

Social Costs and Benefits of Community Home Based Health Care (CHBHC) Delivery System in Roma Valley, Lesotho

Emeka E. Obioha* and Mots'elisi Matsela**

*Department of Safety and Security Management, Tshwane University of Technology,
Private Bag X680 Pretoria 0001, South Africa
Email: eeobioha@yahoo.com*

***Department of Social Welfare, Ministry of Health and Social Welfare, Maseru 100, Lesotho*

KEYWORDS Community Health, Sustainability, Voluntary Care, Challenges, Southern Africa

ABSTRACT. This study investigated the costs and benefits of community home-based caregivers in Roma Valley Lesotho. It made use of a population that consists of health professionals at St. Joseph hospital, village chiefs and caregivers in the villages, from where a sample size of 20 interviewees was selected to respond to the interviews. The study revealed mixed feelings of costs and benefits from this unique health care system on the care givers, the care recipients and the relatives of the care recipients. While the care givers are happy that they contribute to their society, their services also present some costs to them and their family. They experience challenges, which include disputes with their families due to non-remunerated work that they do. Emerging from the findings, this study suggests formulation of a social policy that will govern the system and other government's political and material supports to sustain the programme.

INTRODUCTION

Community Home Based Health Care is not a new phenomenon in Lesotho. It was the only method used to provide care and support to sick people before the colonization and westernization of the country. After colonialism, new institutions emerged such as the schools, hospitals and others which have taken the role of the family from taking care of their sick members in their homes to hospitalization in various care institutions. Due to the increasing number of HIV/AIDS patients and patients of related diseases such as tuberculosis, cancer and many others there is a large number of people queuing at health centers for health services, which has caused congestion in such institutions (emphasis, mine). This results to shortage of medication, beds and staff members such as nurses and doctors in the hospitals that cause poor provision of health services. Hence Community Home-Based Health Care (CHBHC) came up as an intervention measure where patients are taken care of at their homes and through community action.

According to Van Dyk (2001), Community Home-Based Health Care is the care given to

individuals in their own homes when they are supported by their families, their extended families or those of their choice as members of a community. Home-Based Health Care assumes community action when units of community such as nearby hospital, spiritual leaders, traditional healers and professional such as social workers, counselors, and nurses and volunteers work on an integrated perspective to care for patients in their own home environment. (Burke and Laramie 2000:578). It is evident from culture and community based perspective that home care giving was not strictly a social and health issue, it was simply the way people respond to dependent family member during sickness. Nonetheless, HIV/AIDS has prompted demands on the community and society that cannot be met by hospitals alone. Families, loved ones and the community therefore have indispensable role to play in support and care of individuals with HIV/AIDS, Orphans, and other categories of chronically ill including the elderly (Burke and Laramie 2000:501). In ideal circumstances, family community care-givers are supported by a multi disciplinary team that can meet the specific needs of the individuals living with HIV/AIDS and others in critically ill health conditions (Van Dyk 2005:260). She further contends that community home based care programmes are meant to empower the community and families to cope effectively with the physical, psychosocial and spiritual needs

**Address for correspondence:*

Professor Emeka E. Obioha
Department of Safety and Security Management,
Tshwane University of Technology,
Private Bag X680 Pretoria 0001, South Africa
E-mail: eeobioha@yahoo.com

of those living with HIV infection and AIDS and others with other ill health conditions.

Community Home-Based Health Care team is descriptively a community oriented or team that composed of different categories of people with diverse skills and exposure in social and health areas, which is meant to provide patients with care at social, health, spiritual, emotional and psychological level. However, in most third world countries including Lesotho home care is not provided at all necessary levels as it should be in ideal sense. Hence, a number of problems confront the caregivers in this system as it functions as an important component of health care delivery in the country. The need for community home-based health care delivery system in Lesotho is eminent in the glaring rate of HIV/AIDS infected and affected people in the country, which has brought the need for every Mosotho in the communities to help such categories of people to meet their daily needs of survival at a very minimal cost. This situation calls for community action to support such people and their families, as Van Dyk (2005:260) evinced that the AIDS pandemic has left behind millions of orphans and other children made vulnerable by HIV/AIDS in Africa. Specifically in Lesotho, there is a fast growing rate of orphans¹ observed in various parts of the country at present, which is largely as a result of HIV/AIDS pandemic.

