Home Based Care for HIV and AIDS Patients: A Case of Rujeko C Suburbs Masvingo Urban Zimbabwe

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Abstract

The study investigated the care of HIV/AIDS patients during home based care. The study was located in Rujeko high density suburb of Masvingo in Zimbabwe. A qualitative case study approach was used to collect data. The population of the study comprised HIV and AIDS patients, care givers and health workers. Convenience and purposive sampling was used to come up with a sample for the study. The sample comprised nineteen respondents. Data were collected through interviews, questionnaires and observation. The study revealed that effective care of patients on home based care was hindered by lack of financial resources resulting in poor provision of essentials like food sanitary facilities and adequate housing. Some of the meals for the patients were not balanced not due to lack of knowledge but resources. It was established by the study that care givers had fair knowledge on the nutritional needs of their patients but required more assistance on patient care on limited budgets. The study also revealed that caregivers and patients preferred home based care to hospital care as at home the patients are usually provided with a loving caring environment. It was evident from the study that there was some support from the community and organisations for home based care. The study recommends that there should be more efforts to support caregivers with resources and projects to supplement their income. The study also recommends furnishing care givers with knowledge on the utilisation of low cost and nutritious food sources and low cost ways of caring for the sick.

Keywords: Home based care, caregivers, primary caregiver, secondary caregiver, support system, bed ridden.

Introduction

Zimbabwe has been hit hard by the HIV/AIDS pandemic since 1982 and there are signs that the impact would worsen (UNICEF 1990). The impact is mainly felt at household level and because of adverse socio-economic factors; most families cannot afford access to private and public health care. HIV/AIDS patients need unrestricted support from their families, friends and communities. (Jackson 2002).

The HIV/AIDS pandemic and the socio-economic environment have given rise to the patients being taken care of at home. National HIV/AIDS Estimates (2003) says that community home based care has emerged as an effective and compassionate care to those affected and infected by HIV/AIDS. Effective community home based care improves quality of life for individuals who are ill and their families. Jackson (2002) shares the same view when he says “dying patients themselves may much prefer to be at home than be in hospital. At home the ill person is surrounded by family and friends.” Jackson (1992) is of the view that dying patients prefer to be with friends and relatives at home rather in the hospital. At home they have access to material support, love, emotional and spiritual care and provision for their needs.

Home based care involves primary health givers and secondary health care givers Primary care givers give support and care to the patients in the home environment. The primary player is the family. The secondary care givers give information and important skills to the family or the primary caregivers. They offer services such as dressings, bathing and nutritional knowledge for the HIV/AIDS patients.

In view of what has been discussed above, the study attempted to examine how the patients were being cared for during home based care.

**Purpose of the Study**

The purpose of the study was to find factors which promote or hinder effective home based care. The study also examined the support systems involved in home based care.

**Literature Review**

Literature was reviewed on support systems on home based care, challenges faced in home based care, HIV/AIDS, exercises and resources and sanitation.

**Support System**

For every programme to be successful, it should be supported. The home based care programme is supported by the government and non governmental organizations. Jackson (2002) propounds that the main response of the government was not only through the Ministry of Child and Health Welfare but various organizations were involved. WHO (2002) established community home based care to poorer communities in response to the growing of the realization of their valuable roles in dealing with the HIV/AIDS epidemic. Jackson (2002) says the National AIDS Coordination Programme appointed community liaison officers for home based care as way back as 1989.
Family support is crucial in the home based care programme. The family is the main player in the HIV/AIDS patient’s life. Jackson (2003) says support from other support groups such as the Non-Governmental Organizations, the government and other organizations vary, but the bulk of day to day care is provided by the family. It is easier for the family to provide care and support and also being at home reduces the health care cost as well as movement to and from the hospital.

The chief player in home based care is the care giver because he/she is the one who looks after the terminally ill at home. Zimbabwe National Community Home Based Care Guidelines (2001) states that the caregiver plays an important role by providing basic care to the HIV/AIDS patients. For effective care of patients on home based care, the care giver needs training to maintain hygiene, increase the patient’s comfort and provide appropriate food which is required by the body for a balanced diet. A properly trained caregiver who is aware of the patient’s health status knows what to do and will have less problems in providing the patient with adequate care, (Jackson 2002). Women’s Action Group (2002) says caregivers sometimes feel stressed and emotional because their best efforts may not effect any change. This is because some care givers may not be knowledgeable about the disease and how to properly handle patients.

