

ARTICLE ORIGINAL

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda



J Uwimana, P Struthers

ABSTRACT

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). This study investigated met and unmet palliative care needs of PLWHA in selected areas in Rwanda. The study sample included 306 participants: PLWHA, health care professionals and coordinators of HIV/AIDS units. Quantitative and qualitative methodologies were used. The data were analysed separately and then triangulated. In the findings, over 50% of PLWHA had symptoms related to HIV/AIDS most of the time, with the most common symptom being pain. Participation in activities of daily living was significantly associated with the health status of PLWHA ($p < 0.001$). The most common perceived palliative care needs of PLWHA were medical needs, psychosocial needs and the need for financial assistance (77%); home-based care (47%); nutritional support (44%); and pain relief and management of other symptoms (43%). Most PLWHA indicated these palliative care needs were unmet, in particular the need for pain relief, symptom management, financial assistance and nutritional support. Over 50% of health care professionals reported they were not trained in palliative care. They indicated that inadequate policy and resources were the main obstacles to the provision of optimal palliative care. Addressing unmet palliative care needs would enhance the QoL of PLWHA. In addition, developing policy related to the provision of palliative care and building the capacity of health care providers is essential for the provision of adequate palliative care services in Rwanda.

Keywords: Palliative care, needs, people living with HIV/AIDS (PLWHA), terminally ill, quality of life, Rwanda.

RÉSUMÉ

Le nombre croissant de personnes vivant avec le VIH/SIDA (PVV) dans le monde entier a amené les professionnels de la santé et les décideurs à chercher des soins accessibles qui pourraient satisfaire les besoins des malades du SIDA et aussi améliorer leur qualité de vie (QoL). Cette recherche a étudié les besoins de soins palliatifs satisfaits et non-satisfaits des PVV dans des provinces sélectionnées au Rwanda. L'échantillon de cette étude comptait 306 participants: des PVV, des professionnels de santé et les responsables de services de VIH/SIDA. Des méthodologies qualitatives et quantitatives ont été employées. Les données furent analysées séparément et par la suite triangulées. Selon les résultats, plus de 50% de PVV ont souvent présenté des symptômes liés au VIH/SIDA ayant la douleur comme le symptôme le plus banal. La participation dans les activités de la vie quotidienne était associée à l'état de santé des PVV ($p < 0.001$). Les plus aperçus besoins par les PVV en rapport avec soins palliatifs inclus palliatifs des PVV étaient les besoins médicaux, psychosociaux et l'aide financière (77%); les soins en foyer (47%); le soutien alimentaire (44%); le soulagement de douleurs et la gestion d'autres symptômes (43%). On constate que chez la plupart de PVV ces besoins ne sont pas satisfaits, en particulier, les besoins suivants: le soulagement des douleurs, l'entretien de symptômes, l'aide financière et le soutien alimentaire. Plus de 50% de professionnels de la santé ont signalé ne pas avoir reçu de formation en soins palliatifs. Ces derniers ont également signalé que la politique et des ressources inadéquates furent les obstacles majeurs vis-à-vis la mise à disposition des soins palliatifs optimaux. La prise en mains des besoins palliatifs non-satisfaits pourrait améliorer la QoL des PVV. De plus, le développement d'une politique liée à la disposition de soins palliatifs et le renforcement de capacité de services de santé sont essentiels à la mise à disposition des services adéquats des soins palliatifs au Rwanda.

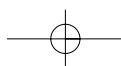
Mots clés: soins palliatifs, besoins, PVV, mourants, qualité de vie, Rwanda.

Jeannine Uwimana, she is a HIV/AIDS Program assistant and assistant lecturer at Kigali Institute of Science and Technology (KIST). She has been involved in various HIV/AIDS programmes related peer education and VCT in institution of Higher learning in Rwanda (2001-2004) and research related to HIV/AIDS and palliative care. The present article is part of her Msc. in Physiotherapy and the present study was the pioneer study in palliative care in Rwanda. She is currently enrolled in PhD programme at UWC, working on the Good start project (August-2006 to date) which implements TB and HIV/AIDS integration programmes in Umzimkulu LSA, KwaZulu-Natal, South Africa.

P. Struthers (PhD Public Health, University of the Western Cape)

Note: The abstract of the above article is part of the XVI International AIDS Conference's abstracts, Toronto, Canada, 13-18 August 2006. <http://www.aids2006.org>

Correspondence to: Jeannine Uwimana, School of public Health, University of the Western Cape, Private Bag X17, Bellville 7535, South Africa, Email: jeannine_uwimana@yahoo.com



ORIGINAL ARTICLE

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

Introduction

HIV/AIDS is still a threatening pandemic that has eroded many lives and affected the growth and development of many countries, especially in sub-Saharan Africa where the pandemic is increasing and the quality of life (QoL) of people living with HIV/AIDS (PLWHA) has been undermined. According to the epidemiological report on HIV/AIDS of the Joint United Nations Programme on HIV/AIDS (UNAIDS), an estimated 38.6 million (33.4 million – 46.0 million) people world-wide were living with HIV at the end of 2005, 4.1 million (3.4 million – 6.2 million) people became newly infected with HIV, and 2.8 million (2.4 million – 3.3 million) people lost their lives to AIDS (UNAIDS, 2006).

In Rwanda, it has been estimated that nationally the adult HIV prevalence is between 4–11% among women attending antenatal care services and 3% in the general population (MoH, 2005; WHO, 2005). In 2003 an estimated 80 000 new cases of HIV infection were reported in Rwanda, with 49 000 deaths attributable to HIV/AIDS (UNAIDS, 2003). According to the WHO/UNAIDS report, the need for anti-retroviral therapy (ART) in Rwanda in 2005 had risen to 49 000 people but only 17 781 (36.2%) PLWHA were receiving ART (WHO, 2005).

