Children experiencing orphanhood: The role of the health sector

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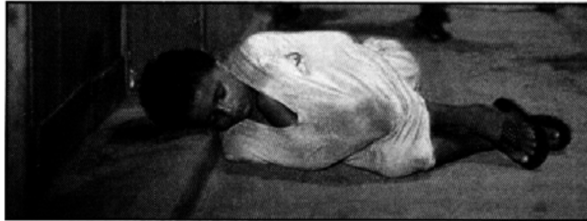
Introduction

South Africa has a population of over 46 million, of whom 6.5 million are estimated to be HIV-positive. Of direct significance to children is the fact that an estimated 3.2 million women of childbearing age (15 to 49) were living with HIV/AIDS in July 2002. As a result, between 1 January and 31 December 2002, 89 000 children (around 7.5% of the total number of children born during this period) were infected with HIV, either at birth or through breast-feeding, and 150 000 children lost a mother to AIDS (Dorrington, Bradshaw, & Budlender, 2002).



In August 2001 the Children's Institute was awarded a tender from the National Department of Health to conduct research to inform an appropriate and co-ordinated national response to children experiencing orphanhood (i.e. children who had been orphaned or who were living in the care of a terminally ill caregiver). The research was designed as a multi-site qualitative research project, based in 6 sites in 5 Provinces.

Information was collected through a combination of child participatory research activities, interviews, focus group discussions and observation. Research participants included children and caregivers (from 118 households), a range of service providers who contributed to the households' well-being and/or vulnerability, and a number of other people identified as playing an important role in children's lives in the research sites.

This article presents some of the findings of the research and is an adaptation of the chapter on Health in the full research report (Giese, Meintjes, Croke & Chamberlain, 2003).

Health-related needs of children and their caregivers

Malnutrition is first and foremost on the list of health needs experienced and expressed by children and observed by health workers participating in the study. In every one of the children's group activities, hunger was raised as a primary concern. Health workers substantiated children's experiences with descriptions of increasing numbers of children presenting with Kwashiorkor and Marasmus, with accounts of children begging or stealing, and of caregivers pleading with health staff for food.

Apart from malnutrition, the most common health-related issues raised by health workers in relation to children were diarrhoea, chest infections and the consequences of child sexual abuse. HIV infection in children was not noted as a major concern by most clinic staff (except in the case of clinics rendering prevention of mother-to-child-transmission - PMTCT - services). At tertiary level facilities, however, doctors were very concerned about the proportion of beds in paediatric wards occupied by HIV-infected children and the inadequate care available to terminally ill children and adults within their homes.

Children's descriptions of caring for sick and dying relatives at home alert us to a range of other health-related needs of children experiencing orphanhood. Care for the sick by children almost always took place in conditions of poverty, with poor access to sanitation facilities and water. Health workers expressed their concerns about the health risks of children caring for adults and of children's increased exposure to opportunistic infections in HIV/AIDS-affected households. Another health need that these care arrangements highlight is the psychological and mental health impact of illness and death on children. This is possibly the most poorly understood and certainly one of the most neglected health needs of the children who participated in this research.

The health sector response

In the face of these experiences, the health sector response at the sites was inadequate in many ways.

Eligibility criteria, administrative hurdles and irregular supplies for the clinic-based protein-energy malnutrition scheme (available in 9 of the 13 clinics) and the school-based feeding scheme rendered these limited nutrition-related interventions ineffectual in the face of such widespread and severe hunger. The impact of HIV/AIDS on children living in poverty calls for a far more substantial and co-ordinated response from the Department of Health, as one of several key partners needed in a national food security strategy.

The research showed a heavy reliance on tertiary level health care facilities for the treatment and care of HIV-positive children. Many of the clinics involved in the research reported that they did not have the facilities to test children for HIV and most clinics reported that they referred HIV-positive children and children whom they suspect to be HIV-positive to hospitals. Given the emphasis in policy and programmes on health service delivery at primary level facilities, there is a need for primary level health care staff to be better trained, resourced and sensitised to address the health needs of this particularly vulnerable group of children.