With the prevailing general poor health conditions of many and the compounding problems associated with home care, Nyanguru (2003) observed that most home care givers for Orphans and Vulnerable Children (OVC) and HIV/AIDS patients, under CHBHC are poor and vulnerable too. Besides, quite a large number of these caregivers are old and frail, with little or no other opportunities to sustain a comfortable living. The fact that these groups of people who render their services for the benefit of their community members are poor does not preclude the fact that there is an opportunity cost on them in terms of other activities that should be, *viz-a-viz* their care for the sick. In other words, participation in community home based health care has both social cost and implication on the care providers. However, there may be seemingly other calculated or expected benefits that the participants in this care obtain from their services. The question then lies on the balance between the costs and benefits of providing community home

based health care in the selected communities of Roma Valley in Lesotho, which is the main objective of this study. The study specifically articulated on the operational modalities and objectives of Community Home-Based Health Care services, the individual and personal problems during care provision and the possible solutions and the way forward regarding Community Home Based Health Care in the area of study specifically and the country at large. Major questions considered as the guide in the study include: What are the operational modalities of Roma Valley Community Home-Based Care Organization (RVCHBCO)? What are the objectives of the organization? What are the personal and other problems encountered by the caregivers during service? What are the economic problems encountered by the caregivers during service? What are the social and economic benefits received by the caregivers? What are the possible solutions to the problems and a way forward?

Understanding Community Home Based Health Care System through the lens of Functionalist social theory

The functionalist theory is rooted in the writings of Spencer and Durkheim and the work of scholars such as Parson and Merton in sociology and those of Malinowski and Radcliffe Brown in the British School of social anthropology. Functionalist theory views society as a system of highly interrelated parts that function or operate together harmoniously (Tischler 2000:20). Functionalists analyze society by determining what each and different part contributes to the smooth functioning of the whole in a belief that integration is the fundamental direction in which all society tends. From the functionalist perspective, society appears quite stable and self-regulating, though very broad theory that attempts to account for the complicated interrelationships of all elements that make up human societies. Lee and Newby (1990:262) pointed out that the common denominator of all versions of functionalist theory is the expectation that whatever adjustments and changes that occur in social behavior and organizations, there is a set of basic underlying pressures which work towards the maintenance of stability, the coordination of activities and even the conformity of individuals with the life of the group.

Therefore, one could view the functionalist perspective as capable of explaining the coordinated work of community home based health care givers. The care givers carry out their care provision work with support from the care system units more especially professionals such as doctors, nurses, social workers and counselors functioning through a multidisciplinary approach. In the running of the care giving system, there are often problems encountered as a result of deficiencies and changes and this adversely affect the work of the care givers on the ground. Similarly, as the functionalist theory emphasizes some adjustments and adaptations a society should develop for harmony with changes, community home based health care units ought to adapt to changes so as to maintain the essence of the care-giving system. Therefore, the more successfully the care system adapt to changes or problems, the more the care givers would effectively and efficiently carry out their work.

Another theory that could be used to explain how the community home based care system operates especially with regard to constraints that are imposed on the caregivers in the process of their service is the role strain or role conflict theory, which is rooted in Merton's classical writings. The role conflict refers to a kind of role problem which occurs when an individual is expected to perform one role with built-in inconsistencies or two roles that are incompatible (Federico 1979:114). This theory views some role strains not as a result of a lack of clarity in role definition or incomplete socialization; rather the problem is simply that the role itself does not work. According to Kendall (2000:139), when role strain occurs, individuals feel pulled in different directions which sometimes can be attributed not to the roles themselves but to the pressures individuals feel when they do not fit into culturally prescribed roles. Based on this proposition, women experience role strain because they are expected to perform multiple roles in the society as mothers, wives, daughters-in-law and as well as the caregivers, for example. Achieving, performing and success in definite or defined roles do not imply absence of strains as Kendall (2000:139) pointed out that success in one area may create difficulties in the other, which may result to guilt and frustration. Federico (1979) indicated that many women today have become increasingly

torn between their traditional obligations to family and the options that are becoming available to them as a result of gradual equalizing of opportunities for both sexes. Gender socialization in the society has taught them that they should respond to often times conflicting demands of being a wife and mother, yet they may desire or need to help with family finances to express their individuality. Interestingly, most of the care givers in the community home based care system in Lesotho are women whose lives and activities descriptively fit into the theoretical postulations of the functionalists and related theorists in the social theory.