With the growing number of PLWHA needing medical care, the demand for resources is increasing and challenging the health system in Rwanda. It is against this background that efforts are being made by health care professionals and policy makers to search for accessible health care for PLWHA. An approach that is receiving considerable attention worldwide is palliative care (Abdu-Saad, 2000; Sepulveda, Habiyambere, Amandua *et al.*, 2003; WHO, 2002a). However, most countries in sub-Saharan Africa, including Rwanda, have not yet incorporated palliative care into their health care delivery system and palliative care is not yet seen as a public health issue (Sepulveda *et al.*, 2003; Spence, Merriman and Binagwaho, 2004).

Research findings indicate that 80% of PLWHA in Africa require palliative care and that most palliative care needs of PLWHA are still unmet (Grant, Murray, Grant & Brown, 2003; Harding & Higginson, 2004; Karus *et al.*, 2004; Kikule, 2003; Sepulveda, Amanda, Tokwo, & Ullrich, 2002). This study was undertaken to identify palliative care needs of PLWHA in selected

areas in Rwanda. These findings were further investigated to determine if these needs were met or unmet.

BACKGROUND

Rwanda is one of the ten countries in Africa that have been identified by the WHO as most severely affected by HIV/AIDS (WHO, 2005). It is facing a generalised epidemic, which has undermined the QoL of many people who are either infected with HIV or affected by family members who are ill.

In addition to risky behavioural factors such as multiple sex partners and low levels of condom use, the 1990 civil crisis in Rwanda and the 1994 genocide war also contributed to the rapid spread of the HIV infection in Rwanda, since rape was used as a weapon. The UNAIDS 2003 report states that 3.2% of women in Rwanda reported being raped during genocide (UNAIDS, 2003). Half of these women became HIV positive. The 1994 genocide war also affected the health system's infrastructure, as many health facilities were demolished. This affected the health care system in terms of health delivery and access (USAID, 2004).

Furthermore, the HIV/AIDS pandemic has caused extreme hardship in already impoverished populations. Only 28 % of households with HIV/AIDS patients are able to pay for even the most basic health care (USAID, 2004).

Despite the burden of HIV/AIDS on the country, various attempts have been made by the Rwandan government to fight the pandemic and enhance the treatment and care of PLWHA. In June 2003, the government approved a five-year HIV/AIDS treatment and care plan, which included the availability of ART and other supportive services to PLWHA. The ART protocol states that only PLWHA with a CD4 cell counts below 200/mm³ are eligible for free ART. However, treatment for opportunistic infections and other conditions is provided to patients, which can account for almost 10% of the total medical bill. Additionally, the national HIV/AIDS treatment plan includes voluntary HIV testing and counselling (VCT), coordination of services, medical treatment including anti-retroviral drugs (ARVs), clinical monitoring and adherence support, psychological care, ancillary support services, prevention and education, community and home-based care (HBC) which include palliative care (GoR, 2004; William John Clinton Foundation, 2003).

ARTICLE ORIGINAL

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

Most of the HIV/AIDS treatment and care has been delivered in inpatient hospital settings, where supportive care and treatment for opportunistic infections are provided, to the extent that resources and drugs are available (GoR, 2004; William John Clinton Foundation, 2003). However, most PLWHA are poor and live in non-urban areas, so it is largely only PLWHA who live near the well-equipped hospitals, which are in the urban centres, and are able to afford the medical bills, who have access to HIV/AIDS treatment and care. This suggests that there are still many PLWHA without coverage for treatment and care. This is linked to the limited resources available in the country to cover the needs of PLWHA. However, through PEPFAR funding, the government has decentralised the provision of ART to the district level throughout the country in order to rollout ART (MoH, 2005).

The provision of opioid drugs has not yet been well integrated into the HIV/AIDS treatment plan in Rwanda, and their provision is very limited, particularly the provision of opioid drugs for management of pain. Where palliative care has been delivered, it is mainly in tertiary hospitals, such as Centre Hospitalier Universitaire Kigali (CHUK), and in a few district hospitals. The national policy on narcotic and opioid drugs describes how they can only be provided at the tertiary hospital by a qualified physician and they should only be dispensed as the last option for management of severe pain. This suggests that PLWHA who are not able to reach tertiary hospitals for pain control with opioid drug such as morphine are likely to experience a lot of pain during the course of their disease, and die in pain.

In Rwanda morphine is the most common opioid drug used for cancer or AIDS patients with severe pain. However, the access is very limited and its consumption is very low. A recent study of opioid analgesics in the world showed that the morphine dose that is used in Rwanda is low, with a consumption of 0.0088 milligrams per capita (Joranson, Ryan, & Jorenby, 2004). The low consumption or insufficient availability of morphine or opioid drugs could be due to regulation and pricing. Therefore, there is an urgent need for the Rwandan government to revise the policy on opioid analgesic drugs to increase the availability of, and early access to opioid drugs.

Like in other sub-Saharan African countries, the HIV/AIDS epidemic has stretched the already poorly resourced health care infrastructure. Schneider, Nandakumar, Porignon, Bhawalkar, Butera and Barnett (2000) argue that in Rwanda only 10% of the total per capita health expenditure is spent on prevention and treatment of HIV/AIDS and related care. Consequently, the health care system has been affected regarding health delivery and access (USAID, 2004). This has also influenced the delivery of palliative care in Rwanda since palliative care is mostly delivered at the hospital level.

