

A SYSTEMATIC LITERATURE REVIEW OF THE INSTITUTIONALIZATION OF CHILDREN LIVING WITH HIV, WITH A SPECIFIC FOCUS ON LATIN AMERICA

UNA REVISIÓN SISTEMÁTICA DE LITERATURA DE LA INSTITUCIONALIZACIÓN DE NIÑOS QUE VIVEN CON VIH, CON ESPECIAL FOCO EN LATINOAMÉRICA

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RESUMEN

Con la prevalencia del VIH / SIDA en todo el mundo actual, la institucionalización muchas veces se convierte en la única opción viable para los niños cuyos familiares y amigos son incapaces de cuidar de ellos. En ausencia de parientes cercanos o amigos para cuidar a estos niños, los niños institucionalizados tienen necesidades que no son tan específicas de su tratamiento contra el VIH. Si las necesidades biológicas y psicológicas de los niños VIH-positivos se cumplen en estas instituciones se mantiene en tela de juicio en este estudio. Esta revisión sistemática, por lo tanto, recopila la literatura existente en bases de datos electrónicas y organizaciones de Internet de la institucionalización de los niños que viven con el VIH, más concretamente, los de América Latina, con el fin de examinar los efectos de dichas instituciones. Un efecto importante es la falta de apertura en la comunicación entre el cuidador y el paciente: se encontró que la necesidad de la divulgación es cada vez más importante en la promoción de la conciencia del paciente acerca de su enfermedad.

ABSTRACT

With the prevalence of HIV/AIDS around the world today, institutionalization often times becomes the only viable option for children whose family and friends are unable to care for them. In the absence of close relatives or friends to care for these children, institutionalized children have needs that are not just specific to their HIV treatment. Whether the biological and psychological needs of HIV-positive children are being met in these institutions is held into question in this study. This systematic review, therefore, gathers existing literature from electronic databases and internet organizations on the institutionalization of children living with HIV, more specifically those in Latin America, in order to examine the effects of said institutionalization. One pronounced effect is the lack of openness in communication between caretaker and patient: it was found that a need for disclosure is increasingly important in promoting patient awareness about his/her disease.

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INTRODUCTION

An estimated thirty-three million people worldwide live with Human Immunodeficiency Virus, two and a half million of which are children¹. Of these children, UNICEF reported that more than thirty six thousand live in Central and South America¹. Since 1987 when the first cases of the disease were detected in Chile, HIV has made its virulent mark on the lives of many children living in Chile². AVERT, an international HIV/AIDS charity organization, purports that the most important supporter and protector of children living with HIV is their family, friends, and community³. Research done by this organization has revealed that taking children away from their families should only occur as a last resort.

Because around 16.6 million children under the age of eighteen have lost one or both parents due to AIDS, institutionalization often becomes the only viable option in caring for children living with HIV/AIDS, especially for those living in resource poor areas¹. Although institutions often provide the fundamental necessities of food, shelter, and basic medical care, many wonder whether institution-based care falls short in providing all of the psychosocial and emotional needs that these children require for proper development. Pilot studies have suggested that children raised in these types of institutions are more likely to experience impaired cognitive and social development⁴. Thus, this literature review seeks to explore the extent to which both the biological and psychological needs of HIV-positive children are being met in institutional environments.

Moreover, with more than one thousand children being newly infected with HIV every day, a deeper understanding of their development within an institution is crucial to controlling the disease and promoting a healthier life³. This review will, therefore, explore just how important a level of communication is established between caretaker and patient in order to promote an increased level of patient awareness

about his/her HIV/AIDS: the negative consequences of a lack of this patient knowledge is also examined.

All in all, existing literature on the institutionalization of children living with HIV, more specifically those in Latin America, will be analyzed in this systematic review. Based on this review, the effects of said institutionalization will be investigated in order to add to the existing body of knowledge on the subject and identify areas that lack adequate research.

METHODS

In order to investigate the institutionalization of children living with HIV/AIDS, electronic databases including Ebscohost, Pubmed, Science Direct, and Scielo were systematically searched. Fifteen articles were ultimately used in this systematic review after deliberate searching and selection based on specific criteria: keywords used in this review were defined to be "children," "institutionalization," "HIV or AIDS," and "Latin America." Furthermore, internet searches of appropriate organizations including UNICEF, World Bank, AVERT, and UNAIDs were used to identify relevant background information. Studies involving the institutionalization of children with advanced oncological diseases and mental illnesses like schizophrenia were excluded. Inclusion criteria consisted of peer-reviewed articles written in English, French, or Spanish that were published in the past six years. The information gathered was then organized into clear categories of the negative and positive effects of institutionalization and possible solutions to improving these factors.

RESULTS

Biological Needs

Studies have suggested that the biological needs of institutionalized children living with HIV are met^{5,6}. In a study of twenty-three double-orphaned children living in AIDS orphanages (those children who lost both parents to the disease), Zhou et al.

found that medical care in institutions is superior to family care in homes, as reported by children who experienced both situations⁵. Institutions are often able to provide regular doctor visits, routine medical examinations related to their specific condition, and timely administration of antiretroviral drugs. One fourteen-year-old girl recalled the lack of medical attention while living at home and felt fortunate to be living in the orphanage where the caretakers loved and cared for⁵. Another fifteen-year-old boy noted the care that the workers at the institution felt for him and the fact that they were always available to take him to the hospital, even if he got sick in the middle of the night⁵. The stability of basic medical care that these children find in their institutions is an important advantage over kinship care.

