

Chronic Illness in the Home: Implications for Children in KwaZulu-Natal, South Africa

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Key Findings

Chronic illness was prevalent: over one-third of OVC had an ill primary caregiver.

Chronic illness likely goes beyond HIV and AIDS to include health conditions of the elderly.

A high proportion of caregivers with a chronic illness reported poor health and unmet need for critical health services.

Ill caregivers were twice as likely as those without chronic illness to have suffered psychosocial distress.

Children living with an ill household member were at greater risk than other OVC for a variety of adverse outcomes.

Introduction

South Africa is home to the world's largest HIV epidemic; in 2009:

- 5.6 million people living in the country were HIV positive;
- 310,000 people died of AIDS; and
- 1.9 million children had been orphaned due to AIDS [1].

Orphanhood, defined as the loss of one or both parents, has long been used as a marker of the epidemic's impact on children. The true impact, however, begins long before a parent's death: millions of children are living with and frequently caring for a sick parent or other family member.

Living with someone who is chronically ill impacts children's wellbeing in many ways. Illness reduces the amount and quality of time that parents or other primary caregivers can spend attending to children's needs [2, 3]. This is true both when the caregivers themselves are ill, and when they are caring for another ill family member. Illness, especially HIV with its associated stigma, can also generate considerable

emotional distress for the caregiver [4]; this may in turn alter the quality of the caregiver's relationship with and treatment of the child [5, 6]. Third, when a primary caregiver becomes ill, children may be forced to take on caregiving or domestic chores [7, 8]—often at the expense of normal childhood activities like schooling. Finally, the financial impact of medical care and lost income may reduce the family's ability to provide for the child's essential needs [9]. Together, these effects can produce extreme vulnerability and situations of marked adversity for children living with someone who is ill.

Programs for orphans and vulnerable children (OVC) have responded to these challenges by expanding their enrollment to include children living with sick parents or caregivers, regardless of orphan status. However, relatively little is known about these children's experiences, and thus about how best to design and implement effective interventions. The current study was undertaken with the ultimate goal of providing information that can be used to improve service delivery for OVC, including children expe-



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riencing chronic illness within the home. This brief describes the extent and potential impact of chronic illness in a population of children enrolled in OVC programs in KwaZulu-Natal, South Africa.

This study is part of the Enhancing Strategic Information project (ESI), funded by the United States Agency for International Development (USAID) in Southern Africa. ESI supports the availability of useful, high quality health systems information that contributes to sustainable policy planning and programmatic decision-making. Tulane University School of Public Health and Tropical Medicine works in partnership with the prime ESI funding recipient, John Snow Incorporated, to produce knowledge that will improve existing practices and guide future investment in OVC programming.

Study Methods and Sample

The findings presented here are drawn from the baseline assessment of a longitudinal study designed to assess the efficacy of a range of interventions for OVC. The study sample includes children newly enrolled in OVC programs operating within predominantly rural areas in 7 districts of KwaZulu-Natal province. Baseline surveys were administered to 1782 children ages 10-17 and their primary caregivers (N=1305) between April and June 2010. Children represent newly recruited beneficiaries of OVC programs, and reflect program eligibility criteria: 87% of children were orphans (either single or double), 38% lived with a chronically ill caregiver, and 98% lived in households with monthly incomes under 2500 Rand. One-third of the children in the sample resided with a parent and nearly all (97%) were cared for by an immediate family member - typically a grandparent (40%) or surviving mother (25%). Further details on the study aims, methodology and baseline sample characteristics are available elsewhere [10].

Chronic illness was self-reported and defined as having had an illness for three or more months in a row over the past year; this is a commonly used survey indicator for presumed AIDS in countries where prevalence is high [11]. Interviewers asked each child's primary caregiver whether he/she, the child's parent(s) and/or other household members were chronically ill according to these criteria. In addition, caregivers

were asked to respond to the question "In general, how is your health" using the response options excellent; very good; neither good nor poor; poor; or very poor. Caregivers were also asked whether they needed any health services or medicines that they were not currently receiving; if so, these respondents were classified as having unmet need.

Two outcomes were examined as potential indicators of caregiver psychosocial wellbeing: negative feelings and family functioning. Caregiver negative feelings (e.g., sadness, depression, worry) were measured using the four item World Health Organization's Quality of Life sub-scale [12]; caregivers scoring less than 3 points on the 5-point scale were considered to have high levels of negative feelings. Overall level of family functioning was measured using the 8 item Family Assessment Device which includes questions pertaining to confiding in one another, the ability to make decisions together, and accepting individuals for what they are [13]; scores above a 2-point cut-off on a 4-point scale were considered indicative of poor family functioning [14].

