

**FACTORS AFFECTING THE QUALITY OF PALLIATIVE CARE TO
PATIENTS WITH ACQUIRED IMMUNODEFIENCY SYNDROME IN
DAR ES SALAAM CITY**

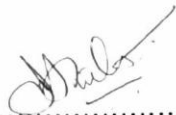
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MAY 2009

CERTIFICATION

The undersigned certifies that he has read and hereby recommends for acceptance by Muhimbili University of Health and Allied Health Sciences: a dissertation entitled: **Factors affecting the quality of Palliative care to patients with acquired immunodeficiency syndrome in Dar es Salaam City** in partial fulfilment of the requirement for the degree of Master of Public Health.



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Date..... 25/5/09.....

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DEDICATION

I dedicate this work to the memory of my late father Kassim Abdallah Maphingo, my mother Fatuma Zuberi Mbuguni, my wife Mwansiti Rasi Mbega and our children; Amina and Ibrahim.

ABSTRACT

In response to the negative impact of HIV/AIDS pandemic on health care services in the developing world, governments have adopted the Home Based Care strategy for People living with HIV/AIDS (PLWHA). However, little is known about the quality of care given to AIDS patients in the terminal stages. This study descriptive study used a mixed method of both quantitative and qualitative designs to determine factors affecting the quality of palliative care given to AIDS patients by caregivers within communities in Dar es Salaam region in July/August 2008. The aim of the study was to determine patient's satisfaction with palliative care services, related factors and described the palliative care given to AIDS patients within communities. The study has shown that majority of the caregivers 74% (n=37) were female. Majority of the caregivers (52%, n=26) had primary education, and fourteen individuals (28%) had formal employment as nurses. Among the eighty eight patients that received care, 59(67.1%) were female; most of the patients had attained primary education 70(79.6%). General physical care provided as the main home based care and a third (30%) of caregivers provided nutritional and general counselling. Patients with a longer duration of illness (19-24 weeks) were ten times more likely to report unsatisfactory provision of care (OR, 10.4: 1.6 – 68.6); p-value 0.01. The main problems found included inadequate supplies of essential materials, inadequate training among caregivers and informal caregivers (volunteers) and unsatisfied care given to patients. From the findings caregivers providing palliative care services to HIV/AIDS patients face challenges most of which is beyond their abilities to solve. Given the importance of palliative care, the study recommends the government to workout a policy stating clearly the duration of training course for all caregivers. Streamline HBC, PC services provided by community volunteers and caregivers into the comprehensive health plans may provide needed solutions to problems like salaries, transport, supplies and training, which address their needs. Access to uniform package for community volunteers regardless of where they are geographically or under which organization they are, Will motivate them and increase the quality of care to their clients.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
AMREF	African Medical Research Foundation
CCBRT	Comprehensive Community Based Rehabilitation and Treatment
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
IDC	Infectious Disease Centre
MOH	Ministry of Health
NACP	National AIDS Control Programme
NGO	Non Governmental Organization
ORCI	Ocean Road Cancer Institute
PASADA	Pastoral Activities and Services for People with AIDS Dar-es Salaam Archdiocese
PC	Palliative Care
POS	Palliative Care Outcome Scale
TACAIDS	Tanzania Commission for AIDS
PLWHA	People Living With HIV/AIDS
UNAIDS	Joint United Nations Programme for HIV/AIDS
WAMATA	Walio Katika Mapambano ya UKIMWI Tanzania
WB	World Bank
WHO	World Health Organization
GTZ	Gesellschaft für Technische Zusammenarbeit (German International Technical Cooperation)

Definitions of words and terms

Some of the terms used and words used need to be defined as their meanings may vary from one situation to another depending on social-cultural background, work experiences, and geographical location.

Palliative care at home

Palliative care is defined as any form of care given to patient with HIV/AIDS or patients with chronic illness in their own home and within their community. Care services given by their relatives, friends or health workers within their homes and community. Palliative care is meant to maximize and utilize the existing available resources within the community while family and community participate is taken as a basic component in providing such care. The World Health Organization defined palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and careful assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care regards dying as a normal process and offers support to help the patient and family cope during the patient's illness and in the bereavement period [36,41].

Home based care

The HBC aims at providing a continuity of care for persons with chronic conditions from any level of health care facility to the home environment. It shall be linked and integrated in the existing district health care delivery services. It is important to realize that inputs from the family, and the health care system will be necessary in provision of HBC. The family shall be the main actors of implementing home based care, the HBC provider could be a public servant, private person, volunteer from the community or NGO. The World Health Organization defines home care as “the provision of health services by formal caregivers in the home. Such care includes physical, psychosocial, palliative and spiritual activity on to stay that the goal of home based care” is to provide hope to high quality and appropriate help ill people

and families to maintain their independence and achieve the best possible quality. This study will use the terms palliative care and home based care interchangeably [20, 26, 36].

Quality

Is a measure of how good something is, or the degree of excellence or superiority which a thing possesses. A service is said to be of quality if it meets or exceeds the expectations of the user. The concept of quality is one of the leading forces in improving health services. The perception of what quality entails differs between countries and sectors because of different value systems. Many definitions are in use, and all may be justified depending on the perspectives and objectives. A common aspect at the centre of the concept of quality is the needs of a client or community. The International Organization for Standardization (IOS) defines quality as “the totality of features and characteristics of an entity that bears on its ability to satisfy a stated or implied need”. In health care, the perception of the needs of a client or community varies with the different views and perspectives of the client, service provider and society and the social, political and economic environment. Quality palliative care/home based care is defined as delivery of care services for patients at home or hospital following the standards, which have been set [36].

Quality of care

The degree to which health care services for individuals and population increase the likelihood of desired health outcomes and is consistent with current professional knowledge, including quality of life, overall enjoyment of life and the ability to perform various tasks. Good quality of care enhances clients’ satisfaction and their use of services; it increases job satisfaction and motivation among services. Quality of care is based on the “Right of the client and Needs” of service providers framework. To ensure good quality of care, clients have the right to information, access to services, choice, safety, continuity of services, and opinion [22]. This study will describe the quality of palliative care by identifying the relevant training for care received by carers and patient’s satisfaction of the care provided.

CHAPTER ONE

1:0 Introduction

1.1 Background

1.2 HIV/AIDS, global overview

The HIV/AIDS pandemic is still a major public health problem worldwide that has continued to affect more than forty million people by the end of 2005 [1]. Sub-Saharan Africa continues to be the worst hit region of the world with nearly 25.8 million HIV infected adults and children. Based on UNAIDS estimates, about 3.1million deaths per year that occur globally, are due to HIV/AIDS [1]. Though HIV/AIDS was first described in the early 1980s, the first case of HIV/AIDS in Tanzania was reported in Kagera region in 1983 [2]. The current HIV/AIDS prevalence (7%) in Tanzania, places the country among countries burdened with HIV/AIDS in, Sub-Saharan Africa [3]. Heterosexual transmission accounts for over 90% of all new cases followed by maternal to child transmission [3]. Other modes of transmission can be through infected blood, blood products and contaminated injections.

The magnitude of AIDS related morbidity and mortality, adds to the burden of the existing hospital infrastructure for most countries in Sub-Saharan Africa, such that the quality palliative care at home by relative, and communities is now necessary for continuity of care of patients affected by HIV/AIDS [4, 5, 6]. In doing so, the term “palliative care” was introduced in which we recognise that specialists should not treat all patients but rather, treat patients whose distress cannot be controlled by the primary doctor or nurse [7]. Governments in the developing world adopted and developed palliative care (PC) as one of the strategies to mitigate the impact of HIV/AIDS on the health system. Palliative care is expected to meet the expectations of the sick, families and community. The task to provide the needed PC lies on the governments, non-governmental, and civic organizations. This is important when considering that HIV/AIDS is the leading cause of the Burden of Disease (BoD), accounting for about 6% of the morbidity burden globally [8]. Given the magnitude of HIV/AIDS related deaths, a substantial proportion of such patients need palliative

care that is often not standardised, thus subjective and a public health and health system problem.