Different understandings of the definition or concept of palliative care affect the provision of palliative care in Rwanda, particularly for PLWHA. The WHO defines palliative care as an approach that improves the QoL of patients with life threatening illnesses, such as cancer or HIV/AIDS, as well as that of their families (Singer & Bowman, 2002; WHO, 2001; WHO, 2002a). Palliative care support includes the prevention and relief of suffering. This includes the early identification, careful assessment and treatment of pain, physical problems, psychological problems and spiritual problems (WHO, 2002b).

However, most health professionals view palliative care as hospice care or terminal care rather than a continuum of care (Sepulveda *et al.*, 2003). Furthermore, palliative care is also considered as home-based care (HBC). WHO defines HBC as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death (WHO, 2006). HBC is thus a way of providing palliative care services at home. However, HBC in most of African countries, including Rwanda, only focuses on psychological care. As a result, in Africa, palliative care cannot said to be the same as HBC. Bereavement counseling, spiritual support and medical aspects of palliative care also need to be included.

HIV/AIDS has become a chronic, progressive disease since the introduction of highly active anti-retroviral therapy (HAART) (Selwyn & Rivard, 2003). As a result comprehensive treatment now requires the integration of palliative and curative approaches, unlike in the pre-HAART era (Selwyn & Rivard, 2003).

ORIGINAL ARTICLE

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

This suggests that there is a need to raise awareness among health professionals of the new concept of palliative care and the importance of integrating palliative care into the continuum of care for PLWHA, rather than viewing it as only terminal care.

Given the increasing spread of the HIV/AIDS epidemic in Rwanda and the backdrop of limited resources, the identification and prioritisation of patients' needs would assist in designing appropriate palliative care services for PLWHA, especially within the context of the financial constraints of the health services. Nonetheless, palliative care needs of PLWHA are multifaceted, depending on many factors such as the stage of the disease, the health infrastructure and health system of the country, and the socio-economic status of the PLWHA.

Studies in many countries across the globe, and in particular in developing countries, highlight pain relief and symptom management, psychological support, spiritual support, food and financial support as the predominant palliative care needs of PLWHA (Coughlan, 2004; Harding & Higginson, 2004; Karus, Raveis, Marconi *et al.*, 2004; Lasechinger, Van Manen, Stevenson & Fothergill-Bourbonnais, 2005). A few studies have assessed to what extent palliative care needs are met. These studies suggest that the needs least likely to be met are those for: pain relief and symptom management; psychological support; training of family caregivers; financial support; food provision; HBC and in-patient care (Lasechinger *et al.*, 2005; Sepulveda *et al.*, 2003; Williams, 1999). Where palliative care needs are met, this is mainly through the support of families and relatives (Beedham & Wilson-Barnett, 1995; Lasechinger *et al.*, 2005; Sepulveda *et al.*, 2003; WHO, 2002b).

The WHO progress report on its palliative care projects in Uganda, Ethiopia, Zimbabwe, South Africa and Botswana highlights challenges African countries face in providing optimal palliative care (WHO, 2002b). This report states that problems in providing palliative care include: the lack of trained human resources, especially health professionals and social workers; a poor understanding of palliative care among health providers; the shortage of hospices and day care centres; an inadequate regulatory framework; inadequate funds for palliative care activities;

insufficient training for HBC providers; poor physical health facilities; the lack of a multidisciplinary palliative care team; inadequate treatment modalities for pain and other symptoms; and an inadequate national palliative care strategy. The report indicates that assessment of both met and unmet needs is crucial for effective health service planning (Willes, Payne & Jarrett, 1999).

For effective planning and implementation of palliative care for PLWHA in Rwanda to take place, identification of their needs is imperative. To date there has been no published study that has examined palliative care needs of PLWHA in Rwanda. To meet this gap, this study focused on the identification of met and unmet palliative care needs of adults living with HIV/AIDS in Rwanda. To achieve this aim, the study firstly identified palliative care needs of PLWHA, and secondly determined the extent to which palliative care needs were met.

Methods

This descriptive cross sectional study was carried out between December 2005 and February 2006 in Kigali City and Butare,¹ Rwanda. The study used both quantitative and qualitative methodology.

The study population included PLWHA, healthcare workers (i.e. medical doctors, nurses, physiotherapists, social workers, dieticians and counsellors/psychologists) and coordinators of HIV/AIDS units. PLWHA included in the study were outpatients and inpatients from six health facilities: two national referral hospitals, one district hospital, two health centres, and a day centre run by Treatment and Research AIDS Centre (TRAC). The inclusion of both inpatients (who are mainly on ART) and outpatients from different levels of health care was to get a general picture of PLWHA's palliative care needs.

A purposive sampling method was used in order to gather in-depth information from PLWHA and from key informants (HIV/AIDS coordinators and health care professionals) who had an overview of palliative care services for PLWHA. According to Bless and Higson-Smith (2000), purposive sampling is used in special situations in which a researcher selects unique cases that are especially informative for in-depth investigations.

ARTICLE ORIGINAL

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

There were 306 participants in the study including PLWHA, health professionals and coordinators of HIV/AIDS units. The inclusion criteria for the PLWHA were people who were sero-positive; registered at health facilities included in the study; who could read and write; and those with a cognitive ability to comprehend and communicate. Exclusion criteria were individuals under the age of 15 years; those with severe cognitive problems; and those with disabilities such as people who were blind or deaf. Inclusion criteria for health professionals were any health professionals, i.e. medical doctors, nurses, physiotherapists, counsellors, psychologists, social workers, and nutritionists; working at a health facility included in the study; and were part of the HBC/palliative care team or had been involved in HIV/AIDS care for more than one year.