Zimbabwe National Community and Home Based Care Guidelines (2001) believe that care givers should also be cared for; they need appropriate technical supervision and psychological support to prevent stress and burn out. Caregivers should have enough rest and should eat good food to keep their own good health.

Zimbabwe National Community and Health Based Care guidelines(2001) says that the care givers need support, encouragement and acceptance from their community members as motivation to care for patient’s without fear of being isolated. This protects caregivers from the social isolation and stigmatization.

Jackson (1992), advocates for the community based initiatives to provide the necessary support for home based programmes. The United States Agency for International Development (USAID 2008) point out that the delivery of effective care and support can make a significant difference to patients and communities involved.

### Challenges Faced in the Provision of Home Based Care

#### Care Giver Nutritional Knowledge

A healthy diet is very important for a person living with HIV/AIDS on home based care. According to Lesotho (2000) good nutrition is a life long process and malnutrition increases the severity of HIV/AIDS related diseases. Malnutrition can impair organ function but can be reversed if caregivers have adequate nutrition knowledge. In a supportive community, stigmatization and discrimination of the infected and affected is reduced. In support Mandizha and Chiutsi (1995) point out that people should be taught the values of food because healthful
food retards the progression of HID/AIDS and also improves the health status of the patient. FAO (2002) says that nutrition intervention is important since it reduces chances of malnutrition in patients.

To be healthy, a patient on home based care should be provided with a balanced diet. According to Guidelines to Dietary Management (2004) a balanced diet provides the right food in the right amounts and combination. This means the diet should contain adequate amounts of; proteins, carbohydrates, fats, mineral elements and vitamins. Healthy food and a clean environment help increase the quality of life of patients. Authorities go on to say that good nutrition improves the performance of the immune system of patient’s on home based care. The authorities recommend a six meal pattern as this provides small frequent meals since the appetite might be low.

Most nutritional needs are met by eating a variety of foods which provide carbohydrates, fats, proteins, mineral elements and vitamins. Carbohydrates provide energy for physical activity (Bonnie and William 2002). Patient on home based care who doesn’t have protein in their diet may waste away and oedema may develop in HIV and AIDS with TB, (Baker 1999, Anderson 1997). There might be a high mortality rate in a malnourished home based care patient because of lack of proteins in the body. This results in failure to produce antibodies. Patients on home based care need carbohydrates for energy.

Mineral elements and vitamins are essential for maintenance good of health especially when someone is suffering from ill health. For patient’s on home based care to enjoy a certain level of health in the condition they are in, nutritional education should be promoted and adopted for good nutritional practices (ADRA Zimbabwe 2011).

Resources

The patient gets malnutrition when the caregiver fails to provide sufficient nutrients. If caregivers have limited resources they face problems in providing a balanced diet, a sanitary environment and adequate living space. Jackson and Mhambi (1992) observed that caregivers were taking care of patients in an unhealthy environment e.g. living with a big family in a squashed space. Sometimes a family would be sharing a room. Baldwin (1990) says that the size of the dwelling should fit the number of occupants to avoid overcrowding.

The public health authorities’ need to ensure proper sanitation refuse collection and clean streets to provide a sanitary environment for families. Failure to provide proper sanitation for HIV and AIDS patients may lead to diarrhea and death. Madden (1989) views healthy housing together with clean water, proper food and clothes as basic human requirements.

According to Jackson (2002) for a family to cope with currently terminally ill patients at home they need improved access to a variety of resources. In home based care both material and human resources are required. Women’s Action Group (2002) notes that caring for someone whose mobility and bodily functions have deteriorated can place great demand on the health of
the care giver if the work load is more than one person can provide. Jackson (2002) says that lack of support from other family members was found to be a significant factor in the overburdening of caregivers. Taking care of HIV and AIDS patients without adequate support places huge demands on care givers; affecting their mental and social health often resulting in mental and physical collapse.

