

CARING FOR HOME-BASED CARE WORKERS

Understanding the needs, fears and motivations of front-line care workers in South Africa

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Home-based care has emerged as a service delivery model to cope with the devastation caused by the HIV/AIDS epidemic in sub-Saharan Africa, where medical and traditional care infrastructures have been overwhelmed. In these communities home-based care workers provide critical services, which include physical, psychosocial, and palliative care activities.¹ A quantitative and qualitative study of home-based care workers in South Africa was conducted in 2005 to better understand the needs, fears and motivations of front-line care workers at Thembaletu Home Based Care (THBC), located within the Nkomazi region of South Africa's Mpumalanga province. The objectives of this study were to:

- Describe the socio-demographic background of home-based care workers to better understand worker demographics, workers' finances and job characteristics
- Assess THBC care workers' willingness to undergo voluntary counselling and testing (VCT) to determine their HIV status
- Explore the emotional impacts of care work for THBC frontline care workers to determine what mechanisms could be put in place in order to support and expand the current care work infrastructure.

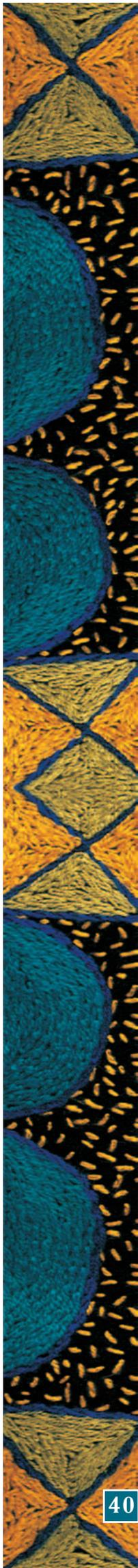
Findings suggest that THBC care workers value the emotional support from weekly group meetings and use this time to process the emotional impacts of their care work. Although rates of testing are low, 83% of participants would consider undergoing VCT to learn their HIV status. Specific strategies to ensure that care workers receive appropriate medical care and supportive services are discussed.

Sub-Saharan Africa has 25 million, or 60%, of the world's HIV-infected population. Many communities within this region are facing two fundamental obstacles making them especially vulnerable to the effects of HIV and AIDS: HIV infection rates as high as 39%² and extreme levels of poverty.³ The challenges created by these two coinciding factors include caring for large numbers of sick and dying adults and children, orphans, psychological distress associated with the stigma around HIV/AIDS, and managing the symptoms of opportunistic infections such as tuberculosis. Poverty, unemployment, underdeveloped utilities and lack of infrastructure exacerbate the care responses of many resource-poor communities. The deleterious impact of HIV/AIDS has overwhelmed traditional familial and communal care-providing structures, making home-based care (HBC) the emerging service delivery model to cope with the physical, psychological and social devastation of the AIDS epidemic. Particularly in non-urban communities, the traditional and limited medical care infrastructures have been inundated resulting in a severe lack of basic medical services, including access to antiretroviral therapy (ART).²



A THBC worker in her garden. Seeds are provided by THBC and are given to patients, orphans and care workers to provide sustainable agriculture within the communities THBC serves.

Home-based care is defined as any form of care given to ill people in their homes in order to 'promote, restore and maintain a person's maximum level of comfort, function, and



A team of THBC care workers meet in THBC's outdoor auditorium area to discuss a question together. Separate groups of care workers were set up throughout the site to facilitate private group discussion.

health; including the right to a dignified death.^{1,4} The goal of HBC is to provide hope through high-quality and appropriate care that helps ill people and families to maintain their independence and achieve the best possible quality of life through physical, psychosocial, spiritual and palliative care activities.⁴ Staffed by care workers who give their time, services and often personal resources to improve the lives of those infected and affected within their communities, care workers offer a vital resource within the communities they serve. While there has been literature citing the programmatic difficulties HBC agencies face,⁵ additional research on the emotional impacts of front-line caregiving is still needed.