Two questionnaires, adapted from literature, were used for quantitative part of the study. The questionnaire used for the PLWHA to assess their palliative care needs, was adapted from Kikule (2003). The questionnaire for health care professionals was adapted from Steward, Ormond, Linnebach and Schellenberg (2000). Prior to administration of the questionnaires, a professional translator translated the questionnaires into Kinyarwanda (local language) and French. These translated questionnaires were piloted in Rwanda in an attempt to ensure validity and reliability, minimising instrument bias. The interviewer checked the questionnaires with the respondents to avoid errors in completing the questionnaires. Patients' medical files were also used to gather factual clinical data on the PLWHA's CD4 cell counts, symptoms, stage of HIV infection, and medication.

A total of 250 questionnaires were administered to PLWHA who gave consent to participate in the study and 50 questionnaires were distributed to health professionals who gave consent to participate in the study. The purpose of the quantitative data was to quantify the perceived palliative care needs.

In the qualitative part of the study, interview guides were used for the individual interviews with HIV/AIDS coordinators and a focus group discussion for PLWHA. The interview guides included questions needing more in-depth information to supplement the information provided by questionnaires, and was thus

developed after the questionnaires had been administered.

Four coordinators of HIV/AIDS units at the health facilities were interviewed to explore their perception of the palliative care needs and the strengths and gaps in the service provision. Twelve PLWHA, who were members of an association affiliated to the national association of PLWHA (ANSP+), were purposively selected for a focus group discussion to explore in greater depth their perceived palliative care needs and their experiences of palliative care and other health services.

The quantitative data were captured in Excel and analysed using SAS and SPSS. Qualitative data were transcribed, then analysed by coding and identifying themes. The quantitative findings were compared to the qualitative findings using triangulation (Rees & Bath, 2001). These findings are integrated in the results.

Permission to conduct the study was obtained from the Rwandan Ministry of Health Ethical Committee and the Research Study Grant Committee of the University of the Western Cape (where the researcher was a student). The purpose of the study was explained to the participants and verbal consent obtained from PLWHA. Written consent was obtained from the health care workers and coordinators of HIV/AIDS units. PLWHA were assured that information would be treated in confidence and that they would still receive care from the programme if they chose not to participate in the study.

Results

All 250 questionnaires from the PLWHA and the 40 questionnaires from the health professionals were returned. The socio-demographic characteristics of the PLWHA who participated in the study are presented in Table 1 below. The mean age of the PLWHA was 38 years.

Symptoms reported by PLWHA

Most PLWA reported experiencing symptoms related to HIV/AIDS, with 69% of PLWA having symptoms most of the time and 10% having symptoms regularly. Physical symptoms were reported by 92% of PLWHA, and neuromuscular conditions were reported by 70% of PLWHA. One coordinator of a HIV/AIDS unit

ORIGINAL ARTICLE

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

TABLE 1. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PLWHA (N=250)

	Characteristics	n	%
Gender	Female	176	71
	Male	72	29
Marital status	Single	25	10
	Married	96	38
	Widowed	109	44
	Divorced	20	8
Level of education	No schooling	42	17
	Primary	155	62
	Secondary	48	19
	Tertiary	4	2
Occupation	Housewife	15	6
	Businessperson	36	14
	Civil servant	46	18
	Unemployed	153	61

suggested that the presence of neurological symptoms might be due to the side effects of certain drugs:

Most of the HIV/AIDS patients who have neuromuscular symptoms such as hemiparesis, paraparesis or paraesthesia and numbness are as a result of the toxicity of most of the ARV's drugs such as D4T, and NIH for those who have TB.

Some PLWHA reported difficulty performing activities of daily living (ADL). PLWHA who reported having no symptoms indicated they could participate more easily in ADL than those with symptoms. The association between the reported health status and the ability to perform ADLs was significant ($p < 0.001$).

Palliative care needs identified by PLWHA

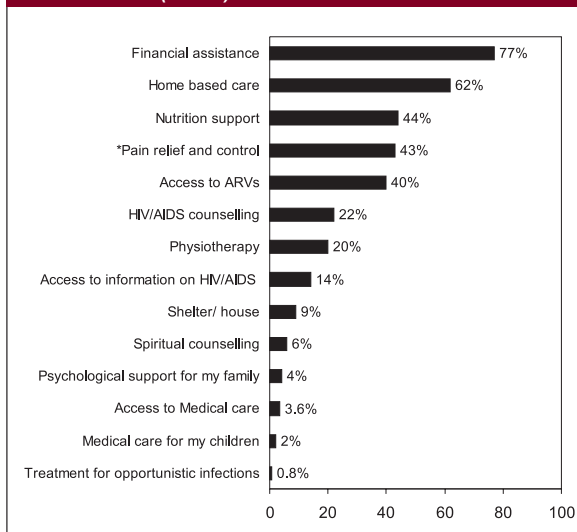
The palliative care needs identified by PLWHA are illustrated in Figure 1.

Financial needs

The majority of PLWHA (77%) identified the need for financial assistance. Most PLWHA were unable to pay for their medical care or that of their family members:

Some of us have children and husbands who are sick too [HIV positive] but the medical care provided to us does not cater for our children unless you pay yourself for your spouse and kids, while at the moment we cannot afford that. (PLWHA)

FIG. 1. PERCEIVED PALLIATIVE CARE NEEDS OF PEOPLE LIVING WITH HIV/AIDS (N=250)



* Pain relief includes symptom management

Beside the need to pay for medical expenses, there was a need for financial support for the family, as many PLWHA were unable to work:

I need financial assistance so that my kids will continue to go to school. Due to my sickness I cannot work any longer. (PLWHA)

The majority of PLWHA (91%) reported having financial problems, and only three PLWHA (1%) received financial support. Out of the three PLWHA who received financial support, only one participant had support which he considered "helped a lot" to meet his needs.