Children's welfare was measured over multiple dimensions. Food insecurity was measured using the Household Food Insecurity Access Scale [15], completed by the caregiver. Children's unmet need for health care was ascertained using 3 questions about access to clinic visits, medicines, and other health care services; questions were posed to both the child and caregiver. Unmet need was calculated only among those children with an indicated need for any health service, and was defined as the inability of the child to access needed services at least once in the past year.

To better understand the impact of household illness on childwelfare, questions were also asked directly of children. Children were asked if they had ever been kept home from school to take care of household activities and members or to help earn money or food in the past year. Children were also asked to report the frequency of maltreatment by adults in the household (including punching, disciplining with an object, name calling and threats) in the year preceding the survey, using a standardized set of responses ranging from "not at all" to "a lot." Any affirmative response, regardless of frequency or type of offense,

was considered indicative of maltreatment. Finally, children’ depressive symptomology was measured using responses on a brief version of the Center for Epidemiological Studies Depression Scale for Children [16]; the scale includes questions such as “In the last week, how often did you feel down and unhappy?” The scale is scored from 0-30; scores over 10 were considered indicative of depressive symptomology.

Descriptive analyses were performed on the baseline data to assess the extent of chronic illness in children’s households and the reported health status and unmet need for health services among children’s caregivers. Multivariate regression analyses were used to identify the associations between chronic illness and caregiver psychosocial status, household food insecurity, and indicators reflecting child wellbeing (e.g., maltreatment, depression, and access to school and health services). Each model controlled for factors at the level of the household (poverty, neighborhood, number of children; household chronic illness was also included for child outcomes) and caregiver (gender, age, education, marital status; caregiver chronic illness was also included for caregiver outcomes). Models assessing child-level outcomes also controlled for child characteristics, specifically gender, age, orphan status; in some models this also included whether he/she lived with a parent. Unless otherwise indicated, all results reported as significant were statistically significant at $p < 0.05$ in multivariate models controlling for these factors. For notable significant relationships, the unadjusted percentages for outcomes among those living with and without a chronically ill household member are presented.

Key Findings

Chronic illness was prevalent: over one-third of OVC had an ill primary caregiver

Almost half (44%) of the OVC in the sample were living with at least one – and in some cases more than one – chronically ill adult (see Table 1). Importantly, over one-third of children’s primary caregivers reported living with chronic illness. Given the high burden of chronic illness in this population, there is a significant need for

family succession planning. However, 33% of ill caregivers had not identified someone else to care for the child in the event that they become unable to do so.

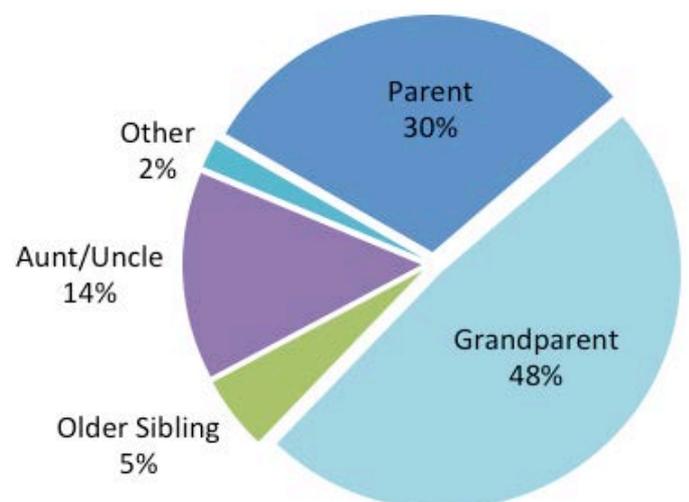
Table 1. Prevalence of chronic illness in the home

Children living with:	%
Ill Adult Household Member	44
One Ill Member	30
Two or More Ill Members	14
Ill Non-Caregiver Adult Household Member	21
Ill Parent at Home	14
Ill Caregiver	38

Chronic illness likely goes beyond HIV and AIDS to include health conditions of the elderly

Figure 1 provides a profile of children’s caregivers who reported chronic illness. Many ill caregivers -parents, siblings and aunts -were likely suffering from HIV or AIDS. However, almost half of all caregivers who self-reported as chronically ill were grandparents. On average, ill grandmothers and grandfathers were 66 and 70 years old respectively, suggesting that illnesses affecting the elderly may also be a common phenomenon for OVC caregivers. The health care needs of grandparents – and perhaps the services or extra care they require at home – may be distinct from caregivers living with HIV.

