

***ASSESSMENT OF THE QUALITY OF SERVICES PROVIDED BY THE
HOME COMMUNITY BASED CARE PROGRAMME TO PEOPLE
INFECTED AND AFFECTED BY HIV/AIDS.***

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***Dissertation submitted in partial fulfilment of the requirements for the
degree***

**MAGISTER ARTIUM (SOCIAL WORK)
in the**

**FACULTY OF HEALTH SCIENCE
at the**

NORTH WEST UNIVERSITY (POTCHEFSTROOM CAMPUS)

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Potchefstroom
2007**

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2007**

ACKNOWLEDGEMENTS

My utmost gratitude goes to the mighty Lord who gave me life and time to work on this project. I am also grateful to the following people/institutions:

- My supervisor, Dr Wessels for her support and guidance
- NRF for their financial support.
- My family for their undying support and understanding
- My colleague, friend and supervisor Ms Julia Scholtz Maralack for her encouragement, motivation and support.
- Finally, my loving partner and friend Billy Modikwane for his unending support and the late nights he spent with me when I had to meet deadlines

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This report is dedicated to my family, especially my loving husband who stood by me through thick and thin, and believed in my abilities and supported me throughout this long and difficult road. My lovely son Obakeng who always sat with me until I went to bed and my two daughters Kelebogile and Thandeka.

SUMMARY

TITLE: Assessment of the quality of services provided by the Home Community Based Care Programme to people infected and affected by HIV/AIDS.

KEY WORDS: Home Community Based Care, HIV and AIDS

The North-West Province has the fifth highest prevalence of HIV/AIDS in the country and has an estimated HIV prevalence of 22.9%. On the 24th November 1999 cabinet approved a special allocation of funds to finance a National integrated programme in the fight against the HIV/AIDS pandemic. They involved Departments of Social Services, Health, Education and Agriculture. The plan comprised three main components, which included the implementation of Home Community Based Care models for children and youth infected and affected by HIV/AIDS. The North-West Province was one of the provinces identified to pilot the programme and funds were allocated for the establishment of the programme.

This study was undertaken with the aim of assessing the quality of services provided by the Home Community Based Care Programme to people infected and affected by HIV/AIDS. An empirical survey as well as a literature study was undertaken to determine whether the caregivers that are part of the Home community based care programme play their set role. Forty-five beneficiaries of the programme were randomly selected as respondents. An evaluative research design was utilised to test the progress of the Programme and check whether the programme is consistent with programme design specifications. A structured self-administered coded questionnaire with descriptive questions was developed and self administered to 45 respondents in Ikageleng Location in Zeerust who were randomly selected from a list of beneficiaries. The findings of the study indicated that caregivers who are part of the Home Community Based Care Programme play their set role. The programme provides good quality services to beneficiaries. The programme provides palliative care services, material support, care and support services, awareness and education and income generation.

OPSOMMING

TITEL: Assessering van dienslewering deur Gemeenskaps Tuisversorgingsprogramme vir persone wat geïnfekteer en geïmpak word deur MIV/VIGS

SLEUTELTERME: Tuisversorging, MIV/VIGS

Die Noordwes Provinsie het die vyfde hoogste voorkoms van MIV in die land, naamlik 22%. Die 24ste November 1999 het die kabinet 'n spesiale allokering van fondse goedgekeur vir 'n spesiale geïntegreerde program in die bekamping van die MIV/VIGS pandemie. Die departemente hierby betrokke is Maatskaplike Ontwikkeling, Gesondheid, Onderwys en Landbou. Die plan bestaan uit drie komponente en een hiervan in die implimentering van 'n Gemeenskaps Tuisversorgingsprogram vir kinders en jeugdiges wat geïnfekteer en geïmpak word deur MIV/VIGS. Die Noordwes Provinsie was een van die Provinsies wat geïdentifiseer is om die program te loods en fondse is daarvoor beskikbaar gestel.

Die studie is onderneem met die doel om die kwaliteit van dienslewering deur die Gemeenskaps Tuisversorgingsprogramme te assesser. Om die doel te bereik is 'n literatuurstudie sowel as 'n empiriese studie onderneem om vas te stel of die tuisversorgers, wat deel is van die program hulle rol na wense vervul. Vyf en Veertig respondente wat deel is van die program is ewekansig geselekteer as respondente. Daar is gebruik gemaak van 'n prosedure om die vordering van die Tuisversorgingsprogram te evalueer en om te kyk of die program voldoen aan programontwerp en spesifikasies. 'n Selfopgestelde en selfgeadministreerde vralys is ontwikkel. Vyf en Veertig respondente in Ikageleng woonbuurt, in Zeerust is ewekansig geselekteer van die lys van persone betrokke.

Die studie het bevind dat die versorgers van die Tuisversorgingsprogram 'n bepaalde rol speel. Die program voorsien 'n goeie kwaliteit diens aan respondente en sluit die volgende in: sterwensbegeleiding, materiële voorsiening, versorgings- en

ondersteuningsdienste, voorkomings- en opvoedkundigeprogramme en inkomste genereringsprogramme.

FOREWORD

This manuscript is submitted in article format in accordance with regulations A.11.2.5 for the degree MA (SW). The article will comply with the requirements of one of the journals for Social work, entitled *Maatskaplike Werk Navorsers–Praktisyne/Social Work Practitioner–Researcher*. This article comprises 10 percent of the total mark for the course.

INSTRUCTIONS TO AUTHORS

The Social work Practitioner-Researcher is an interdisciplinary journal devoted to the publication of research concerning the methods and practice of helping individuals, families, small groups, organisations and communities. The practice of professional helping is broadly interpreted to refer to the application of intentionally designed intervention programmes and processes to problems of societal and /or interpersonal importance, inclusive of the implementation and evaluation of social policies.

The journal serves as an outlet for the publication of original reports of quantitatively orientated evaluation studies:

- Reports on the development of validation of new methods of assessment for use in practice;
- Empirically based reviews of the practice literature that provide direct application to practice;
- Theoretical or conceptual papers have direct relevance to practice;
- Qualitative inquiries that inform practice and new developments in the field of organised research.

All empirical articles must conform to accepted standards of scientific inquiry and meet relevant expectations related to validity or credibility, reliability or dependability and objectivity or conformability.