Throughout southern Africa, HIV/AIDS continues to impede the already struggling health care sector. Absenteeism caused by sickness and death results in inefficiency resulting in less care for community members and lost time recruiting additional personnel.⁶ Simultaneously, burnout and emotional exhaustion threaten the existing structure. One strategy to buttress the current situation includes offering and encouraging VCT services for HBC workers and access to ARVs as roll-out programmes are implemented throughout the region. According to UNAIDS/WHO, HIV status provided through VCT remains critical to the effectiveness of HIV prevention.⁷ Care workers aware of their HIV status can help reduce transmission of HIV/AIDS among their own families and clients by serving as change agents within their communities to promote the importance of VCT and the benefits of ARV adherence.

THE STUDY

The purpose of this paper is to illustrate the needs, fears and motivations of front-line care workers from THBC, a community-based organisation that serves terminally ill patients and orphans within 16 villages in the Mpumalanga province of South Africa and neighbouring areas of Swaziland and Mozambique. Mpumalanga, one of South Africa's nine provinces, is situated in the north-east of the country. It was formerly part of the Transvaal province and borders both Swaziland and Mozambique. Mpumalanga, South Africa's seventh most populous province, occupies 6.5% of the land

surface area of the country and is inhabited by approximately 7% (or 2.8 million) of the country's population.⁸ Census data indicate that in 1999, 30% of the population was infected with HIV.⁹

The objectives of this study were to:

- Describe the socio-demographic background of HBC workers in order better to understand worker demographics, finances and job characteristics
- Assess THBC workers' willingness to undergo voluntary counselling and testing (VCT) to determine their HIV status
- Explore the emotional impacts of care work for THBC front-line care workers to determine what mechanisms could be established in order to further support and expand the current care work infrastructure.

METHODS

A mixed research methodology was used to capture both quantitative and qualitative components of care workers' demographics, attitudes regarding VCT and HIV testing and emotional impacts of care work during June - August 2005. Approval of the project was provided by the THBC Management Team in accordance with Harvard Medical School's Office of Research Subject Protection. All participants provided consent before participating in the survey and were compensated for their participation with lunch and a pen.

QUANTITATIVE COMPONENT

A survey was administered to two-thirds of THBC's South African care worker population ($N = 138$). All care workers from Swaziland and Mozambique were excluded from participation owing to the researchers' inability to travel to sites in other countries. The survey instrument was piloted beforehand with seven care co-ordinators who oversee the home-based care programme at THBC on a daily basis. Participation was based on care worker attendance at regularly scheduled care workers training sessions at one of three THBC sites.



The piloting of the survey with THBC's director and founder Sally McKibbin and care co-ordinators. Each care co-ordinator oversees an aspect of the THBC's functioning: HBC team, child and orphan care, administrative responsibilities, and gardening projects.

Items on the survey included demographic information including number of children and orphans in their care, caseload and work-related questions, views on VCT, disclosing HIV status, burnout and motivation for care work, and financial security including type of dwelling and access to electricity and running water. Each participant was randomly assigned a participant ID number. All data were inputted into SPSS statistical software which was used to store and analyse quantitative data.

QUALITATIVE COMPONENT

Qualitative methods included focus group responses, site visits with HBC workers and field observation. Focus group interviews explored, in greater depth, home-based care workers' attitudes to VCT and the emotional impacts of their work ($N = 37$). Participating care workers were divided into small groups and asked four questions relating to VCT and their fears around HIV testing. Each group recorded and presented their responses to the other groups, which facilitated an open yet guided discussion.

RESULTS AND DISCUSSION

SOCIO-DEMOGRAPHIC BACKGROUND

All surveyed care workers were women and natives of South Africa. The mean age was 39 years. Nearly half (46%) had up to a standard 6 (grade 8) education level, similar to provincial census figures (Table I). Almost three-quarters of respondents (72%) were either married or partnered and had a mean number of 5.4 biological children. Additionally, 38% of surveyed care workers had taken in an orphan (related or non-related) into their homes. The investigators noticed a

discrepancy between total numbers of orphans when care workers were asked to specify how many of these children were related or not related to the care worker. One explanation for this discrepancy is that respondents do not consider family members as 'orphans' (Table I).