Non human resources are also important when caring for HIV and AIDS patients especially at the bed ridden stage. Jackson (2002) points out that it is a serious risk to be in contact with an HIV and AIDS patient’s bodily fluids such as vomit, blood and stool because this will increase the risk of caregivers being infected by the virus. The risk is made worse in areas where there are poor sanitation facilities and where no precautionary measures are taken such as wearing gloves and using bleaches. This may cause caregivers to be infected hence there should be provision of education and resources to equip care givers.

Caring for patients in home based care needs dedicated support from the relatives, the community, the government and other organizations to be successful. For the successful implementation of the home based care programme for HIV and AIDS patients, challenges of resources and knowledge of nutrition need to be addressed.

Exercises

Insel and Roth (2008) note that nutrition and exercise are two of the most important things HIV and AIDS patients need to improve their health. In order to stay physically fit a balanced diet and exercise are needed by the body.’ Insel and Roth (2008) say exercise improves one’s wellness, emotional and psychological well being as well as boosting the immune system. However it is noted from literature that it is difficult to motivate a sick person to do exercise.

Methodology

The descriptive survey design was used to conduct the research. Sidhu (2003) refers to a descriptive survey as an investigation technique which concentrates on describing and interpreting the existing phenomenon in the form of process perception and beliefs. Marimba and Moyo (1995) define a descriptive survey as a systematic description of salient aspects of phenomenon, object or situation with a focus on the patterns that emerge. The researchers used the descriptive survey because it allowed the researchers to collect data on how HIV and AIDS patients during home based care in Rujeko C high density suburb in Masvingo Zimbabwe.

Population and Sample

The target population comprised of 18 families with HIV and AIDS patients who were receiving home based care. The study excluded other home based care patients who were not suffering from HIV and AIDS e.g. the elderly or cancer patients. The also population included four state registered nurses, seven health care workers from the local clinic.
The sample for the study comprised 8 caregivers with their respective HIV and AIDS patients and two health workers and the nurse from the local clinic. A total sample of nineteen informants was used. The sample of nineteen was considered reasonable. Leedy (1997) says a small sample is considered reasonable since data collecting procedures for qualitative research are time consuming.

The researchers used purposive sampling to come up with six patients. The basis of selection was condition of patient and living conditions. Two patients selected were bedridden and could no longer feed themselves, four other patients could move but only with assistance, these also needed to be bathed and needed supervision when feeding. Two children on the home based care survey showed signs of malnutrition. The presented patients illustrated different degrees of illness. The caregivers of these patients automatically became part of the sample. Convenience sampling was used to select the two health workers who were available at the time the researchers went to the clinic. Purposive sampling was used to select the nurse in charge of the clinic.

Data Collection Methods

Data was collected through interviews, observation and questionnaires. This helped in the triangulation of data collection methods (Nyarawanda and Vakalisa 2003).

Interview

The researchers interviewed the nurse in charge, caregivers and patients. The interview involved direct, personal contact with the participants (Best and Khan 1993). Through direct contact, the researchers gathered data on what the respondent’s value, think, like and feel about the home based care programme. Semi structured interviews were used to allow probing and provide room for respondents to express themselves.

Observations

Marshall and Rossman (1989) say observation entails a systematic description of events, behavior and activities in the social setting selected for study as seen by the researcher. The observation method assisted the researchers to see for themselves as opposed to being told what the case was like concerning the care of HIV and AIDS patients on home based care.

Data Collection Procedures

The researchers first of all visited the Rujeko clinic to interview the sister in charge in order to establish/identify households with HIV and AIDS patients on home based care. The researchers then visited the sampled families. The first visit was a familiarization visit. The second visit to the clinic was to process the questionnaire for the health workers. The subsequent visits were to interview care givers and to observe how the patients were being taken of i.e. feeding, living conditions, communication between patient and care giver.
Data Presentation and Analysis

Data were presented and analysed narratively basing on the themes which emerged.

