EVALUATION STUDY OF THE PSYCHO-SOCIAL NEEDS OF VOLUNTEER COMMUNITY HOME-BASED CARERS

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
CHBC	Community home-based carer
DOH	Department of Health
DSD	Department of Social Development
FGD	Focus group discussion
HBC	Home based care
HIV	Human immunodeficiency virus
HSRC	Human Sciences Research Council of South Africa
KII	Key informant interview
M&E	Monitoring and evaluation
NGO	Non government organisation
NMCF	Nelson Mandela Children 's Fund
OVC	Orphans and vulnerable children
PLWHA	People living with HIV and/or AIDS
PMTCT	Prevention of mother to child transmission (of HIV/AIDS)
PSS	Psycho-social support
REPSSI	Regional Psycho-social Support Initiative
SAHA	Social Aspects of HIV/AIDS and Health Research Programme
SARCS	South African Red Cross Society
UNAIDS	Joint United Nations Program on AIDS
VC	Voluntary caregiver
VCT	Voluntary counselling and testing
WHO	World Health Organisation

EXECUTIVE SUMMARY

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. The Human Sciences Research Council (HSRC) was therefore commissioned by the South African Red Cross Society (SARCS) to conduct an evaluation of the psychosocial needs as well as challenges that community home-based carers experience on a day-to-day basis.

A mixed methodology was used to assess the psycho-social support (PSS) needs of CHBC. The qualitative phase of the study comprised of 11 key informant interviews (KIIs) with stakeholders in the OVC field and 15 focus group discussions (FGDs) with CHBC and their facilitators. A cross-sectional survey was also conducted with a sample of about 290 CHBC in eight provinces in South Africa.

An overwhelming majority of CHBCs, 82.9% were below 50 years of age, 94.2% were females, 71% were single or never married and 93.1% were Christians. Most of the respondents said they were satisfied with training on HIV and AIDS (64.1%), First Aid (59.5%), home-based care (HBC) (54.1%) and tuberculosis (52.1%). However, fewer respondents said they were satisfied with training on OVC counseling and support (45.2%), palliative care (36.7%) and memory box (35.1%)

More than three quarters of CHBCs said they were getting help with caring tasks for people with chronic illnesses, including HIV/AIDS, while 73% said they were getting instruction or education about the care for people's medical conditions, care needs, treatment and medication. This is encouraging that so many CHBC are getting the necessary help and instruction on caring tasks.

With regard to quality of life issues, about 83% of respondents said they had freedom to interact with friends and family on a social level, 81.5% said they were able to have peace of mind (described as freedom from excessive anxiety about the people they cared for), 80.3% said they had received information on emergency telephone numbers for ambulance, hospital and other services where they can refer their clients, 79.5% said they had positive morale, emotional and mental health and 77.6% said they were able to maintain physical health, fitness and well-being. These findings are astonishing and indicate a generally high quality of life for community home-based carers.

With regard to support services for people they cared for, 89.6% of respondents said they were able to provide personal cleanliness and comfort for the people they cared for, 82.6% said they were able to provide social contact with others apart from their role as carers, 77.2% said they were able to provide maximum independence and mobility to their clients, 76.8% said they were able to maintain dignity and morale to the people they cared for, 73.7% said they were able to provide personal safety and security for the people they cared for and 68.3% said they were able to provide meaningful activity and stimulation to the people you care for.

Again, 85.7% of CHBC said they were able to provide access to health services for the families under their care, 83.4% said they were able to provide education support to the families under their care, 78.4% said they were able to provide psycho-social support (PSS) for children under their care, 78% said they could assists clients to access to social grants, birth certificates and identity (ID) documents, 76.8% said they were able to provide access to health support for families under their care and 61.8% said they were able to provide food nutrition support to the families under their care.

Community home-based carers generally feel they are receiving a high level of recognition and support for their care-giving role. About 75.7% said they are being valued and respected as individuals and the same proportion said they have a sense of shared responsibility, both practically and emotionally, with services including emergency access to help, 74.5% said they have a sense of satisfaction or achievement in providing care to others, 73% said they were informed, prepared, confident, skilled, equipped, or trained for the caring task and 68.3% said their care-giving needs and expertise were being recognized. These results are extremely positive and bode well for the SARCS project.

In general, there was a low level of PSS distress among CHBC during the time of this study. Only about 19.3% said they were mostly bothered by things that usually don't bother them during the past week.

The views of the community home-based carers about their psycho-social well-being were not convincing on whether they had a high sense of psycho-social well-being or not. Only 49.4% said they most often felt hopeful about the future during the past week and the same proportion said they have enjoyed life during the past week, 49.8% said they felt they were happy during the past week and 48.3% said they felt that they were just as good as other people during the past week.

From the findings of the survey and qualitative studies, the following recommendations were made to improve psycho-social issues that were raised by caregivers and stakeholders:

- Provide transport to CHBC who stay far from clients;
- Standardize the stipend for all CHBC to at least R1, 000 per month;
- Provide structured and consistent training and re-fresher courses to all new and existing CHBC;
- Offer psycho-social support through professional counsellors who do not necessarily work in the same organization;
- Protect CHBC against exposure to infectious diseases.

Although there were some issues related to transport, stipend and training which needed to be attended to, it could be concluded that in general, the PSS needs of CHBC working for SARCS had been met.

1. INTRODUCTION AND OBJECTIVES

1.1. Introduction

South Africa has the largest number of people living with HIV/AIDS in the world. Poverty, poor access to basic amenities and health care, limited information, and limited capacity in communities all exacerbate vulnerability to HIV.

As more 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.

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). Informal community home-based carers who provide assistance include household or family members, friends, community members who work through non-governmental or community-based organizations. Households may use one or more of these sources of support in order to cope with caring for sick members (Homan, et al., 2005).

OVC and PLWHA typically face a wide range of stressful events and circumstances and depend on informal CHBC to address these challenging situations. Community home-based carers, on the other hand, have psychological, social, economic, physical needs which need to be met to enable them to do their care-giving work. They also need training and resources, to meet the needs of clients they take care of.

The South African Red Cross Society (SARCS) commissioned, as a part of the European Union (EU) funded project, the Human Sciences Research Council (HSRC) in 2008 to evaluate the psycho-social support needs of CHBC working with OVC and

PLWHA in South Africa. This report provides the results of the survey and qualitative study that ware conducted with community home-based carers working for the SARCS.

1.2. Description of the SARCS Psycho-social Support (PSS) project on community home-based care

The community home-based care, HIV and AIDS programme implemented by the South African Red Cross Society (SARCS) provides community care and support to people living with HIV/AIDS (PLWHA) and affected by HIV and AIDS and support for orphan and vulnerable children (OVC) in their psychosocial, economic and educational needs. Care and support activities include the provision of home-based care, psycho-social and economic support and strengthening of the care network. Communities are sensitised through community health education activities and advocacy for support for PLWHA and OVC promoting their rights, and addressing the health, social and stigma issues associated with HIV and AIDS (SARCS website).

The Psycho-social Support (PSS) project which form part of the CHBC, HIV and AIDS programme specifically aims to increase psycho-social support to OVC and the primary care-givers (often family members) of PLWHA. The project is seen as a vital component of the CHBC programme and identified as an area for considerable improvement by the International Federation of the Red Cross and Red Crescent Societies. This project's strength lies in its community-centred approach in assisting the most vulnerable and the provision of community home-based care through a community volunteer network. The project provides for many vulnerable people the link between providing support at household level to accessing support at community and institutional level. The project provides support not only to people living with HIV/AIDS and OVC but also to their family and community home-based carers.

Stigma and inadequate knowledge still play a major role in increasing the vulnerability of affected communities resulting in continued high rates of new infections and the isolation of PLWHA. The community health education and promotion activities and the promotion of the rights of PLWHA in this project seek to complement the home-based care (HBC) elements of this project to influence a better environment.

It is important that the devastating affects of HIV on the social fabric of the affected communities be countered by interventions that do improve the quality of life. The objectives of this integrated CHBC response is to improve family and social values and dignity, prolong the lives of the infected and their well being, and better protect the future of the children

The project uses an integrated community home-based care approach which links service providers with the clients/OVC and their families to ensure a continuum of care. Integrated CHBC promotes and supports collaboration between the different components of the continuum of care including government structures such as hospitals, clinics, voluntary counselling and testing (VCT) and prevention of mother to child transmission (PMTCT) centres, social welfare and local government; non-governmental organisations, community and faith based organisations; the community itself and community home-based carers such as Red Cross volunteers and families.

As a community home-based care response to HIV the project works to strengthen the capacities of communities and individuals to address not only health and care needs of people living with HIV but also the support needs of families and communities affected by the virus. It works to reduce stigma, increase awareness of HIV and support the orphans and vulnerable children affected by the impact of the pandemic. The project's framework includes the core elements of addressing HIV - prevention, care and stigma reduction, building on elements of community and service provision. This strategy will contribute towards a reduction in new infections and support those infected and affected by the virus (SARCS website).

1.3. Objectives of the evaluation

The objectives of this evaluation were to:

- determine the psychosocial, economic, educational and other needs of community home-based carers (CHBC) working with OVC and PLWHA on behalf of the South African Red Cross Society (SARCS);
- determine the challenges faced by community home-based carers;
- recommend interventions for meeting the psycho-social needs of community home-based carers.