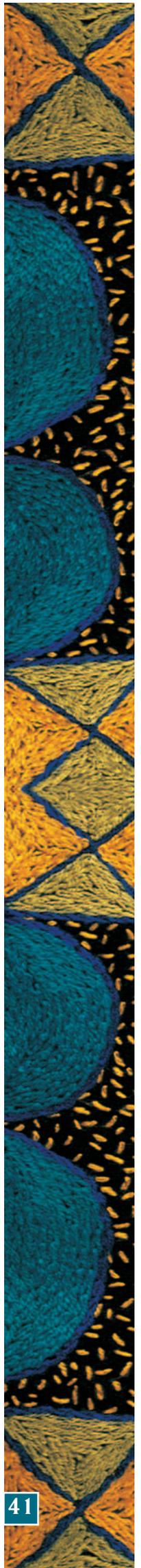
On average there were 2.7 adults in the surveyed care workers' households, of whom 55% were not employed. Although some of these adults may be absorbing some of the household responsibilities, caregiving and/or financial, it is evident that many care workers have significant responsibilities in their homes, with dependent children and orphans in addition to their caseloads within the organisation. Financially, over half (52%) of respondents received a Child Grant from the South African government, yet 23% reported not receiving any additional funds from any kind of government grant or pension and reported lacking financial support if a family member was to die and funeral assistance was needed. These figures suggest high levels of financial insecurity and reflect the general poverty levels in the region. The majority of the sampled care workers (66%) would be dependent on THBC or some other form of charity if a death occurred in their family. Owing to a lack of other resources, it is necessary for HBC organisations to recognise that the expense of funerals will become an increasing responsibility of the organisation, especially when considering the rate of family deaths reported by care workers. Nearly 60% of care workers had experienced the death of at least one immediate family member within the past 6 months alone.

The care workers had a median length of service with the agency of 4 years, responses ranging from 6 months to 6 years. Collectively the sample provided services to 1 038 patients, of whom 507 were in critical condition, and 1 436

TABLE I. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE THBC CARE WORKERS

Variable	%	Mean	Median	Provincial % ¹⁰	National % ¹⁰
Age (range 21 - 65 years)		38	39		24.86*
Highest level of education completed ($N = 138$)				33.1	17.9
No schooling ($n = 16$)	11.6			33.1	17.9
Some primary school/ elementary ($n = 12$)	8.7			16.5	16.1
Completed primary/elementary ($n = 23$)	16.7			6.1	6.4
Some secondary schooling ($n = 37$)	26.8			25.1	30.2
Standard 10/Grade 12 ($n = 46$)	33.3			15.1	20.4
Higher ($n = 4$)	2.9			4.2	9.0
Marital status ($N = 137$)					
Single or never married ($n = 30$)	21.9			50.8	
Married: civil/religious or traditional ($n = 90$)	65.7			28.5	
Partnered or living together ($n = 8$)	5.8			10.3	
Divorced or widowed ($n = 9$)	6.6			2.3	
Other ($n = 0$)				8.1	
Number of biological children ($N = 138$) (range 1 - 9 children)		5.4	3.0	-	2.8 children
Care workers who care for non- biological children/orphans in their home ($N = 52$)	37.6	1.5	0		1.7 children ^{†10}

*This figure reflects the national median age of South African females since all THBC care workers are female.
[†]National figure represents general population caring for orphans.



orphans. On average, each care worker had 8.2 patients under their care, 3.7 of them in critical condition, and cared for 10.5 orphans.

EMOTIONAL IMPACTS OF CARE WORK

When asked how often care workers find themselves upset or sad about patient-related issues when they come home from work, 69% of respondents reported feeling sad or upset either 'every day' or 'a few times each week'. Two illustrative responses from the focus groups include:

'I find myself sad when I come home from work because sometimes I find my patients very critical [critically ill] and there's no way to help them. Sometimes I go to visit them and there's a need to go to the clinic or hospital but they don't have the money to go and I don't have it. So all these things are very serious problems.'

'It is too sad. I am sad. Sad about orphans... Orphans that are orphan-headed households are living a bad life because there's no one to teach or counsel them about their ways. And this course leads to dropout in school at an early age and unwanted pregnancy.'

Despite these emotional challenges, 51% of respondents reported that they 'never' consider stopping their care work and remain motivated because of satisfaction from helping others, training and skill building and religious beliefs (Fig. 1).

