

# COMMUNITY HOME-BASED CARERS: VOICING THEIR NEEDS, VOICING THEIR CHALLENGES!

HSRC RESEARCH OUTPUT

6018

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## BACKGROUND

As more individuals and households in South Africa become affected by HIV/AIDS, there is a growing need for assistance with care and support. Households are increasingly faced with a challenge of coping with the needs of sick family members such as the need for food, assistance with daily living, palliative care and assistance to obtain social security benefits for the young and very old and require assistance from non-governmental organisations. The dire shortage of professional health practitioners in South Africa means that the greater burden of care for orphan and vulnerable children (OVC) and people living with HIV/AIDS (PLWHA) remains with informal community home-based carers (CHBC). In South Africa, there remains a scarcity of information as well as research studies focusing on the psycho-social needs of community home-based carers.

## OBJECTIVES

The objectives of the study were 1.) to determine the psychosocial, economic, educational and other needs of community home-based carers working with orphan and vulnerable children and people living with HIV/AIDS on behalf of the South African Red Cross Society; 2.) to determine the challenges faced by community home-based carers; 3.) to recommend suggestions for interventions for meeting the psycho-social needs of community home-based carers.

## METHOD

A total of 11 focus group discussions (FGDs) were conducted by trained interviewers in selected areas from the 19 SARCS branches in eight of the nine provinces (excluding Mpumalanga) of South Africa.

- Qualitative focus group discussions were conducted with selected participants.
- In total 132 participants were selected for the study from 19 SARCS branches in eight of the nine provinces (excluding Mpumalanga) of South Africa
- All participants provided their full informed consent before participating in the study.

## FINDINGS

### Services provided to clients in the communities

Community home-based carers main task is to provide bed side nursing and psychosocial care of patients that they are assigned. In reality home-based care (HBC) entails much more. This covers everything from bed baths, information, and assistance in the home, basic first aid, support and care to family, adherence information, treatment support, DOTs, care and support to OVCs. Moreover services may vary, from food security which could include daily meals, food parcels, homework assistance, funeral support, social services support, school uniforms, bereavement counseling, and caring for younger siblings.

*"And in some places we find people that don't have ID's, we go to the Home Affairs to help them to find ID's, there are others that don't receive grants or birth certificates for the children, they are poor, they have homes, they don't have incomes, so we are trying to help them"* - Bloemfontein, Free State

### Challenges experienced in the field

The focus group participants provided a host of challenges they experienced as CHBC's from the training provided by SARCS - to the communities in which they work - to the clients they provide home based care services for as well as challenges that affects them on a person level.

#### Challenges related to transport

*"That is the biggest problem we face now so its transport to the clinics which is far from where we stay. So sometimes you don't have that money, and then at the end of the day, it looks like you don't want to help the patient"* - Kimberley, Northern Cape

#### Challenges due to lack of resources

*"Hmm...there is himm...HIV and AIDS clients, there is not enough equipment like the gloves, and the next thing, if its raining, here in Cape Town in winter its really, its raining, its raining in Cape Town, so now we've got nothing to wear like raincoats and boots"* - Khayelitsha, Western Cape

In this section, participants specifically mentioned challenges that effect volunteers on an individual basis. Issues such as the heavy work loads, lack of benefits and too little stipends or no stipends at all are expanded on by the responses of participants below:

*"Because if you come across a patient whose now MDR, and you get that touch of TB, there...there is nothing that you can do there is no doctor money, there is no what do you say, medical aid for you, that is now your baby! And you know the difficult part of that then just like we are caregivers you don't even have the support of whether the organisation you work for all they want they want you in the field to go and work"* - Khayelitsha, Western Cape

One major challenge on par with the challenge experienced with transport by volunteers is the issue of the stipend. Some volunteers

are said to receive a stipend however there are many that do not receive a stipend at all, in light of the type of work they do and how hard they work regardless of them actually getting a stipend or not. The participants expressed that the financial impact does not only affect them as an individual but their families as well.

*"Then again also sometimes you come to work then you don't even have food at home, yes you wake up in the morning with nothing so you just go because you love the job but at the end of the day you are the person who needs...you need everything you need to wash, you need everything you need toiletries because you can't go to a patient when you are dirty, how can you come to me when you are dirty and come and tell me that I must wash!"* - Mafikeng, North West

### Psychosocial stress

Community home based carers (CHBC) play a vital part in supporting families and individual community members who need care (Oyebode, 2003). The CHBC knows what their role entails however this role is often exceeded by the needs of their clients. In this section we aim to explore and understand the psychosocial stressors that are experienced by CHBC and whether they are supported in any way or form.

