MINISTRY OF HEALTH

PALLIATIVE CARE IN VIET NAM:

Findings from a Rapid Situation Analysis in Five Provinces

PALLIATIVE CARE IN VIET NAM:

Findings from a Rapid Situation Analysis in Five Provinces

June, 2006

Principal author:	**Kimberly Green** *Family Health International*
Co-authors:	**Dr. Ly Ngoc Kinh** *Director of Therapy Department, Ministry of Health, Vietnam*
	Dr. Luong Ngoc Khue *Vice Director of Therapy Department, Ministry of Health, Viet Nam*

Acknowledgements

On behalf of the research committee, the Ministry of Health Therapy Department would like to thank all the individuals who actively participated in the design, planning, implementation, and data analysis.

In particular, gratitude and thanks go to experts from international organizations, Ms. Kimberly Green and Ms. Marie Coughlan – Family Health International; Dr. Eric Krakauer from VCHAP - Harvard University; Dr. David Stephens- POLICY project. They brought both their passion and dedication to the practice of palliative care, and their exceptional technical insights into the design and implementation of the rapid situation analysis, and to Eric for his thoughtful review and comments to the draft report.

Special recognition goes to Dr. David Stephens (Policy Project) and to Dr. Eric Krakauer (Harvard University) and Marie Coughlan (Family Health International) who brought both their passion and dedication to the practice of palliative care, and their exceptional technical insights into the design and implementation of the rapid situation analysis. Appreciation also goes to both Eric and Marie, who led assessment teams in the north and south of Viet Nam, and to Eric for his thoughtful review and comments to the draft report.

Many thanks also go to Dr. Nguyen Thi Minh Ngoc, USAID; Dr. Do Duy Cuong, Family Health International; Nguyen Minh Thu, Policy Project; and Dr. Phan Thu Phuong, Family Health International, who helped to guide the data collection and data analysis process of the assessment and without whom this RSA would not have happened; and to Jennifer Innis and Martin Duchesne, palliative care nurses from Canada, who, in the final stages, provided assistance to pull the report together. Appreciation also goes to all the individuals who assisted with the interviews. There are too many to list here but their names are included in the annex of this report. Thanks are also offered to Stephen Mills, FHI Viet Nam Country Director, for his unwavering support in the implementation of this palliative care initiative.

Finally, to all the health care workers, policy leaders and program managers who generously gave their time to the interviewers and to the many people throughout Viet Nam living with HIV/AIDS, with cancer and to their families for sharing their sincere, brave and heartfelt stories.

Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARV	Anti-Retroviral
AusAID	Australian Agency for International Development
CHBC	Community and Home-Based Care
EDL	Essential Drug List
FHI	Family Health International
HAART	Highly Active Anti-Retroviral Therapy
HBC	Home-Based Care
HCMC	Ho Chi Minh City
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug User
NCB	International Narcotics Control Board
NGO	Non-Government Organization
OPC	Outpatient Clinic
PLHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother-to-Child Transmission
RSA	Rapid Situation Analysis
TB	Tuberculosis
UNDP	United Nations Development Program
USAID	United States Agency for International Development
USCDC	United States Centers for Disease Control and Prevention
VCHAP	Vietnam-CDC-Harvard Medical School AIDS Partnership
WHO WPRO	World Health Organization Western Pacific Regional Office

Table of Contents

ANNEX

SECTION 1
EXECUTIVE SUMMARY

RATIONALE FOR RAPID APPRAISAL

In Việt Nam, 263,000 people are estimated to be living with HIV/AIDS and approximately 150,000 people are diagnosed with cancer each year. It is well documented that pain and suffering are prevalent among people with these and other life-limiting illnesses. While international research shows that from 60 to 80% of people with HIV/AIDS and cancer will experience distressing symptoms including pain particularly in the last stages of life, very little is known regarding palliative care needs in Viet Nam.

The rapid appraisal provides the foundation for developing national palliative care guidelines, education and training, and service expansion which are paramount to ensuring that people with HIV/AIDS and cancer do not suffer unnecessarily and are able to attain the highest possible quality of life. Without palliative care services in place, the health care system of Viet Nam will not be able to reduce the pain and suffering experienced by people with life-limiting illness, or to enhance the ability of people to tolerate and adhere to disease-modifying treatments such and anti-retroviral therapy (ART).

Despite excellent small-scale palliative care services offered by the National Cancer Institute, by regional cancer hospitals, and by a handful of NGOs for people living with HIV/AIDS, no service standards, strategies or National Palliative Care Guidelines exist. There are also no policies or national guidelines on the use of opioids for pain control in hospital and community settings or standards for training of providers in palliative care.

METHODOLOGY

To better appreciate and respond to the full spectrum of palliative care needs in Việt Nam, the Therapy Department of the Ministry of Health in cooperation with international partners, FHI, Policy Project, VCHAP, USAID and USCDC through the US Government President's Emergency Plan for AIDS Relief, conducted in summer 2005 a rapid situation analysis (RSA) in five high HIV and cancer prevalence provinces in Việt Nam: Hanoi, Hai Phong, Quang Ninh, HCMC and An Giang.

In total, 451 individuals were interviewed including people with HIV/AIDS or cancer, family caregivers and bereaved family caregivers, health care workers, palliative care program managers, and health and policy leaders.

FINDINGS AND RECOMMENDATIONS

In general, pain and suffering is very prevalent among people with HIV/AIDS and cancer, yet pain and symptom control measures are far from adequate. Health care workers often lack access palliative care medicines needed to treat pain and other symptoms reported by interviewees. Health care workers and palliative care program providers are for the most part not trained in palliative care principles and practice, are unaware that pain should be assessed and treated using the WHO pain treatment ladder and do not practice around-the-clock pain control.

The RSA also revealed that emotional suffering is extremely common among people with cancer and people with HIV/AIDS and that expanded counseling and emotional support services are badly needed.

From the RSA results, it is clear that policy makers are well aware of the fact that palliative care services are insufficient. They are supportive of improving and scaling-up palliative care services including provision of oral morphine to people in severe pain who prefer to be cared for in the home by trained and authorized health care personnel.