2. LITERATURE REVIEW

2.1. Concept of psycho-social support (PSS)

Psycho-social support is defined as incorporating an ongoing process of meeting the physical, emotional, social, spiritual and mental needs of community home-based carers. It is looking beyond the physical needs of CHBC to include the provision of emotional, spiritual and social needs in the care-giving process (REPSSI, 2005).

The PSS indicators' model divides psycho-social support activities into three categories, which provide three different types of needs for community home-based carers.

P – Psychological

When an organisation provides counselling to CHBC, it creates a platform that allows them to express their feelings and emotions. This might include group counselling, debriefing after home visits or home visits to families with quality time spent with children or clients.

S – Social

An organisation can actively influence the social environment and create a comprehensive understanding of the real issues confronting CHBC. The development of safe social structures for CHBC include training on work-related matters, community sensitisations of psycho-social issues, organisations where CHBC can organise themselves into interest groups and CHBC committees.

S – Support

An organisation can explore and systematically empower CHBC with resources that enhance resilience through training on care-giving role, positive feedback to CHBC on their performance and encouraging creative self-expression (REPSSI, 2003)

2.2. Defining community home-based care and volunteers

The Word Health Organisation defines home-based care (HBC) as "the provision of health services by formal and informal caregivers in the clients' home in order to promote, restore and maintain a person's maximum level of comfort, function and health, including care towards a dignified death (DoH, 2001)". This is in-line with the South African Red Cross (SARCS) definition which says that HBC is done at community level and includes the provision of care and support activities at a client's home.

This model of community home-based care is explained by Uys and Cameron (2003) is seen as a single service home-based care model whereby one service provider, in this case SARCS, organises HBC by recruiting volunteers who become community home-based carers, training them and linking them to clients and their families at home. Networking is also seen as very crucial in providing holistic and adequate community home-based care and therefore SARCS works in partnership with South African governmental departments such as the Department of Social Development (DSD), Department of Health (DoH) and Department of Home Affairs (DHA) to mention but a few.

Recruitment and selection of volunteers

A volunteer is defined as someone who, willingly and without receiving any payment, does a specified task that needs doing for a non-profit organisation (FAMSA, 2009). When recruiting volunteers, local communities are often seen a valuable source of volunteers, therefore organizations should consider the people who live and work around the organisation. It is suggested that organisations endeavor to develop a good rapport with local people and in so doing, enabling people to understand why the organization exists and what their specific role within in the organisation may be (Val-L, 2009). After the volunteers have been recruited for the purpose of community home-based care, volunteers need to be carefully screened and recruited into care-giving programmes. Community home-based care organisations in some instances allocate an entire day in order to assist with the screening of prospective community home-based carers – this is done in order to ensure that the prospective community home-based carer is aware of what the actual tasks entail and whether the organisation feels confident in investing its time and resources in that volunteer. These steps are taken to ensure the continuity of uninterrupted service to the clients however this is not always put in practice.

Motivations of community home-based carers caring for PLWHA and OVCs

The motivation of individuals is to help others or to support the larger nation-building effort helps people to contribute to civic service delivery and volunteering for programmes (Perold, Carapinha & Mohamed, 2006). Volunteering is quite demanding especially where high levels of commitment are expected from those individuals who volunteer. However, non-governmental organisations (NGOs) still depend on the efforts of volunteers. Therefore, understanding the volunteers' motivations and what expectations they have in relation to volunteering, may ultimately assist organisations to make the relevant adjustments in order for sustainability and the retention of voluntary staff. Studies on national and social service organisations further indicate that participation of community members for the role of community home-based carer may be largely determined by the individuals' perceptions of opportunities to participate (Ramirez-Valles, 2002).

Akintola (2004) provides a few broad factors that should be taken into account as motivation factors for CHBC to possibly volunteer in care activities. These include:

A. ***Pure altruism:*** Community members, who are compassionate see volunteering as a way of contributing their own quota to solving common problems that are currently affecting their communities. Love and empathy for the sick are commonly mentioned by caregivers as a primary reason for becoming volunteers.

B. ***Unemployment:*** The scarcity of employment is a common denominator amongst people who have volunteered to be caregivers**.** Some decide to volunteer whilst searching for a job. However there are many volunteers who find it difficult to quit because of the emotional bond they have built up with their respective clients and their families.

C. ***Hope for future reward and reciprocity:*** Some volunteers believe that volunteering is seen as "sowing a seed that will later provide reward". Some volunteers state that the hope for some sort of reward from the government is one of the motivations for giving care although in most cases this is not the primary reason but an underlying wish.

D. Religious considerations: There are also religious considerations in volunteering as caregivers. Some volunteers indicate that it is godly to volunteer. There is also a common belief that volunteering is synonymous to doing God's work. Therefore they see the role as home-based carer as an enactment in the image of God and therefore bring them closer to Him.

E. Experience of HIV/AIDS in the family: Some people who enrol as home-based carers recognize the need to give adequate supportive care to HIV/AIDS clients, because of the chronic nature of the disease, and the complex nature of the activities that are required to care properly for the sick. Some volunteers experience multiple illnesses in their families and believe that if they are trained to care for the sick it will be of great help to them in dealing with their own families.

F. Hope for securing employment: In various studies conducted, although volunteers do not necessarily make this explicitly known, the hope of securing a job is a covert reason for people to volunteer as home-based carers. In studies conducted it was found that some volunteer home-based carers receive some form of stipend to cover some of their expenses. There are some instances where volunteers may not necessarily receive a stipend but who receive incentives such as light meals and material goods which may have been donated to the programme which satisfies their material needs to some degree.

2.3. Key psycho-social support needs

Psycho-social needs are the needs that all people have to be happy, creative, to belong in social groups, and to have hope for the future. Psycho-social well-being is the positive age- and stage-appropriate outcome of a person's physical, social and psychological development. It is determined by a combination of capacities and their social and material environment. Psycho-social well-being is essential for survival and development, especially in chronically difficult circumstances (Richter, Foster and Sherr, 2006).

In this study, psycho-social needs include formal and informal services that address psycho-social well-being of community home-based carers either 1) directly and specifically (e.g. through interpersonal moral support, counseling, spiritual support, etc.) or 2) indirectly (e.g. financial and physical support that may alleviate worry and stress).

Psycho-social interventions and psycho-social support programming, that are reviewed in this study include specific and formalized activities, programmes and services such as counselling, debriefing and cognitive behaviour therapy.

SARCS identified five key psycho-social support needs which, when holistically and adequately met, promote well-being. These include social, emotional, spiritual, physical and mental needs. Psycho-social care and support, which focuses on the social and emotional needs, is inextricably intertwined with and mutually supportive of the other three needs -the physical, mental and spiritual needs. HIV/AIDS, poverty and conflict threaten the capacity and capability of families and communities to meet these above-mentioned needs (SARCS).

For adult CHBCs, psycho-social care and support is provided through interpersonal interactions that occur in caring relationships in everyday life, at home and in the community. This includes the love and protection that CHBC experience in family environments, as well as interventions that assist families in coping. Care and support enable CHBC to have a sense of self-worth and belonging and are essential for them to provide care and support to others, to develop additional care and support skills, to participate in society and to have faith for the future (Richter, Foster and Sherr, 2006).

Community home–based carers may recognise the psycho-social needs of PLWHA, especially if health workers and others raise disclosure and adherence issues with them. Few community programmes actively work with CHBC and families to increase their responsiveness to the psycho-social needs of vulnerable children (Richter, Foster and Sherr, 2006).

The impact of HIV/AIDS on psycho-social well being is complex. HIV/AIDS contributes to family disintegration, corrosion of culture, and erosion of family and community safety nets. Illness and death reduce the availability of mentors to CHBC. The limited availability of psycho-social support can reduce resilience, coping skills and social connectedness. These in turn place community home-based carers at risk of isolation, apathy, drug or substance abuse, self-exploitation, and criminal behavior.

Psycho-social care and support needs of CHBC are often overlooked by employing organizations, families, communities, civil society, and governments who come into regular contact with them. Support for psycho-social well-being is a key investment in human capital because it underpins all other processes for the long-term development and stability of societies (Richter, Foster and Sherr, 2006).

2.4. Service needs of community home-based carers

Hirst (2004) distinguishes four kinds of services to voluntary carers in the United States of America (USA). These include services that provide breaks to community home-based carers, specific community home-based carers' services, information and advice, and other services for the cared for person. *Services that provide breaks for community home-based carers* are about CHBC having time for themselves. Respite-services provided to a community carer are considered to be a breaks-service where they actually give the carer a break from direct responsibility of supervising or caring for that person. Services provided in an emergency, such as when a caregiver is hospitalised, or simply to allow the caregiver to visit the doctor or dentist, are not regarded as a breaks service but as a core element of supporting the cared for person and caregiver. Services for community home-based carers are extremely varied and include:

1) Counselling, emotional support;
2) Training in coping skills, for example coping with the difficulties associated
3) with care and support for a person in the terminal stages of HIV/AIDS;
4) Instruction or education about the cared for person's medical condition, care needs, treatment and medication;

5) A short holiday leave for community home-based carers to enable them to have time to themselves.
6) Complementary therapies to relieve stress.
7) Provision of a mobile telephone and/or help with taxi fares to get to work;
8) Workshops for community home-based carers to take up new learning, training, work or volunteering opportunities, including help with confidence building and skills.

Information and advice for carers include a basic service that can be defined as providing a 'baseline minimum set of information' that would include:

1) Social service telephone number for emergencies;
2) National voluntary sector contact information and local numbers, if
3) available;
4) National financial support telephone number.
5) General advice on care and support for children and families in distress;
6) Anything else relevant to the caregiver's circumstances.