1.3 HIV and AIDS, Tanzania Overview

Tanzania is among low-income countries of the world. By July 2005, the estimated population reached 36,766,356 million people and an annual population growth rate of 2.4%. The life expectancy at birth was 43.5 years, and the Gross Domestic Product per capita, was US\$580 (purchasing power parity, PPP) when compared to an average of US\$4,054 for all developed countries and US\$2,149 for low-income countries [9]. The recent measured doctor-patient ratio in Tanzania was 1 to 25,000 and health expenditure (PPP) US\$26 per capita. The estimated number of people living with HIV/AIDS reached 1,820,000 while about 140,000 deaths were due to AIDS with a few of these patients receiving any palliative care. By 2005, about 1,100,000 Tanzanian children under 17 years old that were alive had lost either one or both parents due to AIDS (Orphans) [1]. The level of HIV/AIDS infection is high with a current prevalence of seven per cent among adults aged between 15 -49 years; women are disproportionately affected with HIV/AIDS prevalence at 8% compared to men (6%). The HIV epidemic shows strong variation among regions in the mainland; with the highest HIV prevalence being in Mbeya (14%), Iringa (13%) and Dar es Salaam (11%). Regions with the lowest HIV prevalence were Kigoma and Manyara with a prevalence of 2% respectively [10]. Heterosexual transmission is the main mode of HIV transmission in the country and accounts for 76.8% of all cases, while mother to child transmission (MTCT) infects about 5.5% children, and 0.5% by means of blood transfusion [11].

The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness through prevention and providing relief of suffering by early identification and careful assessment and treatment of pain and other problems; whether physical, psychosocial and spiritual. Unfortunately, this type of care is simply not available to most of patients in Tanzania. Most of them endure much

suffering in the terminal phases before they die. However, the HIV/AIDS epidemic's impact on health has changed Tanzania's policy to include palliative care in order to improve the quality of life and reduce suffering among patients with incurable conditions. Concurrently, several palliative care programs introduced by both the government and non-governmental organizations (NGO) are in place, in an attempt to provide care and support to people living with HIV/AIDS

1.4 HIV/AIDS and the health sector

In all affected countries, the HIV/AIDS epidemic is bringing added pressure to bear on the health sector. The demand for care for those living with HIV/AIDS rises with the maturing epidemic, likewise is the toll among health workers. In Sub-Saharan Africa, the annual direct medical cost of AIDS patient has been estimated at US\$ 30 Per capita when the overall public health spending is less than US\$10 for most African countries. Health care services face different levels of strain depending on the number of people who seek services, the nature of their need and the capacity to deliver the care. In Tanzania, it is estimated that an infected person would require over 280 days per year of care given as a summation of sick days at a cost of Tshs.359, 600 in nursing and drugs [12].

Beside costs, HIV/AIDS results in excessive use of health resources. Reports from urban hospitals in Tanzania show that patients with HIV/AIDS occupy nearly 50-60% of hospital beds. Thus at patient, family and community level, HIV/AIDS leads to loss of lives, loss of production and increased need and utilisation of medical care [13]. It has been estimated that AIDS expenditure for care would currently absorb one quarter of the governments recurrent health budget, thus governments will have to decide on treating AIDS versus treating other illnesses. Incidentally, HIV/AIDS has also brought with it, a new challenge of how to provide care and support unique to those who fall sick and surviving family members.

HIV has added a great burden to a grossly under funded and already overstretched health sector, outcomes that are likely to compromise the quality of health care provision. Likewise, the demand for health care services is increasing, as more health care professionals succumb to HIV/AIDS [5]. To mitigate the

HIV/AIDS impact on the health system, governments have adopted among other strategies, to promote palliative care. The quality of palliative care in sub-Saharan Africa had not been considered as a public health and health care problem previously. This study was prompted by the need to investigate that quality and challenges of palliative care in the community and identify if it is a public health and health system problem in a Tanzanian context.

1.5 Statement of the problem

The HIV/AIDS pandemic has increased the number of people living with HIV, the demand of health care services also expanding at the same time. More health professional are affected by HIV/AIDS, resulting into increased workload for those who remain [5]. Reports from urban hospital in Tanzania show that patients with AIDS occupy around 50-60% of hospital beds [5]. The government cannot afford to accommodate such big numbers of patients because of inadequate health care infrastructure. The promotion of palliative care at home for AIDS patients has led to some concerns on quality of the care. Because, many of those who provide this care are not professional workers, such as family members, friends or volunteers from the community. In addition, the literature provides information about coping strategies where, in many communities, care providers are struggling to cope with the enormous need for care and the lack of resources, support and training needed to provide it.

Despite, interventions, mitigations and strategies used by governments, there is lack of adequate information on the situation of the quality of services provided to AIDS patients. The concept of “the quality of palliative care” has been clarified by the Institute of Medicine in the US, which identified several elements important in quality of palliative care. These included the overall quality of life, physical and psychosocial well-being, spiritual well-being, and patient and family opinion of care and the well-being. However, aspects of quality of palliative care identified by expert clinicians differed with those of patients themselves [14]. The work built by Stein Hauser and his colleagues concluded that quality of palliative care has other additional factors that differ by role and by individual [15].

Since most of these type of queries had been conducted in developed countries, literature lacks important elements of quality of palliative care from a developing country's perspective. The lack of data is important to note since applying strategies and concepts from the developed countries may be inappropriate due to the differences in the epidemiological context of death and cultural differences in caring for the sick [14]. This study will address this drawback by investigating the quality of palliative care from the provider and patient's perspective and identify some of the challenges faced by caregivers in a Tanzanian context.

1.6 Rationale

Tanzania has formed several programmes in response to the HIV/AIDS impact as a joint venture between several bodies. The Tanzania Commission for AIDS (TACAIDS) and the National Aids Control Programme (NACP) set up strategies for mitigating the epidemic that include the promotion of palliative care services at home for AIDS patients. This study therefore aims to investigate the quality of palliative care currently provided to AIDS patients by their caregivers. It will provide baseline information that will assess the challenges faced by community members and patients themselves. Findings will highlight the need for improving quality of care as an antecedent measure towards planning for measures to offset the impending burden of health care provision for HIV/AIDS patients in future. Findings would also generate tentative ideas on the means of improving the quality and sustaining palliative care services to people living with AIDS using local resources.

1.7 Study Objectives

1.7.1 Broad Objective

The broad objective of the study is to determine the quality of palliative care given to AIDS patients by their caregivers within communities in Dar es Salaam.

1.7.2 Specific Objectives

- i. To identify the type of palliative care given to AIDS patients within communities and compare these with standard of care.
- ii. To identify the types of palliative caregivers and supporting groups available for AIDS patients.
- iii. To describe knowledge and skills of home-based care providers in the provision of palliative care to AIDS patients.
- iv. To determine availability of relevant resources for basic home-care services.
- v. To determine the patients satisfaction with palliative care services

CHAPTER TWO

2:0 Literature review

2.1 Palliative care worldwide

The World Health Organisation defines palliation as “the active total care of patients whose disease is not responsive to curative treatment”. This approach aims to provide palliation by integrating symptomatic therapy with psychological and spiritual support for both the dying patient and their families [16]. To meet this objective, health care providers must apply the best available evidence to their clinical decisions, through a programme of continuing professional development. The concept of palliative care arose when it was evident that many cancer patients were beyond conventional treatment and would thus need terminal care by integrative therapy that considers all aspects of the human being-holistic care [16, 17]. Five years after the publishing the World Health Organisation report, a review of the literature indicated that the potential of palliative care was still held back by lack of good evidence [18]. These circumstances are largely attributable to practical limitations that compromise the quality of evidence that can be obtained from empirical research on terminally ill subjects [19].

Despite these concerns, the emergence of HIV/AIDS has drawn attention to the concept of palliative care once again. Palliative care now encompasses other terminal diseases. In the era of HIV/AIDS, the term home based care seems more appropriate. Home based care defined as any form of care given to the patient with HIV/AIDS or patient with a chronic illness in their own home or community. Home based care as opposed to palliative care that is more pronounced in high-income countries, is in essence, an informal care largely provided by family members in many low-income countries for AIDS patients. We will use the term palliative care in this study to refer to care given to any HIV/AIDS patient at home by relatives/friends. Informal care lacks formal training and the mere fact that HIV/AIDS is an infectious disease and therefore clinical concerns in the practice and quality of care is unavoidable. This underlies the need for focused research, to develop clinical and policy decisions that will guide general medical and home-based

caregivers in providing quality care of dying patients. Measurement of quality of health care or even the quality of life has been a concept well defined in high-income countries. However, with the advent of HIV/AIDS, palliative care has gained major importance in the public and health care system.