The assessment found that:

- **Severe, chronic pain is prevalent among people with cancer and HIV/AIDS:**

Eighty-one per cent of interviewees reported having been in pain since diagnosed with HIV/AIDS or cancer; of these, 53% stated they were in pain always or at least once a week and 57% reported having very strong to severe pain the last time they were in pain. In addition, 90% experienced symptoms other than pain which caused physical discomfort – the majority reported that last experienced symptoms (other than pain) caused strong to severe physical discomfort.

- **Access to essential pain control and other palliative care medicines is limited:**

Despite 93% of opinion leaders stating that morphine should be used to control pain, access to morphine to manage severe pain is very limited in Viet Nam. Few of the people with HIV/AIDS or cancer interviewed reported receiving morphine to treat severe pain and only 5% of health care workers reported availability of oral morphine in their health care setting. Thirty per cent of health care workers said that parenteral morphine had never been available in their work place. Of the 70% who reported parenteral morphine being available in their hospital in the past, 42% said that there currently was no morphine supply available in their hospital. Thirty-nine per cent of health care workers stated there were no pain relief policies or guidelines in their health care setting.

Access to oral and injection morphine was equally limited in palliative care programs and in general health care services. Other essential palliative care medicines such as tricyclic anti-depressants (used to manage neuropathic pain and depression) and benzodiazepines for anxiety also limited in availability.

- **Service availability and cost are a barrier to accessing care:**

Of the palliative care programs surveyed, 31 in total, only a few major cancer centers were reaching significant numbers of people in need. The remaining programs, which comprise of the majority of the palliative care programs in the country, were reaching from three to 60 people a year. Given that a minimum of 50,000 people with HIV/AIDS and require palliative care services immediately, current coverage is far from adequate.

A recent UNDP study in Viet Nam found that health care costs for households with a PLHA were 13 times higher than the average household. This finding corroborates with responses from people with HIV/AIDS and cancer and their caregivers, who cited money concerns as one of their greatest worries. It also correlates with responses from palliative care program managers who affirmed the cost of their services as the major barrier to client access.

- **Health provider training in palliative care is inadequate:**

From interviews with HIV and cancer health care providers, it was found that only 57% of health care workers caring for people with HIV/AIDS and cancer had been trained in managing pain. Of those, only 26% could identify correct pain management strategies. Even fewer could correctly define or explain palliative care. Palliative care program managers surveyed were also unable to correctly define palliative care. Only one health care worker interviewed referred to the WHO pain treatment ladder as their basis for assessing and treating pain.

- **Psychological support and help for family caregivers are urgently needed:**

The vast majority (82%) of people with HIV/AIDS and cancer said that they were either unhappy or very unhappy. In addition, 45% of people with HIV/AIDS stated that they had experienced stigma and discrimination. Sixty-four per cent of family caregivers reported spending more than 10 hours a day providing care to their family member with HIV/AIDS or cancer, and 30% of family caregivers expressed feeling stressed and worried because they did not know how to provide care.

- **There is support for providing pain relief medicines in the home:**

Fifty-two per cent of health care workers expressed support for prescription of oral morphine to people with HIV/AIDS or cancer who prefer to receive care in the home, administered in the home by a trained health care worker.

- **Policy makers feel that pain in people with cancer and HIV/AIDS is not well addressed:**

Eighty-five per cent of policy makers recognized that measures to address pain were not adequate in Viet Nam and that much more needs to be done to ensure palliative care for people with life-threatening illnesses.

Based on the above findings, key recommendations are:

1. **Develop national palliative care guidelines**

The findings from the RSA clearly indicate that palliative care guidelines are needed in order to set standards and norms for palliative care practice for people with life-limiting illnesses, including adults and children with HIV/AIDS and cancer. These guidelines should be developed as soon as possible to provide much needed guidance in palliative care to leaders, health care providers and communities. The guidelines should cover all the essential elements of palliative care including symptom and pain identification and control, psychosocial support, spiritual and end-of-life care and counseling, and care of caregivers.

2. **Complete national opioid control policy**

Without greatly increased availability of opioid analgesics, especially oral morphine clear and parameters for health care workers regarding the use of opioids, Viet Nam will not be able to achieve quality palliative care for people with HIV/AIDS and cancer. Moderate to severe pain can only be reduced or altogether eliminated by opioids, medicines which are inexpensive, rarely cause side-effects that cannot be easily

---

[1] Impact of HIV/AIDS on Household Vulnerablity and Poverty in Vietnam, USAID – UNDP Project, VIE98/006, 2005

managed and do not lead to dependence in the vast majority of patients. Therefore, national guidance specifying the handling and prescription of opioids in pain control so as to maximize availability for pain control and minimize diversion is essential.

In addition, the following opioids should be approved for use and made available in Viet Nam, ideally through local production:

- Codeine (not compounded with other medications)
- Long-acting morphine
- Fentanyl should also be classified as an analgesic on the Viet Nam Essential Drugs List

3. **Disseminate guidelines and policies**

Once guidelines and policies are developed, they will need to be widely disseminated among leaders, hospital managers, health care workers and home-based care services. Hospital administrators and provincial and district leaders will need to be aware of the new guidelines so they can update and improve their palliative care practices accordingly.

4. **Upgrade and expand availability of palliative care education, training and certification in accordance with national guidelines**

In-service training and certification should be provided in a step-wise fashion, starting first with cancer and HIV/AIDS care providers and then extending to other health care providers who do not provide care solely for PLHA and people with cancer.

In addition, palliative care training needs to be a part of basic education for nurses, pharmacists, doctors, social workers and psychologists. In order to develop a basic palliative care education curriculum for clinicians, an assessment would need to be undertaken for students of nursing, medicine, pharmacy, social work and psychology.

5. **Scale-up national, provincial and local palliative care programs, support development of model palliative care programs, including community provision of oral morphine by trained health workers.**

Both the availability and quality of palliative care services urgently need to be improved, particularly in areas of high HIV and cancer prevalence. In order to do this, the following actions should be taken:

- Priority should be given to incorporating palliative care within current cancer and HIV care and treatment programs including HIV outpatient clinics and 09 centers at central, regional, provincial and district hospitals. Staff at these facilities will need to be trained and equipped to assess and treat pain and other distressing symptoms. Palliative care and pain control centers should be establish in each cancer hospital with a complete range of pain control medicines including morphine and beds to accommodate local need.
- Coverage and quality of community and home-based care programs need to be extended so they are able to reach more people with HIV/AIDS and cancer with palliative care including pain control. Current home-based care and hospice service providers need to be better trained and equipped with essential palliative care medicines.
- Provision of oral morphine at the community and home based care level, prescribed and monitored by trained and certified health care workers should be piloted in a few

high HIV and cancer prevalence settings. As many people with cancer and HIV/AIDS prefer to be cared for in the home, such programs could vastly reduce suffering and enhance quality of life. Pilot programs could be conducted in high HIV and cancer prevalence provinces in the north and south. Based on lessons learned, a nationwide program of community administered oral morphine could be considered, as has been done in several other countries.