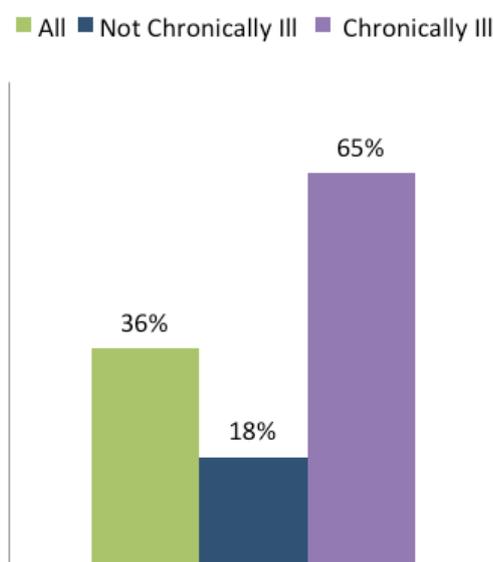
Figure 1. Relationship to child among ill caregivers



A high proportion of ill caregivers had poor health and an unmet need for critical health services

Over 63% of ill caregivers reported poor or very poor health status as compared to 17% of non-ill caregivers. There was also a high unmet need for health services and medicines among chronically ill caregivers. Well over half (65%) of chronically ill caregivers reported that they were not currently receiving necessary medical care compared to only 18% of non-ill caregivers (Figure 2). Unmet need rose to 70% when the ill caregiver in question was a grandparent.

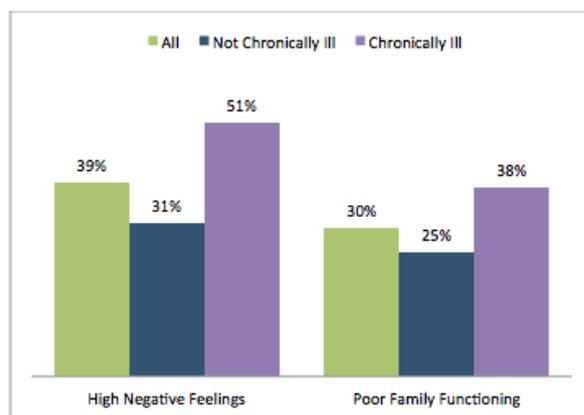
Figure 2. Caregivers’ unmet need for health services or medicines



Ill caregivers were twice as likely to experience psychosocial distress

Figure 3 displays the prevalence of two indicators of caregiver psychosocial wellbeing (negative feelings and family functioning) for the sample overall and for ill and non-ill caregiver groups separately. Results indicate a disproportionate burden for these negative outcomes among chronically ill caregivers. These differences remained significant in multivariate analyses controlling for other household and caregiver level factors: ill caregivers were about twice as likely to have high negative feelings (Adjusted OR 2.24, $p < 0.001$) and poor family functioning (Adjusted OR 1.96, $p < 0.001$).

Figure 3. Caregiver chronic illness and psychosocial distress



Children living with an ill household member were at greater risk — relative to other OVC — for a variety of adverse outcomes

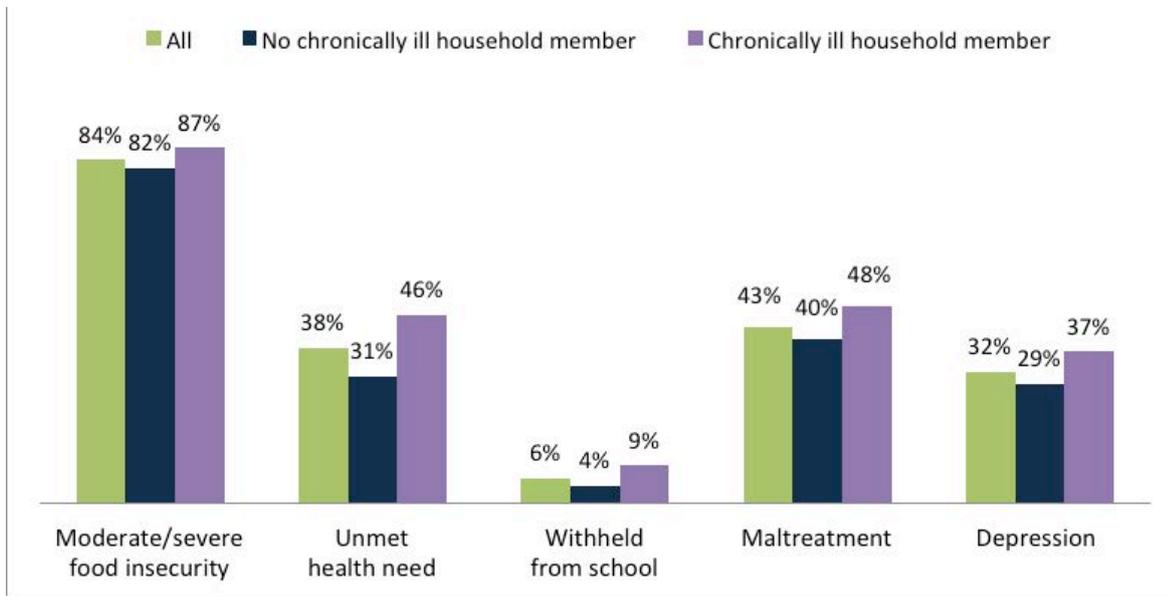
This study investigated whether children living with an ill adult were at greater risk for adverse outcomes relative to the rest of this sample of OVC. As seen in Figure 4, unfavorable outcomes were more common among children living with an ill adult. Households where an adult was ill were found to be at higher risk for household food insecurity; children living with ill adults were at higher risk for maltreatment from adults within their homes and for high depressive symptomology. Children’s access to health and education was also compromised. Each of these disparities held within multivariate analyses controlling for other background factors.

