

# Giving Children with HIV and AIDS a Future; The need for occupational therapy of HIV-positive children with developmental delay

\*J. Schurgers<sup>1</sup>, S. Sinyangwe<sup>2</sup>, S. Burger<sup>3</sup>, J. van Nieuwkerk<sup>3</sup>, E. Kamanga<sup>4</sup>

<sup>1</sup>University of Zambia (UNZA), Department of Medical Education, Lusaka, Zambia

<sup>2</sup>University of Zambia (UNZA), Department of Pediatrics, Lusaka, Zambia

<sup>3</sup>Hogeschool/University Rotterdam, Occupational Therapy Program, The Netherlands

<sup>4</sup>Livingstone General Hospital, Rehabilitation Department, Livingstone, Zambia

## INTRODUCTION

The HIV pandemic has created an increase in the number of children with disabilities and chronic illnesses, seriously affecting their daily functioning. The World Bank in their HIV/AIDS and Disability Global Survey (2004) addressed the need to identify programming interventions for HIV-infected children.<sup>1</sup> These children might present with developmental delay, communication, motor, emotional, psychological and mental problems. It is necessary to identify the neuro-developmental, functional abilities and needs of a child. Rehabilitation intervention can accordingly stimulate the child's overall development and support optimal daily functioning. Holistic intervention includes an exercise program by various rehabilitation specialists, care-giver education, and family-centered care, promoting participation and integration of the child in the community. This approach encourages independent living skills and provides better future perspectives for the HIV-infected child.

It is imperative to identify the occurrence of developmental problems and functional problems due to HIV/AIDS, which might lead to long-term consequences and disabilities. Normal development and integration in society require an understanding and awareness of the significance of early detection,

prevention and intervention for these problems. This article describes the role of occupational therapy in addressing HIV-related developmental and functional deficits.

## HIV AND AIDS

About 2.1 million children under the age of 15 are infected with HIV worldwide, and approximately 80% of them live in sub-Saharan Africa.<sup>1,2</sup> UNICEF reported in 2008 about 40,000 children under 5 living with HIV/AIDS in Zambia.<sup>3</sup> Until recently, the prognosis for HIV-infected children in sub-Saharan Africa was very poor, with about a 50% death rate.<sup>2, 4, 5</sup> With improvement of clinical management and the upscale of availability of Highly Active Antiretroviral Therapy (HAART), the mortality rate in children has dropped and has transformed HIV/AIDS from a fatal disorder to a chronic illness.<sup>2,5</sup> A relatively new phenomenon has emerged – children needing lifelong health services while living with stigma and reduced functional ability as a result of HIV/AIDS. There is need for initiatives that encourage and equip children to achieve optimal functioning within society.

## HIV AND AIDS, DISABILITY AND DEVELOPMENTAL DELAY

HIV/AIDS can affect children's development, depending on the extent of neurologic involvement, the stage of the HIV infection, CD4 count, and the

**Key words:** occupational therapy, developmental delay, HIV, children, Zambia

### \*Corresponding author

Julie Schurgers

University of Zambia

Department of Medical Education, Lusaka, Zambia

Email: juulschurgers@hotmail.com

presence of opportunistic infections. Between 10% and 50% of HIV infections in children manifest as encephalopathy, as early as in the first year. Children with clinically evident AIDS encephalopathy often present with catastrophic neurological illness and loss of developmental milestones, followed by severe hypertonicity and hyperreflexia.<sup>6,7</sup>

In children, HIV and AIDS affects the central nervous system (CNS) to a greater extent than the peripheral nervous system, causing deficiencies in developmental milestones. Over 70% of HIV-infected children exhibit cognitive, motor, or speech deficits, frequently resulting in loss of independent living skills.<sup>6, 8, 9</sup> Neurological deficits, including ataxia, spasticity, rigidity, tremor and seizures, emerge as the disease progresses.<sup>10, 11</sup> Apparent symptoms include poorly developed senses, problems and delay in motor skills (both gross and fine motor skills), cognition and perception (including attention, memory and processing speed problems), communication, swallowing, saliva control and emotions. Functionally, there is loss of play, social interaction and participation; and integration into the community is very limited.

## CHILDREN'S RIGHTS

The United Nations (UN) and others have advocated for including in the Millennium Development Goals the rights of children with disabilities and HIV.<sup>12, 13</sup> Furthermore, the UN and WHO recommend the incorporation of the human rights and needs of persons with disabilities into national HIV strategic plans and policies.<sup>14</sup> In Zambia, the ENGAGE project found that stereotypical views of HIV-infected persons with disabilities can add to barriers faced by people with disabilities.<sup>7,15</sup> For children with HIV/AIDS and disabilities, this often means that access to health care, education, and socializing is limited, and the children become more dependent and vulnerable to their environment.<sup>12, 13, 15, 16</sup> Children with HIV/AIDS have the right to be stimulated in normal development and every child has the right to education, development of life skills, and a meaningful existence.