2.2 Quality of Palliative care worldwide

In recent years, there has been greater attention paid to the quality of health care. While in developed countries, such as the U.S, spend more on health care per capita than any other nation, it ranks much lower than other countries on several health measures. Which focused on improving the quality of life for patients with serious illnesses, for critically ill patients and their loved ones, high-quality health care includes the provision of excellent palliative care. To achieve this goal, the healthcare system needs to identify, measure, and report specific target for quality palliative care for critically ill patients. The rising number of people living with HIV/AIDS (PLWHA) worldwide has made health care professionals and policy makers search for accessible health care that will meet the needs of people who are suffering from the disease and enhance their quality of life (QoL).

2.3 Palliative care in Tanzania

The practice of palliative care in Tanzania was started in 1992 by a small self-help group of people living with HIV when searching for alternatives that can efficiently serve the needs and improve the quality of life of PHLWA. Motivated by the wish to do something for themselves and others living in similar situations, they applied to the Catholic Church that gave them a small building in Dar es Salaam. The number of members steadily increased to offer basic medical support and drugs for treating opportunistic infections. By the end of 1994, there were 150 registered HIV positive clients and by 2004, this number had reached over 12, 000 clients. The number of registered clients reflects the trend of the epidemic in this city and the success of such services [20]. Mark Jacobson described the approach of the Selian Lutheran Hospital hospice team to integrate faith into home based care. “where people come together to pray with patients, we simply grafted onto that some skills, and training

that improved their ability”, the community immediately recognised this was something that they needed.

The Ministry of Health through several health stakeholder established home based care (HBC) model in 1995 in pilot districts, the model extended care services from the health facilities to the community, households and to families. The support consisted of drugs, supplies and equipment. One year later the MOHSW and the German International Cooperation (GTZ) also established a program for palliative care services, their main aim was to answer the needs of HIV/AIDS infected patients and their families at reasonable cost [13]. In their model of palliative care they planned one visit to PLWHA once every week or more frequent depending on the patients needs and their families. All palliative care initiatives provided a kit to areas after training a provider and family. In addition, other benefits included the observation that palliative care services were closer to the communities and which meet the quality enhanced the acceptance of people living with HIV/AIDS.

Expansion and coverage of palliative care has been increasing from time to time, donor support strengthened the continuity of palliative care services at district level for general care to HIV/AIDS patients [6]. In July 2001, Tanzania was selected among 10 African countries to benefit from Italian initiative for the fight against AIDS in Africa that aimed at strengthening of community palliative care services in 11 districts in Tanzania mainland and Zanzibar. Through the support, palliative care providers have been trained, medicines and resources for palliative care have been supplied, communities have been made aware of the services and clients are being cared for in the participating Districts [13]. The 2003-2006 Health sector HIV/AIDS strategy for Tanzania recognizes care and support as a critical component in the response to the epidemic, currently there are several groups providing palliative care in the country through community volunteers, PASADA, Pathfinder International, Wamata, AMREF, CCBRT, IDC [20].

The National Aids Control Programme (NACP) strategy envisages that about 5000 people will be receiving palliative care by the year 2006. This is a very small number compared to a total of 1,820,000 people living with HIV and 176,102 AIDS cases that have occurred since the beginning of the epidemic in Tanzania [21]. It can then be concluded that palliative care for HIV/AIDS is still at its formative stage.

More important is that, there are many stakeholders both foreign and local with different interests and capacities. Palliative care is now reported and acknowledged as the most appropriate way of responding to the ever-increasing problems and needs of incurable ill due to HIV/AIDS and other causes, but the problem facing the all process is the quality of care provided meet the standard to AIDS patients in terms of supplies, care provider, medicine.

2.4 Quality of palliative care in Tanzanian context

Despite the practice of palliative care in Tanzania was started in 1992, quality of palliative care still has not been measured to ensure efficient provision of care. WHO has initiated a “community health approach to palliative care for HIV/AIDS and cancer patients in Africa project” The goal of this project is to improve the quality of life of patients and their families in selected Africa countries (Botswana, Ethiopia, Tanzania, Uganda and Zimbabwe) by development of palliative care with a public health approach will provide pain relief and comprehensive care, mainly home based. In resource-poor areas with poor healthcare infrastructure, home based care may be the only feasible means of providing adequate access to palliative care. Although all five countries have made the development of home based care/palliative care a priority in order to deal with the HIV/AIDS epidemic, only Botswana has an operational home based care programme integrated into the national health system. In the other four countries, home based care is mainly provided by private organizations. However, in Botswana, the quality of palliative care services has been reported to be inadequate; 28% of the caregivers interviewed were dissatisfied with the quality of care and treatment received by patients [22]. The focus of the governmental home based care programmes in Tanzania is to reduce overcrowding in hospitals and to involve the community in providing care for patients.

2.5 Palliative Care Needs

Globally it is estimated that about 40 million people are HIV infected [11]. In Tanzania it is estimated that 1,820,000 people are currently HIV positive among

these less than 5000 patients are under palliative care Tanzania. A study done in Nairobi has shown an insufficient number of providers are involved in palliative care due to stigma that is still attached to people living with HIV/AIDS; however there are many people in need of these services. The study findings suggested the need to move from awareness creation to assisting the suffering through palliative care [23].

Many people living with HIV/AIDS feel isolated and alone, often the people closer to them feel overwhelmed. The medical and social services system are unknown to those most needing them [8]. Medical needs are determined by the stage in the natural history of the disease, and types of morbidity. The most important thing would be the provision of palliative care kit that contains medicines and supplies for treatment of opportunistic infections and HIV transmission to others. The importance of human resources that is skilled on palliative care that will provide quality services to AIDS patients, as well as finance resources, transport, necessary equipment for palliative care services. Apart from the health care services, the patients and family would need spiritual support, counselling, psychosocial support from religious leaders, friends, relatives, neighbours and significant others needs legal support, food (provision of adequate nutrition is thus a crucial component of AIDS case management). There is a need for collaboration with other sectors which deals with food production while giving education to patient and family caregivers about nutrition supplementations using locally available foods.

Political commitment and continued support is crucial for the success and sustenance of palliative. At the National level, Policy makers and politicians should address issues favouring palliative care. There should be Multi-sectoral and International collaboration employment opportunities, women empowerment, support of vulnerable groups such as orphans. The pathfinder International CPC conducted a baseline and needs assessment survey in Dar es Salaam. The aim was to generate information to guide to palliative care in community programme and determined areas of focus in designing and implementation of community palliative care services and training. The findings were that; only 7% of respondents report to have had access to palliative care services. About satisfaction from palliative care providers 40% needed home visit, 28% required guidance on treatment and counselling, 16.75% needed incentives for caregivers, 14% said they would

appreciate any kind of palliative care given. Regarding chronically ill respondents, 22.5% would like free medicine to treat opportunistic infections, and regular check-ups, 10.1%, 9.8% needed financial support and 8.95% needed food supply. Almost a half of the respondents stated that they didn't know their needs. Seven out of ten households caring for an ill patient expressed that they experienced nutritional problems including lack of money to purchase food, access to only one meal per day. The main source of care and support was from distant family members (57%), neighbours and friends (17%), local catholic church kigamboni(70%), PASADA(7%), CCBRT(5%) and Kiwohede (2%) [24]. The quality of services given to patients which is provided by community volunteer was not addressed if it met the standards of care.

2.6 Benefit and Constraints of Palliative care

The benefit of palliative care services includes; improved health of the patient, identified needs to the community, and breaking stigma. Improved health of patient is evaluated both from the patients and providers perspectives. It includes description of positive changes witnessed among patients. It requires availability of correct interventions and has one in place to make sure the patient take their medication and following up trivial changes before they become a serious health risk [25].