RESEARCH SETTING AND METHODOLOGY

This study was carried out in Roma, confined to a covering territory called Roma valley. The name Roma valley as it suggests corresponds with the topographical outlook of the area, where there is a group of 16 villages that are found at Roma region, located between two ranges of plateaus such that the location assumes the shape of a valley. In Roma valley, the concept of Community Home Based Health Care was initiated in 2001, with the purpose of caring for HIV/AIDS patients as to alleviate burden and pressure on health professionals at the local hospital and clinics. The Community Home Based Health Care establishment at Roma valley was facilitated by Lesotho Catholic Bishop Conference, and professional back up from St. Joseph's hospital located at *Ha-Mafefooane*, one of the settlements in the valley. The Community Home-Base Health Care team comprises of group of nurses, doctors, HIV/AIDS patients, a social worker, a counselor, catholic pastors and women who are caregivers from various villages in Roma valley. The population for this study therefore includes the health professionals at St. Joseph hospital who are members of the Roma Valley community home based care, the village chiefs and women who are caregivers at Roma valley villages. The study utilised a purposive sample that consists of 20 individuals drawn from different sections of the community home based health care team (Social Worker, Care givers, Nurses, Patients/Clientele and Village leaders). Community home based health care system consists of various units that could not be easily accessed collectively. The snowball

sampling fits well in this study since the identified caregiver were asked to help locate others.

The study which was carried out in 2009 made use of oral interviews as the main source of data. In this regard, in-depth interview guide was used to obtain information from Health professionals as members of Community Home Based Health Care organization and from individual care givers, village leaders and patients at their own homes. This technique was advantageous because interviewees are able to express their feelings as much as possible. The method is also flexible and allows a researcher to probe as much information as possible (Sarandakos 1998:42). Similarly, Focus Group Discussion guide was introduced as the instrument to collect data from the caregivers during the team's monthly meeting as arranged with the team coordinator. Group discussion is primarily a way of gaining information in a short period of time about the breadth or variation of opinions. This technique assisted the researcher to get information about group processes, spontaneous feelings, reasons and explanation of attitudes and behavior as adequately as any other methods as alluded by Sarandakos (1998:182), which was exactly the case the present study.

RESEARCH FINDINGS

Purposes and Operational Modalities of Community Home Based Health Care

Undoubtedly, the main purpose of the Community Home Based Health Care is to provide health services at homes by certain people called Village Health Workers or Support Group Members together with the relatives of the sick people but the extent to which this intention radiates in reality is the main question that was interrogated in this study. This system further aimed at reducing the rate of HIV/AIDS infection through campaigns that are held by these trained community health workers for the community members. These campaigns are held with the aim of informing the community members about HIV related issues as many people continuously die of HIV/AIDS related illness due to ignorance. These campaigns focus more on the people of reproductive age category because of the apparent high rate of HIV infection among these people.

Precisely, Community Home Based Health Care also enables the relatives of the patients to

take care of them when they are sick due to the acute shortage of facilities such as wards, beds, medication and staff in the health centers. It has become apparent that patients do not receive adequate care that they expect from the health centers, which has necessitated the health centers to shift or delegate care services from institutions to homes. However, it should be stressed that the health centers do not necessarily push the burden of professional care to the community members because when the patients are very ill or deteriorating in health they are taken to the hospitals to consult with the Doctors and other health professionals. This community care practice and model essentially point to the responsibility of the community to take care of the sick members. This idea was reechoed in the response from the hospital social worker who said:

"This shows that it is not only the responsibility of the nurses and doctor to take care of patients but also the responsibility of community members to look after their sick relatives."

Trainings and workshops are held for community health workers and members of support groups, which aim at providing them with basic skills in caring for the patients of different illnesses. They are also being taught the basic diagnostic criteria and symptoms of some common diseases such as HIV/AIDS and tuberculosis and how they could best deal with them and also protect themselves from being infected during care provision.

Individual and Personal Difficulties and the Challenges for the Caregivers

There are numerous personal psychological, social and economic difficulties and challenges on the caregivers in the process of rendering their services to the sick and poor as was found among this group of people in Roma Valley. Specifically, the psychological problems that could be encountered by the caregivers in the course of their service to the sick and poor in their respective homes in the communities were revealed in this study. The study found that caregivers usually suffer from psychological problems such as stress and depression that result from caring for the patients. Some interviewees pointed out that the patients' often moody, uncooperative and hostile response usually triggers stress on the side of the caregivers.

This stress and frustration is usually worse when they are caring for patients from poverty stricken families who have nothing to eat before taking their medication. This is further compounded by the fact that the caregivers and their families also do have enough for at home because most of them are neither employed nor work in any remunerative industry. Most of the caregivers were of the opinion that it has been stressful and practically discouraging to take care of poor, hungry and sick persons. This was confirmed by the statement of one of the caregivers who said "...how can one be strong enough to look after angry and hungry- sick people when they are hungry too?"