## Access to health care in order to stimulate development = a child's right



## EARLY REHABILITATION INTERVENTION FOR HIV-INFECTED CHILDREN

HIV-infected children go through periods of medical instability due to complications, opportunistic infections and malnutrition, before being diagnosed with developmental delay or disabilities. They make repeated trips to the health centre or hospital for medical examinations, treatment and antiretroviral therapy. Even when the children become medically stable, they fatigue quickly. Many lack adequate preparation for school, having received little stimulation so far. Most of them are not referred at an early stage for rehabilitation services, as that is often not perceived as a first priority. However, there is growing awareness that, due to the broad spectrum of the symptoms and the nature of HIV, this vulnerable group needs special attention and a specific approach in screening, early detection and treatment.<sup>4, 6, 8, 16-18</sup>

Studies in Africa and elsewhere provide documentation that early rehabilitation and developmental intervention programs of all HIV and AIDS-infected children are vital.<sup>4, 11, 19</sup> The most successful programs focus on developmental stimulation, with involvement of family and caregivers throughout the intervention process. If functional problems are left unaddressed, they frequently become permanent disabilities.<sup>8, 16, 18</sup>

Best practice involves multidisciplinary care in a community-based setting. The magnitude of the HIV pandemic demands a community-wide approach. Community involvement can reduce the impact of HIV on children's overall development, as well as reduce misconceptions, which are currently leading to stigma, isolation and segregation.<sup>8,15-18</sup>

Rehabilitation modalities recommended include Physiotherapy (PT), Occupational Therapy (OT), Speech & Language therapy (SLT), Child Psychology, and Educational services.<sup>16</sup> Intervention approaches include regular evaluation of the child's development, identification of needs, provision of hands-on treatment, and family and care givers guidance and support. Such multidisciplinary therapy aims to achieve normal development, optimal daily functioning, and social integration and inclusion of the HIV-infected child.

### **OCCUPATIONAL THERAPY APPROACH FOR HIV-POSITIVE CHILDREN**

Occupational Therapy (OT) is a relatively unknown rehabilitation specialty in Zambia. OT deals with children with a wide variety of diagnoses and functional problems, including HIV-infected children, using a holistic approach<sup>5</sup>. Acknowledging that environmental factors influence a child's ability, OT insists on active participation of parents/care givers and values community involvement. Best practice treatment models include the Sensory Integration (SI) approach from Ayres and the Neuro-developmental treatment (NDT) from Bobath.<sup>20,21</sup>

Play is considered a primary childhood occupation and the key to development for children. Through play, children learn about the world around them, developing skills and interests that later affect choices and success in school, work and leisure. Hence, play is used in OT as a therapeutic medium; to assess and determine a child's level of development in performance areas, to reflect upon their development and to build up specific functional skills.<sup>20,21</sup>

OT assessment of HIV-infected children is done by interviewing the mother or caregiver, and through observations of spontaneous and stimulated play, intake forms and assessment tools. In Zambia, a

manual from Ministry of Education is available for child development assessment.<sup>22</sup> The Sensory Integration Pyramid is a conceptual model of child development, guiding OT in stimulating development in children.<sup>20,21</sup>

### **CASE STUDIES**

Two cases will illustrate OT intervention with HIV-positive children. Although the cases describe real patients, names have been changed to maintain confidentiality.

#### **Case 1**

Joshua, a 4-year-old boy, was diagnosed with HIV and meningitis at 3 months. He has partial hearing loss as a result of the meningitis and had a seizure at 3 years of age. Currently, he is on HAART. Joshua lives with both parents and two older siblings. He does not attend school, and his mother stays home during the day. Joshua was referred to OT one year ago for behavior problems, hyperactivity, and speech and language delay. Autism is suspected.

#### **Testimony of the mother:**

*"J. is difficult, I do not know how to handle his behavior. He is doing things that I do not like. I am worried how to communicate with him and how to stop him doing something naughty. I am worried about him going to the toilet. He does not give any sign at all of needing to go to the toilet. When playing with friends, he argues with them."*

#### **OT assessment:**

Joshua demonstrates hyperactivity and attention-seeking behavior; his mother cannot cope. She gets very irritated. Motor skills are functional, but postural control and more refined complex motor skills are poor. Ability to focus is meager. He has a scattered attention span and is easily distracted. Task performance is not satisfactory; he has difficulty finishing a task. Initiative is limited; he is very absorbed in his own world and gets angry when disturbed. Problem-solving skills and praxis are poor and not up to age level. Activities of daily living (ADL) are not appropriate for his age: He does not indicate his toilet needs. Communication is difficult. Joshua makes

sounds and some gestures to communicate, but no words. Joshua shows frustration surrounding his difficulty communicating his needs, and this adds to his misbehavior. He demonstrates problems interacting with others, cooperating, or taking turns. His behaviour can be destructive when in a bad mood or frustrated. He easily gets into fights with other children, breaks toys, screams and runs away.