All reviews will be conducted using blind peer review procedures. Authors can expect an editorial decision within three months of submission. Manuscripts and an abstract should be submitted in triplicate to **The Editor, the Social work Practitioner/Researcher**, P.O.Box 524, Auckland Park; 2006. Articles should be typewritten and double spaced, with tables and figures on separate pages. Manuscript should follow the publication Manual of the American Psychological Association, 4th edition, Abstracts are compulsory.

A copy of the final revised manuscript saved on an IBM – compatible disc and formatted in Ms Word format should be included with the final revised hard copy, or e-mailed to swjournal@uj.ac.za submitting manuscripts to the journal should not simultaneously submit them to another journal, nor should manuscripts have been published elsewhere in substantially similar form or with substantially similar content. A publication fee is payable by authors before publication.

ASSESSMENT OF THE QUALITY OF SERVICES PROVIDED BY THE HOME COMMUNITY BASED CARE PROGRAMME TO PEOPLE INFECTED AND AFFECTED BY HIV/AIDS

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1 INTRODUCTION

This article gives a report on a study that was conducted to assess the quality of services provided by the Home Community based care programme to people infected and affected by HIV and AIDS. The report will give an overview of the HIV and AIDS prevalence in the country and in the North West Province. The report will also outline the research questions, the aim, objectives, assumptions of the study and the research methodology. The results of the study are discussed, conclusions drawn and recommendations made.

2 PROBLEM STATEMENT

This study formed part of the Tshwaragano project of the subject group: social work at the North West University (Potchefstroom campus).

The spread of HIV across South Africa was confirmed when in 1990 the first survey was carried out. This found out that 0, 8 percent of women attending antenatal clinics were HIV positive. According to the Department of Health (2000:49) it was estimated that there were between 74 000 and 120 000 HIV infected people in South Africa.

According to the Kaiser family foundation (2001:4) the epidemic has created a cumulative figure of 13.2 million orphans. In the same year an estimated 600 000 children aged 14 or younger became infected with HIV. Over 90% of these were babies born to HIV positive women, who acquired it before or at birth or through breast-feeding. In South Africa, it is estimated that around 4 million people are HIV infected and the number is expected to rise over the next 10 years.

The North West Province has the fifth highest prevalence in the country. The province has an estimated HIV prevalence of 22.9%, with the Southern region and Bophirima region being the lowest at 17.1% prevalence. The projected number of orphans expected in the North West by 2021 according to low and high impact scenario is that the Province will have 515 378 and 764 328 thousand respectively (Department of Economic Development and Tourism, 2003:37). On the other hand the North West Department of Social Development conducted a rapid appraisal for identification of orphans and vulnerable children in 2001 and 2002 and was able to identify 4411 orphans and 8369 vulnerable children (Social Development, 2002). This is an indication that one of the worst consequences of AIDS is the large number of children orphaned as a result of parents dying of AIDS (Department of Economic Development and Tourism, 2003:6).

The reality of orphanhood begins long before the death of the parents when the household is without income and the parent is no longer able to support the children. This and the trauma of watching the parents slowly dying are the first stressors the children have to face (Department of Economic Development and Tourism, 2003:6). HIV and AIDS increase the number of orphans and reduce the number of traditional carers and breadwinners. In the past, the extended family met most of the basic needs of orphaned children and provided a protective social environment in which they could grow and develop. It has come under huge strain as a result of loss of many caregivers and breadwinners, and a subsequent strain of providing for additional children in the home with basic requirements. Children end up taking adult roles, taking care of their sick parents and their siblings (Department of Social Development, 2001:3).

On the 24th November 1999 cabinet approved a special allocation of funds to finance a National integrated programme in the fight against the HIV/AIDS pandemic, involving Departments of Social Services, Health, Education and Agriculture. The plan comprised three main components:

- Rolling out of life skills and HIV/AIDS education in schools,
- Providing increased access to voluntary HIV/AIDS counselling, and
- Testing service and implementation of Home Community Based Care models for children and youth infected and affected by HIV/AIDS (Department of Social development, 2002/2003).

The overall goal of the National integrated plan was to ensure access to an appropriate and effective integrated system of prevention, care and support services for children and youth infected and affected by HIV/AIDS. The North West province was one of the provinces identified to pilot the programme and Klerksdorp was selected as a pilot site in the Province. Funds were allocated for establishment of the Home community Based Care programme; six income generating programmes and for monitoring and evaluation (Department of Social Development, 2002).

The programme is currently located in the four districts of the province namely, **Central, Bophirima, Bojanala and Southern** where the HIV/AIDS infection; terminally ill people and Orphans and vulnerable prevalence is the highest. A total of 46 programmes have already been established. Most parts of these areas are predominantly rural in nature, others are informal settlements and few are urban, with high unemployment and poverty levels. The impact of HIV/AIDS is understood within the context of the community, taking into account their needs, socio-economic conditions and constraints. The programme is intended to offer holistic, integrated, comprehensive services.

Home Community Based Care is defined as provision of comprehensive services, which include Health and social services, by formal or informal caregivers in the home in order to promote, restore and maintain a person's maximal level of comfort, function and health including care towards a dignified death. These services can be accessed

nearest to home, which encourages community participation, responds to the needs of the community, encourages traditional community life and creates responsibility (Department of Social Development, 2001:9). Government, non-governmental organisations, community-based organisations, faith-based organisations as well as other institutions within the community offer them. This broad definition of HCBC covers a wide spectrum of services offered in the care and welfare of individuals in the home. Although these services are not restricted to people living with HIV/AIDS and the services address poverty alleviation, most of the services are targeted to families and people affected by the disease (Department of Social Development, 2001:59).

It is intended to provide the following services:

- Facilitate access to food, so that the sick do not die because of poverty or children do not suffer because they are undernourished.
- Distribution of food parcels to orphans and vulnerable children and people infected by HIV/ AIDS.
- Management of the sick in order to prolong their lives and create a conducive environment for those whose life cannot be prolonged to die in dignity.
- Educate family members about care and management of the sick and the use of antiretroviral drugs for those on treatment.
- Identification, referral, care and support of orphans and vulnerable children so that they can lead a normal life.
- Assist terminally ill parents to develop memory boxes for their children to prepare them for life after the death of the parent or to open up communication between parents and their children (Social Development, 2003:31-35).
- Facilitate the process for children to acquire registration documents and for those who qualify to be placed in alternative care.
- Initiate aftercare programmes for children in distress – assisting and supervising their schoolwork and empower them with life skills.
- Supervise families that receive food parcels and encourage them to participate in programmes initiated for their benefit and for the benefit of the children.