Socially related problems encountered by caregivers during their service are those aspects that touch on their human relationship, well-being and personal worth. The caregivers are in consonance that their relationship with family members are in jeopardy and therefore not good because they are accused by their family members of spending most of their time away from home either on trainings or caring for sick people. They do little or nothing in their respective homes because they work very hard to take care of the sick yet they are not paid. Unfortunately, the social relationship between them and their neighbours and the relatives of the patients are also not in good shape. One discouraging but common observation is when relatives of patients hide the sickness of their family members for a long time until the situation becomes very critical and more difficult to manage. The study revealed that some caregivers are not accepted by the relatives of the patients even when the patients need to be visited by the caregivers because these relatives feel undermined by the caregivers' intervention and care. This is coupled with the frustration that caregivers hardly manage to reach patients in far communities where there are no Village Health Workers, as it was the case during "Know Your Status Campaign" (KYSC) when some villages and their members could not be reached for sensitization and HIV testing.

Besides the challenges encountered from the home front of the caregivers and the relatives of the sick, the caregivers were found to be entangled in a relationship problem with the community leaders and local chiefs. The study revealed that some chiefs hardly support or cooperative with the caregivers especially when it

comes to the issue of public gatherings (locally known as *pitso*). The uncooperative attitude of the chiefs stems from the observation that there are so many Support Groups getting back ups from different organizations, which had left them being confused on which groups or who are truly members of approved or legitimate support groups. The reality of this situation manifests in the number of uncoordinated groups that participate in this home health care delivery system in Roma valley. Most of these groups were found to have little or nothing that brings them together, even though they all target and work in the same population.

Interestingly, another imminent source of challenge was the outcome of HIV testing by most community members who wished to test HIV positive. The investigation revealed that as HIV positive people receive food packages, positive rather than negative HIV test outcome brings short term relief for most poor community members in the form of free food packages that are distributed to those found positive. The study confirmed that some community members especially, those who are poor test for HIV with the intention of having a positive outcome because of the expected benefits given to HIV positive people. Hence, some poor people who tested negative to HIV develop negative attitude towards Community Home Based Health Care givers as they do not receive food packages because of their negative HIV test outcome.. They often grudge that the caregivers use them to get benefits in their names or that the caregivers dishonestly did not pronounce their status as positive, even when they know that they are HIV negative.

Individual and Personal Psychosocial and Socially Related Problems of the Care Recipients

Like the caregivers, the care recipients' position in the network of community home based health care delivery system is one that is descriptive of some encapsulated personal psychosocial and socially related challenges. Some of the care recipients (the sick) explained that in some cases when they need medication, such as pain killers, disinfectant and other necessities which are supplied from the health centres through the caregivers, they are usually told that such medications are either finished or not avail-

able. This controversial but suspicious angle in itself makes Community Home Based Health Care system appear unreliable and nonresponsive to the needs of the patients, which leaves the patients more depressed and neglected. Some of the care recipients reiterated from their experience on what goes on in the system, which invariably leaves them depressed. According to one of the care recipient

"When we are discharged from the hospital, the nurses would inform us that we would get some caring items from community health workers who would all the times tell us that those items are finished. Really I, myself find it better to go back to the hospital or else I would die."

It is a common belief among care recipients that if the caregivers are indeed responsive to their health problems or magnanimous in dealing with their sickness they would not even consider being dishonest or stealing some items that are meant for the sick. This revelation raises the question on the motive behind volunteering as a caregiver, whether it is for self seeking interest or out of humanity.

It was substantiated that some social problems encountered by home care recipients are indeed more related to their belief and superstition about their sicknesses. Some of the care recipients indicated that Community Home Based Health Care is not always a good system to care for the sick in the rural communities due to some preconceived notions and superstition. There is a common notion among the Basotho that if the "emphasised others" know that someone is sick that sick person will hardly recover from his illness, especially when some imagined enemies pay visit to them. This is based on a superstitious belief that such people would bewitch the sick, which may eventually lead to death. This belief resonates very strongly among the care recipients who were interviewed in this study. One of the interviewees stated:

"I do not trust some these village health workers. They might take an advantage and mix some poisonous "muti"² with these drugs of theirs and give it to people if those are their enemies. Besides, here at our village, most of these health workers are witches."