- Determination of quality standards of palliative care services which are based on national palliative care guidelines and international best practice. Palliative care programs in the community, hospices and hospitals should develop operational plans and standard operational procedures which include quality standards and rules for maximizing both availability and safe handling of opioids.

As much as possible, palliative care services and access to palliative care medicines should be offered at low or no cost for people with life-limiting illness. The RSA and a number of other research studies in Viet Nam reveal that people with chronic illness require multiple hospital admissions, medicine prescriptions, laboratory tests and clinical procedures, and outpatient clinic visits, are unable to afford the associated costs of chronic care. By minimizing or waiving the cost of palliative care services, people with cancer and HIV/AIDS will be able to live and die in greater peace and comfort.

SECTION 2:

INTRODUCTION AND BACKGROUND

WHAT IS PALLIATIVE CARE?

Definition of palliative care

Palliative care improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

For those with life-limiting illnesses, it is imperative that the principles of palliative care be practiced from the time of diagnosis through the end of life to the bereavement process for families.

Principles of palliative care

The following are international principles of palliative care, which are the foundation for Palliative Care Guidelines. Palliative care :

- is provided to all people with life-limiting illnesses such as HIV and cancer;
- provides relief from pain and other distressing symptoms;
- promotes adherence to medications, and mitigation of medicine side effects;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- focuses on helping patients live as actively and as independently as possible until death; promoting client and family empowerment, and self-care knowledge and skills
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a multidisciplinary team approach which focuses on the patient as its central team member and comprises both formal and informal caregivers to address the physical and psychosocial needs of patients and their families, including bereavement care;
- will enhance quality of life, and may also positively influence the course of illness;
- is provided early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications, and which may also be done to provide emotional and spiritual support.

WHY CONDUCT AN ASSESSMENT OF PALLIATIVE CARE IN VIET NAM?

In Việt Nam, 263,000 people are estimated to be living with HIV/AIDS and approximately 150,000 people are diagnosed with cancer each year. While a handful of excellent small-scale palliative care services are offered by the National Cancer Institute, by regional cancer hospitals, and a few NGOs, little is known regarding palliative care needs of people with HIV/AIDS and cancer or the quality of current

---

[2] WHO, Palliative care Guidelines, Geneva in Vietnam.

[3] Ibid.

services offered. Further, no guidelines or formal training programs exist which define the parameters of quality palliative care service provision or describe the medicines required in palliative care.

It is well established that pain and suffering are prevalent among people with HIV, cancer and other life-threatening illnesses. International research shows that from 60-80% of people with HIV and cancer will experience distressing symptoms, including pain particularly in the last stages of life. Physical symptoms coupled with the emotional, spiritual and social pain often associated with life-limiting illnesses can lead to tremendous anguish and suffering. However, very limited data are available which describe the prevalence and types of symptoms experienced by people with HIV/AIDS and cancer in Viet Nam.

The Vietnamese government has made scaling-up of treatment, care and support for HIV/AIDS and cancer a priority but has primarily developed guidance and training for disease-specific therapy. Palliative care services need to be available along-side of antiretroviral therapy (ART) and cancer treatments in order to fully address physical, social, emotional and spiritual suffering and result in quality of life for people with HIV/AIDS and cancer.

The World Health Organization and the International Narcotics Control Board recommend that all countries have national palliative care programs in place. They advise that countries follow five steps to achieve quality programs:

1) Assess palliative care needs, gaps and barriers,
2) Develop palliative care guidelines to establish uniform standards of care,
3) Remove barriers to essential palliative care medicines which may include reviewing and modifying national narcotic control policies to facilitate access to essential pain control medicines,
4) Improve pre-service and in-service palliative care education, training and certification,
5) Scale-up home, hospice and hospital based palliative care services.

An analysis of palliative care needs and the development of national palliative care guidelines based on analysis findings and recommendations provide an essential framework from which quality standards, training, funding, and the expansion of palliative care services are built. Guidelines facilitate the education and training of health care workers as well as the general public. As well, they can play a major role in facilitating an improved balance between drug control and the availability of drugs for pain and symptom management. Countries as diverse as Canada, Uganda, Singapore, South Africa, China and the US have followed the WHO recommended steps to develop national palliative care programs.

Based on the need to develop guidelines, training and expanded palliative care services, the Viet Nam Ministry of Health Therapy Department took the first step of developing a national palliative care program by assessing palliative care services, needs, gaps and barriers through a rapid situational analysis in five high HIV and cancer prevalence provinces.

The analysis examined palliative care needs expressed by people with HIV/AIDS, cancer, family caregivers, health care workers and opinion leaders. It also examined the medicine availability and needs of PLHA and people with cancer since medicines are critical to managing distressing symptoms resulting from HIV/AIDS and cancer.

THE NEED FOR PALLIATIVE CARE ESSENTIAL DRUGS

The WHO Action Program on Essential Drugs recommends that every country have an Essential Drug List, which is a list of drugs needed to treat diseases and conditions in that country. These lists should also include medications for palliative care. In particular, these lists need to include non-opioids, opioids and adjuvant analgesics, based on the recommendations of the WHO cancer pain relief program.[4]

On November 1, 1998, Viet Nam became a signatory to the Single Convention on Narcotic Drugs of 1961. This international treaty exists to prevent narcotic addiction and trafficking and at the same time to ensure that narcotic drugs are available to meet national pain and suffering control needs. The treaty binds governments to guarantee that opioids are available for medical purposes including pain management. The global body responsible for enforcing and managing the implementation of the treaty is the International Narcotics Control Board (INCB).[5]

The INCB and WHO have collaborated for nearly two decades on a global campaign to review and improve opioid analgesic availability in medical care. This partnership is based on mutual agency recognition of the many barriers to accessing narcotics for palliative care including legal and regulatory restrictions, lack of training among health care workers and inadequate supply of opioids for medical use.