- Provide basic counseling, bereavement and ongoing counseling to family members and orphans.
- Visit the identified families 3 times a week.

Home Community Based Care Programmes operate with full-time paid personnel or volunteers and with donations received and supplied. They also operate with skilled, semi-skilled or unskilled community caregivers, contributing to differing cost structures and quality of service (Social Development, 2003:36-50).

From the above, the following questions are asked:

- Do the caregivers that are part of the Home Community Based Care Programme play their set role?
- Does the Home Community Based Care Programme offer quality services to beneficiaries?
- Which types of services are rendered by the Home Community Based Care Programme?

3 AIM

The aim of the study was to assess the quality and type of services provided by the Home Community Based Care Programme to people infected and affected by HIV/AIDS and whether they are responsive to the needs of the beneficiaries.

4 OBJECTIVES

- Determine through an empirical study whether the caregivers that are part of the Home Community Based Care Programme play their set role.
- Determine the type of services offered by the Home Community Based Care Programme to people infected and affected by HIV and AIDS.
- Determine through a literature study as well as an empirical study the quality of services provided by the Home Community Based Care Programme.

5 CORE THEORETICAL ASSUMPTIONS

Caregivers who are part of the Home Community Based Care Programme provide good quality services to beneficiaries. Beneficiaries receive services in line with the Home Community Based Care Programme implementation guidelines provided by the Department of Social Development.

6 RESEARCH METHODOLOGY

The methods used for investigation were a literature study and empirical research.

6.1 LITERATURE STUDY

The central focus of this study was on the type of services that the Home Community Based Care Programme is providing to people infected and affected by HIV/AIDS.

Both national and international literatures were utilised. These include:

Home Community Based Care and HIV and AIDS *journals*, *National guidelines and strategies* for people infected and affected, draft norms and standards for Home Community Based Care services, *information from the internet* on best practice models on Home based care. *Books* on HIV/AIDS and its impact on people infected and affected, *statistical and narrative reports* on HIV/AIDS also played a vital role as there's limited literature on the topic. The *database* utilised for a systematic library search, is Social Work Abstracts, Social Sciences Index and EBSCO HOST WEB.

6.2 EMPIRICAL RESEARCH

An evaluative survey procedure was used which determines whether interventions, programmes, policy or strategy have been properly implemented. It also determines whether the target group has been adequately covered and whether intervention was adequately covered. A structured and self-administered questionnaire was used to investigate the quality of services by investigating the type of services provided to beneficiaries of the service (Mouton: 2001:158).

6.3 RESEARCH DESIGN

An empirical research design (Mouton: 2001:159) was used to investigate the type of services offered within the Home Community Based Care Programme and the quality of services provided.

6.4 MEASURING INSTRUMENT

A structured self-administered questionnaire (De Vos, Strydom, Fouché & Delport, 2002:168) comparable to that of other studies was used. The instrument was piloted to determine its validity and reliability. The questionnaire had closed questions which required information from beneficiaries on the type of services they received, how they feel about the quality of services provided by the Home Community Based Care Programme and whether it is responsive to their needs and problems.

6.5 PROCEDURES

Permission was obtained from the Department of Social Development. Forty-five beneficiaries were randomly selected from the list of all beneficiaries of the service. A questionnaire with descriptive questions was developed, tested and personally administered. It was also ensured that the findings do not impact negatively on the respondents. All the selected respondents were called to the hall of the centre where they were briefed on the study and what needs to be achieved out of the study. They were also requested to sign a consent form to give written permission to be interviewed. They were interviewed individually to protect their identity and their right to confidentiality as there were respondents who were HIV and AIDS positive.

6.6 PARTICIPANTS

The research was conducted in the Ikageleng Location in Zeerust. A probability sampling technique and specifically a simple random sample was used (De Vos, et al., 2002:200). The researcher was provided with a list of beneficiaries of the Home Community Based Care Programme funded by the Department of Social Development. There were one hundred beneficiaries of the programme. Forty-five of them were

randomly selected, interviewed and the findings of the study generalized to the total population.

6.7 LIMITATIONS OF THE STUDY

The study was limited to a few beneficiaries who were generalized to the whole programme. The study was also limited to assessment of quality focusing on services provided and the responsiveness of the programme to the beneficiaries (Mouton; 2001:159).

7 ETHICAL ASPECTS

According to Grasso & Epstein (1992:118) ethics are those principles that are intended to define rights and responsibilities of the researcher and practitioners in social work, in their relationship with each other and with other parties including employers and researcher's subjects. According to De Vos, et al (2002:58) subjects can be harmed in a physical or emotional manner. Respondents were all addressed and informed about the nature and purpose of the study and permission was sought to interview them, respondents were requested to complete consent forms. The issue of confidentiality was considered and respondents were anonymously interviewed with the intention of protecting their privacy as some of them are either infected or affected by HIV/AIDS.

This study was part of the Tshwaragano project and ethical permission had already been requested and approval was granted by the Faculty Board of Health Sciences of the University of the North West (Potchefstroom Campus) on the 5th September 2007. Permission was also obtained from the Department of Social Development.

8 DATA ANALYSIS

The researcher collected and analysed data manually. Qualitative and statistical methods of data analysis were used through simple and group frequency distribution tables. Coded data was manually categorized, organized and analysed and the results generalised to the whole programme (Mouton: 2001:159).

9 TERMINOLOGY

The following definitions of terms were formulated

- **AIDS**

AIDS is an acronym for Acquired Immune Deficiency Syndrome. According to Orr and Patient (2005:6) AIDS is a medical term to describe a wide range of illnesses that people living with HIV get, which can cause serious illness or death. AIDS is not a specific illness. Instead, it is a condition of poor health caused by HIV, plus another serious illness. When an illness – such as tuberculosis, cancers, pneumonia, or malaria comes along, they cause person living with HIV to become very ill, because the person is already weak from HIV.

- **HIV**

According to Orr and Patient (2005:5) HIV refers to the human immune deficiency virus. This virus destroys the immune system and diseases that someone with a healthy immune system can usually fight off easily. AIDS refers to acquired immune deficiency syndrome. This is when a person's immune system has deteriorated so much that they start becoming ill with life threatening and often-unusual diseases. The presence of HIV infection in a person is usually recognized by analysis of the blood for the presence of the antibody to HIV. A positive HIV test does not mean that you necessarily have AIDS, but you could have it in the future. It is not known whether everyone infected with HIV eventually develops AIDS but it is known that some people have had HIV infection for several years and have not developed AIDS. It seems that by taking very good care of them, both physically and emotionally many of these people are living normal productive lives for many years with the HIV infection. HIV infects and multiplies not only in T helper cells but also in other body cells such as Monocytes and tissue cells in mucous membranes (Van Dyk, 1999:16).