Finds and discussions

The research findings were organized into themes which emerged

- Nutritional knowledge
- Resources
- Support systems

Nutrition and HIV and AIDS

One of the themes which emerged centered on knowledge of nutrition for HIV and AIDS patients by caregivers. Care giver knowledge is very important for the good health of the patient (Jackson 2002, Adra 2011). It was observed from the study that most of the caregivers were knowledgeable on the nutritional needs of HIV and AIDS patients. The findings showed that the main challenge was not lack of knowledge but inadequate resources that hindered the provision of the right diet for HIV and AIDS patients. This was evidenced by some of the responses from the interviewed caregivers who said “I know that my son needs a balanced diet but I do not have any form of income. My son was the breadwinner but due to illness he now needs to be cared for”. Another caregiver had this to say “I give my patient only available food, due to economic hardships. My patients’ health status is being worsened by lack of nutritious food. He needs to also have proteins but food like meat is expensive.” Poverty is a contributory factor to poor nutrition (Jackson 2002).

Judging from the above statements, caregivers have the knowledge of nutrition for HIV and AIDS Patients but lack the resources. The care givers are aware that good nutrition forms the backbone to good health (Williams 1992, Chiutsi and Mandizha 1994). Nutrition is an essential tool for prolonging lives of HIV and AIDS patients, Drugs work with good nutrition to improve the health status of a sick person. Good nutrition can slow the progress of HIV and AIDS (Lesotho 2000). As one of the respondents pointed out “balanced food is important in improving the health of an ill person. Medicine on its own without food does not work”
<table>
<thead>
<tr>
<th>Patient</th>
<th>Breakfast</th>
<th>Morning Tea</th>
<th>Lunch</th>
<th>Afternoon tea</th>
<th>Supper</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Movite porridge</td>
<td>Tea with milk and sugar beans brown bread boiled egg</td>
<td>Sadza, stewed beef, boiled green leaf vegetable. Maheu drink</td>
<td>Honey and cinnamon drink, bread with margarine, apple</td>
<td>Roast potatoes and chicken, lettuce salad, banana</td>
</tr>
<tr>
<td>2</td>
<td>Peanut butter mealie meal porridge</td>
<td>Tea and bread</td>
<td>Sadza and sour milk</td>
<td>maheu</td>
<td>Sadza and fried green vegetables</td>
</tr>
<tr>
<td>3</td>
<td>Sour porridge</td>
<td>Tea and bread</td>
<td>Sadza and soya chunks stew</td>
<td></td>
<td>Rice and potato and tomato stew</td>
</tr>
<tr>
<td>4</td>
<td>Plain mealie meal porridge, tea and bread</td>
<td>maheu</td>
<td>Sadza and lacto(sour milk)</td>
<td>Tea and scones</td>
<td>Sadza and stewed fish</td>
</tr>
<tr>
<td>5</td>
<td>Left over rice and milk</td>
<td>Tea and bread</td>
<td>Sadza and stewed beans</td>
<td>Drink and bread</td>
<td>Macaroni and stewed mince, orange</td>
</tr>
<tr>
<td>6</td>
<td>Mealie porridge with milk</td>
<td>Scrambled eggs, plain bread and cocoa</td>
<td>Mashed potatoes and stewed fish, fried rape</td>
<td>Fruit drink and biscuits</td>
<td>Fried liver, boiled rice carrots and green beans</td>
</tr>
<tr>
<td>7</td>
<td>Sour plain porridge</td>
<td>Lemon tea and plain bread</td>
<td>Sadza and stewed okra</td>
<td>Banana</td>
<td>Sadza and boiled meat</td>
</tr>
<tr>
<td>8</td>
<td>Tea and bread with peanut butter</td>
<td>Sadza and boiled green vegetables</td>
<td></td>
<td>Maheu</td>
<td>Rice and stewed beans</td>
</tr>
</tbody>
</table>

The study revealed that both patients and care givers were aware of the nutritional needs of HIV and AIDS patients. They were generally educated on the important of a balanced diet constituting a daily intake of carbohydrates, proteins, vitamins and fats. As one caregiver pointed out “I have all the necessary knowledge on nutrition. I know that my patients needs body building food e.g. meat, eggs, food for protection like fruits and vegetables and energy from food like sadza. My problem is not ignorance but where to get the food. The care givers
have knowledge on the dietary requirements of their patients from teaching by health personnel (Chiutsi 1995, FAO 2002)