Community care services delivered to the cared-for person such as help with cleaning and laundry, are provided primarily to support the carer to care and maintain their own health and well-being. As described above, a carers' service may take the form of a service delivered to the person cared for because the cared for person has refused an assessment or the delivery of services to them in their own right. Advice, information and social work that forms part of the care management process (for the cared for person) might also support carers in their caring roles. Caregivers' involvement in planning the development and delivery of community care services may itself be construed as a service to carers when accounting for funding of administration relating to the carers' plan and consultation with carers (Hirst, 2004).

Richter et al, (2006) believe that children's difficulties are intertwined with the difficulties and coping capacity of their community home-based carers. Support for community home-based carers can have strong knock-on effects for children, and it is unlikely that lasting effects will be achieved in ameliorating children's distress if efforts are not made to simultaneously alleviate the distress of their CHBC.

Supportive care-giving and family relationships are key to children's coping and their capacity to recover from severe stressors. Emotionally responsive care-giving, confident parenting, and warm and supportive family relationships are fundamental to children's achievement, adjustment and well-being. The inner circle of proximal influences on children is so strong that, if these break down, they can cause problems for children independently of external stressors. Similarly, positive experiences outside of the family, while helpful to children, may have little long-term beneficial effect if countered by ongoing negative family relationships.

Children are best cared for by committed and affectionate adults. When the care-giving circle is broken, for whatever reason, extended families must step into the breach. When the circle of care provided by kin is broken, community initiatives have to plug the gap. When the circle of care provided by community is broken, external agencies have a role to play. Embracing all efforts should be a strong and continuous circle of support provided by government provision and legislative protection (Richter et al., 2006).

2.5. Other psycho-social needs contributing to the well-being of community home-based carers

Hirst (2004) identified four distinct but interrelated dimensions of outcomes that are important to CHBCs. These are: *quality of life for the cared for person*; *quality of life for the caregiver*; *recognition and support in the caring role*; and *service delivery outcomes*. Achieving *quality of life for the cared for person*, includes the caregiver providing:

- Personal cleanliness and comfort;
- Maximum independence and mobility;
- Personal safety and security;
- Social contact with others (apart from the caregiver);
- Meaningful activity/stimulation;
- Maintain dignity and morale.

These activities cover the physical, mental and psycho-social aspects of the cared person's life and require community caregivers who are motivated, trained and have support to do their work.

Achieving *quality of life for the caregiver* requires that the community caregiver should:

- Maintain physical health, fitness and well-being;
- Have a positive morale, emotional and mental health;
- Have peace of mind (freedom from excessive anxiety about the people cared for);
- Have freedom to have a life of their own and feel in control e.g. pursue his/her own interests and other commitments and maintain friendships;
- Avoid social isolation.
- Have a positive relationship with the people cared for and managing conflict sensitively; and
- Have adequate material circumstances and financial security like income and housing (Hirst, 2004).

Community home-based carers require *recognition and support in their caring role*. They yearn:

- To be able to define the limits of their caring role and to make informed choices about the level of their involvement and the nature of care-giving tasks;
- Feeling informed, prepared, confident, skilled, equipped or trained for the caring task;
- A sense of satisfaction or achievement in caring;
- A sense of shared responsibility, both practically and emotionally, with services including emergency access to help; and
- Being able to manage the physical and practical tasks of care-giving.

Service delivery outcomes refer to the way in which services are organized and delivered, how care plans are made, and the quality of the CHBC' interaction with facilitators and supervisors. This dimension includes:

- Being valued and respected as an individual;
- Recognising carers' needs and expertise;
- Having a say in how a service is provided;
- Achieving a good fit with existing life routines and patterns of care-giving;
- Responsive to changing needs;

- Positive relationship with facilitators and supervisors; and
- Providing care and support services that are accessible, non-bureaucratic, and available at the point of need (Hirst, 2004).

Schenk and Williamson (2005) identified several qualitative and quantitative approaches that can be used in the assessment of community home-based carers' well-being. These include:

- *Orientation to work*: Incorporating a culture of feedback and evaluation allows for self-reflection and the evolution of approaches. Evaluation is sometimes seen as alien, time-consuming and wasteful of resources. In addition, self-reflection and change in programmes can be difficult.
- *Evidence base*: Interventions can be based on "what we know". Interventions are often based on anecdotal evidence, on "what we believe" and hope
- *Credibility*: Interventions that are evaluated are seen as more important than those that are not, and are more likely to be funded and/or scaled up. Interventions to improve psycho-social well-being of CHBC are in danger of being devalued because there is as yet a limited evidence base to support them.
- *Measurement*: Monitoring and evaluation (M&E) can use a range of designs and tools to give reliable and valid measurement. Avoiding evaluation is a cheap and easy option in the short term, but with a price to pay in the long term.
- *Ethics*: Ethical considerations are a prerequisite when working with children, especially in relation to consent and confidentiality of responsible adults and assent by children. Concerns about ethics should not be used to avoid or abandon evaluation, especially where children and the use of valuable resources are concerned. Ethical issues can be addressed in work with children and families.

In 2007, the South Africa Red Cross Society (SARCS), with British Red Cross (BRC) support, undertook a survey on people's knowledge, attitude, practice and behaviour regarding HIV and AIDS in KwaZulu-Natal (KZN) province. Comprehensive knowledge about HIV and AIDS remains low in the four districts surveyed across all adult and youth target populations. Adults and youths expressed difficulties in accessing information and services. Incorrect beliefs about HIV are still prevalent among adults and youth populations. This leads to fear and increasing stigma and discrimination (SARCS, 2007).

2.6. Psycho-social stress factors and psychological needs of community home-based carers (CHBC)

Care-giving is seen as a demanding role and very often the activities involved in being a community home-based carer (CHBC) goes beyond the call of immediate bed care and providing psycho-social support to orphaned and vulnerable children (OVC). Volunteers take on many duties such as carrying, lifting and bathing of clients; house-hold chores as well as assisting with the care of children. Their work involves visiting several homes a day which entails working long hours sometimes seeing to their own transport in order to do so.

Research studies such as Guman et al, (1991) indicate that there are various psycho-social stressors that are experienced by volunteers and found that emotional overload is a factor experienced by volunteers which can be described as an overall emotional stress on volunteers (Nesbitt, Ross, Sunderland & Shelp, 1996). Akintola (2004) further explains that the possible contributing factors of emotional stress are that of anxiety and worrying by the caregiver/volunteer about the deterioration in the physical state of their clients, as well as the economic conditions of the family.

Physical stress is also seen as a key stressor experienced by volunteers – as care-giving often entails activities such as carrying, lifting and bathing of clients; visiting several homes a day on foot and in the heat. Care-giving at times also goes beyond immediate care – where volunteers often do household chores and assist with the children in that particular household. Akintola (2004) states that in effect, because of the many roles the volunteers have to fulfill and who eventually are seen as the main caregiver in the family this leads to stress related illnesses. And because the volunteers, like the family, often do not use protective devices when caring for the sick, they also face the risk of infection whether it be with tuberculosis (TB) or human immunodeficiency virus (HIV).

Another factor of stress experienced by volunteers is said to be socio-economic stress. Akintola (2004) found that the social and economic stress that is experienced by volunteers are as a result of many of the volunteers being unemployed and who live in similar socio-economic conditions as the sick people that they care for. This stress factor is further exacerbated by the fact that clients' are unable to get the resources and support they need (Nesbitt, Ross, Sunderland & Shelp, 1996). Other stress factors that directly affect volunteers is said to be lack of training – relating to the organization as well as insufficient preparation of the volunteers as they often trained and put to work immediately (Nesbitt et al., 1996).

3. RESEARCH METHODS

A mixed methodology was used for the assessment of PSS needs of community home-based carers. These include a qualitative phase focusing on key informant interviews (KIIs) and focus group discussions (FGDs) and a baseline survey with a sample of community home-based carers (CHBC). Two methods that were used to evaluate the project include:

- The qualitative study comprising of key informant interviews and focus group discussions. We conducted 15 KIIs with SARCS project staff and other stakeholders in community home-based care, and 11 FGDs with community home-based carers;
- A cross-sectional baseline survey of 290 randomly selected CHBC in the provinces where SARCS operates.

This section describes the methodology used to conduct the survey and the qualitative study.

3.1. Survey methods

There were approximately 777 community home-based carers for the OVC project in eight provinces (excluding Mpumalanga) where the SARCS operated in 2008. They were spread in 19 SARCS branches and 32 sites. A cross-sectional baseline survey was conducted with community home-based carers and care facilitators from the 19 branches of SARCS. A random sample of 290 (37%) respondents was selected using the sampling frame in *Table 1*.

3.1.1. Sample selection

A three-stage cluster random sampling design was used to select the sample. In Stage 1 all the eight provinces were included in the sample. In Stage 2, we selected one site from each of the 8 provinces (in the 19 branches) of SARCS. The sites that were randomly selected during this stage were Khayelitsha (WC), Kwanobuhle (EC), Mangaung (FS), Alexandra (GP), Zululand (KZN), Mokopane (LP), Galeshewe (NC) and Mafikeng (NW). In Stage three, all the CHBC and facilitators who were available at the selected site were invited to participate in the study. If they accepted the fieldworker would obtain written consent and then administer the questionnaire.

All efforts were made to include both male and female CHBC as respondents. The cross-sectional survey was a snap-shot of the psycho-social needs identified by a sample of CHBC in late 2008 and early 2009.