Mother's expectations of the OT intervention:  
*"For him to change for the better."*

Joshua and his mother attended 10 group sessions. Joshua's mother participated and received guidance on play, communication, boundaries, and influencing behaviour using a positive confirmation approach. She practiced alternative communication. She and other mothers shared ideas on the importance of play, how a child can utilize energy in a positive way, and how to practice this at home on a daily basis.

Evaluation:

Improvements included less disruptive behaviour and less shouting. Joshua calmed down, and became more sociable and motivated to participate in the group. Following therapy, Joshua communicates more successfully, using more signs and symbols to express himself. This has reduced his frustration. Joshua's attention span improved, and he learned to share, take turns, and participate in an activity and plan. Joshua and his mother appreciate that he is able to achieve and accomplish something, self confidence has increased, and he has adapted social behaviour, resulting in reduced conflicts.

Testimony of mother after treatments:

*"His behavior has changed. My expectations of the treatment are fulfilled. I am very happy and appreciate what OT did for him. I have learned that playing together is important for my son, that sharing and a positive approach of my son's behavior is important. I went to the clinic and saw other mothers with children with similar problems as my son, struggling as I did before. I can see that I am more confident to handle my child than those mothers."*

Case 2

Brian is a 3-year-old boy, diagnosed with HIV by PCR in early infancy, on HAART, with cerebral palsy. He lives with his mother and three siblings; his father is deceased. Brian's mother is mostly out of the home during the day, and Brian is looked after by a 16-year-old cousin. Brian was referred for OT at 2 years, with motor problems due to spasticity and developmental and speech delay.

OT assessment:

Brian demonstrated problems in motor skills due to hypertonicity in all extremities. He was not able to roll, sit without support, or bear any weight on his legs. He could not stand or walk. It is difficult for him to make deliberate, voluntary and targeted movements. Not able to hold items in his hands, no fine handgrips, hypersensitive to touch and tactile stimulation, not able to make any sound and not able to be engaged in play. Communication is difficult, due to spasticity. Mother finds it difficult to handle and love her child, being so disabled.

OT treatment:

Brian was engaged in group therapy for 6 months twice a week, where he was stimulated to play and encouraged to communicate with others at the same time. During play, tone regulation and sensory, tactile stimulation was facilitated. Activities such as supported sitting, trunk control, reaching out, handling of objects, rolling and weight bearing of both lower limbs were integrated in a form of play. Desensitization of the hands using different textures was done during play activities. With the mother present at the intervention, she was taught how to continue with the treatment at home. She was also encouraged to discuss the problems and experiences with other parents, so they could learn from each other and be stimulated in problem solving.

Evaluation:

Over time, Brian was able to roll, bear weight, sit unsupported, stand independently, and reach out for objects and manipulate them independently. He can engage in play, and he is able to communicate his needs. Sharing with other parents helped his mother to accept her child in a more positive and loving way. She was able to support him constructively without making him too dependent.

The cases present the role OT can have in assessing functional problems of HIV-infected children at an early stage. OT could benefit children by stimulating their development and thereby preventing the occurrence of further delay and disabilities, giving a better perspective of normal development and integration into society, including attending school. These cases also demonstrate the importance of understanding the problems in development and the strength of the guidance of parents and caregivers. This will create more understanding of the needs of these children, including developing a more positive attitude toward this vulnerable group.

## CONCLUSION

This article highlights the future of HIV-infected children, who are living longer as a result of more adequate and available medical treatment. Early identification of developmental and functional problems coupled with effective OT interventions helps to reduce the long-term consequences of HIV and equips children with productive life skills. This approach also leads to more community understanding and awareness for the needs of these children, and facilitates integration into society.

Additional research is necessary to understand the complex relationship between HIV/AIDS and disability, and to assess the adequacy of the current response in the field of HIV-related rehabilitation and child development. We advocate for improved educational opportunities for HIV-infected children with disabilities. We also recommend the scale up of intervention programs facilitating access to OT services in the community as well as further impact research on OT-based community intervention modalities in Zambia.

## ACKNOWLEDGEMENTS

We would like to acknowledge the support of the International Centre for Disability and Rehabilitation (ICDR), Toronto, Canada, for assisting in the literature research. Support was provided by a CDC interagency agreement with NIH, D43TW001035-11-S1 (Vanderbilt-CIDRZ AIDS International Training and Research Program).