As part of an effort to improve access to opioids for medical purposes, the INCB formally requested governments to assess barriers opioid use in the health care setting and to enact a process of rectifying identified problems. In 1995-1996, the INCB asked governments to report on progress made in improving medical access to opioids: 65 governments responded to the INCB survey saying that they had begun to address barriers – most of which were legal and regulatory. Viet Nam did not respond to this assessment as they had not yet signed the Single Convention on Narcotic Drugs of 1961.

The Viet Nam MoH review of palliative care needs and barriers through the Palliative Care RSA is a positive first step in identifying and addressing barriers to palliative care including access to opioids and other essential pain control medicines.

---

[4] World Health Organization (2002). National Cancer Control Programes: Policies and Managerial Guidelines. 2nd.WHO, Geneva.

[5] WHO Palliative Care Newsletter, david E. Joranson, MSSW and Sophie M. Colleau, PhD, 1996

Recommendations from the INCB Assessment

From the INCB assessment of country barriers to access to opioids for medical purposed, they prepared the report, “Availability of Opiate for Medical Needs”*. The report recommendations form the basis for steps each government needs to take in improving access to opioid, reduce suffering and improve quality of life of people with pain. The recommendations are:

(1) Examine existing legislation and policies to identify potential impediments to adequate opioid availability.

(2) Examine existing methods to assess future medical needs for opioids.

(3) Establish administrative authority for managing import and export licenses, for estimating future medical requirements, for supervising adequate controls over distribution.

(4) Establish a system to collect information about medical need for opioids from medical institutions and from manufacturers, distributors, importers and exporters.

(5) Anticipate possible increases in consumption when preparing the official annual estimates of medical need.

(6) Prevent interruptions in supplies of opioids.

(7) Insure that national legislation recognizes the obligation to ensure availability of opioids for all medical purposes.

(8) Inform health professionals about the WHO analgesic method for cancer pain relief.

(9) Communicate with health professionals about legal requirements for prescribing opioids.

Educational institutions and nongovernmental organizations should:

(1) Teach health professionals and medical students how to use opioids and how opioids are regulated.

(2) Communicate with government regulators about un-met needs for the medical use of opioids and impediments to their availability.†

PALLIATIVE CARE APPROACHES IN OTHER COUNTRIES

China

The Chinese Ministry of Health initiated the development of palliative care guidelines, training and service implementation in 1993 after a survey of health care workers found they were uncomfortable in using morphine and not been trained in pain management. Several improvements have been made to the palliative care policy since it was first published and services are more widely available. The program is an illustration of how government and health-care professionals can work together in a systematic way to develop guidelines, training and certification programs and quality service delivery to relieve pain for those with life-limiting illness

Uganda

The Ministry of Health made palliative care for patients with HIV/AIDS and cancer a priority in its National Health Sector Strategic Plan 2000/01 – 2004/05.[6] In March 2004, the Minister of Health authorized palliative care nurses and clinical officers to prescribe morphine as part of their clinical practice. Uganda imports powdered morphine and prepares oral morphine in country which is then made available through the Hospice Uganda Africa network. This approach has significantly improved the quality of palliative care offered to people with life-limiting illness who prefer to receive care in the home or hospice.[7,8]

Canada

Health Canada has a national strategy for palliative and end-of-life care through the Secretariat on Palliative and End-of-Life Care, which was established in 2002.[9] The Canadian Palliative Care Association published "A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice" in 2002. This guide is being used to influence the design and implementation of hospice palliative care programs and services across the country. While pain medicines and opioids in particular are regulated, health care providers are empowered to assess and treat pain and prescribe according to pain control needs.[10]

COUNTRY BACKGROUND

The current population of Việt Nam is estimated at 81,377,000.[11] In 2003,an estimated 29.25% of the population was aged 0 -14 years, and 6.53% greater than 65 years. The percentage of the population less than 15 years has decreased, while the percentage of those over 64 years has increased. This trend will eventually place pressure on the health care system in Viet Nam, as rates of chronic disease and illness increase with age.[12]

The population growth rate was 1.5% in 2003. The last 10 years has seen the general improvement of health status. In 2003, the life expectancy at birth was 68 years for males and 74 years for females. During the latest available period 1998-2002, the infant mortality rate was 24 per 1000 live births and the under-5 mortality rate was 18 per 1000 live births. Despite the improvements made, there have been widening gaps between the poor and the non-poor in terms of health status and access to health care services.[13]

---

[6] Foley, Aulin A. KM, and Stjernsward, J. Chapter 19: Palliative Care in Resource Poor Settings. A Clinical Guide to Supportive and Palliative Care for HIV/AIDS. HHS-HRSA: Washington, DC, 2003.

[7] International Observatory on End of Life Care. Opioid Availability and Consumption in Uganda. www.eolc-observatory.net/global_analysis/uganda/opioid/pf.htm.

[8] Harding R, Higginson IJ. Palliative Care in Sub-Saharan Africa: An Appraisal. The Diana, Princess of Wales Memorial Fund, King's College: London, 2004.

[9] Health Canada. Canadian Strategy on Palliative and End-of-Life Care: Progress Report of the Coordinating Committee. Health Canada: Ottawa, 2002.

[10] Quality End-of-Life Care Coalition of Canada. Framework for a National Strategy on Palliative and End-of-Life Care, Quality End-of-Life Care Coalition of Canada: Ottawa, 2005.

[11] World Health Report Vietnam. WHO: Hanoi, 2005

[12] Ibid

[13] WHO Regional Office for the Western Pacific. Vietnam. Health Situation. www.wpro.int/countries/vtn/health-situation.htm. WHO: Manila

Although there continues to be migration to urban areas, the majority of the population is still rural. In 2003, 74.2% of the population lived in rural areas, and 25.8% in urban. Among different geographical regions and population groups, there are considerable disparities in health status. Health indicators in the Mekong River Delta, the Central Highlands and the Northern Uplands are considerably worse than in the rest of the country. The maternal and infant mortality rates among ethnic groups can be as much as four times higher than the national average.[14]

In 2003, HIV disease was the fourth leading cause of mortality, though this may be an underestimate if deaths attributed to [15] pneumonia and septicemia are related to HIV and/or cancer and if deaths attributed to respiratory tuberculosis are related to HIV co-infection.