Table 1: Sampling frame for the baseline survey of PSS needs of community home-based carers

Sites where interviews were conducted	Province	Number of carers [population]	Number of interviews [sample]
Cape Metro (Khayelitsha)	Western Cape	40	25
Port Elizabeth (Kwazakele)	Eastern Cape	191	69
Bloemfontein (Mangaung)	Free State	50	18
Johannesburg (Alexandra)	Gauteng	150	54
Pietermaritzburg (Zululand)	Kwazulu-Natal	65	23
South Coast, Pietermaritzburg (Edendale)	Kwazulu-Natal	80	29
Mokopane	Limpopo	80	29
Kimberley (Galeshewe)	Northern Cape	76	27
Mafikeng	North West	45	16
Total		**777**	**290 (37%)**

3.1.2. Data collection techniques

A questionnaire consisting of closed-ended items exploring community home-based carers' demographic characteristics (including the presence of a spouse and of orphaned children), well-being, needs, resources, and perceptions and experiences of care was used for data collection. The questions were reviewed for content and appropriateness by researchers at the Behavioural and Social Aspects of HIV/AIDS (BSAHA) Unit at the Human Sciences Research Council (HSRC), discussed in-depth with SA Red Cross Society managers, and pilot-tested with 15 CHBC at one SARCS site in Cape Town, undergoing revision at each step.

The criteria for inclusion were as follows:

- Fieldworkers must be able to access the participants, and
- Participants must be willing to participate in the survey

3.2. Qualitative methods

In the qualitative phase of the study, 15 key informant interviews (KIIs) were conducted with SARCS project staff and other stakeholders with community home-based carers, and 11 focus group discussions were conducted with SARCS CHBC themselves.

3.2.1. Key Informant Interviews with programme staff and other role-players

The Human Sciences Research Council (HSRC) evaluation team conducted 15 key informant interviews (KIIs) with SARCS management and other role-players in the Orphan and Vulnerable Children (OVC) and community home-based carers (CHBC) sector. They interviewed SARCS managers, OVC and CHBC programme staff at the SARCS offices in Cape Town and in the provinces where they are based and regional managers/coordinators and selected SARCS board members who are familiar with the work of carers.

Representatives from other organizations such as the Department of Health (DOH), Department of Social Development (DSD), Nelson Mandela Children's Fund (NMCF) and the AIDS Foundation were also interviewed as they too employ and work with carers.

KIIs was determined by their level of involvement and understanding of CHBC and OVC project's goals and objectives, care-giving and the psycho-social support needs of voluntary carers.

Table 2: Schedule of Key Informant Interviews with SARCS OVC staff and other role-players

Key Informant	Organisation	Number
Manager: OVC	SARCS	1
Coordinator: Health and Care	SARCS	1
Regional CHBC & OVC Coordinators	SARCS	9
Director: OVC	Department of Health	1
Director: OVC	Department of Social Development	1
Manager: OVC	Nelson Mandela Children's Fund	1
Manager: OVC	AIDS Consortium	1
	Total	**15**

Key informant interviews were scheduled at the convenience of the individuals. They were conducted in the community or at an office where an undisturbed and confidential atmosphere was guaranteed.

The interviewers consisted of HSRC researchers who have had previous experience in conducting qualitative research namely, in-depth interviews in this case. All interviews were digitally recorded and brief notes were compiled by the interviewer during the course of interview with the KII.

The selection of respondents were done by an invitation letter containing consent to participate.

3.2.2. Focus Group Discussions (FGDs) with community home-based carers

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. The FGDs were conducted with the CHBC in eight provinces were based at nine selected sites, which appear below:

- Western Cape
- Port Elizabeth and Uitenhage

- South Coast, Pietermaritzburg and Umzimkulu
- Bloemfontein
- Kimberley
- Johannesburg
- Zululand
- Mokopane
- Mafikeng

Respondents from different sites travelled to convenient venues, which were arranged ahead of the FGDs. Every effort was made to ensure that male and female carers were included in FGDs.

FGDs as a research tool were employed for a variety of reasons. Firstly, the evaluation team wished to generate interactive data on the psycho-social support needs of community-based carers. Focus groups involve discussions in a group where providers of services focus collectively on psycho-social issues affecting their work. As such, participants talk mostly to each other rather than to the interviewers so the focus group discussion is an ideal way to understand how providers of services in the community collectively understand the work they do in providing care and support for OVC and their families.

Secondly, FGDs result in increased disclosure. Focus group research has shown that people are more likely to self-disclose and share personal experiences in a group rather than one-to one settings, particularly when in the presence of others whom they perceive to be like themselves, because they can feel relatively empowered and supported in a group situation, surrounded by their fellow carers and peers.

Lastly, focus group discussions have been shown to be particularly useful for investigating issues that are perceived to be sensitive, such as those undertaken in this evaluation. And it is for these reasons stated above, that FGDs were used to collect data for this particular study.

3.3. Ethical considerations

This was a minimal risk evaluation study and participants were not asked to divulge personal information. The endorsement and active support of local political, traditional, and community officials was sought and obtained through the help of SARCS Manager for the psycho-social project.

Ethical principles adhered to were:

- *Risks and discomforts:* There was no appreciable risk or discomfort from participating in the survey and qualitative studies. Questions were posed in general terms.
- *Benefits:* There were no direct benefits to participating in this study.
- *Reimbursement:* Participants were not paid an incentive to participate.
- *Consent:* All participants in the baseline survey, KIIs and FGDs were asked to provide written informed consent.
- *Confidentiality:* Investigators treated information collected in the study in a confidential manner. The data collected were stored on two computers at the HSRC. No names or personal identifiers were recorded in any of the data collection methods, and information collected was only made accessible to people authorised to assist with transcription or translation of the data into English, and investigators involved in the analysis and write-up of study results. Data collected electronically were kept safe in a computer which is password-protected. Hard copies of questionnaires and field notes were locked in a cupboard.
- *Language considerations:* The questionnaire was administered in the local languages, in settings intended to ensure privacy such as the carers' homes. Fieldworkers were fluent in the major local languages where the evaluation was conducted. Participants were interviewed in the language of their choice. Consent forms and questionnaires were available in English and other local languages.

3.4. Data capturing and analysis

3.4.1. Capturing and analysis of survey data

Survey data were double captured by a statistical assistant and one of the team members into a data capturing template created in the Statistical Package for Social Sciences (SPSS) software. Data analysis was conducted in three stages to:

1) Produce a profile of the sample of community home-based carers working for the SARCS,
2) Determine their psycho-social needs, and
3) Determine relationships between psycho-social measures and demographic characteristics of the sample.

3.4.2. Capturing and analysis of qualitative data

Qualitative data that had been recorded during the KIIs and FGDs were transcribed as well as translated into English where the KIIs and FGDs were conducted in a language other than English.

Research team members including the consultant who are qualified in qualitative research methodology undertook the responsibility of doing the qualitative analysis of the focus groups using both thematic content analysis and discourse analysis. In order to facilitate the process, a computer-based qualitative software programme known as *Atlas.ti* was used to analyze the transcripts.

The purpose of *Atlas.ti* was to help researchers uncover and systematically analyze complex phenomena hidden in text and multimedia data. The programme provides tools that let the user locate, code, and annotate findings in primary data material, to weigh and evaluate their importance, and to visualize complex relations between them. *Atlas. ti* consolidates large volumes of documents and keeps track of all notes, annotations, codes and memos in all fields that require close study and analysis of primary material consisting of text, images, audio, or video data. In addition, it provided analytical and visualization tools designed to open new interpretative views on the material.

Thematic content analysis was done on all the (translated) transcripts. In general, a qualitative thematic analysis is an intuitive method of data analysis guided by the particularities of the research goals, in which some areas covered in the focus group discussion are used as broad thematic areas within which emerging themes and sub-themes are generated (Banister, Burman, Parker, Taylor & Tindall, 1994). This was done using grounded theory approach which involves making some inductions from the data collected.

4. FINDINGS AND DISCUSSION

> *"If we lose the thousands of 'angels' out there, our health system will collapse. They play a major role, with little support or resources. Mobilisation of this cadre of workers, standardised package of serviced, training and remuneration could enable us to implement task shifting and mitigate the human resources crisis".*
> *KII GP*

This opening quote from a KII to some degree provides one with some insight into how important community home-based carers (CHBC) are to communities and to the health care system as a whole. It also further indicates some of the over-arching needs of CHBC and ways in which it could be addressed. Our hope is that the findings of this study will used to inform specific and targeted psycho-social programmes directed to CHBC in SARCS as by other NGOs throughout South Africa.

4.1. Recruitment and profile of community home-based carers

4.1.1. Recruitment of community home-based carers (CHBC)

Informants reported that there are various ways in which volunteers are recruited and that there are differences in the manner in which a volunteer is referred to the organisation, as one key informant asserted:

> *"Well in every project it differs somewhat, there's one rule but it differs somewhat between the rural and the urban. In the rural you have meetings with your Traditional Leaders, the Chiefs and the community would identify people and they would then be recruited and trained by us ...but if you come to the urban areas the carers are identified by the community members as well as Department of Health. So our carers are identified by the hospitals maybe or...by the committees that are in the community because it is a community-based project" – Western Cape*

When recruiting the volunteers, the minimum education level needed but not necessarily adhered to, is Grade 11 or 12 after which they are put on probation and acquire practical skills from their respective facilitators.

