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## Family centred approach for HIV services: Pilot study in South Africa

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# FAMILY CENTRED APPROACH FOR HIV SERVICES: PILOT STUDY IN SOUTH AFRICA

In 2003, UNICEF estimated that nearly 250,000 children were infected with HIV in South Africa (UNICEF 2004). While scale-up of prevention of mother-to-child transmission (PMTCT) programs has improved testing and care for perinatally infected infants, uptake of these services remains low in much of sub-Saharan Africa and few HIV infected children are diagnosed and receive services through PMTCT programs. HIV-infected children often come to the attention of health care providers only after becoming symptomatic, with mortality as high as 50 percent before two years of age (Newell et al. 2004). Further, there are limited opportunities for testing children after the antenatal period.

Earlier research by the Horizons Program suggests that approximately three-quarters of HIV-infected children live in households where another member of the family is HIV-positive (Michaels et al. 2006). This strong family link to childhood HIV infection, coupled with the absence of diagnostic services available to children beyond the perinatal period, suggests a broader approach to childhood HIV testing and diagnosis is needed. Because HIV infection is clustered in families, new programs must also recognize the critical role of caregivers and other family members for the early diagnosis and management of childhood HIV infection.

With support from USAID/PEPFAR, the Horizons Program adapted a family centred model for children and families in need of broader reaching HIV diagnostic services in South Africa. The Family Centred Approach (FCA) pilot intervention was designed to expand access to HIV testing for family members with children ages 0–14 years in their care. This approach gives health care providers a method for encouraging



PHOTO: MELISSA MAY@POPULATION COUNCIL

*The Family Centred Approach pilot intervention was designed to expand access to HIV testing for families, especially those with children who may not otherwise access services.*

HIV-positive individuals to refer family members for HIV testing, with the aim of identifying HIV-positive children ages 0–14 years that may have been missed through PMTCT early infant diagnosis programs.

The FCA pilot intervention aimed to assess the strength of this new intervention by:

1. Describing the sociodemographic characteristics of persons with known HIV status, who are already accessing HIV services.
2. Determining the feasibility of a patient-initiated referral card system for encouraging family members to seek HIV testing services for themselves and for their children.
3. Describing the characteristics of successful referrals.

To read more about this study, go to

[www.popcouncil.org/horizons/projects/SouthAfrica\\_FamilyCenteredApproach.htm](http://www.popcouncil.org/horizons/projects/SouthAfrica_FamilyCenteredApproach.htm)



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## Methodology and Intervention

A total of five health facilities under the Tapologo HIV/AIDS Programme in the Rustenberg Dioceses in the North West Province of South Africa were selected to implement the FCA pilot intervention. These sites included Phokeng, Ledig, Chaneng, Kanana and Boitekong clinics. Clinics were selected because of their existing voluntary counseling and testing and antiretroviral therapy (ART) infrastructure, which could be expanded through the FCA pilot intervention. In addition, previous observational studies indicated that the predominant population accessing HIV services at these clinics were single women, of which a large proportion had children. These conditions were ideal for assessing the FCA pilot intervention on the effectiveness of using existing patients of known HIV status to 1) increase the number of children in their care who have been evaluated for HIV, and 2) to increase uptake of HIV testing among family members and their children ages 0–14 years.

This study used a quasi-experimental design with interventions occurring at the health facilities. Data was collected to evaluate the effectiveness of delivering the FCA method to a population of patients with known HIV-positive status who were accessing services at these clinics. Data collection occurred at the described health facilities over a period of six weeks between August and September 2007, with each clinic delivering HIV services on different days of the week.

A total of 12 service providers were trained to deliver HIV/AIDS services using the FCA method. Delivery of the FCA method focused on providing additional psychosocial support to patients accessing HIV services. Patients were encouraged to bring family members and children with unknown HIV status to the health facility for counseling, testing, and treatment. Provider trainings included a referral card component unique to the pilot FCA study. Service providers were taught to issue referral cards to participants of known HIV status, encouraging the referral of family members and their children into FCA health facilities for HIV counseling and testing services. In addition, service providers held morning health talks on the importance of referring family members.

Data collectors administered adult and child survey instruments after participants received family centred HIV counseling and care. Adult surveys included socio-demographic characteristics, questions regarding access to

Horizons conducts global operations research to improve HIV/AIDS prevention, care, and support programs. Horizons is implemented by the Population Council in partnership with the International Center for Research on Women (ICRW), PATH, the International HIV/AIDS Alliance, Tulane University, Family Health International, and Johns Hopkins University.

health services, self-reported HIV status information, attitudes toward FCA clinic services, child health information, and willingness to refer family members for HIV services. Child surveys included similar information, but were administered to caregivers of children accessing HIV services.

## Key Findings

A total of 278 adult patients participated in the FCA study. Patients enrolled in the FCA study were the primary group receiving the FCA intervention from service providers. The FCA study restricted enrollment to patients of known to be HIV-positive because as mentioned above, evidence suggests that family members of these persons are more likely to be infected with HIV.

### *Characteristics of adult FCA patients*

Adult patients enrolled in the FCA study were 76 percent female and 24 percent male (see Table 1). The mean age of clients was 37.8 years of age. The majority of participants were single (69 percent), with 20 percent married or living as married, and 11 percent divorced, widowed, separated, or of a non-classified marital status. Out of the total number of adult participants 85 percent reported having children, while 15 percent reported having no children. Respondents reported an average of two children.

Only 18 percent of the adult study group was employed; 82 percent was unemployed. Additionally, 36 percent of the adult population was receiving social grants from the South African government.