HEALTH CARE SYSTEM

The health service system in Việt Nam is a mixed public-private provider model. The public health system is under the authority of the Ministry of Health and it plays a major role in health service provision, including prevention and research.[16]

The introduction of user fees to the public health system, the introduction of a private health care system in 1989 and the liberalization of the pharmaceutical industry has shifted the cost of health care financing from the public sector to private households. According to 2004 estimates from the National Health Account, private out-of-pocket expenditures accounted for 63% of total health care financing in 2000. Despite the promotion of health insurance after 1989, only 16% of the population had health insurance by 2002.[17]

The 2005 Impact of HIV/AIDS on Household Vulnerability and Poverty in Viet Nam conducted by the UNDP and AusAID found that total health care costs for households with a PLHA were 13 times higher than the average household's spending in Vietnam. They found hospital and treatment services for HIV/AIDS to be poor and severely limited by resource constraints in the health care system.[18] The study also found that in the four provinces involved in the study, only PLHA households in An Giang were overwhelmingly enrolled in the poor fund, health insurance available to poor households.

In the terminal stages of HIV/AIDS, people tend to use health care facilities more often. The UNDP report found that provincial hospitals accounted for almost 61% of all contacts which occurred one month before death, compared with only 33% in the group of people living with HIV/AIDS. PLHA who were not terminally ill preferred health care facilities in their locality, such as district health centers and private clinics.[19]

---

[14] Ibid8

[15] MOH, Vietnam. Health Statistics Yearbook 2003:HSID. Planning and Finance Department, MoH: Hanoi, 2003

[16] WHO Regional Office for the Western Pacific. Vietnam. Health Situation. www.wpro.int/countries/vtn/health-situation.htm. WHO: Manila.

[17] Vietnam Social Security (VSS). Statistics Yearbook 2002. Government of Viet Nam: Hanoi, 2002.

[18] United Nations Development Programme and Australian Agency for International Development. Impact of HIV/AIDS on household vulnerability and poverty in Viet Nam: Report of UNDP-AusAID supported project – VIE/98/006. United Nations Development Programme, Hanoi. 2005

[19] Ibid

NATIONAL RESPONSE TO HIV/AIDS AND CANCER IN VIETNAM

HIV/AIDS

Việt Nam is undergoing an expanding HIV epidemic. An estimated 40 to 120 Vietnamese are infected everyday.[20] Cases have been reported from all provinces, and there is a number of sub-epidemic "hot spots" in the country, including Ho Chi Minh City, Hai Phong, Quang Ning, Can Tho and An Giang. The epidemic has been concentrated in injecting drug user populations, but there are a growing number of infections due to sexual transmission among sex workers and clients of sex workers, and men who have sex with men (MSM).

National prevalence is estimated to be 0.3% with an estimated 263,000 living with HIV in Viet Nam. The prevalence among injecting drug users is 30% and 6% for female sex workers. However, in a number of areas more than 60% of drug users are infected. Most of those living with HIV/AIDS in Viet Nam are young, between the ages of 20-29. There are four provinces/cities where more than 1% of pregnant women attending antenatal care are sero-positive. The link between HIV and tuberculosis in Viet Nam is also strong. In 10 provinces, more than 3% of tuberculosis patients are also sero-positive, and the figure is more than 9% in Ho Chi Minh City.[21]

In March 2004, the Prime Minister approved the National Strategy on HIV/AIDS Prevention and Control up to 2010 with a Vision to 2020. The National Strategy promotes a multi-sectoral approach to HIV/AIDS, and the mobilization of the whole society. There is a clear assignment of responsibilities to different ministries and sectors to implement the National Strategy. The 2006 national care and treatment program of action details the MoH's strategy for scaled-up treatment and care services. The importance of palliative care is referred to in the plan.

The MoH issued Guidelines for Diagnosis and Treatment of HIV/AIDS in 2005. They have subsequently issued a protocol for ART program implementers.

The National Strategy recognizes that there have been difficulties in the supply of HIV treatment, and that treatment costs are high.[22] Việt Nam does not have a national list of essential drugs in accordance with the WHO standard for the management of HIV/AIDS patients. As well, there is not a list of essential drugs used in palliative care.

Through the national budget and donor funds, HIV treatment, care and support services have been extended to more than twenty provinces in Vietnam. Commune level home-based care services are reaching several thousand PLHA with basic care and support services, and ART is increasingly available in government hospitals.

It is estimated that a basic level of palliative care for people with HIV/AIDS would cost less than one percentage point of government spending on health care.[23]

---

[20] UN Country Team Vietnam. Millennium Development Goals. UNCT: Hanoi, 2003, p. 42.

[21] Nguyen Tran Hien, Nguyen Thanh Long and Trinh Quan Huan. "HIV/AIDS Epidemic in Vietnam: Evolution and Responses." AIDS Education and Prevention, 16 Suppl A, (2005): 137-154

[22] Official Gazette: Decision No. 36/2004/TTg of March 17, 2004 approving the National Strategy on HIV/AIDS Prevention and Control in Vietnam till 2010 with a Vision to 2020.

[23] United Nations Development Programme (UNDP) and Australian Agency for International Development (AusAID). Impact of HIV/AIDS on Household Vulnerability and Poverty in Viet Nam: Report of UNDP-AusAID supported project – VIE/98/006. UNDP: Hanoi, 2005

Cancer

While more than 150,000 Vietnamese are diagnosed with cancer each year, only 5% of them receive prompt treatment.[24] In addition, the number of children with cancer is reported to have risen rapidly in recent years.

The following cancer patterns have been observed by the National Cancer Institute:

"The leading cancers in the country are lung, liver, stomach, colon–rectum and nasopharynx in males and breast, cervix, stomach, liver, colon–rectum and lung in females. Although the country has some common patterns of cancer such as a relatively high incidence of nasopharynx, liver and stomach and a relatively low incidence of breast and prostate cancer compared with international data, the geographical distribution of cancer is not homogenous within the country. The most remarkable difference is observed in cancer of the cervix uteri, of which the incidence in the South is, at least four times higher than that in the North. Other less extensive differences are observed in cancer of the lung, stomach, nasopharynx and breast, the incidence of which seems to be higher in the North than in the South, and the liver, which seems to be more frequent in the South than in the North."[25]

Agent Orange may be contributing factors the uneven distribution of cancers.