Home-based care (HBC) needs

The second most frequently identified need, reported by 62% of PLWHA, was for HBC. Many PLWHA preferred to be looked after at home:

We also need HBC, so that we receive the care at home. Sometimes it is difficult to get to the hospital for treatment due to sickness or transport. I would prefer to be looked after at home. (PLWHA)

Others PLWHA said they felt less stigmatised if they were cared for at home:

Regular visits at home help a lot because you feel not stigmatised or discriminated. Thus also helps health workers

ARTICLE ORIGINAL

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

to know in which ways or condition that I am in so that they will know what I need as support. (PLWHA)

Nutritional needs

The need for food was reported as the third greatest need, by 44% of PLWHA. The need for nutrition was related to their use of medication and their health status:

ARVs help a lot but it requires having enough food because if you don't have food the drugs will weaken you much more and cause you problems. There are some of our friends in the group who did not have a good adherence to ARVs, due to lack of food and they had to stop taking their medication. (PLWHA)

The coordinator at the National Treatment and Research AIDS Centre (TRAC) acknowledged there was a need for nutritional support as part of the palliative care programme:

Palliative care does not include only medical care but the nutritional support is also needed as far as palliative care is concerned. Most of our HIV/AIDS patients require nutritional support since most of them present with some nutritional deficiency.

Medical care needs

There was a need expressed for medical care. This included the need for pain relief which was reported by 43% of PLWHA. Only 40% of PLWHA indicated they needed ARVs as most of the PLWHA (60%) were already on ARVs or prophylactic medication. Additionally, 20% of PLWHA indicated that they needed physiotherapy for the management of neuropathic pain.

Were these palliative care needs met?

Coordinators of the programmes spoke of poor palliative care provision:

The services provided by the palliative care team are very poor. We only concentrate on ARVs while we could incorporate other service such as HBC, nutrition and other support required by the patients. So far we have just covered 50% of the efficacy of AIDS care. Palliative care is still a new concept that why much has not yet been done. (Coordinator)

Although some health care support was provided to PLWHA and their families, many of the needs were described as not having been met. These included access to palliative care, access to ARVs, pain relief, psychological support, physiotherapy support, and health care for the families.

Access to palliative care

PLWHA expressed their negative views of the medical support provided by health service providers in meeting their palliative care needs:

When you are admitted in the hospital, there is no proper follow up by health care workers. You are the only one who takes care of yourself. Apart from medical support there is no another support available for you. (PLWHA)

The medical support the PLWHA were referring to included drugs for pain control and nursing care. In addition to medical support, PLWHA wanted to have more support for their emotional, social and spiritual needs. This support reflects the principles of palliative care as recommended by the WHO, including physical/medical, psychological and spiritual care.

Access to ARVs

One participant commented on the difficulty of getting access to ARVs:

The medical care that we received is not proportional because only those who have a CD4 count which is low, that means 200/mm³, are the ones who have access to medical care such as ARVs and receive other support like food. But for us who have a CD4 count above 200/mm³, we do not have access to medical care. Yet we are still sick. (PLWHA)

Pain relief

Treatment provided for pain in Rwanda includes analgesics drugs such as Ibuprofen or prophylactic treatment such as co-trimoxazole, and physiotherapy for those who have neurological related pain and chest pain. Seventy two percent of PLWHA indicated that they experienced pain. While 50% of PLWHA indicated that they had had treatment to relieve their pain, 23% of these participants reported it did 'not help'. A further 42% of these participants reported that the treatment helped 'a little bit', 27% of these participants reported it helped 'quite a lot' and only 8% of these participants said that it helped 'a lot'.

ORIGINAL ARTICLE

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

Psychological or emotional support

A high proportion of PLWHA (65%) indicated they had had psychological problems. Sixty two percent of participants had received psychological support. Of these, 11% of participants reported that the psychological support helped 'a lot' while 3% reported that it 'did not help'.

Physiotherapy support

Of the 250 participants, only 11 (7%) participants had received physiotherapy support. Of these, 10 (90%) participants had had massage as their treatment with 8 (80%) participants indicating that the massage had helped them. One participant had had joint mobilisation. Six participants (75%) reported that the electrotherapy they had received had 'helped'.

Health care for families

The expressed need for access to medical care by PLWHA did not only focus on their own needs as a result of their illness but also the medical care that was needed by their partners and children who were also ill, including some who have AIDS. As one of the participants stated:

Some of us have children and husbands who are sick too, but the medical care provided to us does not cater for our children and husbands. (PLWHA)

Emotional support for the families was also needed, as one of the PLWHA stated:

We need also counselling service, which will provide psychological support towards my family.

Obstacles to the provision of palliative care

Health workers identified obstacles to the provision of palliative care to PLWHA and their families. These are presented in Table 2.

Seventy eight percent of health workers indicated that there were not have enough staff to meet the palliative care needs of all PLWHA and their families. Additionally one coordinator described the limited capacity of the human resources:

The need for an increase in health workers, who are skilled, is to enable them to deliver palliative care service to people who require it.