Stigma has been a setback in the control of HIV/AIDS epidemic, caring of patients in their homes is a means of breaking the cycle of fear surrounding the terminal illness. The palliative care also increases visibility of PLWHA in the community thereby encouraging the normalization of the virus, discussion and understanding. The implementation of palliative care is still facing some constraints, despite the fact that palliative care has been acknowledged in various studies; there is lack of common understanding of the concepts of home and community care at all levels, even by stakeholders. There is also inadequate number, support, and integration of palliative care services providers from hospital and District Health Management Team (DHMTs). Stigma that is still attached to HIV/AIDS hinders the counselling process, care and support of these patients [26]. Notwithstanding the benefit and constraints there have been efforts to objectively establish cost-effectiveness of palliative care.

An operational research on cost effectiveness of palliative care services and other factors affecting its impact on chronically ill patients due to HIV/AIDS was done in Bagamoyo district. The main focus was on total time spent with patients, distance travelled to see patients, this study revealed that the average cost of palliative care was Tshs.1, 862/= per day for the community located volunteer, Tshs.2, 443/= per day where palliative care was provided by a health worker. An average hospital based care was estimated to cost tshs.4, 921/= per day at Bagamoyo hospital [27].

CHAPTER THREE

3.0 Methodology

3.1 Description of the study area

Dar es Salaam region is situated along the costal line of Tanzania. The current total population approximates 4,603,346 million people, extrapolated from the national census of 2002 using the 0.31 per annum intra-censal growth [28]. Dar es Salaam is one of the most affected regions in the country with HIV prevalence of 11% by the end of 2004[10]. The region is divided into three districts, namely Ilala, Temeke, and Kinondoni; each with a district hospital and several other public and private health facilities. The Muhimbili National Hospital is a national referral facility which is located in the city and receives referred patients from both private and public hospitals in the country.

Given the generalised prevalence of HIV/AIDS in Tanzania, palliative care services for AIDS patients in the region started since 1999 in partnership with non-governmental organisations principally involved in the home-based care provision such as PASADA, WAMATA, IDC, AMREF and CCBRT and public health facilities such as the Ocean Road Cancer Institute in Dar es Salaam region which were chosen for this study because the practice of palliative care services was initially started in Dar es Salaam and has continued to date for almost a decade.

3.2 Study population

This study involved two types of study populations; that of caregivers who provide palliative care to AIDS patients at home and that of patients who are recipients of such services. For the purposes of this study; formal caregivers are those caregivers registered with institutions involved with palliative or home based care, they will be referred as “caregivers” The informal caregivers are usually, patient’s relatives that usually come in as volunteers or a volunteers not related to patients. Each caregiver was a leader to a group of volunteer caregivers, through this link; volunteers receive some support from related institutions. The volunteer caregivers were also identified through the formal caregivers. The approach to getting these study participants

started with Dar es Salaam based institutions and communities, that provide HIV/AIDS related services and palliative or home based care. To identify caregivers, it was necessary to select representative institutions that deal with palliative and home based care and at these institutions, the principal investigator presented an introductory letter from MUHAS and the certificate for ethical clearance to the concerned administrative personnel. Included in the introduction, were two research assistants collected data for the study. The purpose and duration of the study was explained and after permission from the institution was granted, a register of carers was provided. All caregivers from the register (s) were contacted and the introductions were done again, with the purpose of the study explained in detail. Consenting caregivers then served as links to patients before introducing the study team. Initially, the caregivers explained to their patients about the study, aims and purposes. This was followed by introduction of the study team and was only done to consenting patients. Dates and venue for data collection by interview and the FGD were set for the patients and caregivers. The study team then proceeded to interview the available caregivers for that day.

3.3 Study design

This was a triangulation of quantitative and a qualitative study design.. The quantitative study was a cross-sectional design of caregivers and patients. Relevant information on the aspects of palliative or home-based care was collected at one point in time from both caregivers and patients. The qualitative design involved some of the caregivers in a focus group discussion (FGD) and aimed to provide detailed information on the key aspects of palliative or home based care. It was also designed to shed light on the caregivers working conditions, identify other support groups and to further assess the quality palliative care provided.

3.4 Sample size determination

The lack of a registry of all formal caregivers limited sample size determination, thus sample size estimate was conveniently estimated using available institutional registry of caregivers. The study used PASADA registry of caregivers as an estimate, where the total number of caregivers reached an average of 35 caregivers per month, and

these were available at any given time. Additional information revealed that there is variation of the number of caregivers available at times, due to the fact that some caregivers are volunteers and their availability depends on their personal timetables. Thus, a minimum of 70 caregivers was expected to be included in the study during the three weeks of data collection. The study invited to participate; all caregivers found within the study sites during the fieldwork. Recipients of home-based care were reached by the caregivers through the named institutions and included all consenting patients. Each caregiver was able to provide care for at least a five patients per week. Based on this estimate, the expected number of patients was approximately 175 patients. The qualitative study was conveniently selected a homogenous group of caregivers (12 respondents) from the same sample used for the quantitative study.

3.5 Sampling of the study population

In the quantitative study a list of all institutions that deal with home-based care was made, a total of five sites were identified. The study purposely chose two institutions that have been providing home based and palliative care, for a relatively longer duration of time when compared with the rest. These were PASADA and Ocean Road Cancer Institute. The study included all formal home-based caregivers in these two facilities were invited to participate in the study (20 caregivers from PASADA and 14 caregivers from ORCI). Through the formal caregivers, 17 informal caregivers were identified and included in the study. The caregivers were interviewed and used to identify patients and provided them with information about the study. Identified patients were then introduced to the study team by the caregiver and after an explanation of the study purpose was given, consenting patients were interviewed. In the qualitative study, non-probability snowball sampling method was used to invite caregivers within the same institutions. The method involved the same institutions used for the quantitative study. Initially, four respondents for the FGD were conveniently selected based on the experience of care giving and they in turn, identified other carers. The four caregivers were specifically chosen for their varied experience; a retired nurse and a previous caregiver of a relative, a community

volunteer, a retired civil worker who had no previous experience of home based care and the youngest caregiver in the group. The rest of the respondents (8) were chosen based on their long duration of involvement in home-based care.

3.6 Data collection procedures

3.6.1 Design of research instruments

Interviewer-administered questionnaires were used for the quantitative study. The questionnaire adapted a previously developed “Palliative care outcome Scale (POS) and Herth Hope Index” questionnaire by Higginson and Herth and their colleagues [29-31]. The study adapted some questions for both carer’s and patient’s questionnaires. Additional questions were set to answer some aspects of palliative care as described by the National guidelines for home based care. The questionnaires being in English were translated to Kiswahili by a colleague (University of Dar es Salaam) and back translated into English by the principal investigator and forth again for correction of identified ambiguous questions. to ensure the same meaning is conveyed in the Kiswahili version.

The guidelines for the focus group discussion was developed and consisted of five main open ended questions that sought more clarification on the type of palliative care, the knowledge and skills of the carers and in addition, the challenges faced by carers when providing care.

3.6.2 Recruitment and training of research assistants

Two research assistants were recruited and trained for two days on how to use the quantitative research instrument, mainly, the adapted questionnaire. Research assistants were also trained on how to use the FGD guidelines and an audio tape recorder. Instructions on note taking were provided for recording during FGD and note books were given. Correction of any unclear questions was clarified during the training.

3.6.3 Pre-testing research instruments

Before the study began, the questionnaire was pre-tested for clarity of questions, the language used and to estimate the time required for conducting an interview one respondent. The investigator conducted a pre-testing of the instrument to test the internal validity to the questionnaire in measuring the quality of care given for palliative/home based care of patients with HIV/AIDS. This was done in Temeke hospital as a unit of Muhimbili National Hospital Dar es Salaam City and Harvard University collaborative project on HIV/AIDS prevention, care and treatment.