> *"We recruit volunteers we don't take into account the skills or the experience they have with or without skills they can still join the society and from that most of our caregivers either have a Standard 9 qualification or a Standard 10 qualification" – KII Limpopo*

> *"They have a probation period of about 3 months, that they have to serve, be trained and get some personal experience working with the facilitators who then would also do some practical training with them as well as allowing them to attend classes such as home-based care, First Aid, etcetera" – KII Western Cape*

Even though skills and experience are not necessarily taken into account there are specific skills that at least need to be present in order for a volunteer to be recruited:

> *"...a volunteer care giver is somebody who has excellent interpersonal skills...good speaking skills and also a level of understanding" – KII Western Cape*

> *"…confidentiality is one of the important things that we need from a caregiver, we also look at someone who is very passionate about the work…" – KII KwaZulu-Natal*

> *"Patience….good, be reliable… and very good communication skills" – KII Northern Cape*

4.1.2. Profile of CHBCs

Approximately 270 of the 290 sampled community home-based carers accepted to be interviewed for the survey giving a response rate of 93.1%. About eleven (11) questionnaires were incomplete or poorly filled and were not included in the analysis and were left with 259 questionnaires. It was not possible to obtain data from Alexandra – the site sampled in Gauteng as the staff said they were busy with other important projects at the time of the survey.

Table 3 provides an indication of the care-giving role that is provided selected areas where the study was conducted. Zululand in KwaZulu-Natal (21.2%) had the highest number of community home-based carers whereas Mafikeng (6.2%) had the lowest number of carers.

Table 3: Area where care-giving role is provided

	Frequency	Percent
Cape Metro	27	10.4
Port Elizabeth	37	14.3
Uitenhage	21	8.1
Bloemfontein	23	8.9
Zululand	55	21.2
Pietermaritzburg	29	11.2
Mokopane	24	9.3
Kimberly	27	10.4
Mafikeng	16	6.2
Total	**259**	**100**

Table 4 shows some demographic characteristics of respondents. An overwhelming majority of respondents 82.9% were below 50 years of age. This is probably due to the high unemployment rate among young people. Many of them opt to volunteer as community home-based carers with the hope of getting paid a stipend and getting experience for the job market. In our survey, the proportion of primary CHBC aged 60 years and older was 10.8%.

In their international review of AIDS and older people, Knodel, Watkins, and Van Landingham (2003) extensively considered the evidence concerning the socio-demographic impact of AIDS on older people in Africa. Similar levels of parental involvement as primary carers were found in a series of surveys in Uganda. An overwhelming majority of respondents 94.2% were females. It is not surprising that only 5.8% of primary CHBC in this project were men. This is in line with what has been observed in most studies involving care and support in developing countries. For example, research conducted in Botswana, Zimbabwe and Mozambique found that there were generally fewer men involved in voluntary home-based care work and that most of the home-based care work was carried out by women (GEMSA, 2009).

The majority of carers speak IsiZulu (32%), Isixhosa (31.3%) and Setswana (15.7%). There were no community home-based carers whose home language is Siswati and Tshivenda probably because there are no offices of SARCS in Mpumalanga and in the Vhembe district of Limpopo.

In terms of educational background, majority (79.9%) went up to high school level, 12.4% obtained a diploma while 7.3% obtained primary school education.

The majority of the respondents (71%) were never married, similar to this finding, a quantitative cross-sectional survey in the rural Eastern Zimbabwe about care-giving role found that most of the foster CHBC were disproportionately female, and without a spouse (Howard, Phillips, Matinhure, Goodman, McCurdy and Johnson, 2006).

The dominant religion practiced with regard to the carer who participated in the study was Christianity at 93.1%.

Table 4: Demographic characteristics of respondents

Characteristic	Frequency	Percent
Age		
Less than 20 years	7	2.7
20-29 years	73	28.2
30-39 years	86	33.2
40-49 years	46	17.8
50-59 years	18	6.9
60 years and older	28	10.8
Sex	15	5.8
Male	244	94.2
Female		
Home language		
Isixhosa	81	31.3
Isizulu	83	32.0
Sesotho sa borwa	19	7.3
Sepedi	18	6.9
Setswana	40	15.4
Xitsonga	7	2.7
English	1	0.4
Afrikaans	6	2.3
Isindebele	4	1.5
Education level		
No school	1	0.4
Primary school	19	7.3
High school	207	79.9
Degree/Diploma	32	12.4
Marital status		
Married	67	25.9
Single/Never married	184	71
Divorced/separated	3	1.2
Widower/widow	4	1.5
Civil union	1	0.4
Religion		
Atheist/Agnostic	8	3.1
Christian churches	241	93.1
African traditionalists	8	3.1
Muslim	2	0.8

The key findings emerging from both survey and qualitative studies are listed in the Box 1 below:

Box 1: Key Results

- Training and retention of CHBC
- Social services available to CHBC
- Quality of life activities and work coordination
- Support services for people being cared for by CHBC
- Recognition, retention and support of CHBC
- Psycho-social stress and well-being of CHBC
- Motivation for becoming home community based carers (CHBC)
- Psycho-social support and well-being of CHBC
- Challenges identified by CHBC

4.2. Training and retention of CHBC

Table 5 provides a summary of how the training needs of CHBC have been addressed. Training sessions attended for HIV/AIDS, First Aid, Home-based care and TB were all above 50%, however OVC counseling and support as well as palliative care sessions proportion was below 50%. The lowest training session attended was memory book which is a relatively new program and further training sessions are yet to take place according to the respondents.

Table 5: Training attended by community home-based carers

Training attended		Frequency	Percent
HIV/AIDS	Yes	164	**63.3**
	No	95	36.7
First Aid	Yes	162	**62.5**
	No	97	37.5
Home-based care	Yes	152	**58.7**
	No	107	41.3
Tuberculosis (TB)	Yes	143	**55.2**
	No	116	44.8
OVC counseling and support	Yes	116	**44.8**
	No	143	55.2
Palliative care	Yes	105	**40.5**
	No	154	59.5
Memory book	Yes	91	**35.1**
	No	168	64.9
	Total	**259**	**100**

Table 6 provides responses of CHBC with regard to their satisfaction with the training they received from SARCS. When asked how satisfied they were with the training they received from the SARCS, respondent's levels of satisfaction were almost similar to the pattern of training received. Most of the respondents said they were satisfied with training on HIV/AIDS (64.1%), First Aid (59.5%), home-based care (54.1%) and tuberculosis (52.1%). However, fewer respondents said they were satisfied with training on OVC counseling and support (45.2%), palliative care (36.7%) and memory box (35.1%). This was as a result of some of the respondents not being able to attend the some of the training session on these workshops also respondents expressed that although training sessions are offered on various programmes, the needs to be more in-depth training provided on the more essential skills that they need in providing health care to the clients.

> *"According to skill I can say counselling, we need counselling skills; we need more of this training about social support thing, we have just only started with this social support this year and we still need more training, even ourselves we still need to be counselled." Gauteng group*

"If….if they can get us the training on ARVs it will be very good, because most of us we don't understand really the treatment of ARVs." – Western Cape group

Table 6: Satisfaction with training received from SARCS

Satisfied with training provided by SARCS on:	Frequency	Cumulative Percent
HIV/AIDS	166	**64.1**
First Aid	154	**59.5**
Home-based care	140	**54.1**
Tuberculosis (TB)	135	**52.1**
OVC counseling and support	117	**45.2**
Palliative care	138	**36.7**
Memory Book	91	**35.1**

There are a few training sessions identified by the key informants which SARCS in collaboration with the Department of Health, conducts. These include: psycho-social support; palliative care; prevention-treatment-care and support; First Aid and; home-based care. However some informants stated that it is not entirely clear as to whether each of these programs were trained on at every site.

"Look South Africa is huge…we have 22 different branches in eight provinces…so trying to train everyone is…is… very difficult" – KII Western Cape

The overall sense from the key informants was that the training programmes was seen as sufficient however many of the key informants expressed their concern with regard to the volunteers' ability to fully understand the training because of language issues; education level; age and also implement what they learnt into practice because of a poor level of understanding;

"… we've had challenges with regards to the age you'd find that most of our volunteers they are very old people and as a result they also do not have, most skills for example; let me give an example with regards to the issue of language…you'll find that most of them are actually illiterate. So they cannot communicate in English"' – KII Limpopo

"I'll say it's a language problem I've experienced; it's the language because our manual is in English" – KII Western Cape

4.3. Social services available to CHBC

Table 7 provides a summary on the responses about social services available to CHBC. More than two-thirds of respondents (74%) said they were getting help with caring tasks for people with chronic illnesses, including HIV/AIDS, while 73% said they were getting instruction or education about the care for people's medical conditions, care needs, treatment and medication. This is encouraging that so many community home-based carers are getting the necessary help and instruction on caring tasks.

About 60.6% of respondents said there are courses for CHBC to take up new learning and training and just over half (56.8%) of respondents said they had received training in coping skills. Almost the same proportion of respondents (57.1%) said they were getting help with household tasks as carers. Although carers expressed that they do in fact get assistance in completing household tasks, the concern remains that CHBC are exposed to stress and challenges of coping and need to get access to training that will address this specific issue making it possible for carers to fulfil their roles as community home-based carers and provide optimal care for their clients.

Some of the social services that are not adequately provided to CHBC include getting a short holiday to enable them to have time to themselves (44.4%), getting help with taxi/bus fares to get to work (33.2%) and getting complementary therapies to relieve stress (30.1%). These social services are important if CHBC are to do their work well.

