

Identifying and testing children at increased risk for HIV through caregivers: The Caregiver Project

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Background

South Africa has an estimated 280,000 children living with HIV, the largest number of any country in the world (UNICEF 2007)¹. Despite substantial progress in provision of voluntary counseling and testing (VCT) and health services for HIV positive adults, few pediatric testing opportunities exist beyond prevention of mother-to-child transmission of HIV. Most HIV infected children are diagnosed after becoming symptomatic, when antiretroviral therapies (ART) are less likely to be effective.



In addition to limited pediatric testing, many children are orphaned by HIV and at considerably higher risk for being HIV exposed and infected than non-orphaned children. These children are often cared for by caregivers with limited access to accurate information on pediatric HIV testing and treatment. To address this disparity, new programs are needed to expand opportunities for pediatric HIV testing and diagnosis to ensure early treatment for infected children. In this project, we report on an approach targeting caregivers of children in South Africa as a strategy to increase testing opportunities for children.

Goals

- Generate demand for pediatric HIV testing services among caregivers collecting social grants at South African Social Security Agency (SASSA) grant distribution sites.
- Describe the caregiver population and determine factors associated with pediatric HIV testing.

Methodology

- Caregivers receiving grants at SASSA sites were informed about pediatric HIV testing and referred to pediatric testing services from July to September 2008.
- 9 outreach workers were positioned at 6 SASSA grant distribution sites: 2 sites in Rustenburg, North West Province and 4 sites in Mdantsane, Eastern Cape Province.
- Outreach workers were trained to:
 - Approach and recruit caregivers;
 - Administer a short survey;
 - Briefly explain the importance of pediatric HIV testing; and
 - Offer referral cards to grant recipients caring for children aged 0–14 to access 6 participating health facilities for pediatric HIV testing.
- Referral cards provided a method to monitor uptake of testing. 10 cards were provided: 1 card for their children and 9 additional cards for caregivers in their peer network.
- The population of caregivers (parental or non-parental) varied depending on the grant day:
 - Child Grant Day: Biological parents, foster parents, and elderly caregivers
 - Old Age Grant Day: Elderly caregivers
 - Disability Grant Day: Caregivers collecting disability grants, including HIV-positive caregivers
- Approximately 1,425 caregivers were approached at SASSA sites over 3 months.

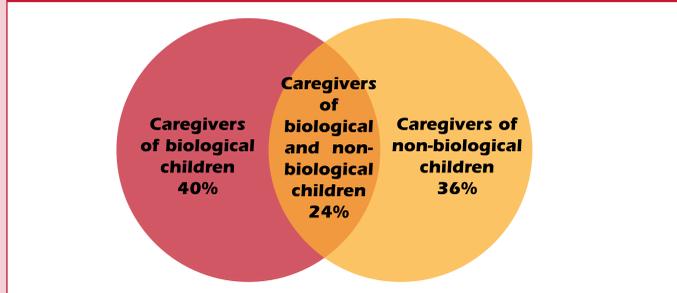
Eligibility Criteria

- 18+ year old primary caregivers (parental or non-parental) of child/children aged 0–14 years
- Accessing SASSA social grants on Child, Old Age, or Disability Grant distribution days.

Sociodemographic Characteristics of Caregivers

Table 1 Sociodemographics of caregivers (n = 1,425)			
Characteristics	n	%	
Gender	1,402		
Female	1,309	93	
Male	93	7	
Marital status	1,417		
Civil/traditional marriage	393	28	
Single	826	58	
Living as married partners	42	3	
Divorced/separated	56	4	
Widow/widower	100	7	
Regular SASSA recipient	1,419		
Yes	1,396	98	
No	23	2	
Grant type	1,419		
Child Grant	857	61	
Old Age Grant	333	23	
Disability Grant	211	15	
Other	16	1	
Education	1,411		
No school /crèche	168	12	
Primary (R-7)	414	29	
Secondary (8-12)	788	56	
Tech/college/university/certificate	41	3	
	Mean	Min	Max
Age of SASSA grant recipient by grant type	43	18	97
Child support	33	18	75
Old age	67	30	97
Disability	45	22	73
Other	45	26	60
Number of children in caregiver's care	2	1	13