- **Home Community Based Care Programme**

Home Community Based Care is the care given to individuals in their own homes when their families, their extended families or those of their choice support them. These home-based caregivers are supported by a multidisciplinary team and complementary caregivers who are able to meet the specific needs of the individual and family (Department of Social Development, 2001:9).

10 RESULTS AND DISCUSSION

A total of 45 Home Community Based Care beneficiaries were interviewed. The following section presents a demographic profile of the participants.

10.1 HOUSEHOLD INFORMATION

- **Household size**

Table 1

Household number	F	%
One - Five	28	62
Six -Ten	17	38
N	45	100

Table 1 illustrates that the majority of respondents from the interviewed households had one to five people staying in the same household whereas a few had six to ten members. This implies that the households are bigger in size. According to the Department of Economic Development and Tourism (2003:77) HIV and AIDS has an impact on the demographic changes in age, sex structure and composition of households. The mortality data shows an increase in adult mortality and a drop in the fertility rate of women. The other reason why we have small families in the North West Province is due to child mortality. According to Bradshaw, Nannan, Laubscher, Groenewald, Joubert, Nojilana, Norman, Pieterse and Schneider (2000:10) HIV and

AIDS deaths in the children under the age of five is exceptionally high, with one in four infants dying of HIV and AIDS.

- **Ages of people living in household including the beneficiary**

Table 2

Ages of people in household	F	%
0-5	15	11.81
5-10	19	14.96
11-16	36	28.35
16-20	16	12.60
Adults	41	32.28
N	127	100

According to Table 2 it is clear that an adult person headed the majority of the households interviewed. There is a high number of children between the ages of eleven to sixteen and five to ten respectively. This could imply that the majority of households receiving services from the Home Community Based Care Programme were not headed by children but were headed by an adult person. Another important factor is that there are more children than adults in these households, which might imply that these are extended families. According to Kalule-Sabiti (2006:6) the HIV prevalence is lowest in the ages 0 to 16 and 55 to 59 which implies that the country has not yet experienced the full impact of HIV and AIDS resulting from child headed households.

- **Source of support of respondents**

Table 3

SOURCE OF SUPPORT	F	%
Income from employment	12	11.54
Disability Grant	16	15.38
Child Support Grant	10	9.62
Old age grant	7	6.73
Foster care grant	7	6.73
Food parcels from the Home Community Based Care programme	45	43.27
Odd Jobs	7	6.73
N	104	100

Table 3 reveals that 12 (11.54%) of the respondents depended on income from employment. Sixteen (15.38 %) of the respondents were dependent on various Government Grants and 7 (6.73) on odd jobs. All the respondents were receiving food parcels from the Home Community Based Care Programme. This statistics indicates that most of the respondents were receiving more than one Government Grant.

According to Statistics South Africa (2003), of the 6 562 residents in Ikageleng location only 817 of the heads of households were in paid employment which, implies that the rest of the heads of households were either unemployed or depended on grants. This is an indication that the majority of residents in Ikageleng live below the poverty line. This is one of the reasons why all the beneficiaries of the Home Community Based Care Programme are dependent on food parcels distributed.

In a study conducted by Kalule-Sabiti (2006:14-15) "Poverty and economic distress in South Africa and in the North West in particular have been identified to contribute to the rapid spread of HIV and AIDS. Poverty and HIV and AIDS are interwoven in many

ways. They are related to poor hygiene, risky sexual behaviour, promiscuity and unprotected sex. It can be easily found that in the North West all boyfriend and girlfriend relationships have an economic component, which means that younger people may be exposed to HIV/AIDS because of poverty. According to Kalule-Sabiti (2006:14-15) “lack of employment opportunities in rural areas of the Province have contributed to rural-urban migration which in turn aggravates urban poverty as urban centres lack capacity to absorb the rural poor. The migration of rural poor girls to the big cities in search of jobs as domestic workers or babysitters continues but, a greater number of them end up selling their bodies to raise money for themselves and their parents at home and in the end are caught up in the HIV web”.

According to Wanless (2007:21) in terms of community services, home based care was found to be the most important intervention for HIV and AIDS patients and has shown to impact on clinical outcomes. Nutrition is also essential for the best response to treatment.

10.2 BENEFICIARY DEMOGRAPHIC INFORMATION

- **Sex of respondents**

Table 4

Sex	F	%
Female	28	62
Male	17	38
N	45	100

The majority of the respondents were female while 28 (62%) were male. This implies that women headed most of the households. This might imply that the men had died due to AIDS related infections or had migrated to cities or mining areas to look for employment and women had remained behind to take care of the children. In another study conducted by UNAIDS (2000:14) in Sub Saharan African countries men are dying first, followed by their infected partners and wives. Women as mothers, grandmothers, head the majority of households; aunts are common guardians of orphans and

vulnerable children. This could be a reflection of the high death rate among men as also suggested by the greater levels of paternal orphanhood compared to the maternal type.

- **Language spoken by respondents**

The dominant home language spoken by the beneficiaries who took part in this study was Setswana at 39 (87%) whereas the remaining 6 (13 %) were made up of Zulu speaking beneficiaries. This is due to the fact that Ikageleng location is in the North West Province, which is the former Bophuthatswana homeland, and the predominantly spoken language in the province is Setswana. According to Statistics South Africa census (2003) Ikageleng location is dominated by Setswana speaking residents. The total number of residents is 6 562 and 5 971 of these residents are Setswana speaking.

10.3 HEALTH STATUS OF RESPONDENTS

Table 5

Health status	F	%
Diabetes and high blood	3	7
TB	7	16
None	13	29
HIV and AIDS	22	48
N	45	100

Table 5 presents statistics of respondents who were asked about their health status and in response three (7%) had diabetes and high blood, seven (16%) had TB , 13 (29%) did not suffer from any illness and 22 (48%) disclosed that they were HIV and AIDS positive. Twenty nine percent of the respondents do not suffer from any illness but benefit from the Home Community Based Care programme due to children who were affected by HIV and AIDS and are staying with them. The majority of respondents were HIV and AIDS positive, this might be because the programme was developed for people infected and affected by HIV and AIDS. According to the Department of Health (2002:6) Home-based care provides an alternative to institutionalised health care, and has received greater emphasis with the advent of HIV/AIDS. Formal and informal caregivers in the home in order to promote, restore and maintain a person's maximal

level of comfort, function and health including care towards a dignified death provide health services.