The revelation from this study has demonstrated the extent and tenacity to which some of the home care recipients lack trust and confidence in the services being rendered to them by

some of the home caregivers. The implication of this is that it adversely affects their recovery, as fear of death is held by most of HIV/AIDS patients and this exacerbates their sickness. This also has led to the lean faith and belief in the efficacy and effectiveness of the Anti-Retroviral (ARV) drugs as can be deduced from the statement of one of the sick care recipients: *"My daughter, I have AIDS and this means definitely I am going to die. So I do not see any use of taking these ARVs of theirs."*

Economic and Social Benefits Received by Community Home-Based Health Care Caregivers

The study revealed that there are some apparent benefits that the caregivers derive from rendering their services to the sick and care recipients in the Roma communities. The caregivers reiterated that they are not paid for their services because they do home care giving voluntarily but they keep on doing their work based on the promise that they will be given some incentives even though that happens very rarely. The monthly payment that was promised to them never happened, though there was a revelation of selective pay outs to few volunteers, which never go round the whole group. Even though the caregivers had different complaints their most common complaint is lack of incentives for the work they do as the economic benefits that they are expected to derive from their services are not yet officially or strictly monetized at the moment. In responding to one of the questions during the field work, one of the caregivers bare her mind to narrate what she could term as the only benefit she had received from the services which she had taken up voluntarily. She said: *"Madam, we do this work voluntarily. We were trained at St. Joseph hospital for this work and were promised to be provided with some 'change' as incentives for us but believe me since my recruitment in 2002, I received that 'change' only once..."* as the caregivers looking heartily touched. Similarly, the caregivers have other complaints that centre on economic issues which revealed very deep suspicion of exploitation and unfair treatment that they receive from the supervisory health system. According to one of the interviewees who is a caregiver: *"This people use us to improve their economic status, by requesting donations say-*

ing they are going to give us allowances while they are not, which is not fair at all.” The above statement implies that the caregivers are either aware of or suspicious of the donations or grants that the supervisory organization receives from charity and development agencies. However, there is no evidence from the caregivers to substantiate this suspicion and claim that the supervisory body receives and keep grants that accommodates their payments.

From the social relation benefit perspective, the study found that the Community Home Based Health Care delivery has helped the caregivers to expand the network of their friendship with people from far villages with whom they even exchange some knowledge on health issues. They further, indicated that they have acquired skills on how best they can communicate HIV/AIDS information among people of different social categories based on the culture, values and norms of their specific society and families, including discussion on sex and HIV/AIDS related issues with their children which they previously considered as a taboo in Basotho culture. It is therefore noteworthy that the involvement of the caregivers in the present system has not only exposed them to internationally acclaimed best practices with regard to information and knowledge sharing but also with proper skills to deal with various sicknesses including HIV/AIDS in a culture specific and acceptable manner.

Perceptions of Community Chiefs and Leaders about Community Home Based Health Care

One of the major challenges faced by the CHBHC system in Roma valley in general and amongst the caregivers in particular are the perceptions, attitudes and behaviours of the community leaders, especially the chiefs towards them. The chiefs believe that the aim of Community Home Based Health Care system is to offer health services at home cheaply by trained people, with the aim of reducing HIV infection among community members, which is done through public gatherings where by members of the communities are being sensitized about HIV/AIDS in campaigns such as “Know Your Status Campaign.” It is a common believe by the chiefs that Community Home Based Health Care is doing nursing job of caring for people

in their homes by Support Group Members. However, it is of concern to some chiefs and community leaders that the caregivers operate without adequate professional ethical conduct that is grounded in confidentiality. It is alleged that some caregivers tend to reveal sicknesses of the home care recipients, which have made people to have negative attitude towards Community Home Based Health Care. Apart from violating the obvious ethical standard observed in medically related practices and professions, there are other implications that are also attached to this problem. This is one of the reasons why the relatives of the patients hide their sickness more often when they suspect that their relatives are HIV positive because of the stigma and unpleasant treatment that they will receive from the community members. Besides, this lack of confidentiality makes many people to be silent about their HIV positive status which hinders them from seeking immediate help.

Furthermore some of the chiefs revealed from their observations that the system has not succeeded in alleviating poverty among the caregivers, but ironically in improving the life standards of certain groups of people who work in organizations that are funded by HIV/AIDS reduction programmes, who use those funds to enrich themselves. In stead of improving the livelihoods of the caregivers by providing them with certain living wages and remuneration which may reduce the rate of unemployment in the country, the contrary is the case.

Another important issue that resonates throughout the system is the conflict generation that has been ongoing as a result of this CHBHC. The conflict is triggered and further amplified as there are different groups of caregivers being supported by different individuals and organizations including St. Joseph’s Hospital, World Vision, and National University of Lesotho. It is the inclination of the chiefs that the system has failed because its operational mandate has not been achieved, given the present increase in the rate of people dying of HIV/AIDS related diseases. This was substantiated by one of the chiefs who made reference to the state of HIV/AIDS in the country. According to him: *“the annual report of deaths of people aged from 18 to 40 since 2002 showed that there was an increase of 10-12 persons each year since then..... this increase in deaths came as a result of the fear to test for HIV because of the*

stigma attached to the pandemic and the improper handling of the situations, including confidentiality attached to HIV/AIDS by the caregivers in the CHBHC." By and large, the general perception of the chiefs and community leaders about the CHBHC is mainly negative and discouraging. They appear to have observed little or no impact of the new and ongoing system in the lives of the people infected and affected with HIV/AIDS, including on the worrisome surge in poverty level in the country.

