their children from their status. This mystifies their transition into adolescence (Bernays et al., 2014). However, Botswana has developed the disclosure model as part of Botswana’s National HIV care and treatment guidelines. The program provides a friendly, supportive environment building on positive living with HIV, based on a counseling approach at regular clinic visits and adherence classes (Lowenthal et al., 2014). The adherence classes are a group learning session for children who initiate and start taking antiretroviral drugs assisted by clinic nurses (Lowenthal et al., 2014) so could enhance adherence of therapy.

3.2.3 Stigma and Discrimination

Stigma and discrimination negatively impact healthcare outcomes for CLWH. Stigma touches on the loss of dignity leading to difficulties in epidemic control (Indonesia, 2012). For example, the loss of

education opportunities, denying healthcare, taking medication secretly, increasing psychological problems, and less up-take on adherence therapy (Bernays et al., 2014; Gokengin et al., 2016; Indonesia, 2012; UN, 2015; Wei et al., 2016).

3.2.4 Health Professionals' Capacities

The capacities of health professionals positively support better quality of care for children with HIV. However, two studies report that the implementation of HIV care has challenges related to limited health professional capacities, such as limited training, providing poor counseling, a lack of referral system management, faking information on medical records, and poor logistic management (Adebimpe, 2013). Furthermore, nurses are more likely to focus on routines, rules, protocol, and become rigid to cope with increasing burdens and limited resources (Richter et al., 2012). Health professionals (nursing, specialist pediatric training) are unwilling to work with caregivers and children due to the stress of care delivery in the wards (Richter et al., 2012). Hence, hospital bureaucracy, resources, staff rotation, and nursing shortages give caregivers an imperatively pivotal role in their children's care but participate very little (Richter, Chandan, & Rochat, 2009).

4 DISCUSSIONS

Disseminating results from this review shows a that a high burden on CLWH still exists. This review identifies that family context, disclosure of HIV status, stigma and discrimination, and health professional practice negatively affect the care of HIV positive children. CLWH depend on their families. Since lack of parental education is one of the barriers to care-seeking behavior, building the knowledge of caregivers is operationally strategic to support the quality of care for HIV positive children, including providing treatment and medicine, nutrition, and psychosocial care in the home. Additionally, discussing disclosure of HIV status within the family is an important factor to support the effectiveness of treatment. UNICEF (2016c) stated that disclosure of HIV status requires good and accurate communication among children, caregivers, and health providers (UNICEF 2016c). Furthermore, UNICEF (2016c) stated that CLWH who experienced stigma, discrimination, and other psychosocial circumstances need to be empowered to improve HIV outcomes and to enhance child protection. Lessons learned from current practice in child protection

reported by UNICEF (2016a) determined that: (1) a comprehensive framework integrating multi sector's collaboration will enable positive outcomes on infected CLWH protection; and (2) empowering children in all programs will provide better understanding on their barriers and challenges to reduce stigma and discrimination. Key lessons from UNICEF postulate future activities for increasing girl's access in secondary education besides conveying proven programs, for example, community empowerment, reducing stigma, discrimination, and marginalization into healthcare settings.

CLWH do not only require adherence of therapy but also supportive intervention. However, it is evident in this review that the capacities of health providers and the healthcare system are still not optimal as limited knowledge and skills are indicated along with limited resources, shortages of nurses, and a poor healthcare system. It is clear from this review that it is important to build the capacity of health providers in terms of providing adequate knowledge such as sexual and reproduction health for young children and teenagers. Therefore, this review provided lessons learned from sub-Saharan experiences, which informed what is known and what is not known about the provision of care for CLWH as listed in Table 1. These gaps may promote or generate a future research project in Indonesia.

5 CONCLUSIONS

In summary, CLWH experienced barriers when seeking healthcare. Firstly, CLWH were living in poverty, which contributed to lack of nutrition, minimal access to school, growth, and developmental problems. Secondly, CLWH experience stigma, discrimination, and disclosure problems, negatively affecting their health outcomes. Due to existing problems, CLWH do not only require ART but also need supportive care. Moreover, health professionals should have good capacities to support children with HIV. Therefore, critical action is needed to ensure that health providers provide good care, support, and treatment for both children infected with HIV and their caregivers.

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