**Table 2: Data on Food Group Sources**

<table>
<thead>
<tr>
<th>Food groups</th>
<th>Observation</th>
<th>Interview</th>
<th>Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Body building</td>
<td><strong>Backyard butchery</strong> (rabbits, chickens) <strong>Market</strong> (variety of meat e.g. beef, chicken, fish, beans, macimbi (Mopani worms), soya meat, milk (fresh and sour) cheese, matemba, dried vegetables) <strong>Garden</strong> (beans)</td>
<td>Care givers and patients were aware of the sources of protein in their community e.g. meat, eggs, fish, beans, milk. They were also aware that they can use traditional foods like macimbi, harurwa, for protein.</td>
<td>On filling the questionnaire the health personnel indicated that care givers were taught sources of protein including exotic sources e.g. macimbi, harurwa, crickets and exotic, like chicken, pork. They were also educated on beans being a substitute for meat.</td>
</tr>
<tr>
<td>2. Protective</td>
<td><strong>Nutrition gardens</strong> (carrots, tomatoes, green vegetables) <strong>Market</strong> (oranges, guavas, apples, bananas, green mealies, carrots, cabbage, tomatoes, butternuts, indigenous fruits e.g. matamba, matohwe)</td>
<td>Generally the care givers and some of the patients realized that vegetables and fruits provide for protective materials however some said they did not have enough space or time for vegetable gardening. Providing fruits was expensive. They indicated that indigenous fruits are not sometimes appreciated by ill persons. Some of them like matohwe are difficult to chew.</td>
<td>The health personnel indicated that protective food could be boosted by gardening. However most household did not do much gardening if at all. The limiting factors were mainly space, and time. Patient care took most of carers’ time. Care givers were made aware of sources of vitamins and mineral elements.</td>
</tr>
<tr>
<td>3. Energy</td>
<td>Mealie meal, rice, potatoes, maize, nuts, pasta, wheat meal <strong>Cooking oil</strong>, margarine.</td>
<td>All respondents did not have problems with energy sources as these were cheap to purchase for example mealie meal is much cheaper</td>
<td>The health personnel generally agreed that sources for energy were not a problem. Sometimes the patients are given too much</td>
</tr>
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</table>
than meat. The patients were given high carbohydrate content diets. Energy food at the expense of other food groups. The main reason of relying on energy is that these are cheap and households grow their own maize and sweet potatoes.

The findings show that food is available to cater for all the food groups but most household with home based care patients cannot afford (Jackson and Mhambi 1992). One care giver pointed out that, “There are plenty of food stuffs nowadays on the market. What counts is your money”.

A balanced diet plays a vital role in the body failure to get required nutrients will result in malnutrition. Guidelines on Dietary Management for People Living with AIDS (2004) notes that provision of the required nutrients in sufficient quantities insures good health and normal body functioning such as growth development and maintenance of immune system. A balanced diet can be achieved by taking a variety of foods representing the different food groups. The findings showed that protein provision was problematic in most households. The reason put forward was that protein foods were expensive. However protein provision is important to prevent wasting away (Baker 1999 and Andersen 1997).

Resources

Responses from the interviews and questionnaires showed that in some households, shortage of resources was a problem. This was also observed by the researchers during home visits. From the research findings it was noted that about 3/4 of the caregivers had problems of resources.

From the responses, it was noted that some caregivers were finding it difficult to care for patients especially where one was handling a bed ridden patient. This was reflected in the interview where one respondent said “I do not have any sources of income and as result resources are a problem. At times I wash spoiled linen with running water without soap or bleaches” another respondent had this to say about resource scarcity “I am having a hard time, my patient is bed ridden and there are no resources such as enough soap for washing. I use plastic papers as gloves when handling bodily fluids” Care givers are at risk of contracting HIV through contact with the patient’s body fluids (Jackson and Mhambi 2002).

From the responses given most of the care givers have problems of resources and food for taking care of people with HIV and AIDS. For a family to cope with a patient on home based care, they need improved access to a variety of adequate resources (Jackson 2002). The resources are essential for achievement of the goal of proper care of the ill person on home based care.