10.4 CHILDREN OF THE RESPONDENTS

Respondents were asked if they had any children of their own and in their response the majority of respondents 30 (67%) had children of their own and 15 (33%) did not have children of their own. This might be due to infant mortality resulting from HIV and AIDS infections or they might have decided not to have children at all. According to a UNAIDS report (2004:88) an estimated 630 000 children worldwide became infected with HIV either during pregnancy, labour and delivery or breast-feeding. Four hundred and ninety thousand children died of AIDS related deaths. At least a quarter of newborns infected with HIV die before the age of one and up to 60 percent die before reaching their second birthday and on the overall most die before they are five years old.

10.5 NUMBER OF CHILDREN OF RESPONDENTS

Table 6

Number of children	F	%
1-2	39	87
3-4	6	13
N	45	100

The majority of respondents only had one to two children of their own whereas the rest had between 3-4 children. Another reason why respondents had a small number of children of their own might be because when their family members become ill, they have to take on the responsibility of providing for their extending family's children. Fewer families have the money to take on deceased relatives children (Education and Training: 2005:3).

10.6 HOUSEHOLDS WITH ORPHANED CHILDREN

Respondents were also asked if they had any orphaned children in their households. Twenty-three (51%) of the respondents had orphaned children staying with them. The majority of households had orphaned children in their households, which is an indication that the worst consequence of AIDS is also the large numbers of children who become orphaned as a result of parents dying of AIDS. Children orphaned by AIDS are found in almost every country of the world. The worst orphan crisis is in Sub-Saharan Africa estimated at 12 million children who have lost one or both parents. The number is expected to rise to 18 million by 2010 (UNAIDS, 2004:40). According to low and high impact scenarios, the number of orphans in the North West Province is projected to escalate to 515 378 and 764 328 respectively by 2021 (Department of Economic Development and Tourism, 2003:37).

10.7 KNOWLEDGE OF THE HOME COMMUNITY BASED CARE PROGRAMME

- **Knowledge of the HCBC programme**

A question was asked whether respondents had full knowledge of the Home Community Based Care Programme. All the respondents 45 (100%) had full knowledge of the Home Community Based Care Programme. Reasons might be that caregivers conduct regular home visits to the respondents and services of the programme are well marketed in the community. They play an important role in education and care but need help in setting and keeping professional boundaries in their HCBC work. According to the Department of Health (2002:22) caregivers and volunteers are often undervalued, overextended and invisible. They experience low morale, stress, burnout, exploitation and abuse. Home community based care services will only be sustainable if the needs of home Community Based Carers are met.

- **Source of information of the Home Community Based Care programme**

Respondents were asked how they found out about the home community based care programme. All the respondents (100%) were contacted by the Home Community

Based Care Programme caregiver. Caregivers form an integral part of HCBC programs and without which many projects would evidently be non-existent. Their relationship with the community is vital to the success of HCBC and the quality of care provided by these programmes (Russell & Schneider, 2000:1-10).

The strength and success of Home Community Based Care Programmes often lies in the kind of caregivers it attracts. A majority of Home Community Based Care Programmes rely on caregivers to provide their skills and services on a voluntary basis, whilst some are able to offer their caregivers a small remuneration for their services. Programs with inadequate funding find it hard to maintain volunteer commitment (Russell & Schneider, 2000:11).

10.8 SERVICES PROVIDED BY THE HOME COMMUNITY BASED CARE PROGRAMME

- Length of receipt of services

Table 7

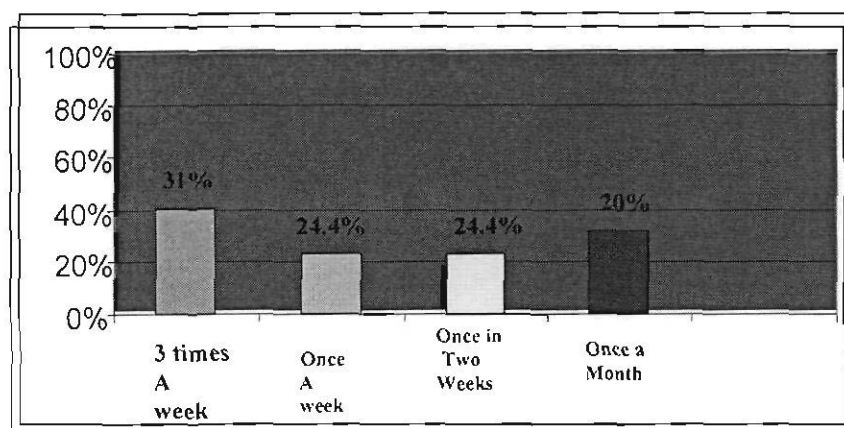
Length of receipt of services	F	%
1- 3 months	11	24
6-12 months	17	38
1-3 years	17	38
N	45	100

Respondents were asked to mention how long they have been receiving Home Community Based Care services. It is pointed out in Table 7 that, the majority of respondents 17 (38%) had been receiving Home Community Based Care services for six months to one year whereas the other 17 (38%) had been receiving services for one to three years. Eleven (24%) had been receiving services for one to three months. This is an indication that respondents are dependent on the Home Community Based Care programme which implies that the programme only benefits a few people. Most of the respondents had benefited from the programme for more than six months.

According to the Department of Health (2002:35) Home Community Based workers are often faced with situations where people living with AIDS and their families have no food and do not qualify for any grants because of lack of identity documents. The pandemic has resulted in tens of thousands of orphans and child-headed households. These children are not only left without an adult to look after them, but are in dire poverty and without birth and death certificates. This leads to difficulties in accessing social grants and services, a situation, which violates their rights of access to education, dignity and basic services.

- **Frequency of caregivers visits to respondents**

Graph 1



Graph 1 demonstrates the frequency of visits made by Home Community Based caregivers to respondents' homes. It indicates that 14 (31%) of the respondents were visited by Home Community Based carers three times a week, whilst 11(24.4%) were visited once a week, 11 (24.4%) once in two weeks and 9(20%) only once a month when they were informed about the food parcels distribution. These results are full proof of the fact that visits to beneficiaries differ from one caregiver to the next. The project manager for quality assurance purposes may attribute this to lack of monitoring and follow up visits.