TABLE 2. OBSTACLES TO MEETING PALLIATIVE CARE NEEDS (N=40)

Obstacle	n	%
No appropriate space for counselling	27	68
Lack of funding	24	60
Rwandan culture	15	38
Lack of policy on palliative care	11	28
Lack of skills	10	25
Stigma around HIV/AIDS	9	23
Lack of time	2	5

A major obstacle to providing pain relief was the shortage of drugs:

Most of the hospitals do not have sufficient drugs for pain control and relief especially opioid drugs. In addition, opioid drugs are very expensive and patients cannot afford to buy them. We really need drugs to effectively manage the pain of our patients. (Coordinator)

They identified a shortage of equipment, with 88% of health workers reporting that they did not have enough equipment at their workplaces:

We need equipment such as motorbikes to facilitate transport for health workers who go for HBC. We also need a department, which is well equipped with a computer so that we can have a database of information on patients' needs and the services provided, as well as hospital wards which will be specifically for patients under palliative care. (Coordinator)

Other obstacles to providing palliative care identified were the Rwandan culture, stigma, and inadequate policy on palliative care as well opioid drugs.

In summary, despite the health care services available for PLWHA and their families to meet needs, many of their palliative care needs were still unmet, especially financial assistance and pain relief. Only 11% of PLWHA indicated that psychological support 'helped a lot', 8% of PLWHA indicated pain relief 'helped a lot', and 1% of PLWHA indicated that the financial assistance 'helped a lot'.

ARTICLE ORIGINAL

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

DISCUSSION

The HIV/AIDS epidemic in Rwanda has undermined the QoL of many PLWHA and their families, affecting all segments of the population, and threatening the development and prosperity of the country. As the numbers of PLWHA continue to grow and the demand for care increases, the limited access to treatment and care will further compromise the quality of life of PLWHA.

The development of palliative care has become necessary to meet the needs of the sick and improve their QoL (Sepulveda *et al.*, 2002). The World Health Organisation recommends the development of palliative care in countries with a low resource base, as a means of ensuring that care is accessible to all patients and their families. Palliative care needs include physical, psychosocial and spiritual care. This could be delivered either in the hospital or at home.

The areas of greatest concern are the economic status of PLWHA and the infrastructure of the health system for the provision of comprehensive HIV/AIDS care including palliative care. In this study, health care workers, the HIV/AIDS unit coordinators and PLWHA had similar perceptions of palliative care needs for PLWHA. There is a need for pain relief and management of other symptoms; access to ARVs and opportunistic infection treatment; nutritional support; HBC; financial assistance; housing; physiotherapy; access to HIV/AIDS information; psychological support for both patients and their families; and spiritual counselling. However, the most frequently mentioned perceived palliative care needs were for financial assistance (77%), HBC (62%), nutrition (44%), pain relief (43%) and access to ARVs (40%). These are similar to needs identified in studies in other countries (Grant, Murray, Grant & Brown, 2003; Harding & Higginson, 2004; Karus *et al.*, 2004; Kikule, 2003; Lasechinger *et al.*, 2005; Lau, Tsui, Li, Chung, Chain & Molassiotis, 2003; Sepulveda *et al.*, 2003).

Most of the palliative care needs that were identified in the study were not met, in particular the need for access to palliative care, access to ARVs, pain relief, psychological support, financial support and health care for families.

In Rwanda, like many African countries, poverty has resulted in poor health care, consequently most of the needs identified by PLWHA were indirectly financial needs. However, provision of ARVs and prophylaxis treatment for opportunistic infections was the most common service provided to PLWHA in all the health facilities that participated in the study. Katz, Cunningham, Mor, Andersen, Kellogg, Zierler *et al.* (2000) argue that the priority form of medical care for PLWHA in many African countries has been the provision of ARVs and other drugs rather than other supportive services, while the availability of opioid drugs for pain relief is often limited or non-existent.

There is evidence that ARVs significantly improve the QoL and survival of PLWHA when they are introduced early (Wang, Vlahov, Galai, Baretta, Strathdee & Nelson *et al.*, 2004). Although the findings of this study indicate that 60% of the PLWHA were on ARVs, the accessibility to ART is still poor and the coverage is low in the general population of PLWHA who require ART. The PLWHA in the quantitative sample were in hospital, so were more likely to be receiving ART than others outside hospital, particularly PLWHA in the rural areas. The low coverage and problems with accessibility to ART has been reported in many other African countries beside Rwanda. Katz *et al.* (2000) argue that despite the increasing accessibility of ART globally, most PLWHA in most African countries have limited access to ART. This suggests that African states, including the Rwandan government, should consolidate their efforts to improve the distribution and uptake of ARVs.

The need for pain relief by PLWHA was not met, although the findings indicate that over 50% of PLWHA had received treatment for pain. However, only 8% of PLWHA said that the treatment received for pain 'helped a lot'. This suggests that the management of pain is limited and ineffective. Health care workers identified the lack of capacity of health workers as a problem for the effective functioning of the palliative care team. This finding is supported by other studies which suggest that inadequate pain management is due to lack of knowledge of health professionals about HIV/AIDS, inadequate palliative care, as well as inadequate access to essential analgesics or ARVs (Gwyther & Rawlinson, 2004; O'Neill, Romaguera, Parham & Marconi, 2002).

ORIGINAL ARTICLE

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

In Rwanda the ineffective management of the pain of PLWHA was largely due to the limited access to opioid drugs and other analgesics drugs. In addition, one could argue that limited access to and availability of opioid drugs in health facilities will affect the delivery of palliative care in Rwanda. There is a need for the health sector to advocate for an increase in the supply of drugs and increased accessibility to the drugs, especially opioids, in order to improve palliative care and the management of pain of PLWHA.

Many people in Rwanda have experienced psychological difficulties as a result of the genocide war in 1994. At that time millions of people died and thousands of women were raped, resulting in the high number of women who are HIV positive. With the additional emotional difficulties that people experience with the HIV/AIDS epidemic, a great deal of psychological support is needed. However, of the 50% of PLWHA who indicated they had had psychological support only 11% of indicated that the support helped them 'a lot'. Franks, Salisbury, Bosanquet, Wilkinson, Kite, Naysmith *et al.* (2000) argue that palliative care should address the psychological problems of both patients and their families. This is even more important in Rwanda, considering the particular situation following the war. Steps need to be taken to plan for psychological services, including bereavement services to be provided to both PLWHA and their families.