FCA adult participants were almost exclusively recruited through the ART program (94 percent) with remaining participants accessing HIV related services for illness or viral load. Overall, 99.6 percent of the adult study population self-reported their HIV status as positive, which indicates a high percentage of acceptance for HIV status among participants. When adult participants with children were asked if they knew their children's HIV status 17 percent reported having HIV-positive children, 50 percent reported having HIV-negative children, and 33 percent reported that they did not know the HIV status of their children.

### *Receipt of FCA method by adult participants*

After taking part in the FCA intervention adult participants answered questions about the services they received

**Table 1 Adult FCA index patient characteristics**

Index patient characteristics	(n = 278)	
	n	%
<b>Gender</b>	<b>274</b>	
Female	209	76
Male	65	24
<b>Marital status</b>	<b>273</b>	
Married civil/traditional or living as married	54	20
Single	189	69
Divorced, widowed, separated, or non-classified marital status	30	11
<b>Children</b>	<b>275</b>	
Yes	233	85
No	42	15
<b>Employment status</b>	<b>273</b>	
Employed	50	18
Unemployed	223	82
<b>Receiving a social grant</b>	<b>262</b>	
Yes	93	36
No	169	65
<b>HIV status</b>	<b>274</b>	
Positive	273	99.6
Negative	1	0.4
<b>Parent's knowledge of children's HIV status</b>	<b>228</b>	
Positive	38	17
Negative	114	50
Don't know	76	33

that day. When morning health talks were offered at the clinic, about half of the adult participants attended. Referral cards for encouraging family members to seek HIV services were accepted by 98 percent of adult participants from providers. Additionally, 98 percent of adult participants believed that family members should provide support in the treatment of other family members who are HIV-positive and 95 percent of adult participants said they were receiving some kind of support from their family members. After the FCA intervention, 68 percent of adult participants said they would approach a family member about HIV testing by giving them a referral card issued by the FCA clinic.

### *Feasibility of the referral card system*

A total of 21 referral cards were returned to FCA clinics by referred individuals. With 292 adult and caregiver participants enrolled in the FCA study, the ratio of referral was approximately 1 referral per 14 participants receiving the FCA intervention. The maximum number of referral cards issued was four.

### *Characteristics of referrals to FCA clinics*

As noted in Table 2, a total of 21 new patients were referred to FCA clinics for HIV services by participating index FCA patients. This population of referred individuals was predominantly female (74 percent). The mean age of persons referred to FCA clinics was 34 years old with a range of 3 to 57 years. It appears the referral card method is highly effective in reaching individuals who are HIV-positive, with 100 percent of the documented HIV tests being positive.

## Conclusions and Lessons Learned

The FCA model was well accepted by participants accessing HIV services in a clinical setting. Adult survey data indicates not only a demonstrated high uptake of additional services offered, such as morning health talks and acceptance of referral cards, but also knowledge of the FCA message and understanding of the importance of family participation in HIV testing and care among FCA participants.

While the FCA referral card system resulted in fewer referrals than initially expected, the system established a feasible method for increasing access to HIV services through the FCA. Although only one referral patient resulted from approximately 14 FCA participants, this ratio could be an underestimation of the total impact of the referral card system for several reasons. The dura-

**Table 2 Characteristics of patients referred by index FCA participants**

Referral patient characteristics	(n = 21)	
	n	%
<b>Gender</b>	<b>17</b>	
Female	16	76
Male	1	24
<b>Relationship to person referring</b>	<b>21</b>	
Mother	3	14
Father	1	5
Grandparent	3	14
Caregiver	1	5
Guardian	2	10
Friend	2	10
Cousin	1	5
Uncle	3	14
Neighbor	5	24
<b>HIV status</b>	<b>19</b>	
Positive	19	100
Negative	0	

tion of data collection at the clinic was only six weeks, which may have resulted in fewer referral patients being captured by the time they accessed clinic HIV services. FCA participants and referrals may have taken a longer period of time than anticipated by researchers to distribute referral cards or seek HIV services. Additional underestimates may have occurred as a result of service providers distributing a maximum of four referral cards per enrolled FCA patient. This may have limited FCA participants who were more comfortable with their HIV status from referring additional family members. Lastly, the amount of discussion generated by the referral cards and subsequent services accessed at other HIV testing facilities cannot be measured by FCA data collection.

For future studies using this method of referral cards, it will be important to extend the window of data collection to further explore characteristics of the referred population. While no clear pattern emerged from this small sample in regard to the most successful referring agent, this information will be essential for expanding the FCA method to targeted individuals who are more likely to refer other family members for HIV services. FCA participants (referees) appear to be highly effective in identifying and referring HIV-positive persons within their family to FCA services.

## Adjunct Caregiver Study

While the goal of the FCA pilot intervention was to establish whether this method was a viable avenue for increasing access to HIV services for children through family members, a population of related and non-related caregivers may have been overlooked in reaching groups of children with a high prevalence of HIV infection. The next phase of the FCA study will include a population of caregivers for children ages 0–14, who are accessing South African Social Security Agency (SASSA) grants. With 36 percent of FCA participants accessing some form of social security grant and a large number of grants distributed to caregivers who are themselves infected by HIV or who care for orphaned children infected with HIV, SASSA grant distribution sites are an ideal point of referral to FCA clinics. Referring caregivers of children from SASSA

sites will also expand on the broader definition of family in South Africa.

## Referral Data

In addition to exploring sub-populations, such as those accessing SASSA sites, the next phase of the FCA study will expand on the characteristics of persons referred by FCA participants. This information will include administration of a brief questionnaire prior to receipt of services which includes information about children ages 0–14 within the family. Upon analysis, this information will enable researchers to better understand the effectiveness of the FCA intervention in targeting children ages 0–14 and their family members. In addition, HIV status will be collected from referred individuals accessing testing services at the FCA clinic to better evaluate the population being reached through the referral system and the FCA method. 

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