3.6.4 Data collection

i. Quantitative design

Interviewer-administered questionnaire was used for both care givers and the patients. Information collected included the general socio-demographic characteristics of caregivers providing PC and those of patients who receive the care. The questionnaire also included questions about the types of palliative care. Problems encountered by the caregivers when delivering care to patients and patients satisfaction. Other information-included organizations, which provide support, types of support provided to enable caregivers to provide service. Training opportunities for the caregivers were explored as well as the type of equipment normally used for care and suggestions for improvement. To have consistency and feasibility of describing the quality of palliative or home based care, we included patient's satisfaction on the care provided at home in addition to the caregivers description of the quality of care they provide.

ii. Qualitative design

A question guide was used to moderate the discussion and addressed the main challenges faced when caring for patients at home, reasons for starting this type of work, means of improving the provision of care and how the caregivers envision the future of home based care. The strategy used to classify and evaluate the data was predetermined by an open ended discussion guide: e.g. what type of working

environment were they faced with, the exact tools they used given certain situations, how did they reach the distant patients, what other support did they get for caring for such patients, and what do they do when faced with for example a patient with a deep wound or mental disturbance. The moderator used the guideline to focus the discussion, but was encouraged to probe the respondents on relevant issues. The discussion took approximately one hour and was carried out in Kiswahili, an audio tape was used to record the discussion and a notebook was also used.

3.7 Data management and analysis

Data was collected daily during weekdays and was completed within three weeks from 21st July 2008 to 11th August 2008. After data collection each day, the researcher and the research assistants checked the data for completeness and accuracy on the same day. All quantitative information obtained was coded and then double entered using excel (Microsoft office 2003) program. Inconsistent data or missing variables were noted and original questionnaires were used to correct inconsistencies and correct errors on data entry. Data were checked and cleaned using a excel spreadsheet that highlighted inconsistent entries when comparing the two data sheets. Epi info version 6 statistical software was used for data analysis. Demographic and other variables of interest will be given by percentages and where applicable, chi-square tests was done and reported accordingly with p-values given. To measure to measure the level of satisfaction of care by the patients, a series of questions were posed to the patients. Some of the questions used included questions that sought the kind of services provided by the carer, frequency of visits, and if pain relief medication was also provided. The level of satisfaction for each question was used to create an overall satisfaction measure. The measure was then dichotomised into 0="Satisfactory" indicating the satisfaction to the type of care being given and 1="Unsatisfactory" indicating dissatisfaction of care. The satisfaction variable was analysed using logistic regression, by analysing each factors associated with satisfaction separately at first (univariate analysis) and for factors or variables that result with p-value 0.05 or less were included in the final multivariable analysis. The final variables that will show association will be reported with odds ratio and 95% confidence interval.

The qualitative data from FGD was transcribed and translated into English. The transcribed conversations, the prompts were listed together and all data that related to the classified themes were identified. The answers were then combined based on the caregivers' relevant training, to determine the ease of providing care or quality. Notes from the discussion and tape-recorded information were then provided as narratives.

3.8 Ethical considerations

Ethical clearance was obtained from Directorate of Research and Publications committee of MUHAS. Permission to conduct the study was also requested and obtained from the HBC organizations in Dar es Salaam upon presentation of the letter of introduction from MUHAS. Individual oral informed consent was sought from the research participants after explaining the purpose of the study. Research participants were assured that their participation in the study was voluntary and that they had the right to refuse participation without any adverse consequences. They were also told that results of the study might contribute towards improvement of the services they were receiving or providing.



CHAPTER FOUR

4.0 Results

4.1 The quantitative study

The overall quality of care was measured by patients and caregivers responses.

a) The care givers

The study was able to enrol all participants and recipients of home based/palliative care from the two purposely chosen institutions that provide such care for patients suffering from AIDS or AIDS with associated cancers. Fifty caregivers in total were identified and they all consented and were recruited into the study, among these, 16 were informal caregivers (volunteers), who were related to the patients but were not formally affiliated with the institutions. The volunteer caregivers assist the formal caregivers as links to collect drugs and essential supplies from the centre of services (PASADA, ORCI) for their sick relatives. Among the caregivers, 37(74%) were females and 34(68%) had received some on-job training relevant to palliative care while 16(32%) of the volunteer carers had not. Provision of palliative care services was not confined to homes but also continued when the same patients were admitted to health facilities. This continuum of care was evident among 26(52%) the caregivers.

4.1.1 Social demographic characteristics of the caregivers

The total number of formal caregivers was 34, 20 caregivers were recruited from PASADA and 14 from ORCI. Sixteen of the 20 caregivers from PASADA were females while 11 of the 14 caregivers from ORCI were females. Among 16 volunteer caregivers, 10(62.5%) were females. Ten of the 16 volunteer caregivers were recruited through PASADA caregivers while six were recruited through ORCI caregiver. The mean age of male caregivers was 47 ± 8 years, ranging from 34-57 years, while for female caregivers; the mean age was 40 ± 9 years with the youngest being 22 years and the oldest 68 years. Twenty six (52%) of the caregivers had

primary education, and 21(42%) had secondary education while three (6%) of the caregivers did not get any formal education. Among all the formal caregivers, fourteen (28%) individuals had in addition formal employment such as nurses, while the rest were involved in petty business besides care work and others with varied means of earning that allowed them to do care work and seventeen (34%) are unemployed. Table 1, describes the social demographic characteristics of the caregivers.

Table 1: Social demographic characteristics of the caregivers

Characteristics	N (%)
<u>Age groups</u>	
21- 40	27 (54)
41+	23 (46)
<u>Education</u>	
None	3 (6)
Primary (1-7 years)	26 (52)
Secondary +	21 (42)
<u>Occupation</u>	
Employed	14 (28)
Unemployed	17 (34)
Petty Business	19 (38)
Total	50 (100)

4.1.2 Knowledge and skills for providing home based care

Knowledge and skills for the caregivers were assessed by responses to questions about skills acquired during training as shown in Table 2a. Overall, 34 (68%) of all caregivers had received some training relevant to home based care while the 16 (32%) volunteer carers had not. Twenty (40%) of all caregivers had received home-based care training and a smaller proportion 10 (20%) had received both home-based care training and counselling skills. The training was provided by the supporting organisation or project. The majority of trained caregivers 32/34 (94%) of carers received training that lasted from one week to six weeks while only two of the carers

had received relevant training that lasted longer than six weeks. One caregiver had been trained for 18 weeks and the other for 52 weeks.

Table 2a: Knowledge and skills for Home Based Care

Skills acquired during training	N (%)	Training organisation
Home based care only	20 (40)	NGO
Counselling for HIV/AIDS	2 (4)	Government
HIV/AIDS care and treatment	2 (4)	Projects
Home based care + counselling	10 (20)	Projects
Not trained	16 (32)	-
Total	50 (100)	

All trained caregivers (34) stated that the training they received was inadequate and they all felt that they needed additional training. The trained caregivers expressed a variety of needs for additional training. Two (4%) wished they had additional home based care training, seven (14%) caregivers identified more need for therapeutic counselling and communication skills, while 25 (50%) commended on special training on infection control and management of emergencies and 16 (32%) volunteer who had not trained in any course, request any training on the mention area. (Table 2b).

Table 2b: Type of course identified as additional training need by caregivers

Course	N (%)
Home based care	2 (4)
Counselling skills	7 (14)
Infection control and management of emergencies	25 (50)
Need training	16 (32)
Total	50 (100)

The caregivers were equipped with a tool kit-containing minimum of essential supplies, which allow them to perform their tasks within acceptable standards. The supplies in the tool kits were reported to be erratic and unavailable at times. The

distribution of the tool kits varies with the location of the caregiver but it is never a constant situation. The caregivers reported that some supplies were often available for use. At least 92% of all caregivers reported having abundant supply of gloves and antiseptics at any one time. The main drugs available in the tool kit were mainly over the counter analgesics as reported by 90% of the caregivers. Twenty five percent of the caregivers also reported to receive morphine from the supporting institution for their patients when the need arises. Facemasks were only to 10% of the caregivers, while mackintosh sheets had never been supplied or used by the caregivers (Table3).