In addition to providing basic medical care, institutions yield better results in controlling the HIV-specific disease⁶. In a study involving 325 HIV-infected Romanian children, Cluster of Differentiation 4 (CD4) count, a method of determining progress of the disease, was analyzed: Ferris et. al found that although the difference in CD4 count between those living in institutions and those living with their biological families was not statistically significant, a trend toward greater decline among those children living under kinship-care was found⁶. This pattern of a survival advantage for children living in institutions is mirrored in the fact that children were “more likely to experience disease progression through either death or CD4 decline than were children in institutions”⁶.

Mental Health

Aside from the biological necessities of these children, the mental needs are perhaps equally as important. A closer look into the psychological development of these children reveals shortcomings in the care that the institutions are able to provide^{7,8}. The environment often proves inadequate in simulating genuine family relationships⁷. In a 2008 study in China, Li et al. found that the

inability of HIV-positive children to recognize grief is often found in those orphaned and living in institutions⁸. The onset of illness marks the beginning of separation from their family and community, in turn leading these children to internalize their grief and fall into a pattern of lifelong “complex grieving”; this grieving process is often manifested in depressive symptoms, dejection, anxiety, guilt, anger, hostility, and loneliness⁸.

In addition to this complex grieving process, institutionalization has other negative psychological implications. In an investigation by He and Ji involving cross-sectional and matched pairs studies on psychological health and life quality, regression analysis revealed that orphanhood leads to low self-esteem and depressive symptoms⁹. Moreover, children living with HIV/AIDS who are institutionalized from a young age struggle to develop emotionally^{7,10}. Researchers at the University of Passo Fundo in Brazil reported that without a constant caregiver, the child often fails to develop a strong sense of identity and establish emotional ties with other human beings⁷. According to a study done by the National AIDS Commission in Chile, researchers found that this inability to develop emotionally may be caused by the lack of attention and affection provided by caretakers at institutions¹⁰.

Yet other emotional problems that children living in an institution suffer from are trauma-related disorders caused by HIV-related death of their peers. In a study done in a rural area of China with high prevalence of HIV, Zhao et. al found that institutionalized AIDS orphans were often deprived of information about the disease they possessed¹¹. Of these children, only sixteen percent reported knowledge of peer HIV infection. The children who have knowledge of their peers dying from HIV suffered from higher levels of posttraumatic stress and sexuality concern¹¹. A lack of general HIV/AIDS knowledge is another relevant stress factor. The qualitative interviews of HIV-positive orphans in China revealed just how little these children knew about their condi-

tion⁵. This lack of knowledge stems from the reluctance of caregivers to discuss important details involved in HIV/AIDS^{12,13,14}. A study done in Belgium which sought to improve the condition of institutionalized HIV-positive children found that caretakers were uncomfortable disclosing information for fear of having potential negative consequences to their well-being¹⁴.

In the Chinese study done by Zhou et. al, when asked what he knew about AIDS during an interview, an eight-year old participant stated, "you should also stay away from AIDS virus. I am not clear about the rest of it. This is what I found from the books myself; the teachers here usually wouldn't tell us anything about this"⁵. Overall, this lack of full disclosure about the details of HIV/AIDS to institutionalized children leads to a lack of general awareness about their disease as they reach maturity, in turn resulting in increased risk of transmission¹¹. In another study done by De Baets, et al in Zimbabwe, more than seventy-three percent of participants felt that HIV-infected children over five years old should be informed of something about their HIV status, while over sixty-nine percent felt that full disclosure should be given to those children older than eleven years of age¹².

DISCUSSION

At a first glance, HIV-positive children living in institutions are typically provided with better biological care than they would have received through kinship care^{5,6}. This is not so clear-cut, however. When a closer look is taken at this physical care in terms of HIV treatment most specifically, it meets the general standards for controlling the deadly virus. While the biological necessities of these children are essential to physical growth, the mental needs are arguably just as important. This systematic review of literature in terms of the psychological development of these HIV-positive children in institutions reveals, however, problems with a child's grieving process that in turn lead to depressive

symptoms, low self-esteem, trauma-related disorders, and other negative emotional consequences^{7,8,9}.

Furthermore, a lack of communication between caretaker and patient in terms of the disease these children possess creates other salient problems that stem from a lack of knowledge about HIV/AIDS: an interruption of the grieving process, a greater confusion about the disease they possess, and an increased transmission of the virus when they reach sexual maturity^{11,12,13,14}. Thus, caregivers working in these institutions need to be more properly trained to better recognize the need for communication in order to fulfill the developmental needs that each child requires. This training should include procedures regarding the disclosure of the HIV-related diagnosis in specific children^{11,12}. In this way, effective communication and a general sense of openness between caregivers and patients can be fostered in a healthy environment. Sufficient knowledge of their disease will likely decrease both transmission and feelings of grieving and dejection⁸.

After reviewing the care models that exist today, a community-based institution that closely mimics an actual familial setting appears to be the best option in caring for HIV positive orphans in resource poor areas¹⁵. While medical treatment of the virus is critical in maintaining the health of these children, a low caregiver-to-child ratio is equally important in order to provide each child with the close familial relationships and sufficient care that are needed for successful emotional development⁶. By combining this care with the biological needs that these children require, trained caregivers are able to create an environment that fosters a strong sense of family. This community-based model, therefore, has the potential to provide the most comprehensive care for orphaned children living with HIV¹⁵.

This literature review also reveals a general lack of published information regarding the biological and mental effects of insti-

tutionalization on children living with HIV, most specifically for those living in Chile. The data available regarding the number of HIV positive orphans in Chile is incomplete, making it difficult to assess the overall scope of the problem, let alone monitor the specific outcomes of institutionalization on the children's well being¹⁰. Additional studies are essential to fully understand the physical, psychological, and developmental consequences that come about when HIV positive children are placed under institutional care. Obtaining this information will be integral to improving current institutions and developing new models for the future care of HIV/AIDS orphans.

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