Table 7: Social services available to community home-based carers

		Frequency	Percent
Getting help with caring tasks for people with chronic illnesses, including HIV/AIDS	Yes	203	**78.4**
	No	56	21.6
Getting instruction or education about the care for people's medical conditions, care needs, treatment and medication	Yes	189	**73**
	No	70	27
Getting help with household tasks as a care giver	Yes	148	**57.1**
	No	111	42.9
Training in coping skills is available for you as a caregiver	Yes	147	**56.8**
	No	112	43.2
Availability of courses to take up new learning and training	Yes	157	**60.6**
	No	102	39.4
Getting a short holiday to enable the caregiver to have time to themselves	Yes	115	**44.4**
	No	144	55.6
Getting help with taxi/bus fares to get to work	Yes	86	**33.2**
	No	173	66.8
Getting complementary therapies to relieve stress	Yes	78	**30.1**
	No	181	69.9
	Total	**259**	**100**

CHBC were provided with support in the work that they do. However the support extended to the development of the CHBC in individual capacity:

> *"…in the last 5 years we've really been supporting our caregivers and raising their standard of living...allowing them to go to Abet classes, even paying for it making sure that...services become available...If they want to study further they can apply and if we have funding. We offer a lot of capacity building, a lot of training to raise their level of understanding and knowledge and make them more marketable for other work" – KII Gauteng*

A service that is seen as critically important is being able to provide CHBC that are HIV positive with access to medication as in the past it was seen as a problem due to far distances that the CHBC had to travel in order to access the medication as described by the informant below:

> *"...we have a fund that can be used to support our volunteers who get infected with HIV. They get access to ARVs. Some caregivers can't access ARVs due to transport problems, living far from the clinics that are accredited. We provide the transport for them to get there and back" – KII Western Cape*

As a result of the various support systems and services put in place to assist the CHBC, the key informants were asked whether, if any, collaboration occurs between SARCS and other organisations in or outside of the communities that the CHBC provides services to, the informants stated that there was collaboration with various agencies and organisations such as the with the Department of Health, the Youth Commission, schools in the communities as well as crèches amongst others:

> *"Yes so we have that partnership with the crèches and schools. Also the Department of Health as I indicated we are in partnership" – KII Northern Cape*

> *"...with another NGO, at the moment we have a relationship with "Life Choices". We mobilise the community, counsel the people...they test" – KII Western Cape*

4.4. Quality of life activities and work coordination

4.4.1. Quality of life activities

Table 8 shows quality of life activities that CHBC engage in. About 83% of respondents said they had freedom to interact with friends and family on a social level, 81.5% said they were able to have peace of mind (freedom from excessive anxiety about the people they cared for), 80.3% said they had received information on emergency telephone numbers for ambulance, hospital and other services where they can refer their clients, 79.5% said in trying to achieve quality of life, they had positive morale, emotional and mental health, 77.6% said they were able to maintain physical health, fitness and well-being, 73% said they received general advice on AIDS care, and handling of chronically ill clients while 55.6% said they knew the telephone number for the local office of the South African Social Security Agency (SASSA), which administers the grants. These findings are astonishing and indicate a generally high quality of life for community home-based carers.

Table 8: Activities that community home-based carers engage in to maintain quality of life

Quality of life indicators		Frequency	Percent
Have freedom to interact with friends and family on a social level	Yes	215	**83.0**
	No	44	17.0
Able to have peace of mind (freedom from excessive anxiety about the people cared for)	Yes	211	**81.5**
	No	48	18.5
Received information on emergency telephone numbers for ambulance, hospital and other services where you can refer your patients	Yes	208	**80.3**
	No	51	19.7
In trying to achieve quality of life, have positive morale, emotional and mental health	Yes	206	**79.5**
	No	52	20.1
Able to maintain physical health, fitness and well-being	Yes	201	**77.6**
	No	58	22.4
Received general advice on AIDS care, and handling of chronically ill patients	Yes	189	**73.0**
	No	70	27.0
Knows about telephone number for the local office of SA Social Security Agency (SASSA), which administers the grants	Yes	144	**55.6**
	No	115	44.4
	Total	259	100.0

Many primary CHBC, especially the elderly, are impoverished, ill, tired, and emotionally drained from having cared for and buried relatives and taken in their orphans (WHO, 2002). As the World Health Organization has noted, orphan care is "provided mostly in circumstances of diminished or non-existent forms of external support, be it familial or state-provided" (WHO, 2002).

Government programmes are under-funded and difficult to access (UNICEF, 2002); a study in 2000 found only 2% of households were benefiting from such public education, food, and health-care assistance, while family and community capacity was dwindling. Without such support, a carer's illness or age-related frailty may thrust the foster child into the role of caregiver or head of household. Moreover, given current population dynamics resulting from AIDS, the next generation of orphans will have far fewer grandparents as potential CHBC (Howard et al., 2006).

In our study, CHBC were generally happy about the quality of life activities that were available to them.

4.4.2. Work coordination of CHBC

Key informants were asked exactly how CHBC work was coordinated on a daily basis and whether any support systems were put in place to assist them. Some snippets of answers to these questions are indicated below.

In SARCS there is a structure that is put in place for the management of volunteers. This hierarchical structure is duplicated in each of the SARCS sites country wide:

> *"The facilitators manage a group of volunteers, from 5 to 10 volunteers. The project coordinators comes in a province...and a provincial coordinator will manage the project coordinators...or project officers..." – KII Western Cape*

Respondents in KIIs stated that there is a very clear line of supervision and management, in order to aid the process of monitoring and evaluating the work conducted by CHBC:

> *"So the carers will meet with the facilitators on a weekly basis just to discuss what happened the previous week and to plan for the coming week. They provide us with weekly reports and monthly reports. So they bring those reports to the office and then we also have site visits; like the coordinator would go and visit all of them just to check how far they are and then also to address the challenges they are facing" – KII Limpopo*

The involvement of the CHBC seemed minimal from the structure and report lines that were mentioned, therefore it was asked whether the CHBC did in fact provide any input into the coordination of the work they would essentially carry out:

> *"Yes they are involved because they also provide us with plans like a plan for the month...what they will be doing and then thereafter a report on a weekly basis on the progress made. So they nationally initiate the plan" – KII Limpopo*

> *"Whatever plan that we are doing for whatever activity they need to be there. So they are involved" – KII North West*

Besides the structure of report back as well as input provided by CHBC, key informants were asked whether CHCB are supported in the work that carry out in the communities, this is what a few of them had to say:

> *"I tell them to communicate with the facilitators and the facilitators" – KII Western Cape*

> *"Yes…and I also believe that if we give enough support to them they'll be able to do their work...to do the same to the clients ...because if it was not, if there was no mentoring we couldn't have survived...it is because of the mentoring that we surviving. The regional office for an example once a quarter they come and kind of give support" – KII North West*

4.5. Support services for people being cared for by CHBC

Table 9 provides a summary of support services for people being cared for. About 89.6% of respondents said they were able to provide personal cleanliness and comfort for the people they cared for, 82.6% said they were able to provide social contact with others apart from their role as carers, 77.2% said they were able to provide maximum independence and mobility to their clients, 76.8% said they were able to maintain dignity and morale to the people they cared for, 73.7% said they were able to provide personal safety and security for the people they cared for and 68.3% said they were able to provide meaningful activity and stimulation to the people you care for.

These findings indicate that community home-based carers are able to provide high levels of support to the people they are taking care of. The findings bode well for the community home-based carers' ability to provide the support necessary for the well being of persons they take care of.

Table 9: Support services for people being cared for

Support services for clients		Frequency	Percent
Able to provide personal cleanliness and comfort for the people being cared for	Yes	232	**89.6**
	No	27	10.4
Able to provide social contact with others (apart from them as carers)	Yes	214	**82.6**
	No	45	17.4
Able to provide maximum independence and mobility for clients	Yes	200	**77.2**
	No	59	22.8
Able to maintain dignity and morale to the people being cared for	Yes	199	**76.8**
	No	59	22.8
Able to provide personal safety and security for the people being cared for	Yes	191	**73.7**
	No	68	26.3
Able to provide meaningful activity and stimulation to the people being cared for	Yes	177	**68.3**
	No	82	31.7
Total		**259**	**100.0**

Table 10 shows support services provided by community home-based carers for the people they care for. About 85.7% of respondents said they were able to provide access to health services for the families under their care, 83.4% said they were able to provide education support to the families under their care, 78.4% said they were able to provide psycho-social support (PSS) for children under their care, 78% said they could assists clients to access to social grants, birth certificates and identity (ID) documents, 76.8% said they were able to provide access to health support for families under their care and 61.8% said they were able to provide nutritional support to the families under their care.