Table 3: Availability of drugs and other supplies

Drugs or Supplies	Always: n (%)	Rarely: n (%)	Never: n (%)
Antiseptic/Soap	46 (92)	4 (8)	-
Gloves	46 (92)	4 (8)	-
Face masks	-	5 (10)	45 (90)
Mackintosh	-	-	50 (100)
Drugs(analgesics)	45 (90)	5 (10)	-
Dressing	45 (90)	5 (10)	-

4.1.3 The type of care provided to patients at home

The type of care provided by home based caregivers for their clients at home involved various tasks that vary depending on the identified need. Table 4 details some of the tasks performed by caregivers though they are not fixed. General physical care was given by 29 (58 %) of the caregivers while counselling was provided by a third (30%) of caregivers. A relatively smaller number of caregivers 6 (12%) provide wound care and rehabilitation. However, due to the small number of caregivers the differences were not statistically significant.

Table 4: The type of care provided to patients at home

Type of care	N (%)	95% CI
General physical care	29 (58)	43.3 – 71.5
Counselling +nutritional counselling	15 (30)	18.3 – 44.8
Wound care + rehabilitation care	6 (12)	4.9 – 25.0
Total	50 (100)	

The caregivers were sometimes faced with emergency situations when patients manifested other symptoms, which present a challenge to the caregiver's knowledge and skills. Among conditions that carers were asked as single questions, included the course of action taken by the caregiver when their patients presented with high fever, anaemia or severe chest pain. Table 5 shows that more than half of the caregivers reported to refer the patients to the hospital for situations of high fever (56%), severe chest pain (76%), and mental confusion (92%)

Table 5: Identified conditions and caregivers interventions

Type of Carer's intervention	N (%)
High fever	
1. Sponging	4 (8)
2. Analgesics	18 (36)
3. Hospital(referral)	28 (56)
Severe chest pain	
1. Drugs (antibiotics, analgesics, home remedies like honey)	12 (24) 38 (76)
2. Hospital(referral)	
Anaemia	
1. Nutritional counselling	11 (22)
2. Hospital(referral)	36 (72)
3. Nutritional supplements	3 (6)
Mental Confusion	
1. Counselling	2 (4)
2. Hospital(referral)	46 (92)
3. Drugs (sedatives)	2 (4)

Twenty six (52%) caregivers reported to continue providing care to their patients even when they had been admitted to health facilities for more specialized care. The type of care provided by home based caregivers for patients admitted in health facilities included terminal care support which was reported by 9(34.6%), support for medical examinations reported 11(42.3%) and wound care and rehabilitation reported by 6(25.1%) of the caregivers. However, the differences were not statistically significant. Terminal support included spiritual counselling, general body care, nutrition and terminal care support, where the caregiver at this time, works closely with relatives of the patient. Example of services provided when assisting patients undergoing medical investigations included lifting and escorting patients to locations where investigations are done and follow up of treatment based on the outcome of these investigations (Table 6).

Table 6: Type of care provided by carers for admitted patients

Type of care	N (%)	95% CI
Terminal care support	9 (34.6)	17.9 – 55.6
Support for medical examinations	11 (42.3)	23.9 – 62.8
Wound care + rehabilitation care	6 (23.1)	9.8 – 44.1
Total	26 (100)	

b) The patients***4.1.4 Social demographic characteristics of the patients***

Eighty-eight patients were enrolled in the study of whom, 59 (67.1%) were females. Of the total 39(44.3%) were from Kinondoni, 28(31.8%) from Temeke and 21 (32.7%) from Ilala districts. Seventy of the patients (79.6%) had attained primary education, 20 (69%) of males and 50 (84.7%) females, with a smaller proportion 12 (13.6%) of (male and female) patients who had attained secondary education and above. Six (6.8%) patients lacked formal education. Seventy two (81.8%) of the patients were engaged in petty business, 25(86.2%) of males and 47 (79.6%) of females respectively. The mean age of male patients was 44 ± 9.8 years, ranging from 28 years for the youngest patient to 66 years for the oldest patient. Male patients aged between 35-49 years formed the highest percentage (58.6%) of the total, while those aged from 50+ years consisted of the smallest proportion (17.2%). Among female patients, the mean age was 35 ± 9.1 years, the youngest patient being 22 years of age while the oldest patient was 66 years. The proportion of female patients was highest (49.2%) the youngest age group while it was lowest (5%) in the oldest age groups. Table 7; describe the social demographic characteristics of the patients.

Table 7: Social demographic characteristic of the patients

Characteristics	Males N (%)	Female N (%)	Total
<u>Age groups</u>			
20-34	7 (24.2)	29 (49.2)	36 (40.9)
35-49	17 (58.6)	27 (45.8)	44 (50.0)
50+	5 (17.2)	3 (5.0)	8 (9.1)
<u>Education</u>			
None	3 (10.3)	3 (5.1)	6 (6.8)
Primary (1-7 years)	20 (69.0)	50 (84.8)	70 (79.6)
Secondary +	6 (20.6)	6 (10.1)	12 (13.6)
<u>Occupation</u>			
Employed	3 (10.3)	3 (5.1)	6 (6.8)
Unemployed	1 (3.5)	9 (15.3)	10 (11.4)
Petty Business	25 (86.2)	47 (79.6)	72 (81.8)
Total	29 (100)	59 (100)	88 (100)

4.1.5 Factors affecting patients satisfaction with palliative care

The measure of quality of palliative care provided by the caregivers was examined by assessing patient's satisfaction of these services. Satisfaction levels for the services was dichotomised into "Satisfactory" and "Unsatisfactory" and examined by logistic regression. Overall, 72 patients, 81.8% (95%CI: 71.8 – 88.9) reported to be satisfied with the care provided, while 16 patients, were not (18.2%: 11.1 – 28.1). In the analysis, this measure was analysed with each variable of interest separately, factors that resulted in p-values ≤ 0.25 on univariate analysis, were all included in the multivariate analysis for determining the unbiased determinant of the quality of care. Table 8 shows the results of unadjusted and adjusted regression analysis of these factors and variables that were included in the final analysis. In the preliminary unadjusted analysis, female patients were more likely to be satisfied with the quality of care given, OR=2.4 (0.81 – 7.32) compared to men, but the association was not statistically significant (p=0.115). The level of education did not influence satisfaction of care, OR=0.5 (0.03 – 5.90), p=0.98. Longer duration of illness was negatively associated satisfaction of care, OR= 0.15 (0.04 – 0.53); p= 0.03, while

frequency of visits more than twice per, week was significantly associated with satisfaction of services. Patients who were visited two or more times per week by the caregiver were four times less likely to be satisfied than those visited only once ($p=0.05$). In multivariate analysis, the sex of patients and the duration of illness between 19 – 24 months remained associated with dissatisfaction of care. Female patients were significantly at risk, almost six times likely satisfied with care, (OR, 5.6: 1.31 – 24.09) compared to male patients. Patients who have been receiving palliative care for more than 12 months, were significantly not satisfied with the provision of care, compared to patients of shorter duration (OR, 0.16: 0.04 – 0.62) and this was statistically significant at p -value =0.01.

Table 8: Factors affecting patient's satisfaction with palliative care services

	N	Yes	Unadjusted OR, (95% Confidence Interval); <i>p</i> -value	Adjusted odds ratio (95% Confidence interval); <i>p</i> -value
<u>Sex*</u>				
Males	29	21	1	1
Females	59	51	2.4 (0. 81– 7. 32); (<i>p</i> =0.16)	4. 6 (1. 31 – 24. 09); <i>p</i> = 0.02
<u>Level of education</u>				
<u>Education</u>				
None	6	5	1	
Primary (1-7 years)	70	58	1.0 (0.10 – 9.03); <i>p</i> =0.98	
Secondary +	12	9	0. 5(0. 03 – 5.90); <i>p</i> =0.56	
<u>Duration of illness (months)*</u>				
0 – 12	53	49	1	1
13 +	35	4	0.15(0.04 – 0.53); <i>p</i> =0.03	0. 16 (0. 04 – 0. 62); <i>p</i> =0.01
<u>Frequency of visits by carer* (number of times per week)</u>				
1	31	21	1	1
2 +	57	51	4. 05(1. 30– 12. 56); <i>p</i> = 0.02	5. 7 (1. 36 – 23. 4); <i>p</i> =0.02
Total	88			

Satisfaction of care provided by logistic regression

* Refers to variables that were used in the final model to determine patient satisfaction.