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The emotional and mental health needs of children who are surrounded by illness and death were largely unrecognised in the health service response. While voluntary counselling and testing and/or support groups for adults were available to varying degrees at most of the health facilities, the research revealed a distinct lack of health worker capacity to counsel and support children.

At most of the sites the only palliative care available to terminally ill children and caregivers was hospital-based, and hospitals lacked the capacity to accommodate the number of people requiring these services. Given the responsibility of care that many children carry in HIV/AIDS-affected households, we argue that palliative care services for sick adults and children constitute an essential component of a service response to children experiencing orphanhood.

In addition to the need for facility-based palliative care, health outreach and home-based care services are also required. Of the 21 health facilities that participated in this research, health workers at every one emphasised the importance of health outreach services, yet 16 of the facilities were unable to do outreach work. The main reasons cited for this were lack of staff capacity and transport . A key component of Government's response to the impact of HIV/AIDS on children is the provision of financial and professional support and medical supplies to non-governmental organisations rendering home- and community-based care services. In reality however, the research found very few instances where facility-based health workers were able or willing to provide support or supplies to home-based carers. In addition, most organisations delivering home-based care services complained about the difficulties they experienced in accessing State funding. To ensure accessibility, quality and continuity of care, health facilities need to be more integrated into organisations rendering home- and community-based care services, and (financially and professionally) support and be supported by them.

Barriers to health service access

Access to health facilities varied between and within the sites. The research found several barriers to health care access more pronounced among children and caregivers living in rural areas. The consequences of poor access were evident in accounts of people dying while attempting to get to hospital, of children arriving at clinics with advanced kwashiorkor, and of large numbers of children who are not immunised. Barriers to service access and delivery described in the report include those related to transport and distance, user fees, limited operating hours or limited access to after-hours facilities, HIV/AIDS-related stigma and discrimination, negative staff attitudes, erratic drug supplies, long waiting times, and the requirement that children accessing health care are accompanied by an adult.

Policies regarding the treatment and care of children who arrive unaccompanied at health facilities differed from one facility to the next in the research sites. Some facilities were rigid about their policies and would not see unaccompanied children younger than 16 or 17 years, whereas others treated unaccompanied children of any age.

Early identification of vulnerable children

The early identification of vulnerable children lends itself to timeous interventions, making it imperative that these opportunities are optimally utilised. Health workers reported a range of mechanisms for the identification of vulnerable children. These were almost always limited to contact with children directly, and few health workers used the opportunity to identify vulnerable children through adult patients. Similarly, organisations rendering home-based care services in the research sites focused almost exclusively on meeting the health care needs of sick adults. With a few notable exceptions, home-based carers frequently overlooked contact with sick adults in households as an opportunity to address the needs of vulnerable children in those households.

Overall, the extent to which socio-economic vulnerabilities were identified and followed up by health workers or home-based carers was largely dependent on the awareness of individuals and on the strength of collaborative partnerships between health services and other services. The research suggests strongly that in most health facilities, these collaborative partnerships were not functioning optimally and that, as a result, orphans and other vulnerable children are falling through the service gaps.

Going the extra mile

Within the context of limited resources and health service challenges, the research documented many cases of individual health workers attempting to fill the gaps in service provision. The report describes for example how doctors in Phuthaditjhaba, Orange Free State, are personally financing a step-down facility to provide palliative care to adults and children who would otherwise be discharged. In Ingwavuma, KwaZulu-Natal, doctors have established a NGO to provide food and school fees to orphans, recognising that these children needed services and support beyond that which the hospital could provide. The research showed unequivocally that where health workers and other service providers worked together, their capacity to identify and support orphans and other vulnerable children was greatly enhanced.

Without exception, every one of the health facilities cited "more staff" and "better staff support" as key areas of need for improved service delivery to orphans and other vulnerable children in the context of HIV/AIDS. It is essential that we recognise the impact of HIV/AIDS on service providers, personally and professionally, and make every effort to ensure that the needs of health workers are met and that adequate support systems are in place.

For further information on this research, please contact Sonja Giese or Helen Meintjes on (021) 689 5404 or email: sonja@rmh.uct.ac.za or helenm@rmh.uct.ac.za.

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