Care and protection needs were evident among the entire OVC population studied; however, they were particularly pronounced among children living with an ill household member. Eighty-four percent of all OVC households exhibited either moderate or severe food insecurity. However, these high levels of food insecurity were even more common among households with an ill adult (Adjusted OR =1.43, $p < 0.01$). Similarly, children with an ill household member were twice as likely to be kept home from school to either take care of household activities and members or to help earn money or food (Adjusted OR =2.01, $p < 0.01$). Children in these circumstances also had diminished access to health services. Those with a chronically ill household member were almost twice as likely as other children to report having unmet need for one or more health services (Adjusted

OR =1.88, $p<0.001$). Children were also more likely to have experienced physical or verbal maltreatment by adults within their home in the year preceding the survey if they were living with an ill household member

(Adjusted OR 1.32; $p<0.01$). Finally, children living with someone who was chronically ill were at greater risk for high depressive symptomology (Adjusted OR =1.52, $p<0.001$).

Figure 4. Negative outcomes among OVC by chronic illness in the household



Programmatic Implications

Adopt a family-centered approach to assessment and care

Children frequently live with chronically ill caregivers, and this may have serious implications for their well-being. A narrow focus on the child, absent program approaches that address household contextual factors, will not be sufficient to improve children’s welfare. Conducting family assessments in addition to child focused ones has the potential to improve the delivery of appropriate support, whether to the child, caregiver, or household. By adopting a family-centered approach, programs can identify households where adults are ill, assess what additional support may be warranted, and provide services that strengthen the caregiver’s ability to parent. To facilitate this change, home visitors will require additional or expanded training to conduct family assessments.

Create linkages between OVC programs and palliative care programs

Too often, HIV care and support programs have a narrow focus—on the child in the case of OVC initiatives, and on the HIV positive adult in the case of palliative care and treatment services. A coordinated model of care would best address the myriad needs of HIV affected families. Indeed, this study demonstrates both the critical health needs of OVC caregivers as well as the significant influence of household chronic illness on children’s wellbeing. Programs committed to the wellbeing of OVC should ensure that all HIV positive parents or caregivers receive appropriate medical treatment, including access to antiretroviral medications, basic medical care to prevent and treat AIDS-related infections, and ongoing health monitoring and support. OVC service providers can ensure more holistic child care either by integrating these caregiver focused services into their programming or by creating linkages with existing palliative care programs. Further opportunities for co-

ordination between palliative care and OVC programs exist. For instance, when caregivers become severely ill, OVC home visitors can be alerted, can ensure that children remain in school by relieving them of caregiving and other domestic responsibilities, and can provide much-needed emotional support.

Facilitate basic health services and additional support for elderly caregivers

Grandparent caregivers commonly reported experiencing chronic illness (44%), and those who were ill frequently (70%) reported not having access to the health care or medicines they needed. Their illnesses may often not be AIDS-related, especially as ill grandparents were commonly age 60 and older. OVC programs could facilitate access to primary health care services for elderly caregivers, such as by offering free or subsidized health services, monitoring referrals, ensuring treatment adherence, and/or providing transport to clinics. Even with proper health care, many elderly caregivers affected by chronic illness may require extra assistance to create healthy home environments; OVC home visitors could expand their focus and activities to include delivering the additional care and support these caregivers need.

Scale-up psychological counseling for both the caregiver and child

Psychosocial distress was prevalent among chronically ill caregivers and their children. A wealth of previous research has illustrated how children's mental health can be negatively affected by the psychological state of their caregivers [17-19]. Increased attention to caregivers' psychological needs may be necessary to sufficiently promote children's resilience. Facilitating caregivers' access to social support may be a particularly powerful intervention approach. For chronically ill caregivers, social support has been found to contribute to constructive coping skills, which in turn reduce children's distress levels [19]. Support groups for ill caregivers may improve their mental health, as well as provide practical guidance on how to parent successfully and address family dysfunction while coping with illness. High levels of depression among children in households with an ill member suggest that children living in these circumstances could likewise benefit from psychological services. Many programs currently offer bereavement counseling to children who have lost a loved one; such interventions could be adapted to address the needs of children grappling with the illness of parents and caregivers.

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