Solutions to the Problems of Community Home-Based Health Care and the Way Forward

Concerning the issue of ill social relationships that exist between the caregivers, their family members and their neighbours, there should be public gatherings to sensitize people on the issue of Community Home Based Health Care. This will include how it operates, the aims; the importance, and the expectations from the community, which should be facilitated by people who are knowledgeable in this field such as the nurses, social workers and other health professionals. Sensitization is believed to be an appropriate strategy in addressing social issues because the community members including neighbours and the family members would be able to ask questions for more clarification so that they would understand what Community Home Based Health Care is all about. Also, the community members would understand the roles played by the caregivers in the community, which in realization would make them develop positive attitude towards caregivers.

The caregivers are inclined that it would be better and more encouraging if they could be paid because of the enormous and demanding time that is required from them in the caring process. Evidence from the study suggests that most of the care givers are not working and have no real means of generating income to sustain their family. This is factually a de-motivating and discouraging situation for this group of people who are believed to be ready to assist the sick and the poor in need of services. An effort towards creating a remuneration package for them will attract many people to join the caring process especially youths because at the moment, Community Home Based Health Care system is composed mainly of old people who do not possess the required energy do the work properly.

Also, they should be provided with adequate facilities such as plastic gloves so that they could render services effectively without fear of being infected by HIV virus during care provision.

In addressing confidentiality, which is one of the major challenges and concern that was raised against the caregivers in the communities, one of the chiefs suggested adoption of relatively old and primordial practice for the care of the sick in the community. In his words he suggested: *"the best way is that the relatives should care for their sick family members like in the past and it should not be the responsibility of the community but of the family only. This is because the family members of the patient would manage to keep the principle of the confidentiality which is considered to be a problem with the caregivers."* While the above opinion is genuine, it tends to be silent on other requirements of care giving that include professional training in paramedical care, which the care givers have received from trained health professionals. It is most likely that most family members and relatives of care recipients do not have any professional knowledge and training in care giving, which renders their care as simply an emotional assistance based on human responsibility.

Lastly, the organizations that fund the HIV/AIDS programmes should provide training courses and counseling sessions for the caregivers. Conventional wisdom supports this principle where Community Home Based Health Care can only be successful if caregivers are thoroughly trained and if some on-going support and advice are available in order to equip them with skills necessary to face caring process challenges. This suggestion is in line with the practical understanding and experience of the care recipients who regularly observe the deficiencies in the caregivers as a result of their inability to provide workable basic drugs. The study found that the care recipients are motivating that the caregivers should be provided with facilities in order to help them because it appears the caregivers are not as competent as they are supposed to be, especially in administering first aid medications and palliatives.

DISCUSSION

In Lesotho, Community Home Based Health Care (CHBHC) system is aimed at caring for the sick by providing some services directly to

them at their homes. As a result of increasing HIV/AIDS pandemic and the associated cost of care in the formal hospital setting in the country, the system seems to have gained more popularity and is highly recommended as being very cost effective. The increasing problem of HIV/AIDS and the associated social and economic burden in Lesotho have been cited in Bureau of Statistics (2003:171)³ and Kimane (2002:213).⁴ HIV/AIDS is predominantly affecting the individuals in their sexually reproductive and economically productive ages. This shows that if cultural beliefs that govern sexual behaviour such as polygamous marriages, extra-marital relationships, and others that are risky for HIV/AIDS infection are not revised or changed, HIV/AIDS would also swallow the future generation, which may lead to the end of our society (Matsela 2008).

In regard to the individual and personal difficulties and problems for caregivers, the study found that the major cause of depression and stress among the caregivers is poverty. During care giving process, the home patients or care recipients usually expect some food packages from the poor caregivers who also expect some incentives from the respective health authorities in Lesotho. The expectation of food packages from the caregivers by the patients is totally not out of question. They are supposed to eat and stay positively well in consonance with the global message of the UNAIDS as directed to home patients, especially those who are living with HIV/AIDS, which encapsulates aspects of living positively, eating well and caring for basic health needs (UNAIDS, 2000:28). Furthermore, the caregivers often experience stress because they lack or do not have necessary facilities they need in order to help the patients, which makes them feel inadequate and guilty when they cannot help their patients. These care givers experience and feel a great pitiful loss when patients die and have a lasting anxiety about the left behind family especially if these are children, as has earlier documented in UNAIDS, (2000) in similar findings from other developing countries. In most situations, many caregivers that look after sick family members experience stress from the sick members negative attitudes that are encapsulated in moody, uncooperative and hostile expressions. The source of this uncooperative attitude from the sick can obviously be linked to a host of factors that were