According to the Department of Health (2002:23) there is a need to always assess whether the Home Community Based Care programme is a sustainable response to the epidemic, to ensure that funds are wisely spent and community needs effectively met. Some families receive support from several organisations and others from none because of communication breakdown. The debate is who should be conducting monitoring and evaluation and how to decide on key indicators.

- **Length of visits conducted by caregivers to respondents**

Table 8

Length of visits	F	%
Less than 20 minutes	20	44
Less than one hour	13	29
Two hours	12	27
N	45	100

Respondents were asked to state the duration of visits from caregivers. Twenty (44%) stated that caregivers stayed with them for less than 20 minutes, whereas 13 (29%) said that caregivers stayed with them for less than an hour and 12 (27%) stayed for two hours. The time caregivers spend with clients differs from one caregiver to the next. It might be due to the fact that some clients might need caregivers more than others. There are no norms and standards set for provision of Home Community Based Care programmes.

This indicates that there is a need to standardise the work caregivers are doing to ensure that the same quality of services are provided. According to Van Dyk (1999:149) people who are diagnosed with HIV usually experience a lot of stress. Follow up visits are therefore necessary to give them an opportunity to ask questions, talk about their fears, feelings and other problems and just need someone who can provide them with the necessary support.

- **People taking care of the terminally ill person other than the caregiver**

Table 9

Other caregivers	F	%
Family members	32	71
Friends and neighbours	1	2
Religious organisation/ leader/ congregation	2	4
Staying on their own	10	22
N	45	100

Table 9 illustrates the answer to a question asked whether respondents had anybody else taking care of terminally ill persons at home besides the Home Community Based caregivers. The majority of the 32 (71%) respondents had family members to take care of the terminally ill person, while 1 (2%) had neighbours and friends. Two (4%) also received care from religious organizations or leaders and 10 (24%) of respondents said that they were staying on their own. Some respondents may not be having anyone else taking care of them as their families may have rejected some of them.

Involvement of family and community members in caring for patients in their homes breaks the fear of HIV and AIDS in communities and families. It increases the visibility of people living with HIV and AIDS in the community, thereby encouraging the normalisation of the virus. Educating members of families about the transmission of HIV encourages discussion and understanding. When caregivers become known in the community, they serve as a point of reference for questions families or communities might have about HIV (Fox, Fawcett, Kelly & Ntlabati, 2002:22-23).

- **Respondents' contact with caregivers outside working hours**

All the respondents have never contacted caregivers outside their normal working hours. The Home Community Based Care programme recognizes and attempts to build

on the fact that most of the care received by persons living with HIV and AIDS will be provided by relatives and friends of the patients at their own homes (UNAIDS, 2001:68).

Home Community Based Care plays an important role in the community since one of its core purposes is to empower the community through the building of human capital and the promotion of self-reliance through community action. This makes them less fearful of what is happening to the patient and this gives them confidence because they can then properly care for the patient on their own. Sometimes neighbours also become involved in some aspect of care (Fox et al, 2002:31).

- **Respondents needing assistance of a caregiver outside the normal visiting hours, at night or on a weekend.**

A question was asked if respondents had ever needed assistance of a caregiver outside normal working hours. All (100%) respondents had never required the assistance of caregivers outside office hours. The reason might be because caregivers model respectful care during visits to clients. Families are educated on how to take care of their own terminally ill family member. This makes them less fearful of what is happening to the patient and this gives them confidence because they can then properly care for the patient on their own (UNAIDS, 2001:68).

- **Availability of caregivers when needed in an emergency outside their normal working hours.**

It is evident from the reaction of the respondents that caregivers are always available to them, because even if caregivers were not needed outside their working hours the majority 29 (71%) felt that if they called caregivers outside of their working hours they would take action whereas 3 (7%) felt they would not come and 10 (22%) did not know if they would come or not. The reason why most of the respondents said yes might be because caregivers spend most of their time with them and visit them three times a week.

There is recognition that caregivers and volunteers are the first point of contact for people living with HIV and AIDS and their families and are the role models with regards

to positive attitudes and practices. Caregivers play a vital role in challenging stigma and discrimination (Department of Health, 2002:46). They are perceived as the backbone of community care programmes for people infected and affected by HIV and AIDS. They step in to care for the sick out of a sense of love or duty towards them (UNAIDS 2000:14).

10.9 SERVICES OFFERED BY THE HOME COMMUNITY BASED CARE

Respondents were required to mention all the services they received from the Home Community Based Care programme. These services were categorized into service Clusters and services received differed from one respondent to the next. The first service cluster was palliative care.

- **Palliative care services**

Most of the respondents 37 (82%) were assisted with taking medicines. Two (4%) of them were assisted with medical supplies and 2 (4%) are assisted with cleaning, fetching wood and cooking. Four (9%) of the respondents were assisted with eating and drinking. Palliative care is necessary within the Home Community programme as most of the respondents are assisted with taking medication as antiretroviral sites are linked to all the Home Community Based Care sites to monitor compliance with treatment. Clinic and hospitals work with home community based carers to ensure that there is ongoing care for someone who is discharged from hospital. People who are ill with AIDS need much more care than what hospitals and clinics can provide (Department of Health: 2002:12).

- **Awareness and education programmes**

Respondents were asked if they have been involved in awareness and education programmes. Seventeen (16.7%) respondents received life skills, 21 ((20.6%) were provided with information on HIV and AIDS, 37 (36.3%) who are the majority of the respondents received information on nutrition and 27 (26.4%) on hygiene. It is clear from the response of participants that awareness and education services are vastly implemented because prevention of HIV and AIDS and education of communities is of high priority within the Home Community Based Care Programme.