According to the Vietnamese Cancer Society, there are several barriers to patients receiving prompt treatment. First, a lack of community information has led the public to believe that there are no treatments for cancer. Second, when people do not have symptoms of disease, they do not see the need to undergo screening tests. Last, there is the belief that cancer can be cured by traditional Chinese medicine and therefore that cancer treatments are unnecessary.[26]

Several hospitals in Viet Nam have been designated cancer specializing institutions, but the largest, oldest and most well respected hospitals are found in Hanoi, HCMC and Hue. In other parts of the country, such as Can Tho, oncology specialty services are available and developing in terms of quality.[27] As with many other health care services in Viet Nam, cancer care is not free and can be a financial burden for middle class and poor families.

The MoH has instituted several efforts to prevent cancers including a national tobacco control program and HBV vaccinations but coverage of these programs have not been adequate.[28]

The National Cancer Hospital in Hanoi published "Care and Management for Pain in Cancer Patients." These guidelines were developed for use nation-wide in cancer hospitals. The guidelines include pain management, symptom management, end of life care, psychological care; as well as palliative chemotherapy and radiation. The National Cancer Hospital has a palliative care unit, which has been responsible for training new oncologists and other health care workers in palliative care. The Ministry of Health has also prepared guidance for health care professionals who are working with cancer patients.

---

[24] Than Nien. Lack of Prompt Medical Attention Leads to High Cancer Death Rate, Vietnam Economy

[25] Pham Thi Hoang Anh and Nguyen Ba Duc, The Situation with Cancer Control in Vietnam, Japanese Journal of Clinical Oncology 32:S92-S97. 2002

[26] Than Nien. Lack of Prompt Medical Attention Leads to High Cancer Death Rate. Vietnam Economy.

[27] Landskroener, Marcia, Profiles in Cancer Medicine, Cancer Medicine in Vietnam, The International Network For Cancer Treatment and Research. 2006

[28] Pham Thi Hoang Anh and Nguyen Ba Duc, The Situation with Cancer Control in Vietnam, Japanese Journal of Clinical Oncology 32:S92-S97 (2002).

SECTION 3

OBJECTIVES AND METHODOLOGY OF RAPID ANALYSIS

OBJECTIVES

The Viet Nam MoH initiated the palliative care rapid situation analysis in order to achieve the following objectives:

- Provide an overview of existing palliative care related laws, policies, trainings and guidance
- Describe the range of palliative services available in Vietnam, including coverage and scope in select provinces
- Identify palliative care needs and gaps among people with chronic illness and family/household caregivers
- Better understand the palliative care training and supply needs of health care workers at the national, provincial, district and commune levels
- Define current laws and practices in use of opioids in pain management
- Outline opinions and perspectives of national and provincial leaders in palliative care needs, gaps and use of opioids in pain management
- Provide the background from which to develop national palliative care guidelines which address the primary needs and gaps related to palliative care in Vietnam

DESIGN AND SAMPLING

The RSA consisted of a combination of qualitative and quantitative data collection methods, as well as a literature review. Key informant interviews were completed using structured questionnaires and focus group discussions were done using discussion guides. Unique questionnaires were developed for each of the seven interview groups: PLHA and people with cancer, family caregivers, bereaved family caregivers, palliative care program managers, health care workers, health leaders and policy leaders. A guide was also prepared for PLHA focus group discussions.

Key informants were selected using convenience sampling; the RSA is not intended to be representative but to afford a snapshot of current palliative care needs and gaps in high HIV prevalence provinces. A number of ethical and cost issues made conducting a representative sample of interviewees untenable. A literature review was to be conducted of palliative care related laws, regulations, policies and training in order to guide the data collection process and to provide background for the development of national palliative care guidelines.

RESEARCH LOCATIONS

The RSA was conducted in five provinces with high rates of HIV prevalence: Hanoi, Hai Phong, Quang Ninh, Ho Chi Minh City and An Giang.

Table 1. Provincial Overview

Province	Population Size (Est.)	HIV Prevalence (2003 HSS) %	Cancer Data*	Health Infrastructure (Hospitals per Province)
Hà Nội	4, 071,000	IDU: 30.5 SW: 15	0	43 hospitals

Hải Phòng	1,500,000	IDU: 60.5 SW: 5.94	0	22
Quảng Ninh	1,029,900	IDU: 54.3 SW: 3.25	0	20
HCMC	5,700,000	IDU: 54.8 SW: 10.5	0	32
An Giang	2,146,800	IDU: 26.3 SW: 14.14	0	12

* *Figures unavailable.*

INSTRUMENTS AND INTERVIEW GROUPS

A combination of surveys and interview guides were used in the palliative care situation analysis:

1. Palliative care program questionnaire
2. PLHA and persons with cancer questionnaire
3. Family caregiver of PLHA or PWC questionnaire
4. PLHA focus group discussion guide
5. Family caregiver bereavement questionnaire
6. Health care worker questionnaire
7. Interview guide for health opinion leaders key informant interviews
8. Interview guide for policy opinion leaders key informant interviews
    - Checklist for analysis of National Drug Control Policy[29]
    - Palliative Care Policy Checklist

The palliative care program questionnaire was adapted from a questionnaire developed for use in South Africa. Questionnaires for PLHA, people with cancer and caregivers were based on interview guides used in Africa as part of the 2004 WHO study entitled, A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients in Sub-Saharan Africa.

Interviews with health and policy leader key informants provided context and data needed in order to describe the current legal and policy framework in place in Viet Nam.

The above tools were used in key informant interviews with:

- PLHA and people with cancer
- Family caregivers of PLHA and people with cancer
- Bereaved family caregivers of PLHA and people with cancer
- Healthcare workers involved in care for PLHA and cancer
- Program managers of palliative care services for PLHA and cancer
- National and provincial health leaders
- National and provincial policy leaders who are knowledgeable or influential in palliative care issues

---

[29] Adapted from: WHO. Achieving Balance in National Opioids Control Policy Guidelines for Assessment. 2002.