not revealed in the study. In the real life situation and from society based explanation for sickness and recovery, the explanation of stress and unhappiness of the sick are usually linked to some latent forces but most likely other socially manifested challenges such as poverty, lack of resources and even poor family relationships. The mere presence and extent of these social challenges in the lives of the sick to a large extent influences their outlook, in which case the severity of these challenges leads to hopelessness, helplessness and fear of dying from the sickness.

Psychologically, the general poverty situation in the country has contributed to the stress on the side of the patients, as they are hungry and expect the caregivers to give them food. This in itself makes the caregivers to become reluctant to visit the patients as they are also hungry with insufficient food for their family which causes even more depression on the side of patients. This is in line with Van Dyk (2001:324) position that when patients are confined to their homes or beds, they feel isolated and therefore become frustrated and hopeless, which makes them to feel hurt, angry, dependent and vulnerable because AIDS has put them in this vulnerable position. Moreover, feeling of isolation and loneliness adversely cause poor recovery rate among patients especially those who are HIV positive (PLWHAs). This implies that community home based care should not only entail care in terms of health but also emotional and spiritual support which home patients need as Van Dyk (2001:327) had previously noted over a decade ago.

In relation to the social problems encountered by the caregivers, the study found that the relationships between the caregivers and their family members and their neighbours are not always cordial because of the roles they play as women in their communities and in their families. These roles include motherly role where they are supposed to bear and to nurture their children and as wives to their husband which implies a responsibility to engage fully in domestic duties. They have to also participate in community activities such as cultural ceremonies and care for the sick community members, especially those from their immediate family or relations. The interpretation of the web of scenario and roles in which the caregivers find selves suggests a possibility of role conflict and

to some extent role strain which result from huge burden of works associated with their multiple statuses in the society. Realistically and from economic standpoint, the fact that care givers are not given some incentives has resulted in deepened strained relationship with their family members, who expect them to contribute toward the economic needs of their immediate family. They are blamed of spending the time that they are supposed to engage in a wage or remuneration based works on the present no-wage based care giving work. Despite the fact that they are volunteers, as adults and mothers their children and spouses usually expect them to bring something back home to support their families. Apparently, this had resulted in some complaints by the family members, especially where the poor caregivers use part of their meager families' resources such as food and money to travel around the villages caring for sick community members in return for nothing to the family.

Traditionally in the Basotho culture, the concept of care has been the responsibility of the productive family members not the responsibility of the community members. The present situation in the communities has obviously created a conflict between the relatives of care recipients and the caregivers and an indictment on relatives of care recipients that they are not capable of providing the required care for their family members. This conflict is sustained due to the growing misunderstanding of the Community Home Based Health Care system by the community members who feel irresponsible for not providing health care for their sick relatives. Burke and Laramie (2000:501) support this as they believe that in the past generations, home care giving was not a social and health issue, it was simply the way people respond to a dependent family member who happens to fall sick. This family, rather than community based conception of care for the sick has brought the care givers to the criticism of the family members of the sick people who they assist. The caregivers experience series of conflicts with some of the families of the patients by either not welcoming them or decide to hide their sick relatives. Such relatives of the sick often claim that the care givers cause some confusion in their families especially when it comes to HIV/AIDS issues. They are accused of non-confidentiality in some extreme cases has given rise to long term en-

mity between the care givers and such families.

This lack of cooperation by some of the community members is also viewed by UNAIDS, (2000) as one of the major social problems encountered by most of the care givers in the fledgling CHBHC system. These conflicts become even more intense when there are different and competing groups of caregivers found in the same villages, with conflicting perspectives. Besides, most community chiefs claim that the organizations funding HIV programmes have some political affiliation and community members tend to favour a certain group of caregivers than others. The politicization of the services or the inclination of the caregivers and funding agencies to political affiliations as the chiefs claim might have contributed in undermining the effectiveness of the system which is supposed to be free of political issues. However, the chiefs in realizing the benefits of the system in their communities advised that the big HIV/AIDS funding associations should stick to their plans conduct evaluation research to observe whether they are on the right track in the achievement of the set goals.