According to the Education training Unit (2005:34) young people should also be:

- Provided with life skills on how to deal with issues like preventing HIV/AIDS and sexually transmitted infections through healthy and safe sexual practices.
 - Helped to understanding drug-use and the spread of HIV/AIDS, sex, reproduction and safe sex.
 - Taught about care and support of people with HIV/AIDS and their families, how to deal with peer-pressure, communication and negotiation skills.
 - Given a platform where they can feel free to talk about sex and can deal with it honestly and openly in their relationships with each other.
 - Provided with support and information and get easy access to prevention measures like condoms, treatment of sexually transmitted infections, testing and counselling.
 - Encouraged to be open about HIV/AIDS and create a more supportive environment for people living with HIV/AIDS.
 - Encouraged and supported (people living with HIV/AIDS) to go public about their status (Education Training Unit, 2005:35).
-
- **Care and support services**

Respondents were asked about care and support services received and in response 12 (25%) children were assisted with home work, 13 (2.1%) received counselling services, Thirteen (27.1) were assisted with grant applications, 5 (10.4%) were assisted with applying for Identity Documents, 3 (6.2%) had memory boxes developed for them and 2 (4.2%) were involved in support groups. Most respondents received care and support services because they are also essential services within the home community based care programme. Counselling services, as well as emotional care and support are an integral part of care and support services within the Home Community Based Care Programme (Russell & Schneider, 2000:110).

Monene (2003:36) is of the opinion that psychosocial support is a creative and sustainable way of reenergizing a child emotionally; as a result the child can re-engage life with hope and confidence and continue to grow and develop in a healthy way.

Psychosocial support should be synergic, meaning it should not interfere with the satisfaction of other needs and should meet a number of needs at the same time. Synergic psychosocial support should enable, empower and motivate a vulnerable child towards appropriate and sustainable interpersonal healing and growth.

Providing emotional care and support to family members of the terminally or chronically ill patient is very important within Home Community Based Care Programs as they provide a substantial amount of the care given to their terminally ill person and they experience considerable emotional strain in the face of this task. Psychological care and support for people with HIV/AIDS, in particular, plays a critical role in assisting people to better understand the need for prevention and to enable them to protect others. Providing counselling support facilitates family and community acceptance of people living with HIV/AIDS (Russell & Schneider, 2000:115).

- **Material support**

The majority of respondents 45 (100%) are receiving food parcels. Material support is high in demand as palliative care services. Orphans and other vulnerable children are provided with food parcels, school uniforms and fees. According to the Social Development (2001:12) the Programmes that support orphans in families should not selectively support these children alone, but in the context of the family.

- **Income generation**

An average of 23 (51%) of respondents were involved in income generating projects. Reasons might be that food gardening is the only income generating activity funded by the Department of Social Development. According to the Department of Social Development (2001:6) there is a demand for income generating programmes for the creation of sustainable income for families who have lost breadwinners and for the unemployed and HIV positive people.

- **Satisfaction of respondents with services provided**

Respondents were asked whether they were satisfied with the services of the Home Community Based Care Programme. All the beneficiaries 45 (100%) were entirely satisfied with the services that were provided. Most of the caregivers spend most of their time with the respondents and are entirely trusted because of the services they provide. This illustrates caregivers' positive attitude and their loyalty towards supporting patients and their families. According to Van Dyk (1999:114) a caregiver involved with helping people living with HIV and AIDS should demonstrate empathy, warmth, congruence, respect and a non-judgemental approach.

- **Responsiveness of Home community based care services to the needs of beneficiaries.**

The study required respondents to assess the responsiveness of the programme to their needs and problems. The majority of the respondents 37 (82%) felt that the services were very responsive to their needs, whereas 8(18%) of them felt services were partially responsive. According to Van Dyk (2001:30) it is less expensive for families to care for someone at home. It also reduces the burden on the caregiver at home in taking care of an HIV positive individual.

- **Rating of the quality of services provided**

Respondents were requested to rate the quality of service of the Home Community Based Care programme. Twenty-six (58%) felt that the services were extremely good whereas 19 (42%) felt that the services were just good as opposed to poor. This might be caused by the fact that caregivers within the Home Community Based Care Programme are providing good quality services to beneficiaries. There is a need to review the quality of care provided by caregivers every six months and the findings on areas of improvement scheduled into a training programme. According to most

respondents caregivers are generous with their time and are willing to spend as much time as is needed with patients or families who need them (Fox et al, 2002:16).

11 CONCLUSIONS

It can be concluded that:

- Households that are visited by caregivers have six to ten members in them, which imply that the food parcels distributed are not enough for the whole family. Most of the respondents had one to two children of their own; this implies that households that were interviewed were extended families.
- The majority of households benefiting from the programme are headed by females and this implies that most of the beneficiaries are women and that women are caretakers of orphans and vulnerable children
- Some of the households are receiving foster care and disability grants and Home Community Based Care food parcels and this implies that these families are benefiting twice from government services, which disadvantages people who are not receiving any services from the government.
- The majority of respondents who are HIV and AIDS infected disclosed their status, which implies that the programme provides a secure environment for people to talk freely about their HIV and AIDS status.
- All the respondents had knowledge of the Home Community Based Care Programme and were informed by Home Community Based Carers. This implies that Carers are a good source of providing information to communities as they are in contact with them on a daily basis.
- Most of the respondents have been receiving Home Community Based Care services for six months to three years which means a small number of people benefit from these services
- Some of the beneficiaries are only visited once a month by Home Community Based Carers and some need to be visited regularly as they are on antiretroviral drugs and need support to comply with antiretroviral treatment. It also implies that some caregivers are not doing what is expected of them. There is a need to standardize services provided to beneficiaries.

- The Home Community Based Care programme provides palliative care services, material support, care and support services awareness and education programmes and income generation in line with the Home Community Based Care programme implementation guidelines.
- All the beneficiaries are satisfied with the services provided by the Home Community based care programme. This implies that the Home Community Based Care services are responsive to the needs of beneficiaries.
- The Home Community Based Care programme offers quality services to people infected and affected by HIV and AIDS. This implies that caregivers that are part of the Home Community Based Care programme play their set role.

12 RECOMMENDATIONS

It is recommended that:

- The organisation ensures orientation of caregivers and subsequent implementation of norms and standards for the Home Community Based Care programme as a means of quality measurement and standardisation of service delivery by caregivers.
- The size of the household is taken into consideration when giving food parcels to beneficiaries to ensure that the basic needs of all the family members are met.
- Regular assessment of services provided by caregivers is conducted to ensure quality control. Caregivers to be allocated patients in the area where they are staying so that they can be able to conduct regular visits to their clients as they might be spending most of their day travelling to clients.
- Caregivers are encouraged to work with Social Assistance to ensure that families that are receiving disability and foster care grants do not benefit from food parcels.
- Programmes are developed for women empowerment to prevent gender-based violence as women end up infected because they cannot negotiate safer sex with their partners.
- The programme needs to make linkages with the antiretroviral treatment sites in order to make easy referrals of the HIV and AIDS full blown patients, to reduce the

number of deaths due to AIDS related illnesses, to reduce the number of children orphaned by HIV and AIDS illnesses.