Figure 1 Who caregivers cared for

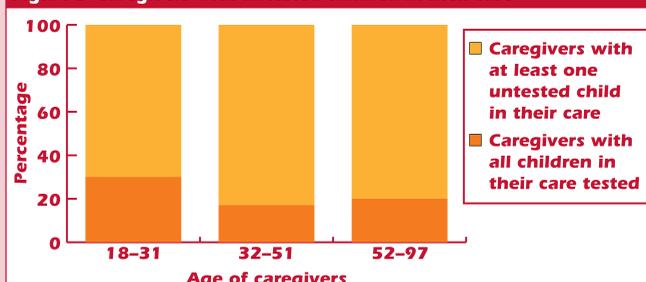


- In total, 64.0% cared for biological children, 60% cared for non-biological children, and 24% cared for both biological and non-biological children

Key Findings

- The majority of these children were untested; fewer non-biological than biological children of caregivers were tested.
 - 77% of all caregivers had at least one child in their care NOT previously tested for HIV.
 - 69% of biological children and 77% of non-biological children were previously untested.
- Older caregivers were more likely to be caring for children who were untested for HIV
 - 70% of caregivers aged 18–31 had at least one child in their care untested compared to 83% of caregivers aged 32–51, and 80% aged 52–97.

Figure 2 Caregivers with untested children in their care



- In multivariate analysis, caregivers age 32–51 were twice as likely to be caring for untested children. In addition, caregivers caring for both biological and non-biological children were more likely to have at least one untested child in their care.
- Most (96%) caregivers knew where children could receive HIV services, including testing.

Table 3 Factors associated with caregivers having one or more untested children in their care*

	N (%)	Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Married or living as married (n = 1,423)			
No	988 (69.4)	1.0	1.0
Yes	435 (30.6)	1.23 (0.94–1.63)	1.08 (0.8–1.46)
Children in care of caregiver (n = 1,416)			
Biological only	569 (40.2)	1.0	1.0
Non-biological only	510 (36.0)	1.81 (1.35–2.40)	1.33 (0.83–2.15)
Both biological and non-biological	337 (23.8)	2.46 (1.73–3.50)	2.47 (1.73–3.53)
Age (n = 1,423)			
18–31 years old	496 (34.9)	1.0	1.0
32–51 years old	453 (31.8)	2.06 (1.51–2.8)	2.05 (1.47–2.84)
52–97 years old	474 (33.3)	1.76 (1.31–2.37)	1.76 (1.05–2.87)

*Sample sizes vary slightly because of missing data

Discussion

- This project resulted in a small increase in testing in area clinics (15 children accessed testing services). However, we consider this to be a minimum estimate for the following reasons:
 - Many caregivers likely did not present referral cards if/when they brought children in for testing;
 - Caregivers presenting after the observational period were not recorded, and anecdotal reports suggest that caregivers did not immediately bring children in their care for testing; and
 - Only 6 health facilities were linked to this project. We hypothesize that more children were tested in clinics outside our referral card monitoring system.
- Older caregivers were more likely to have untested children in their care compared to younger caregivers. Prevention messages should be designed for older caregivers.
- Caregivers caring for their own and others children were more likely to have untested children in their care suggesting that these caregivers may be "overwhelmed" with additional responsibilities.

Lessons Learned

Structural barriers

- Some health providers were not confident administering PCR tests to infants, and were unaware of pediatric testing guidelines.
- Some caregivers seeking pediatric HIV testing services were turned away by clinic staff for various reasons:
 - Child was asymptomatic;
 - Child did not have an immunization card/'Road to Health' card; or
 - Clinic staff assumed that a caregiver who was not the child's legal guardian could not provide consent for the test.
- Few informational materials are available detailing the benefits of pediatric HIV testing.

Social barriers

- Elderly caregivers did not respond as well as we had hoped to pediatric testing promotion messages delivered by young field workers.
- Stigma and the fear of having one's HIV positive status exposed to others.
- Elderly caregivers' knowledge of HIV in general was poor.

Future Steps and Project Modifications

- Address structural barriers to pediatric HIV testing within healthcare facilities.
 - Educate health facility personnel that pediatric testing is important and legal for caregivers presenting with children for testing.
 - Promote child testing among providers who are gatekeepers of this service.
 - Provide technical tools, training, and support to health providers who test children.
- Modify the intervention to address social barriers.
 - Develop tailored pediatric HIV testing messages and materials targeting elderly caregivers (e.g., brochures, posters).
 - Use trained age-appropriate peers to deliver tailored messaging and promote pediatric testing among mature and elderly caregivers.

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1 UNICEF. 2007. The stats of the world's children. New York: UNICEF.