With regard to economic benefits to the caregivers, the study found that the caregivers do not get anything financial or material that worth their work as it has been explicitly emphasized that they should do caring process out of good will. In this case, the caregivers have taken the situation as it is and have groomed a strong conviction that they benefit more socially than economically. However, the caregivers believed that for them to render services effectively and yield the expected results, they should be given some allowance as sort of appreciation of the complicated work they are doing. This will also serve as an encouragement because working for nothing in the present globalised monetary economy is totally depressing, hence, the ineffectiveness in the services rendered. There is no doubt that providing a particular remuneration package for the caregivers will invariably boost their morale and act as a motivation for them to dedicate themselves more in their chosen work. This validates the known practical assumption between work package and pay package in the industrial relation sense. Granting an agreed sum of money to the caregivers will not only boost their morale but also put the responsibility of their actions and services into their hands, which will lead to a greater chance

of rendering quality services to the sick. Usually, when a particular service is rendered free of charge little or no obligatory accomplishment is either attached to the services or to the service providers, even at some points of clear negligent of duty.

Irrespective of the fact that the caregivers do not derive much economic benefits from their work in form of salary or material gains, they admitted to have gained substantially in the realm of knowledge and related issues about HIV/AIDS. The caregivers have no doubts also that they gain enormous personal skills that have even broken the cultural barriers, such as communicating HIV/AIDS issues and preventive measures against HIV/AIDS such as safe sex. This shows that even though CHBHC system is confronted with lots of challenges or problems that hinder its progress and success, it has advantages that point to the realization that CHBHC system would be considered as the best strategy for meeting health needs of the community members with minimum costs.

The care recipients mostly indicated their preference for the Community Home Based Health Care system, which they believed is a good health strategy to render health services to the poor people in a cheaper way. In comparison with the formal hospital care system, the care recipients admitted that the CHBHC system enables them to express their feelings freely on how care could be provided and what kind of food they want at what time, which is different from what obtains in the formal hospitals care and setting. In their homes, they are cared for in the environment they are familiar with, by family members and their loved ones who also support them socially and emotionally. This is in line with Burke and Laramie (2000:578) who pointed out that Community Home Based Health Care assumes community action when units of community such as extended family members, spiritual leaders, traditional healers and professionals such as social workers, counselors, and nurses and volunteers work on an integrated perspective to care for patients in their own home environment.

CONCLUSION

The study found some credible cost and benefits of CHBHC system to the caregivers, who have contributed voluntarily in this informal

health sector in Lesotho. While the benefits are social in terms of favour from the members of the community and the skills which they claim they have gained from the trainings, the social and economic costs of their services to their immediate families and self appear to be an enormous and a discouraging factor in the whole system. Their lack of contribution towards the economic needs of their families and absence of or little of quality time spent with family members have generated social strains and controversies. More disheartening is the uncooperative response from the care recipients and the family members of the sick who seem not to appreciate the contributions of the caregivers in the lives of the sick. It could therefore be concluded that if Community Home-Based Caregivers are to effectively carry out their work, there are two controversial issues to be paid special attention to. First, the caregivers should be given some incentives and adequate working facilities. Second, efforts should be made to promote information dissemination facilities to Basotho communities, more especially on HIV/AIDS and essence behind CHBHC. This could be achieved through an establishment of a social policy governing CHBHC in Lesotho.

RECOMMENDATIONS

Based on the findings and conclusion from the study the following recommendations are made to enhance the CBBHC in Lesotho and the way forward for the best delivery of care services in the communities.

- There should be a policy in place that governs Community Home Based Health Care system under the Ministry of Health and Social Welfare.
- There should be provision of food packages to the patients and their families.
- There should be a strong and firm attempt to integrate men in Community Home Based Health Care since gender inequality appeared to one of the controversies.
- Lastly, Government of Lesotho (GOL), should allocate some budget for Community Home Based Health Care programmes

NOTES

1. According to Kimane (2004), citing UNAIDS, in Lesotho some 100,000 children aged between 0-17 have been orphaned as a result of HIV/AIDS, with the number

- continuing to increase at an alarming rate. In her study report entitled the total number of orphaned children in Lesotho, as adopted by DMA/WFF Survey, of 2003 was 47439 females and 44405 males. Of these figures combined, 41.289 percent are from Maseru.
2. *Muti* is the Sotho name for magical charms and local medicines.
 3. The Bureau of Statistics (2003:171) indicated that the adult prevalence rate of HIV/AIDS has now been estimated at 29 percent with deaths from HIV/AIDS estimated to have contributed significantly to a decline in life expectancy from 58.6 years and 60.2 years respectively for males and females in 1996 to about 48.7 years for males and 56.3 for females in 2001.
 4. In addition, Kimane (2002:213) evinced that the prevalence rates amongst adults of 15-49 years have risen from 4 percent in 1993 to 29 percent in 2005.

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