In addition, health workers identified various obstacles that impede the proper delivery of palliative care of PLWHA. These include limited number of skilled health workers, inadequate policy on palliative care, and availability of opioid drugs, Rwandan culture, stigma and funding. The above listed obstacles have also been identified in other studies in Africa (Coughlan, 2004; WHO 2002b). Therefore, the Rwandan government should take measures to address the above obstacles and improve the provision of palliative care by engaging with stakeholders and international funding agencies.

The need for financial assistance was the need most frequently identified by PLWHA; however, it was not met. Of the three (1%) PLWHA who had received financial support only one (33%) PLWHA reported having received financial support that 'helped' meet their needs. Health care workers indicated that

financial assistance was a service that was not offered by their health facilities. Where the financial support was available it was funded and provided by NGOs. Studies in other African countries have found a similar problem (Kikule, 2003; Sepulveda *et al.*, 2003; WHO, 2002b). The extreme poverty in Rwanda makes it difficult for the health sector to provide financial support to PLWHA and meet their financial needs. Poverty has affected the health infrastructure and the delivery of health care. It is to a large extent the underlying cause of the inadequate provision of ARVs, of drugs for opportunistic infection, and of limited opioid drugs.

In spite of limited financial resources available in the country, the Rwandan government needs to develop strategies to alleviate poverty among the Rwandan population, particularly those who are HIV positive, since many PLWHA have lost their income as a consequence of their illness while at the same time having increased medical expenses. Schneider *et al.* (2000) have shown that HIV seriously impairs the ability of households to meet basic needs. The nutritional needs of PLWHA were highlighted in the study. This is the direct result of poverty, but is aggravated by the illness. The health workers indicated that there was an urgent need for food supplements to be provided by the palliative care teams. The health sector could collaborate with non-governmental organisations to address the financial need of PLWHA and provide food supplements.

Study limitations

This study is not free of limitations that affect generalisation. Firstly, PLWHA were mainly from urban and peri-urban areas in Kigali City and Butare provinces (i.e. Southern Province), with a small number of participants from the rural areas in neighbouring provinces such as Kibuye and Gikongoro. Palliative care needs of PLWHA in the rural areas are likely to be different from those in the urban areas as there is increased poverty and more traditional cultural and religious values and belief systems. There is a need for further investigation to determine the care needs of PLWHA living in rural areas, as well as factors that hinder the delivery of palliative care, including cultural and religious values and beliefs.

ARTICLE ORIGINAL

Met and unmet palliative care needs of people living with HIV/AIDS in Rwanda

Secondly, the ability of the participants to read and write as an inclusion criterion affected the nature of the sample. The limited resources for the study made it impossible to include research assistants to assist those who were illiterate. Finally, the study did not include caregivers or family members of PLWHA. Their participation could have provided a broader picture on palliative care needs, by focusing on both PLWHA and their families since palliative care needs to include the care of the patient's family.

CONCLUSION

HIV/AIDS is a disease with severe social consequences that primarily affects those who are already poor and socially disadvantaged. HIV/AIDS is accompanied by bereavement, loss of relationships, unemployment, disability, increased health care costs, stigma and ostracism, and fear of premature death. Palliative care is recommended as an appropriate form of support for PLWHA and their families. The findings of this study indicate that many needs of PLWHA in Rwanda have not been met through palliative care. This has affected the QoL of PLWHA and their families. Palliative care programmes for PLWHA in Rwanda need to be revised in order to address unmet needs. These are pain control and relief, financial and psychosocial needs. These palliative care needs of PLWHA, and the obstacles to the provision of optimal palliative care, need to be taken into consideration by policy makers and health professionals who plan palliative care services for PLWHA in Rwanda.

Footnotes

¹Since the beginning of 2006, Butare Province has been considered a town in the Southern Province.