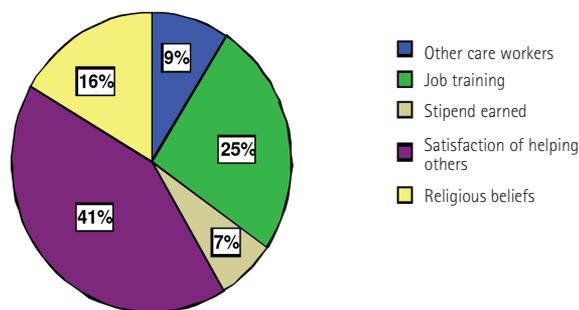


Fig. 1. What motivates care workers?

Generally care workers felt adequately trained by THBC, but 28% requested more training and specified the following:

- Counselling on disclosure and HIV counselling in general
- Basic first aid and medical training
- Information on ARVs (how they work within the body, and where to get ARV medication)
- Palliative care.

Nearly all (91%) of care workers surveyed found the weekly care worker meetings helpful to their problems and concerns, especially in terms of processing their experiences with others who can relate to the work they do. One care worker stated:

'Sometimes we feel like crying because there is nothing that care workers can help our patients with. We need to talk with others, like other care workers, in order to reduce our stress. They understand what my family do[es] not.'

VCT AND HIV TESTING

Despite the increasing prevalence of HIV in the Mpumalanga region, only 16% of the care workers had undergone VCT within the last year. However, a key finding from the survey

was that 83% of respondents would consider being tested for HIV if THBC could ensure confidentiality. Forty-six per cent of surveyed care workers cited 'scared to know results' as the number one reason preventing community members from getting tested for HIV. However, the group interviews highlight how stigma associated with HIV-positive status is a main reason preventing community members from learning their HIV status (Table II).

TABLE II. WHY DO PEOPLE IN THE COMMUNITY NOT GET TESTED?

- 'They are afraid of being rejected by their families'
- 'Women are fearful of their husbands' reaction if they are HIV positive'
- 'The community might ignore them*'
- 'The community might stigmatise'
- 'They would feel ashamed if they were HIV positive*'

* Indicates that a quote was repeated during group interviews.

About a quarter (26.8 %) of surveyed care workers reported that someone in their household had gone for an HIV test, while 72% did not know of anyone from their household who had gone for a test. This suggests that HIV testing is not being spoken about openly among family members, despite their connection to a community-based organisation with available educational resources. During the group interviews care workers elaborated on the reasons why they do not undergo VCT. Fear was a salient factor and can be categorised into fear of family and fear of illness (Table III).

TABLE III. REASONS CARE WORKERS HAVE NOT PERSONALLY UNDERGONE VCT

Fear of family disruption:

- 'My husband will reject me or not support me'
- 'How would I tell my husband I am HIV positive?'
- 'I am afraid of divorce*'
- 'My family will not accept me'

Fear of illness:

- 'I will die soon if I am HIV positive'
- 'I am scared of taking pills for my whole life'
- 'Lack of knowledge/information on HIV'
- 'I don't know enough about antiretroviral therapy'

* Indicates that a quote was repeated during group interviews.

IMPLICATIONS

Local-level strategies that HBC organisations can implement in order to address the needs revealed from survey and group interview results are outlined below. Although the information from the survey and group interviews is specific to THBC, the strategies have been written to be applicable to similar organisations offering comparable HBC services in regions with a high HIV/AIDS prevalence.

In spite of the financial insecurity described above and the large families that care workers are already responsible for, 68% of care workers reported that if given more space, they would be willing to take additional orphans into their homes.



To help demystify the testing process, THBC care workers observed how a fingerprick HIV test is administered and how the results are interpreted. It was the first time many of the HBC workers had seen what an HIV test entails.

This is a significant finding for THBC, since more than two-thirds of care workers would be willing to care for orphaned children in the surrounding area. As the HIV epidemic continues to result in increasing mortality, especially among parents, more children will be orphaned in the region.⁹ It is critical to identify caregivers willing to absorb some of the orphan burden from these HIV/AIDS-related deaths in Mpumalanga province and other regions facing similar circumstances.