## REFERENCES

1. WorldBank/Yale (2004). HIV/AIDS and Disability Global Survey. <http://globalsurvey.med.yale.edu/10/01/2010>
2. Aboubakar, A. Van Baar, F. Van De Vijver, P. Holding, C. Newton. Pediatric HIV and Neurodevelopment in Sub-Saharan Africa Systematic Review. *Tropical Medicine and International Health* 2008;13(7):880-887.
3. UNICEF. UNICEF in Zambia Programme, 2008 Lusaka, Zambia. <http://www.unicef.org/10/01/2010>
4. Botha J. & A. Pienaar. The Motor Development of 2 to 6 year old Children Infected with HIV. *South African Journal for Research in Sport, Physical Education and Recreation* 2008;30(2):39-51.
5. UNAIDS (2007). Report on the global HIV/AIDS epidemic. Joint United Nations Program on HIV/AIDS UNAIDS, Geneva, Switzerland.
6. Shanbhag C., Rutstein M., Zaoutis M. et al. Neurocognitive Functioning in Pediatric Human Immunodeficiency Virus Infection; Effects of Combined Therapy *Archives Pediatrics & Adolesc Med.* 2005;159:651-656.
7. Mitchell W. Neurological and Developmental Effect of HIV and Aids in Children and Adolescents. *Mental Retardation and Developmental Disabilities Research Reviews* 2001;7:211-216.
8. Potterton J., A. Stewart, P. Cooper, L. Goldberg, C. Gajdosik, N. Baillieu. Neurodevelopmental delay in Children infected with Human Immunodeficiency Virus in Soweto, South Africa. *Vulnerable Children and Youth Studies* 2008;4(1):48-57. <http://www.informaworld.com/15/11/2009>.
9. Smith R., Malee K., Leighty R, et al, Women and Infants Transmission Study Group Effects of Perinatal HIV Infection and Associated Risk Factors on Cognitive Development Among Young Children. *Pediatrics* 2006;117:851-862.
10. Koekkoek S, de Sonnevile J, Wolfs T, Licht J, S. Geelen. Neurocognitive Function Profile in HIV-infected School Age Children. *The European Journal of Pediatric Neurology* 2008;12:290-297.

11. Bagenda D, Nassali A, Kalyesubulla I et al. Health, neurologic and cognitive status of HIV infected, long surviving, and antiretroviral naïve Ugandan children. *Pediatrics* 2006;117: 3: 729-740.
12. International Labour Organization (2008); Count us in. ILO office, Geneva, Switzerland.
13. Rouger T. & L. Lawyer. (2006). The Human Right to health within the context of HIV/AIDS and disability rights as embodied in various international instruments. Handicap International, Lyon, France.
14. UNAIDS: Disability and HIV Policy Brief. 2009 [cited 2010 April 30]; Available from URL: [http://www.who.int/disabilities/jc1632\\_policy\\_brief\\_disability\\_en.pdf](http://www.who.int/disabilities/jc1632_policy_brief_disability_en.pdf).
15. American Institutes for Research (2007); Vulnerability for households with persons with disabilities and HIV/AIDS in Chongwe, Zambia. ENGAGE Program, RAPIDS, Lusaka, Zambia
16. Zambia Federation of the Disabled (2003); National Plan of Action on Disability in Zambia (August 2003-July 2008). Zambian Federation of Disabled, Lusaka, Zambia.
17. Nganzi P. & G. Matonhodze. (2008) Disability and HIV & AIDS; A participatory rapid assessment of the vulnerability, impact, and coping mechanisms of Parents of Disabled Children on HIV& AIDS. ENGAGE Project, RAPIDS, Lusaka, Zambia.
18. A. Van Rie, A. Mupuala, A. Dow (2008). Impact of the HIV/Aids Epidemic on the neurodevelopment of Preschool-Aged Children in Kinshasha, Democratic Republic of the Congo. *Pediatrics* 2009;122(1):e123-e128.
19. Chase C., Ware J., Hittelman J., et al. Early Cognitive and Motor Development among Infants born to Women with Human Immunodeficiency Virus. *Pediatrics*, 2000;106:e25-e35. <http://www.Pediatrics.org/11/2009>
20. C. Stock Kranowitz (2004). The Out of Sync Child. Skylight Press, 2<sup>nd</sup> revised edition, New York, USA.
21. Case-Smith J. (2005). Occupational Therapy for Children. 5<sup>th</sup> Edition. Elsevier Mosby, Missouri, USA.
22. D. Ettling, J.T. Phiri, H.J. Msango, B. Matafwali, J. Mandyata, E. Mundaala-Simfukwe, M.O. Mweembe, L. Piez, L. Uribe-Kozlovsky, A.M. Tuchili, A.B. Mwansa (2006). *Child development assessment in Zambia*. 1<sup>st</sup> Edition. UNICEF, Lusaka, Zambia.