Table 2. RSA Participants

Interviewees				**Methodology Used**	
	Male	**Female**	**Total**	**Questionnaire**	**Focus Group Discussion**
People with life-limiting illness	118	93	211		
• People with HIV/AIDS	98	76	174	x	X (11 groups)
• People with Cancer	20	17	37	x	NA
Family Caregivers	17	44	61		
• People with HIV/AIDS	9	28	37	x	NA
• People with Cancer	8	16	24	x	NA
Bereaved Caregiver	5	34	39		
• People with HIV/AIDS	4	23	27	x	NA
• People with Cancer	1	11	12	x	NA
Healthcare Worker	33	43	76	x	NA
Opinion Leaders	26	7	33		NA
• Health	20	7	27	X	NA
• Policy	6	0	6	X	NA
Program Managers	18	13	31	X	NA
Total	**217**	**234**	**451**		

Interviews with PLHA were arranged through independent PLHA support groups. Participation was voluntary and interviewees were free to withdraw at any time. All interviewees were ambulatory and well enough to participate actively in interviews or focus groups. No names or any other identifying information was taken from respondents. All information is being kept confidential.

An informed consent process and form were followed with all participants. Interviewers were trained in discussing sensitive issues and protecting participants' anonymity/confidentiality. All interviewees were remunerated for RSA participation to compensate for time and travel related to participating in the interview.

LIMITATIONS

Interviewees selected for the RSA were based on convenience sampling, and are not representational. The assessment was not intended as a national survey, but a rapid situation analysis in order to gain essential information from which to develop guidelines and policies. Additionally, as HIV status is confidential a random sampling of PLHA and caregivers to participate in the RSA would have not been ethical or feasible. Due to a decision that interviews should not be conducted with individuals who were very ill, results may be biased in the sense that prevalence of pain and other symptoms seen most often in patients with advanced disease may have been were underreported. The RSA did not include children due to ethical concerns.

SECTION 4

FINDINGS

A. CURRENT STATUS OF PALLIATIVE CARE POLICIES, TRAINING AND PROGRAMS IN VIET NAM

PALLIATIVE CARE POLICIES

While Viet Nam does not have a national palliative care guideline there are a handful of national, institutional and programmatic strategies, policies and guidelines related to HIV/AIDS and cancer which provide some guidance for the provision of palliative care in Viet Nam. These include the National Health Strategy, National HIV/AIDS Strategy and the National Cancer Hospital Guidelines.

The National HIV/AIDS Strategy calls for scaled-up treatment, care and counseling services for 90% of all adults by 2010, with 70% of all people with AIDS accessing anti-retroviral therapy. The strategy also calls for research into traditional medicines for symptom care of PLHA. A national action plan on treatment, care and support further outlines the service delivery structure for care in Viet Nam and refers to the role of palliative care. In addition, the 2006 care and treatment program of action mentions palliative care as an essential service for people with HIV/AIDS.

There is no national guideline in home-based, however, the MoH has programmatic guidance in the implementation of the national community care, counseling and management program, also known as QTC, which is a commune level strategy to provide community and home-based care services to PLHA. This program provides primary health care services to several thousand PLHA. With funds from the Global Fund to fight AIDS, Tuberculosis and Malaria, the MoH has expanded QTC within 20 provinces.

The National Cancer Hospital in Hanoi has published clinical guidelines for cancer hospitals, “Care and Management for Pain in Cancer Patients.” The guidelines include pain management, symptom management, end of life care, psychological care; as well as palliative chemotherapy and radiation.

EDUCATION, TRAINING AND CERTIFICATION

Pre-service

Training in palliative care is limited and outdated in Vietnamese medical schools. Students are not taught to use pain scales or the WHO pain ladder to assess and treat pain. The curriculum does not emphasize relief of suffering and client-centered care. There is no specialty training in palliative care. For medical doctors who specialize in cancer care, training in palliative care is available from the National Cancer Hospital.

No specialty training or certification in palliative care is available for nurses, pharmacists, counselors or social workers.

In-service

In Viet Nam, there is no national palliative care training program for care providers. However, some training programs for clinicians provide some instruction in palliative care. These include the Vietnam-CDC-Harvard Medical School AIDS Partnership (VCHAP) HIV/AIDS clinical care curriculum for doctors and nurses and FHI's home-based care training for home-based care teams. Hospitals and clinics that offer clinical instruction in palliative care include the National Cancer Hospital, the Hue Cancer Hospital and the Kim Long Charity Clinic in Hue.

PALLIATIVE CARE PROGRAM ASSESSMENT

Overview of programs assessed

A total of 31 palliative care programs were assessed during the rapid situation analysis. Interviews were conducted with program managers. All known programs in the five study provinces were asked to participate in the RSA. Programs invited to participate in the RSA fell into one of the three following categories: 1) comprehensive palliative care program (see definition below); 2) program with actively applies palliative care principles but which may not be able to provide the full range of services; 3) program which provides elements of palliative care but is not aware of palliative care principles.

Comprehensive palliative care in this analysis is defined as palliative care which is provided by staff trained in the principles and practice of palliative care, with access to the full range of drugs required to provide pain and symptom management and either providing, or with access to, the equally important services needed to provide emotional psychological social and spiritual support.

Overall characteristics of palliative care services

A diversity of palliative care programs were included in the RSA. Interviews were conducted with managers of hospices, home-based care teams, support groups, rehabilitation centers and hospital-based services (Table 3).

The majority (75%) of palliative care program managers interviewed reported having conducted a needs assessment before initiating their services. The types of services provided by these programs include symptom relief, counseling, and end-of-life care. On average, these services had been in operation for 5.5 years.