4.2 The qualitative study

The qualitative part of the study was designed to complement the findings of the quantitative study by shedding light on the caregivers working conditions, and mechanisms of other support groups and to further describe the type of care and services they provide. The narration uses two initials where applicable of a coded name of the respondents to preserve anonymity.

4.2.1 The characteristics and knowledge of the caregivers

Characteristics of the caregivers varied from caregivers trained in health related education to those who joined the care organisations due to previous experience or otherwise non-health jobs. Some of the caregivers had nursed relatives and had not received any training prior to that. So the caring experience was solely based on practice of a caring personality with family values. The following narrative from focused group discussions provides the experiences of some of the providers.

“I joined PASADA as a volunteer to provide home based care when my sister died. PASADA had cared for my sister when she was terminally ill with AIDS. After she died, I had no means of income as I used to depend on my sister. I joined PASADA as a carer I felt I had gained enough experience when caring for my late sister”

Some caregivers were retired nurses or nurses currently not employed in the conventional health care institutions. The level of knowledge of some of the caregivers was inadequate given the various situations they faced in their work. Caregivers with previous health jobs showed confidence in answering questions under any circumstances. Though with previous knowledge, caregivers expressed concern on the importance of appropriate training on skills necessary to provide palliative care. HIV/AIDS is associated with many other health conditions and for

the caregivers, relevant knowledge in some of these commonly associated conditions would be an added advantage, as expressed by a retired midwife in the FGD

“I was thankful that an organisation such as WAMATA was started. I joined the institution a year after my retirement as an enrolled nurse in one hospital. I felt I was strong enough to do this job, after all I needed to do something as being used to go to work every day, staying at home or doing something different was less appealing. Though I do have some advantages over others in terms of knowledge, the relevant palliative care was not taught in class when I was studying. I just apply general principles of nursing when caring for these patients. There are times when I feel unable to provide this care. This usually happens when I face an emergency situation and I am not sure what to do. There was one time when my client showed very aggressive behaviour that scared even his relatives, we had to take him to the hospital and he was diagnosed with some mental illness”

Though home based care is provided by anyone who is compassionate enough, some skills are necessary for the caregivers to provide effective care with a certain quality. Some carers expressed concern over lack of appropriate skills such as those needed when nursing a deep wound. The wound dressing procedure can be tedious for someone lacking specific training, the standards required to practice aseptic techniques during dressing are not common knowledge. This was a concern that Mrs “HN”, a 40 year old volunteer caregiver had to share.

“When I was faced with an extended leg wound some time back, I almost gave up my voluntary work as I felt I was out of my depth. I do enjoy this work as I feel good to assist another human being to be as comfortable as possible given the severity of her illness. When I give such care and see that the patient is comfortable, it is so gratifying to me and I feel spiritually content. It is my way of giving back humanity for what I have been able to achieve in my life. When I felt out of depth with the wound, I realised it was because I lacked the necessary skills for that particular intervention”.

The knowledge required to practice home based care was not readily availed to the carers but was built upon the basic skills they already had. Most of the caregivers had some experience in caring roles and the additional training or skills gained were provided intermittently to the carers, and very often by the coordinating institution. For some caregivers, the experience was a challenge and a Mr KJ a previous clerk and ex-employee of Ministry of Lands had seen

an advertisement seeking nurses/volunteers to provide care to patients at home. He applied and found the on-the-job training skills they were given, very useful.

"I realised that I could help those in need by joining PASADA through the Infectious Disease Centre. For me this kind of work is my sacrifice, I feel gratified if I provide care to someone who is otherwise unable. I partly feel sorry that they are this ill but that could also be me. I appreciate the counselling skills given with this work as it is really difficult at times to remain focused with an otherwise very sick and demanding patient."

4.2.2 Availability of relevant working tools and essential supplies

The Ministry of Health has a minimum intervention package that is required for the provision of quality home based care. However, its components are often subject to inconsistent availability as experienced by the caregivers. Caregivers have experienced shortages at times and abundance in others. Of the total caregivers, 19(55.9%) practiced home based care with a minimum of gloves and some medicines. Though the guidelines on minimum home based care package had only over the counter analgesics to relive pain, changes in the provision of home based care have evolved and some of the caregivers have been trained to provide morphine for pain relief when necessary. Such advancement was shared by one of the caregivers, Mama JT (a 50 year old caregiver).

"When we started home based care, we could only give paracetamol for pain relief; we now can provide morphine injection when the patient is in severe pain, patients with cancers associated with HIV are often experiencing severe pain, or those with brain or nerve disorders. We do not carry morphine in our package, but when the need arises, we have a procedure to request for it and we usually get it. We feel this is an important step in the provision of care. We received on job training to provide this drug and one has to be careful with it".

CHAPTER FIVE

5.0 Discussion

This study found that the majority 37 (74%) of home based caregivers from the study sites were women. Most of the caregivers have basic formal education and received relevant training such as counselling and home based care (68%) though they also report the training to be inadequate based on the challenges faced in caring for patients. Palliative care was not confined to home care but care was also provided when patients were admitted in health facilities, and 52% of caregivers provide such care. Appropriate referral is given by the caregivers when necessary. The quality of care provided was measured by the patient's satisfaction to the care provided. The study found significant differences in the level of satisfaction between male and female patients, with female patients being more likely to be satisfied with the provided care compared to men. Patients who have been ill for longer than 13 months were significantly less satisfied with the provision of care compared to others. Some of the identified problems that the caregivers faced compromised the provision of quality care include inadequate supplies, transport and challenges related to illnesses experienced by patients.

5.1. Characteristics, knowledge and skills of home based caregivers

Women have been known to provide care for their families and sick family members as a gender ascribed social role. In the advent of HIV/AIDS, this role has now extended to caring for the terminally ill patients as found by this study. This finding is consistent with other studies for example in Australia, majority of caregivers are women, thus it is not limited to the African culture but caring for sick persons, appear to be a universal role for women [32]. It is possible that such roles influence the increased likelihood of women to join home based care institutions compared to men. Though the majority of the caregivers had primary education, there were no differences between men and women and it is not certain that the number of women in the caregivers is influenced by the differences in education. The caring role may be a means of earning additional income for some caregivers, as most caregivers had

previous jobs though some had volunteered to do so, in these institutions. The characteristics of the person are likely to influence working as a caregiver, as seen in the study where some caregivers feel that the work has spiritual meaning or they feel gratified in providing assistance to the terminally ill patient. Caring has been described to be neither simply a set of attitudes or theories, nor does it comprise all that nurses do [33]. Thus we are more inclined to reason that for home based care, the caring characteristic is more important in the provision of quality care, given the right training or professional competence. This study found different individuals with caring attitudes to be key people in the provision of palliative care.

Skills and training

Most carers had received training in their affiliated institutions, though the challenges they face led them to feel that the training was inadequate. This finding is not surprising as palliative care/home based care was introduced as a measure to counteract the burden of HIV/AIDS in the population and in health care institutions [34]. In most low-income countries, health care institutions are characterised by weak public infrastructure, inadequate number of trained health personnel as well as other non-human resources, in such a setting, it is unlikely that the home based carer can receive all the necessary training [35]. Though palliative care is appropriate, in sub-Saharan countries, policies and programmes have to consider the training availed to these carers. Some of the caregivers expressed 'out of depth feelings of inadequacy' when faced with challenging situations at times, such as described by the retired midwife. Some of the identified needs for training included infection control procedures, which are vital given the likelihood of pressure sores for bed ridden patients or associated conditions such as "Kaposi sarcoma". Inadequate training may demoralize palliative care providers, as the challenges for attending AIDS patients are many and very serious as it has been found in several studies and described by UNAIDS palliative care report. The palliative care provider needs to be trained in a wide range of psychosocial, medical legal, nutritional counselling, drugs for emergency cases and if possible, on spiritual issues to provide quality services to their patients and the families. Caregivers have suggested various courses; however, the majority have suggested courses on management of opportunistic infections,

nutritional counselling, counselling, and additional palliative care training. However, as the situation stands now, it may not be possible to immediately provide these trainings. Most support agencies lack funds and are unable to access funds from the government. Faith based organizations in low income countries are unable to raise adequate funding on their own. Among identified knowledge needs, most caregivers identify their limits when faced with challenging situations, and refer their patients to the hospital when they cannot handle presenting conditions, such as high fever, severe chest pain, anaemia and mental confusion. Mental confusion ranks the highest reason of referral and this suggests inability of caregivers in handling this condition, followed by severe chest pain, anaemia. Mental health problems have recently been associated with HIV/AIDS and thus likely to manifest in patients that have been ill for a long time as well as in terminal illness. This it would be practical for carers to be given this knowledge.