- The programme ensure paving of a career path for caregivers within the Home Community Based Care Programme to ensure that they are further skilled and trained towards being Social Workers, Social Auxiliary Workers and Nurses as there are bursaries offered by the Departments of Social Development and Health.
- An exit strategy should be developed for beneficiaries who have long been on the programme to ensure that everyone who needs the services also gets an opportunity to benefit.
- The project manager scale up monitoring the activities of caregivers to ensure quality control as services provided by caregivers differ from one caregiver to the next.
- These programmes should be implemented in more areas of the North West Province as they provide good quality services to people infected and affected by HIV and AIDS.
- A programme should be developed and implemented for support of caregivers. Linked to it a personal development plan for each caregiver to enhance service delivery.

13. SUMMARY

The study was conducted in Ikageleng Location in Zeerust at a Department of Social development funded Home community based care centre. Forty five (45) respondents who are beneficiaries of the programme took part in the study. The findings of the study indicated that caregivers who are part of the Home Community Based Care Programme play their set role. The programme is well know in Ikageleng and provides good quality services to beneficiaries. The following services were provided to respondents: palliative care, material support, care and support, awareness and education and income generation. There is a need to establish and fund the programme in all villages and locations in Zeerust.

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Annexure One

ASSESSMENT OF THE QUALITY OF SERVICES THE HOME COMMUNITY BASED CARE PROGRAMME IS PROVIDING TO BENEFICIARIES
BENEFICIARY QUESTIONNAIRE

12.1 Household information

How many people are living in this household?

One – Five	1	Six - Ten	2
Other (specify	3		

What are the ages of the people living in this household including you (beneficiary?)

0-5	1	16-20	4
5-10	2	Adults	5
11-16	3		

What is the main source of support in the your (beneficiary) household?

Income from employment / work	1	Foster care grant	6
Disability Grant	2	Charity / Donations from church etc	7
Child Support Grant	3	Support from family not living in Household	8
Old age grant	4	Food parcels from the Home community based care programme	9
Other government grant / pension	5	Other (specify)	10

12.2 BENEFICIARY DEMOGRAPHIC INFORMATION

12.3 SEX OF BENEFICIARY

Male	1
Female	2

What language do you mainly speak at home?

Setswana	1	Sezulu	3
Sexhosa	2	Other specify	4

QUESTIONS ON THE STATUS OF THE BENEFICIARY

If you are ill, what illness are you suffering from?

Diabetes and high blood	1	Asthma	5
TB	2	None	6
Pneumonia	3	Other (please specify)	7
Cancer	4		

Do you have any children?

Yes	1
No	2

How many children do you have?

1- 2	1	5-6	3
3-4	2	More than six	4

Are there orphaned children in this household?

Yes	1
No	2

KNOWLEDGE OF HOME COMMUNITY BASED CARE PROGRAMME HOW THEY FOUND OUT ABOUT IT

Do you know anything about the Home Community Based Care programme?

Yes	1
No	2

Through which sources did you hear about Home Community Based Care programme?

Health	1	Media	5
Sangoma	2	Social / Youth worker	6
Councillor	3	Contacted by HCBC worker	7
Government Department	4	Other specify	8

THE KIND OF SERVICES PROVIDED BY THE HOME & COMMUNITY BASED CARE PROGRAMME PROVIDES TO BENEFICIARIES

Do you get visits from caregivers?

Yes	1
No	2

How long have you received services from the Home & Community Based Care?

1- 3 months	1		1-3 years	3
6-12 months	2		Other specify	4

How often are you normally visited by a caregiver from the Home & Community Based Care Programme?

More than once a day	1		Every two weeks	5
Once a day	2		Once a month or less	6
Every two to three days	3		Never	7
Once a week	4		Other please specify	8

How many minutes does the caregiver normally spend with you per visit?

Less than 20 minutes	1	Two hours	3
Less than one hour	2	Other(please specify	4

Apart from caregivers who else is taking care of you at home?

Family members	1		Community members	4
Friends and neighbours	2		Health professional, e.g. nurse	5
Religious organisation / leader / congregation	3		Other	6

Have you or your family ever contacted a HCBC caregiver outside the normal visiting hours, e.g. at night or on a weekend?

Yes	1
No	2

Did a HCBC caregiver visit you at your home outside the normal visiting hours when you contacted them?

Yes	1		No visit was required	3
No	2			

If you contacted a HCBC caregiver in an emergency, would they visit you outside the normal visiting hours?

Yes	1
No	2
Don't know	3

Which services do the caregivers provide when they visit you?

Palliative care		Care and support	
Changing of bed-linen	1.	Assisting your children with home work	16.
Rolling to prevent bed sores	2.	Food parcels	17.
Washing yourself	3.	Assisted with applying for an ID document	18.
Exercise (walking/stretching)	4.	Assistance with applying for a disability grant	19.
Advice about foods to eat	5.	Counselling/ spiritual guidance	20.
Going to the hospital	6.	Assistance with grant applications	21.
Help taking medicines	7.	Support group	22.
Help with medical devices / equipment	8.	Memory boxes	23.
Assistance with going to the toilet	9.	Bereavement counselling	24.
Help with housework e.g. cleaning, fetching wood, cooking	10.	Cooked meals	25.
Assistance with eating / drinking	11.	School uniform, fees and second clothes	26.
Awareness and education		Income generation	
Life skills	12.	Involved in food gardens	27.
HIV/AIDS information	13.	Back yard gardening	28.
Nutrition, i.e. what food you should eat	14.	Involved in bead work	30.
Hygiene, i.e. methods of keeping your body and environment clean	15.	Other : Please specify	31.

20. Are you entirely satisfied with the kind of service you receive from the home community based care programme

Yes	1
No	2
Don't know	3

21. If no, why are you not satisfied?

Care givers are not assisting in any way	1
Services offered are not satisfactory	2
Not applicable	3

22. How responsive is your HCBC organization to your needs and problems?

Very responsive	1
Partially responsive	2
Not very responsive	3

23. How would you rate the quality of care / services provided by your HCBC organization?

Extremely good	1
Good	2
Poor	3
Other (specify)	4