References

- Abdu-Saad, H.H. (2000). Palliative care: An international view. *Patient Education and Counselling*, 41(1), 15-22.
- Beedham, H. & Wilson-Barnett, J. (1995). HIV and AIDS care: Consumers' views on needs and services. *Journal of Advanced Nursing*, 22(2), 677-686.
- Bless, C. & Higson-Smith, C. (2000). *Fundamentals of social research methods: African perspective*. Cape Town, SA: Lansdowne: Juta.
- Coughlan, M. (2004). Rapid appraisal of palliative care and community and HBC in Abidjan, Cote D'Ivoire. (Full text: www.fhi.org)
- Franks, P.J., Salisbury, C., Bosanquet, N., Wilkinson, E.K., Kite, S., Naysmith, A. & Higginson, I.J. (2000). The level of need for palliative care: A systematic review of the literature. *Palliative Medicine*, 2(14), 93-104.
- Government of Rwanda. (2004). Rwandan Ministry of Health: Annual report on ARV's distribution. [Online] Available: <http://www.moh.rw.gov> [8/20/04]: 6.30 p.m.
- Grant, E., Murray, S.A., Grant, A. & Brown, J. (2003). A good death in rural Kenya? Listening to Meru patients and their families talks about care needs at the end of life. *Journal of Palliative Care*, 19(3), 159-67.
- Gwyther, L. & Rawlinson, F. (2004). Symptom control in palliative care: Essential for quality of life. *South Africa Medical Journal*, 94(6), 437-454.
- Harding, R. & Higginson, I.J. (2004). Palliative care in sub-Saharan Africa: An appraisal. http://www.theworkcontinues.org/causes/pall_library.asp
- Joranson, D.E., Ryan, K.M. & Jorenby, J.P. (2004). Availability of opioid analgesics in Romania, Europe and the World. (Full text: www.medsch.wisc.edu/painpolicy)
- Katz, M.H., Cunningham, W.E., Mor, V., Andersen, R.M., Kellogg, T.M.A., Zierler, S., Crystal, S.C., Stein, M.D., Cylar, K., Bozzette, S.A. & Shapiro, M.F. (2000). Prevalence and predictors of unmet need for supportive services among HIV-infected persons: Impact of case management. *Medical Care*, 38(9), 58-69.
- Karus, D., H.Raveis, V., Marconi, K., Hanna, B., Selwyn, P., Alexander, C., Perrone, M. & Higginson, I.J. (2004). Service needs of patients with advanced HIV disease: A comparison of client and staff reports at three hospital care projects. *AIDS patients care and STDs*, 3(18), 145-158.
- Kikule, E. (2003). A good death in Uganda: Survey of needs for palliative care for terminally ill people in urban areas. *British Medical Journal*, 327(7408), 192-196.
- Lau, J.T.F., Tsui, H.Y., Li, C.K., Chung, R.W.Y., Chain, M.W. & Molassiotis, A. (2003). Needs assessment and social environment of people living with HIV/Aids in Hong Kong. *AIDS Care*, 15(6), 699-706.
- Lasechinger, J.S., Van Manen, L., Stevenson, T. & Fothergill-Bourbonnais, F. (2005). Health care providers' and patients perspectives on care in HIV ambulatory clinics across Ontario. *Journal of the Association of Nurses in AIDS Care*, 1(16), 37-48.
- Ministry of Health (MoH) (2005). Demographic and health survey. Preliminary results on HIV sero-prevalence. (Full text: www.moh.gov.rw)
- O'Neill, J.F., Romaguera, R., Parham, D. & Marconi, K. (2002). Practicing palliative care in resource poor settings. *Journal of Pain and Symptom Management*, 24(2), 148-151.
- Rees, C.E. & Bath, P.A. (2001). The use of between methods triangulation in cancer nursing research: A case study examination information sources for partners of women with breast Cancer. *Cancer Nursing*, 24, 104-111. [IN TEXT?] yes
- Schneider, P., Nandakumar, A.K., Porignon, D., Bhawalkar, M., Butera, D., & Barnett, C. (2000). Rwanda National Health Accounts, 1998. Partnerships for health reform technical report 53. (Full text: www.usaid-rwanda.rw)
- Selwyn, A.P. & Rivard, M. (2003). Palliative care for AIDS: Challenges and Opportunities in the Era of Highly Active Anti-Retroviral Therapy. *Journal of Palliative Care*, 6(3), 475-487.
- Sepulveda, C., Amanda, M., Tokwo, Y. & Ullrich, A. (2002). Palliative care: The WHO's global perspective. *Journal of Pain and Symptom Management*, 24(2), 91-96.
- Sepulveda, C., Habiymbere, V., Amandua, J., Borok, M., Kikule, E., Mudanga, B., Ngoma, T., & Bogale, S. (2003). Quality care at end of life in Africa. *British Medical Journal*, 324(7408), 209-214.
- Singer, P.A. & Bowman, K.W. (2002). Quality of care at end of life. *British Medical Journal*, 324, 129-192.
- Spence, D., Merriman, A., & Binagwaho, A. (2004). Palliative Care in Africa and the Caribbean. *Plos Med*, 1:1-5.
- Steward, P.A., Ormond, M., Linnebach, K., & Schellenberg, J. (2000). HIV/AIDS palliative care: Needs in the prairies region. Research report presented to Canadian Palliative Care Association. (Full text: www.google.com)
- UNAIDS (2003). Epidemiological fact sheet on HIV/AIDS in Rwanda. (Full text: www.unaids.org)
- UNAIDS (2006). Report on the global AIDS epidemic, 2006: Executive summary: A UNAIDS 10th anniversary special edition (Full text: www.unaids.org)
- USAID (2004). United States Agency for International Development/ Rwanda: Annual report, Kigali. June 2004. (Full text: www.usaid.org)
- Wang, C., Vlahov, D., Galai, N., Baretta, J., Strathdee, S.A., Nelson, K.E. & Sterling, T.R. (2004). Mortality in HIV-seropositive versus -seronegative persons in the era of highly active anti-retroviral therapy: implications for when to initiate therapy. *Journal of Infectious Diseases*, 190(6), 1046-54.
- Willes, R., Payne, S. & Jarrett, N. (1999). Improving palliative care services: A pragmatic model for evaluating services and assessing unmet need. *Palliative Medicine*, 13(1), 131-137.
- Williams, A. (1999). An assessment of community palliative care needs: The case of Niagara. *Journal of Palliative Care*, 15(1), 45-52.
- William J. Clinton Foundation (2003). Government of Rwanda HIV/AIDS Treatment and care Plan. May 2003. (Full text: www.google.com)
- WHO (2001). World health report, 2001. Mental health: New understanding, new hope. Geneva. (Full text: www.who.int)
- WHO (2002a). National cancer control programmes: Policies and management guidelines. Geneva. (Full text: www.unaids.org)
- WHO (2002b). Community health approach to palliative care for HIV/AIDS and cancer patients in Africa: Progress Report, October. (Full text: www.who.int)
- WHO (2005). Rwanda: Summary country profile for HIV/AIDS treatment scale-up. (Full text: http://www.who.int/3by5/support/june2005_rwa.pdf)
- WHO (2006). Home-based long-term care. (Full text: www.who.int)