Table 10: Services provided by community home-based carers

Services provided by Community home-based carers		Frequency	Percent
Access to health services for the families under your care	Yes	222	**85.7**
	No	37	14.3
Education support to the families under your care	Yes	216	**83.4**
	No	43	16.6
Psycho-social support (PSS) for children under your care	Yes	203	**78.4**
	No	56	21.6
Access to social grants, Birth certificates and identity (ID) documents	Yes	202	**78.0**
	No	57	22.0
Access to health support for families under you care	Yes	199	**76.8**
	No	60	23.2
Food nutrition support to the families under your care	Yes	160	**61.8**
	No	99	38.2
	Total	**259**	**100.0**

Community home-based carers main task is to provide bedside nursing and psycho-social care of clients that they are assigned to. In reality HBC entails much more. Broadly, they have a set of clients in a given area, they walk long distances to reach their charges, and offer home-based care. 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, school lunches, food parcels, homework assistance, funeral support, social services support, school uniforms, memory boxes, bereavement counselling, and caring for younger siblings. These are only a few of the services that were mentioned by focus group participants which they themselves deliver. A few more detailed services are expanded on by the focus group participants:

Educating clients on how to use medication:

> *"Sometimes we tell them how important it is to take the medication on the right time" – Northern Cape group*

Assisting families with children to get grants and attend school:

> *"We teach them because the other families, if you enter the house, there is some kids who don't go to school, when you look you see those children is the age of school (school going age), you want to know what is the reason why those children are at home. They have finance problems, you try to help that those kids can get a grant, and then from there on you'll help to go with them to one school for those children and put them in the school. - Western Cape group*

> *"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" – Free State group*

4.6. Recognition, retention and support of CHBC

4.6.1. Recognition and support for CHBCs

Community home-based carers generally feel they are receiving a high level of recognition and support for their care-giving role. About 75.7% said they are being valued and respected as individuals and the same proportion said they have a sense of shared responsibility, both practically and emotionally, with services including emergency access to help, 74.5% said they have a sense of satisfaction or achievement in providing care to others, 73% said they were informed, prepared, confident, skilled, equipped, or trained for the caring task and 68.3% said their care-giving needs and expertise were being recognized. These results are extremely positive and bode well for the SARCS project.

Table 11: Recognition and support received in the care-giving role

Indicators for recognition		Frequency	Percent
I am being valued and respected as an individual	Yes	196	**75.7**
	No	63	24.3
I have a sense of shared responsibility, both practically and emotionally, with services including emergency access to help	Yes	196	**75.7**
	No	63	24.3
I have a sense of satisfaction or achievement in providing care to others	Yes	193	**74.5**
	No	66	25.5
I am informed, prepared, confident, skilled, equipped, or trained for the caring task	Yes	189	**73.0**
	No	70	27.0
My care-giving needs and expertise are being recognized	Yes	177	**68.3**
	No	81	31.3
	Total	**259**	**100.0**

4.7. Motivation for becoming community home- based carers (CHBC)

The focus group participants were very vocal about their motivation in becoming CHBC, especially in the communities in which they live. Their motivations ranged from their love for their community to treating the illness and suffering and feeling the need to assist where they can. According to the focus group participants creating awareness of HIV/AIDS is seen as a very important need within their communities as the prevalence rates of HIV are on the increase and although there is a lot dissemination of knowledge around the topic, people are still ignorant about transmission and continue to discriminate against people living with HIV and AIDS.

> *"Because I want to help the people in my community to stop the virus of HIV & Aids, because the rate of it is getting up I want it to get low, and the people to live a positive lifestyle. I am in home- based care because I love to help other people, so to help those who are infected and don't know about any kind of treatment, HIV Aids, TB, I love to make sessions to sit down and talk and explain the little bit I have, I love to be in home-based care" – Northern Cape group*

> *"I chose to be a home-based carer because the community in which I live is very poor, I saw how many patients die and I felt that I can be part of the Red Cross as a caregiver, so that I can try and make this a better place" – Western Cape group*

> *"I wanted to be in home-based care, our people are suffering very much, so they don't have enough help from us so we are the only ones who can help them. So for us to go to them every morning at least we are giving them that support. I can see other people are staying alone at home so seeing no one at the end of the day, it will make him feel better so that's why I've decided to come on home-based care"*
> *– KwaZulu Natal group*

Other focus group participants when on to mention reasons such as having a passion to work with people; personal growth; having had a personal experience with loss with regard to AIDS and the reward they receive when from clients that are healed back to health.

> *"My reward is and the reason why I got into home-based care, I get some people who are very, very, ill, and I helped them and they came back to me and say thanks to me." – Eastern Cape group*

4.8. Psycho-social stress of community home-based carers

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. Additional energy, time and work often occurs in providing care, alongside emotional demands which has a wider impact on support systems, it is therefore easy to see that this role could have a significant impact on the carers well-being (Oyebode, 2003). In this section we aim to explore and understand the psycho-social stressors that are experienced by CHBC and whether they are supported in any way or form.

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

> *"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" – Western Cape group*

> *"Sometimes at the end of the day because of load that we having you need sometimes to offload to someone" – KwaZulu Natal group*

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.

> *"So that is also something that we need. 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* dis*tressed because you come from work with all those" – Free State group*

> *"It can be hard when you know you are HIV positive and you see face to face what happens to your clients who are now also having HIV…but you stay strong" – North West group*

Table 12 outlines the psycho-social distress outcomes experienced sometimes or most of the time in the past week**.** In general, there was a low level of PSS distress among community home-based carers during the time of this study. Only about 19.3% said they were mostly bothered by things that usually don't bother them during the past week, only 9.3% said they felt like not eating; their appetite was poor during the past week, 15.4% said they felt that they could not shake off the blues even with help from family or friends, 16.2% said they had a problem keeping their minds in what they were doing during the past week and 17% said they felt depressed during the past week.

However, 34.7% said they felt that everything they did was an effort during the past week. This could be interpreted as carers not having sufficient motivation to complete their duties or that as a result of carers not having the necessary resources needed such as psycho-social support which is addressed in the next section.

Table 12: Psycho-social distress outcomes experienced sometimes or most of the time in the past week

Indicators of psycho-social distress		Frequency	Percent
How often were you bothered by things that usually don't bother you during the past week?	Mostly	50	**19.3**
	Occasionally	45	17.4
	sometimes	93	35.9
	rarely	71	27.4
How often did you feel like not eating; your appetite is poor during the past week?	Mostly	24	**9.3**
	Occasionally	44	17.0
	Sometimes	102	39.4
	Rarely	89	34.4
How often have you felt that you could not shake off the blues even with help from your family or friends?	Mostly	40	**15.4**
	Occasionally	40	15.4
	Sometimes	95	36.7
	Rarely	84	32.4
How often have you had a problem keeping your mind in what you were doing during the past week?	Mostly	42	**16.2**
	Occasionally	41	15.8
	Sometimes	107	41.3
	Rarely	69	26.6
How often have you felt depressed during the past week?	Mostly	44	**17.0**
	Occasionally	39	15.1
	Sometimes	97	37.5
	Rarely	79	30.5
How often have you felt that everything you did was an effort during the past week?	Mostly	90	**34.7**
	Occasionally	53	20.5
	Sometimes	70	27.0
	Rarely	46	17.8
	Total	259	100.0

The informants were very aware of the psycho-social stressors that impact CHBC on a daily basis with regard to the services they provide to their clients. CHBC have to deal with the death of the clients whilst they themselves sometimes are suffering from the same disease.

> *"Yes volunteers have to deal with many patients who have chronic diseases mostly its TB and HIV and AIDS. Yeah it really is sort of draining them emotionally when they loose some of the clients you know sometimes you, you get a referral from the clinic whilst the patient is like terminally ill and the poor caregiver would feel bad if that patient passes on" – KII Free State*

The informants spoke about the different psycho-social stressors that impact volunteers and that there are many times where the volunteer has little or no control over situation which causes further stress on their health:

> *"They are often open to trauma, exposure to illness (TB etc) bereavement, abuse, sexual and otherwise with little support and debriefing and limited concrete information" – KII Gauteng*

> *"They get so use to clients and then they just see the clients go (pass away). Here they have to get to into the house, they see the poverty, they see the deprivation, they see the situation, they see the orphans, they see people going to bed with out food, children crying because they hungry…and there's very little that they can do" – KII North West*

4.9. Psycho-social support and well-being of CHBC

4.9.1. Psycho-social support provided to community home- based carers (CHBC)

A distinction was made with regard to providing psycho-social support to the CHBC, firstly on entry level to the organisation if the volunteer is HIV positive, the volunteer would receive the appropriate counselling and psycho-social support before entering into community home-based care.

> *"Look I think the key thing there; whoever comes into our service as diagnosed, we start from counselling, individual counselling" – KII Western Cape*

The second type of psycho-social support offered to the CHBC whether infected or not is for issues relating to work – such as psycho-social stress (personal trauma, burn-out, emotional and physical stress) where counselling or de-briefing is needed by the CHBC.

> *"… We actually have a policy on...psychological support. Basically what it says is that we should have long term plans like you know programs and activities that will ensure that all volunteers and even staff members of the Red Cross are supported psychologically" – KII Limpopo*

> *"Once a week they do (de)briefing and then, they release all their stresses and then they will share the ideas and then they try to come up with solutions" – KII Pietermaritzburg*

Although psycho-social support is offered in varying degrees to the CHBCs, key informants themselves are unsure as to whether it is offered at each and every SARCS site and whether it is seen as enough, since many psycho-social support services do not include the families of CHBCs:

> *"Its not structured as you are saying but in different branches they do it in different ways because I know here in the Western Cape they have a Church they work with they go and talk to their Pastor and in PE they have a psychologist who sees them once a month" – KII Western Cape*

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

> *"The debriefings are there but they are offered once in a while, but this is not a once in a while thing…you need to go and offload." – North West group*

> *"Yeah, we do talk to them (supervisors) but there is nothing improving, it stays the same, and you cannot talk like 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!" – Northern Cape group*

4.9.2. Psycho-social well-being

Table 13 describes the outcomes of psycho-social well-being that were experienced sometimes or most of the time by respondents in the past week. About half, 49.4% of respondents said they most often felt hopeful about the future during the past week and the same proportion said they have you enjoyed life during the past week, 49.8% said they felt they were happy during the past week and 48.3% said they felt that they were just as good as other people during the past week. These findings about psycho-social well-being are not convincing on whether community home-based carers had a high sense of psycho-social well-being. The focus groups discussions provide a more in-depth explanation as to CHBCs psycho-social well-being as well as psycho-social stress they experienced (as mentioned in section 4.8). However as the results above indicate, the CHBC seems to separate their actual psycho-social well being from the stress that they experienced in the work that they did i.e. not linking how they cope in relation to the level of psycho-social support received. Therefore, it may seem that that the CHBC is experiencing a high sense of psycho-social well being as illustrated by the survey results but when the CHBC were asked personally asked during the focus group discussions their responses differed. It is there important that more in-depth further research be conducted with CHBC to assess their actual levels of stress and whether the support they receive is indeed adequate and effective in dealing with psycho-social stress.