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Money as resource is essential for effective care of patients on home based care. The findings reflected that most households with patients on home based care had financial problems. Home based care requires a substantial amount of money for successful implementation in order to cover medication, food, shelter and other needs. The following statements reflect problems with finances “I do not have any form of income except that at times I sell firewood and vegetables but this is not enough to cover all the requirements for caring for the patient and my family. I need money to buy the much needed items for sanitation”. Another care giver said “if only we had enough money, our situation would be better” money is needed to cover what is needed to protect care givers from contact with body fluids (Jackson 2002). Caring for someone whose morbidity and bodily functions have deteriorated can place great demand on the health of the care giver hence more human and non human resources are needed (women Action Group 2002). Healthy housing, clean water, proper food are essential in ill health to improve the health status of a patient (Madden1989).

Support system

The findings indicate that there are quiet a number of support systems that help those on home based care. These include the government through the Ministry of Health and Child Welfare, non governmental organizations, churches and other independent groups.

These supports groups appear to be quite helpful. One respondent was quite appreciative of the part played by support systems by saying “If it was not for the help I get from my support groups, I would have collapsed way back. Because of poverty. I am receiving help especially from Action Faim and Hope Tario”

However it was noted from the findings that although the home based care programme was supported by government and Non governmental organization, the support is not adequate to cover what is needed. It is the poorer families who are badly affected as propounded by (Jackson 1992). The assistance needed is in form of resources, skills and knowledge to avoid unnecessary loss of lives.

The findings shows that support system provide different forms of assistance. The assistance could be provision of material resources. One respondent showed her appreciation of support system when she said “I am very thankful for the assistance I am getting from support groups such as Action Faim, Red Cross, National Aids Council and churches. These groups are providing food, clothing and knowledge for caring for our loved ones”.

The research has also shown that support groups provide social and moral support to care givers and patients. One respondent said “I get confidence from other people I meet such as the support groups for HIV and AIDS counseling Trust, National Aids Council and Hope Tario” another respondent appreciated the counseling services provided “There are some volunteers who visit me and do some counseling on positive living”.

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It was noted from the research that support systems are helping with knowledge on caring for the home based care patient. Action Faim has introduced some boreholes so that when there is no shortage of water in the area, households can get clean water. Most of these boreholes are located in nutrition gardens. As one respondent said “Nutrition gardens are meant to help caregivers to get nutrients needed by patients from the garden produce without being worried”

The support groups provide the care givers and patients with emotional and psychological support as was indicated from the findings “support groups are very important. They provide us with emotional support. In a support group you can open up and talk about the problems you are facing with people who understand what you are faced with” another respondent said “In a support group you are able to talk about your hopes and fears to people who understand your problems”. Support groups provide care givers with emotional, social, psychological and material support (Zimbabwe National Community and Home Based Care Guidelines 2001).

However from the findings it was evident that support systems did not provided all the necessary support. One of the community health workers who was interviewed said “I wish Government could inject more through other organizations because patients are dying due to lack of proper care resulting from shortage of resources”.

Conclusions

A number of conclusions were drawn from the findings

It may be concluded from the findings that most of the care givers and HIV and AIDS patients have knowledge on nutritional requirements. However provision of a balanced diet for some of the patients was negatively affected by lack or limited resources. This resulted in some patients having mostly carbohydrates in their diets lacking proteins, vitamins and mineral salts.

In the case of resources it may be concluded that some of the households with home based care patients had limited resources. The lack of or limitations in resources had negative effects on the care of some patients. In some households there was inadequate living space, sanitation facilities and nutritious food. Limited resources militated against provision of a conducive environment for the care of HIV and AIDS home based care patients.

From the research findings on the aspect of support, the conclusion is that, the home based care program is supported by government, community and non Governmental Organisations. This support is in form of resources, education on care of patients, and emotional, and psychological needs of both care gives and patients. However the support given is not adequate enough to cover the needs of families with low income.

Recommendations

• Exposing caregivers to knowledge on the preparation of dishes using low cost food e.g. soya chunks, indigenous vegetables
• Care givers should make greater efforts of providing patients under their care with balanced diet by exploiting cheaper sources of nutrients e.g. indigenous and low cost foods like beans, matemba, and macimbi.
• Care givers should augment their resources through gardening and keeping of small livestock.
• The government should increase its material contribution towards the care of HIV and AIDS patients on Home based care especially from low income households.
• A similar study be conducted in a rural setting to see how home based care is managed.

References

Zimbabwe National Community Home Based Care Guidelines (2001)