The hardships care workers are experiencing in their homes, both from their familial caregiving burden and from grief normally associated with death in the family, are important findings. Recommendations such as those suggested below need to be implemented to ensure that care workers feel supported and remain nurtured as much as possible by THBC. As a community-based organisation, it is essential for THBC to continue to sustain their care worker population by understanding the typical household composition, financial security and family structure that comprise their home environments.

The findings of this study have important implications for the care workers at THBC and similar HBC organisations. The following recommendations, which aim to improve the care worker programmes in southern Africa, will ultimately result in improvements for the patients, orphans and communities being served.

- HBC organisations should seize upon care workers' willingness to raise orphans as a viable placement option for children who would otherwise live in orphan-headed households or group-home settings. It is imperative that building funds are specifically procured for the purpose of building additional rooms in the homes of care workers who are willing to take orphaned children into their homes.
- It is critical for HBC organisations to explore additional funding streams that specifically target the transportation of patients in a critical condition. This tangible strategy will address a primary source of frustration and disempowerment that many of the care workers expressed during the group interview.
- Based on the responses of questions regarding government grants, it is likely that many of the surveyed care workers are eligible for welfare grants that could ease their personal financial burden. The number of eligible care

workers may increase, particularly if care workers continue to take orphans into their homes. HBC organisations should consider extending their administrative infrastructure to assist care workers in accessing government services. An alternative strategy would be to create a training module to assist care workers with the logistical information about government grants, including eligibility requirements and application procedures, to ensure a minimal financial safety net.

- Since care workers have expressed desire for training in all aspects of HBC, THBC and other HBC organisations should have a rotating schedule so that each care worker completes training in all areas related to their work.
- Care workers expressed a consistent appreciation for the value of weekly care worker meetings. Opportunities for expanding additional care worker support groups, especially after patient deaths, should be explored further.

CONCLUSION

As the AIDS epidemic continues to ravage the populations of sub-Saharan Africa, the number of sick individuals and orphaned children will continue to increase. Those infected and affected by HIV/AIDS will continue to rely on HBC workers, further stressing an already overburdened care network in resource-limited settings. Understanding the needs, fears and motivations of front-line care workers is necessary to inform public policy and care-providing programmes at the local level throughout many regions in southern Africa. Assessing care workers' willingness to undergo VCT to determine their HIV status and exploring the emotional impacts of care work in the front line allow HBC community organisations and non-governmental organisations to determine the mechanisms needed to support and expand the current care work infrastructure. Care workers are simply too valuable to the community to be lost to premature death from a manageable HIV infection.

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REFERENCES

1. World Health Organization. *Community Home Based Care in Resource-Limited Settings: A Framework for Action*. Geneva: World Health Organization, 2002.
2. Asamoah-Odei, E, Garcia Calleja, JM, Boerma JT. HIV prevalence and trends in sub-Saharan Africa: no decline and large subregional differences. *Lancet* 2004; **364**: 35-40.
3. UNAIDS/World Health Organization/United States Government. Consultative Meeting on HIV Testing and Counseling in the Africa Region. Johannesburg, Joint United Nations Program on HIV/AIDS, November 2004.
4. World Health Organization. *Home Based Care and Long Term Care: Home Care Issues and Evidence*. Geneva: World Health Organization, 1999.
5. UNAIDS. *Reaching Out, Scaling Up: Eight Case Studies of Home and Community Care For and By People with HIV/AIDS*. Geneva: UNAIDS, 2001.
6. UNAIDS. *2004 Report on the Global HIV/AIDS Epidemic: 4th Global Report*. Geneva: UNAIDS, 2004.
7. UNAIDS/WHO. UNAIDS/WHO Policy Statement on HIV Testing. United Nations AIDS & World Health Organization, June 2004.
8. Statistics South Africa Census 2001. Achieving a Better Life for All: Progress between Census '96 & Census 2001. <http://www.statssa.gov.za/Publications/Report-03-02-16/Report-03-02-16.pdf>
9. Brookes H, Shisana O, Richter L. *The National Household HIV Prevalence and Risk Survey of South African Children*. Cape Town: HSRC Publishers, 2004.
10. UNICEF South Africa Statistics [online]. 2004 Available from: http://www.unicef.org/infobycountry/southafrica_statistics.html