Table 13: Psycho-social well-being outcomes experienced sometimes or most of the time in the past week

Indicators of PSS well-being		Frequency	Percent
How often have you felt hopeful about the future during the past week?	Mostly	128	**49.4**
	Occasionally	31	12.0
	Sometimes	46	17.8
	Rarely	54	20.8
How often have you felt you were happy during the past week?	Mostly	129	**49.8**
	Occasionally	41	15.8
	Sometimes	46	17.8
	Rarely	43	16.6
How often have you enjoyed life during the past week?	Mostly	128	**49.4**
	Occasionally	51	19.7
	Sometimes	39	15.1
	Rarely	41	15.8
How often have you felt that you were just as good as other people during the past week?	Mostly	125	**48.3**
	Occasionally	46	17.8
	Sometimes	41	15.8
	Rarely	47	18.1
	Total	**259**	**100.0**

4.10. Challenges identified by CHBC

According to the key informants, CHBCs face and have to deal with many challenges in providing home-based care services to families and individuals in the communities that they work. One key informant sums it up very succinctly:

> *"No pay, or very small stipends, or months of "dry season" when government is late with funding trenches…lack of equipment - gloves, First Aid equipment, no water, poor infection control and exposure to infection, no resources, lack of transport, heavy reliance by patients and OVCs, heavy burden, huge and growing case loads and workloads, high expectation beyond what they are trained or able to fulfil, sexual, physical and verbal abuse, vulnerability to crime and violence, rape etc, elements and weather, lack of standardised training, mentorship, career pathing, job descriptions, and conditions of service" – KII Gauteng*

4.10.1. Challenges related to transport

Issues relating to transport in the field was the most highlighted challenge experienced by the CHBCs that work in various communities. The participants stated that they have to travel long distances to provide services to their clients in different areas. Many of the CHBCs stated that they would have to make use of their own money in order to travel to their respective clients and if no money was available at that point in time, they would have to walk extremely far from one point to the other, sometimes in extreme weather conditions.

> *"... that's a big problem…it's a big worry, because you have to use your own taxi fare to go to the hospital. Sometimes you have to take the patient to the hospital and you don't have money, the patient must take out his money out of his pocket and we are going to the hospital with him." – Northern Cape group*

4.10.2 Challenges dealing with clients living in poor conditions

The participants reported that having to deal with clients living in poor conditions was a huge challenge as they often have to bear the responsibility of making sure that the clients have food in the house in order to take their medication. Some community home-based carers have to travel at night in order to feed their bedridden clients and in some cases for the reason of that the clients refuse to be fed by their family members.

> *"... the patient is sick and at home they are staying all together but the patient feel that normally I don't want the food from this person that I'm staying with, I want the caregiver who looks after me everytime, and then you must come from your home; at night sometimes you must go and feed that person - Northern Cape group*

> *"Whereby you come across a family that does not have any income, you should run around as a caregiver and at least see to it that that people are having something before they go to sleep – Western Cape group*

4.10.3. Challenges experienced due to lack of resources

Resources are seen as a critical tool in providing home-based care services to clients however many community home-based carers do not get the appropriate resources and materials that are needed in order for them to fulfil their job. Participants reported that some community home-based carers are left empty handed having to cope on their own resulting in them being exposed to infectious diseases.

> *"And we need gloves also, when we are working in the field we are unprotected because we don't know who we are working with" – North West group*

> *"Sometimes you want to get in a house, you want to bath the clients, you don't have gloves you don't have soap there is nothing! You can't do your work proper. And we use all those things even aprons also now we don't get it" – Northern Cape group*

4.10.4. Challenges experienced in training

Although most of the participants agreed that the training schedule and the modules covered by SARCS is extensive and the information is easily understood, some of the participants felt that more emphasis should be placed on First Aid and counselling and therefore to have refresher courses to enable community home-based carers to assist community members whenever help is needed.

> *"And if we can just continue with First Aid, for instance if you come across an injured person, you'll know how to help that person" – Western Cape group*

> *"You are given home-based care, and First Aid, and TB, palliative care, but we don't have the certificates of that. Palliative care and counselling, HIV and AIDS. The first training I got when I started at Red Cross, I got the dissemination training. From there on it was home-based care. What we need is the refreshers and updates on what we have already learnt…things in health change all the time" – Northern Cape group*

4.10.5. Challenges experienced at the individual level

Participants specifically mentioned challenges that affect community home-based carers on an individual basis. "Research undertaken by UNIFEM in Botswana, Mozambique and Zimbabwe and GEMSA in Swaziland, Lesotho and South Africa revealed a lack of incentives such as stipends, travel allowances or other forms of assistance for some voluntary home based care workers (GEMSA, 2009 p.2)". In the focus groups that were conducted for this study, similar 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:

> *"… if you can go out for 2 days with me out in the field and do what I do, if you come back you going to see really, really this people there is no one who appreciate what I do, I did tell them, I said to her I'm not satisfied, because really you don't appreciate what I do. It is too much work I do" – North West group*

> *"Because if you come across a patient who is an MDR, and you get that touch of TB, there is nothing that you can do as you do not have money to see the doctor, no medical aid, and that is now your baby." – Western Cape group*

> *"I am asking them to please take us into consideration. Our work is dangerous; our lives are also in danger. And as home-based caregivers we don't have benefits, we don't get UIF" – Northern Cape group*

Another major challenge experienced by community home-based carers is the issue of the stipend. Some CHBCs 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. The participants go on to mention that not being supported financially also impacts their work as mentioned earlier, sometimes CHBC have to make use of their own money in order to provide food and transport for their clients.

> *"… sometimes you come to work and 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 with needs….you need to wash, 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!" – North West group*

> *"Now at the end of the month, we are going back home with bare hands, we have got big families, really it's hurting. Can't you people change the situation of the NGO's that if I'm working in there as a volunteer, voluntary work for the first three months I must get paid? That is my problem!" – Northern Cape group*

5. RECOMMENDATIONS AND CONCLUSION

5.1. 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. We also recommend that there should be some kind of transport provided during winter as it is quite cold in the morning and the sun sets early. This might help CHBC to reach home safely and on time.

Standardize the stipend for all CHBC

The stipend for the Department of Social Development was around R1, 000 per month in 2008. The volunteers paid by the Department of Health got a stipend of around R850 per month, whereas those who were paid by the Red Cross were getting about R500 per month in 2008. All the CHBC are doing similar kind of work. The differences in the amount of the stipend cause tension among the volunteers. 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.

Provide structured and consistent training and re-fresher courses

CHBC are being given training on HIV/AIDS, First Aid, home-based care, TB, OVC counseling and support, palliative care and memory book. These enable them to do their caring task with confidence. However, the training is not consistent and sometimes it is not enough. We recommend that structured and standardized training be provided to CHBC throughout all SARCS sites in South Africa. We furthermore recommend that refresher courses should be arranged as part of the annual programme.

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

This study has shown that home-based carers play an overall role in the well-being of OVC and PLWHA. Through services they provide, they breach the gap between hospital, home and community by bringing services closer to those who need them the most. They alleviate the strain on overburdened and under-resourced health professionals. However, CHBC are exposed to high levels of stress related to their work and from time to time they need to debrief and get the necessary psycho-social support. 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. We also recommend that the debriefing and counseling of CHBC who have psycho-social stress and their immediate families, who might be affected by their work-related stress, be attended by a professional counselor such as a counseling psychologist, where possible.

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 be protected against exposure to common infectious diseases such as meningitis and cholera through various means.

1) 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.

2) CHBC should be trained on proper disposal procedures and basic hygiene practices. They should also be provided clean swabs and the necessary means of disposal.
3) CHBC should be immunised against common infectious diseases that nurses and health professionals are immunised against.

5.2. Conclusion

An overwhelming majority of CHBC working for the SARCS in 2008 were young women under 50 years of age, who are single or never married and were also Christians. Their training needs on HIV/AIDS, First Aid, home-based care and tuberculosis had been met by the SARCS.

More than two-thirds, of CHBC working for the SARCS were getting help with caring tasks they did for people with chronic illnesses, including HIV/AIDS. With regard to quality of life issues, most of the CHBC had freedom to interact with friends and family on a social level, they had peace of mind (freedom from excessive anxiety about the people they cared for), they had positive morale, emotional and mental health. CHBC were also successful in providing physical, emotional and psychological support to people they cared for. Community home-based carers generally feel they are receiving a high level of recognition and support for their care-giving role and also had low levels of PSS stress.

Although there are some issues related to transport, stipend and training which need to be attended to, it can be concluded that in general, the psycho-social (PSS) needs of CHBC working for SARCS had been met.

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