*"We are exposed to chronic diseases mostly its TB and HIV and AIDS from day to day...it really is draining us emotionally especially when we loose clients you know"*

*"Sometimes there are personal problems but the work comes first so you just push it at the back of your mind...you don't realise what it is doing to you, you just get sick"*

Participants reported that emotional and physical stress has a huge impact on their service delivery and although they try to cope by having brief talks with their relevant supervisors/facilitators, it is not seen as enough.

*"...a debriefing...or maybe offloading or de-stressing...we have our own counsellor who can give you the days over every end of the week you go and sit for a session. Now we are working...sometimes you are so crazy, if you come at home you can't concentrate, you can't do nothing, you can't help your kids we have small kids, you must help with the schoolwork, you are so distressed because you come from work with all those"*

### Psychosocial support

There was a mixture of responses with regard to whether the participants receive psychosocial support and if the support received is seen as sufficient. The participants' responses were as follows:

*"Yeah, we do talk to them but there is nothing improving, it stays the same, and you cannot talk about anything with your facilitator I like talking to someone who doesn't know me at all. It is better talking to someone who don't know your background, but if you speak to someone who knows your background he is going to judge you!"* - Kimberley, Northern Cape

## KEY RECOMMENDATIONS

From the findings of the survey and qualitative studies, several recommendations are made to improve psycho-social issues that were raised by carers and stakeholders.

### Provide transport to CHBC who stay far from clients

We recommend that transport should be arranged for carers who travel long distances to their clients so that they can be picked up in the morning and collected later in the afternoon.

### Standardize the stipend for all CHBC

There is a need to ensure that standardized stipend is provided to the carers. It is recommended that all organizations offering a stipend to CHBC should standardize it to at least R1,000 per month.

### Offer psycho-social support through professional counsellors who do not work in the same organisation

CHBC indicated that they do not prefer to be counseled and to debrief with facilitators. They prefer someone from outside the organizations in which they work to provide debriefing and counseling to them. We recommend an external person rather than people from within the organisation to facilitate the debriefing session.

### Protect CHBC against exposure to infectious diseases

CHBC are exposed to infectious diseases such as tuberculosis, including multidrug resistant TB (MDR) and extreme drug resistant TB (XDR), HIV/AIDS, meningitis, cholera and other haemorrhagic diseases. We recommend that CHBC should be provided with appropriate protective and safety materials such as gloves, gowns, masks and other measures to help them sterile equipment at home which should be ongoing and consistent. CHBC should be immunised against common infectious diseases that nurses and health professionals are immunised against.





## **Community home-based carers: Voicing their needs, voicing their challenges!**

*Alicia Davids, Geoffrey Setswe, Nokhona Lewa, Mmapaseka Majaja, Yogandra Naidoo, Ms Janine Clayton*

### **Background**

As more individuals and households in South Africa become affected by HIV/AIDS, there is a growing need for assistance with care and support. Households are increasingly faced with a challenge of coping with the needs of sick family members such as the need for food, assistance with daily living, palliative care and assistance to obtain social security benefits for the young and very old and require assistance from non-governmental organisations. The dire shortage of professional health practitioners in South Africa means that the greater burden of care for orphan and vulnerable children (OVC) and people living with HIV/AIDS (PLWHA) remains with informal community home-based carers (CHBC). In South Africa, there remains a scarcity of information as well as research studies focusing on the psycho-social needs of community home-based carers.

### **Objectives**

The objectives of the study were 1.) to determine the psychosocial, economic, educational and other needs of community home-based carers working with orphan and vulnerable children and people living with HIV/AIDS on behalf of the South African Red Cross Society; 2.) to determine the challenges faced by community home-based carers; 3.) to recommend suggestions for interventions for meeting the psycho-social needs of community home-based carers.

### **Method**

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- In total 132 participants were selected for the study from 19 SARCS branches in eight of the nine provinces (excluding Mpumalanga) of South Africa
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### **Findings**

#### ***Services provided to clients in the communities***

Community home-based carers main task is to provide bed side nursing and psychosocial care of patients that they are assigned. In reality home-based care (HBC) entails much more. This covers everything from bed baths, information, and assistance in the home, basic first aid, support and care to family, adherence information, treatment support, DOTS, care and support to OVCs. Moreover services may vary, from food security which could include daily meals, food parcels, homework assistance, funeral support, social services support, school uniforms, bereavement counseling, and caring for younger siblings.

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### ***Challenges experienced in the field***

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### **Key Recommendations**

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