Pain control is another important dimension that needs to be addressed. Pain due to cancer and AIDS could be relieved by home based caregivers given the right skills, as this study revealed some limitations and the administration of morphine, is still not documented in the guideline despite the WHO's encouragement for a public health approach to pain management and palliative care [36]. The right knowledge and skills for drug administration is important for the procurement control and regulation of such drugs. Such activities may serve as advocacy for home based and palliative care. Uganda has been active in adopting the WHO guidelines and has managed to prioritise palliative care under essential clinical services and provided oral morphine for specialised palliative care nurses [37], this is a commendable achievement that Tanzania would benefit if adopted.

The government and all organizations involved and support in providing palliative care services need to take this scenario as a means to establish sustainable human resource base for palliative services by providing adequate training for this potential manpower. Regarding occupation of the caregivers, the study has shown that the majority of the caregivers can use this task as a form of employment this may provide an opportunity with future expectation for an employment, but also in the delivery of quality services.

5.2 Availability of relevant working tools, essential materials

The findings of this study have demonstrated the inconsistent availability of working tools and equipment as seen in table 3. There is some equipment that most carers have found readily available; and some rarely available. Such scenarios are part of the problems faced by the health care systems of most countries in the sub-Saharan Africa [38]. The study has shown that most of caregivers do not get enough working supplies, the most frequently offered assistance by supporting organization is nutritional support and drugs for the management of symptomatic manifestation even though not in adequate quantities as demonstrated in the respondent for improvements. Palliative care provider needs to have sufficient supplies to attend AIDS patients to meet the needs of the patient and to protect himself and other people from being infected.

The main reason for inadequate supplies in most cases is inability of the palliative care providing organizations to cope with an increasing need for services. The cost of providing palliative care will depend on a number of factors, the supplies and medications, and the involvement of trained home based care workers. The decentralisation of the Tanzania's health systems has empowered districts health facilities to plan and finance its health care interventions, such that if the need for palliative care is identified within a district; priority for such provision of care can be planned locally thus ensuring adequate procurement of supplies and training that eventually translates into provision of quality palliative care. While the role of palliative care organizations in the care of PLWHA is acknowledged, these organizations are by no means without challenges. Thus, the expansion of such services through government facilities is the key method of assuring sustainability of such services, given that the burden of HIV/AIDS is still high in Tanzania.

5.3 Patients satisfaction with the care provided as a measure of quality

The demographic characteristics of patients that have been receiving home based care reflect the general pattern of HIV/AIDS epidemiology in sub-Saharan Africa as

well previously described in Tanzania [39]. Women are infected at younger ages (female patients were relatively younger 21-40 years) as was seen in this study compared to men (41-50years). This finding has potential implications in the need for expanded palliative care given the substantial role women play in the provision of care and that they also present a group most affected by the infection. The study used a modified indicator to estimate the quality of palliative care, and this was patient's satisfaction on the care provided. It may be that since most caregivers were women, and they cared for fellow women, the degree of satisfaction of services provided is likely to be higher based on the mutual understanding and identification of gender sensitive needs. Patients who have been ill for a longer duration were less likely satisfied with the care provided. This finding is likely to reflect the fatigue and burden of caregivers when caring for such patients for an extended period as discussed by the UNAIDS [40]. These stresses in developing countries are said to be exacerbated by lack of resources and in turn, affects the quality of care provided, and the findings of this study also reflect this in addition to identified training needs.

The feasibility of using patient reported data to provide information about quality of care has been used by other studies [41] and was found to be useful for long term monitoring of the quality of medical care. On the other hand, studies of palliative care that rely on patient data have been considered to be biased as they tend to include patients with fewer problems [42]. This study combined both caregivers and patients in order to overcome that bias. Uncertainty of the quality of care provided cannot be excluded since the caregivers were used to identify patients and they may have chosen patients who were well care for. However, the findings show that the care provided was less satisfactory with the extended duration of illness, and this is likely given the workload by the caregivers and as a consequence of long term caring exhaustion.

Patients satisfaction to the care provided at home is more likely translated that the patient received home based care safely, in a competent manner within the appropriate time frame with the desired outcomes. This study did find significant differences on the quality of care provided between men and women as well as with respect to the duration of illness. This is inline to what has been is felt by the caregivers. The caregivers feel they have not managed to provide their best quality of

home based care due to lack of adequate resources and necessary skills. It is likely that after a long duration of illness and care provision, both the caregivers and patients experience weariness since patients do not get better and this translates into dissatisfaction of services.

Palliative caregivers in developing countries reportedly, are more likely to experience stress at work compared to caregivers in developed countries. The stress is said to be exacerbated by the lack of resources that eventually leads to hopelessness [1]. In such scenarios, the mental health of the caregivers is vital for them to remain emphatic in the provision of care. On the other hand, patients who have been ill at home for longer than 12 months, show that they were less likely than the previous patients, to be satisfied with care OR 0.16 (0.04-0.62) $p=0.01$ and the result was statistically significant. These findings may imply that the type of care provided was perceived positively by patients who have suffered less than 12 months, or on the other hand, it may be that after a longer duration of illness, patients are less likely to find any type of care satisfactory given the physical and psychological strain of their illness. They may feel that the caregivers are not doing enough to help them and that may be a consequence of severity of illness rather than poor care provision.

The study is likely to reason this was the case since patients who were too ill to respond negatively or not conscious of the care they receive, were not included in the study due to ethical reasons. Despite the shortcomings experienced in terms of inadequate resources or training. On the caregivers perspective most were concerned with inadequacies of equipment and supplies and felt they could not provide the standard quality care.

5. 4 Limitations

The findings of this study provide a detailed description of the types and quality of palliative care in Dar es Salaam. However, results have to be interpreted with caution due to the small sample size available for the caregivers. The variation on the type and quality of general health care services in Tanzania varies depending on the geographical location, distribution of resources as well as availability and qualification of the health care provider. The type and quality of palliative care provision is likely to be influenced by similar factors. Moreover, the smaller sample

size of the quantitative study may have underestimated the findings of some of the variables that resulted in non-significant differences due to small numbers. This adds further to the limitation of generalising the study findings though it may hold true for the study sites.

CHAPTER SIX

6.0 Conclusion and recommendations

Conclusions

This study has described the type and quality of palliative care provided by home based care workers to HIV/AIDS patients. Based on patient's perspective, the quality of home based care provided was satisfactory though this was not similarly supported by the caregivers. There are more women caregivers than men and most of the caregivers had received supportive training for provision of care.

The study has identified some gaps in the palliative care provision which include the following:

Firstly, only a small number of caregivers are currently in place considering the high burden of patients with HIV/AIDS. Secondly, most of the institutions providing palliative care are non-governmental organisations, which have no mandate to provide for expanded access and provision of palliative care nationally. Finally, though most caregivers have received training specific for home-based care. The training was inadequate to equip them with enough skills and competence to face the unpredictable challenges of caring for HIV/AIDS patients at home.

Recommendations

1. In order to improve the quality and expansion of home based care, the government needs to integrate such services into the community in order to expand access and yet use families and communities support systems to provide care. Despite the scarcity of resources, such services need training to be a major component to ensure care is provided with a certain minimum quality.
2. There is need for national policies and community integrated strategies to support quality of palliative care/home based care should be established to ensure the availability of supplies and drugs such as oral morphine, and other essential drugs at low cost. Restrictive drug regulations should be revised; these and pricing policy obstacles often limit the accessibility of opioids for pain relief. In

most case only the few available medical doctors, are allowed to prescribe morphine, while in many areas non-doctor caregivers are the only healthcare provides who come into contact with patients.

3. The mental health component and management of mental disorders should be evaluated in the context of palliative care and if found to be an unmet need, it should be included in the package of palliative care training.

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