Table 3. Programs Surveyed

	Province	District	Program Name
1	**An Giang**	**Chau Doc**	**Chau Doc Hospital – HIV Out-patient clinic (OPC)**
2	An Giang	Long Xuyen	Global Fund – Provincial HBC and OPC program
3	An Giang	My Phuoc-Long Xuyen	HBC program of the Commune Health Center
4	An Giang	Tan Chau	District Preventive Medicine Team
5	An Giang	Thanh Pho Long Xuyen	Provincial Preventive Medicine Center
6	**Ha Noi**	**Ba Dinh**	**CEPHAD**
7	Ha Noi	Ba Dinh	Tue Tinh Duong
8	Ha Noi	Dong Da	Global Fund HBC and HIV OPC
9	Ha Noi	Hai Ba Trung	HIV OPC Bach Mai; CDC-Lifegap
10	Ha Noi	Hoan Kiem	National “K” Cancer Hospital
11	Ha Noi	Long Bien	Bright Futures
12	Ha Noi		Ha Lan- Viet Nam Foundation
13	**Hai Phong**	**Du Hang Kinh**	**Flaming Tree Support Group**
14	Hai Phong	Hong Bang	Community Care and Support; Norwegian Association Viet Nam (NAV)
15	Hai Phong	Ngo Quyen	Home-based care team Dong Khe Ward; FHI
16	**Ho Chi Minh**	**Cu Chi**	**Mai Hoa Hospice**
17	Ho Chi Minh	District 3	Traditional Medicine Hospital -HCMC
18	Ho Chi Minh	District 4	Community Counseling and Care Center; MDM
19	Ho Chi Minh	District 5	Cho Ray Hospital
20	Ho Chi Minh	District 5	Pham Ngoc Thach TB Hospital
21	Ho Chi Minh	District 8	Community Counseling and Care Center; FHI
22	Ho Chi Minh	Binh Thanh	K Cancer Hospital
23	Ho Chi Minh	Thu Duc	Tam Binh Care and Support Center

24	Ho Chi Minh	Binh Thanh	Community Counseling and Care Center (HBC and OPC); FHI
26	Ho Chi Minh	Trong Diem	06 Center
27	Ho Chi Minh	District 8	HBC Team; World Vision
28	**Quang Ninh**	**Van Don**	**District Health Center HIV OPC; FHI**
29	Quang Ninh	Van Don	Bright Futures
30	Quang Ninh	Van Don	Van Don Preventive Medicine Team
31	Quang Ninh	Hang Gai	Provincial Preventive Medicine Center

Palliative Care Programs: Highlights and Constraints

The palliative care programs which participated in the RSA were run by highly dedicated staff committed to helping people with HIV/AIDS and cancer live and die with dignity. While it was very evident that the intention of participating programs was to improve the quality of life of their clients, most need further training in palliative care principles and practice, and support in accessing essential palliative care medicines. Programmers offering care to children also need further training to better respond to their physical and emotional needs at each developmental stage. Lack of access to essential palliative care medicines was identified as a significant problem among most programs and will remain a barrier to quality care unless addressed in the near future.

The only program participating in the RSA which provides comprehensive palliative care is the National Cancer Hospital in Hanoi. For the remaining programs, much work will need to be done to enhance the quality of their services, improve their access to resources and increase their awareness of what comprehensive palliative care entails.

Palliative care awareness

Program managers were asked to describe their understanding of palliative care. The majority of interviewees (58%) did not know that pain management is part of palliative care. However, 79% of interviewees defined palliative care as care that makes people who are sick more comfortable. While these respondents were not aware of the definition of palliative care this response indicates they understood elements of it. In addition, 30% felt that palliative care also meant health care counseling.

Services provided

About half of the programs (48%) provided outpatient care, 43% in-patient care, and 12% home-based care. However, 100% of the programs reviewed reported offering psychological support to clients. Other services offered include legal support (38%) and services to children (see below).

Interviewees were asked whether or not they had guidelines or operational procedures in place for services offered, 79% said that these were in place. Contents of the guidelines included the following areas: treatment, home-based care, code of caregiver conduct, counseling and patient recruitment.

Children

A total of 21 or 64% of programs also offer care and treatment services to children with and affected by HIV and cancer. Managers were also asked to describe their opinions of what services children would need compared with adults. Pain relief: 77% of respondents felt that children experienced pain on par with adults and that their pain was treatable. Respondents were also asked if they felt children could feel depression as adults could. Only 27% agreed that children could suffer from depression. Similarly, 33% stated that children would not feel sad losing a relative as would an adult.

More training in palliative care for children is clearly needed for service providers to increase their ability to identify and treat physical and emotional pain and suffering.

Coverage of and access to services

Reach of the palliative care services interviewed is limited. A few programs (14%) reported reaching from 200-750 patients per month, while 36% were providing care to 100-200 patients per month and 50% of programs cared for three to 60 people per month.

Program managers said their services were advertised primarily through word of mouth, PLHA support groups, and working in collaboration with hospitals. Half of the programs had service eligibility criteria in place which included being diagnosed with HIV and/or cancer, being homeless or poor. Admission to 06 centers was limited to IDUs.

Just over a third (38%) of program managers reported that their clients faced barriers in accessing their services. The primary constraint cited was the inability of clients to pay for the services -- 27% of programs reviewed charged user fees. Stigma was named as another reason why people might not access the program.

Resources

The total combined number of staff at the palliative care programs assessed were as follows: doctors (617); nurses (1,179); and social workers (85). More than half of the programs (59%) indicated that they encouraged PLHA to work in their facility. All programs were funded with 70% receiving funds from government sources, and 55% received funds from NGOs or other sources. One program manager reported their service was funded through staff contributions.

64% of programs received material or other donations for clients; these included food, waiving of hospital fees, clothing, school fees, vocational training, and medicines.

Medications for palliative care

Of the 31 programs assessed, 15 said they had to access opioids for their clients. Need planning for medications was done by either the head of the pharmacy department (36%) or unit head (29%).

Prescriptions were written either by attending doctors (43%), specialized doctors (29%) and the head of the provincial health department (7%). Medicines were given to patients by medical assistants (46%) and nurses (15%).

Despite the fact that the programs interviewed expressly provide palliative care, many of the essential palliative care medicines needed to provide quality care and relief of suffering were not available through these programs. For example, paracetamol was not available in 16% of programs and combined paracetamol/codeine was not available is about half of the programs surveyed. The below table details the medicines which the palliative care programs included in the RSA reported having available:

Table 4. Palliative Care Program Medicine Availability

Palliative Care Medicines	**Currently available at your center?**			**Reasons of not having this medicine?**
Name of medicine		N	(%)	
Q1. Oral Morphine (tablet or liquid) n=30	Yes	3	10	- gov. management mechanism - lack of supply
	No	27	90	
	Total	30		
Q2. Morphine (injection) n=28	Yes	11	39.3	
	No	17	60.7	
	Total	28		
Q3. Codeine (tablet or liquid) n=29	Yes	1	3.4	- no demand - lack of supply
	No	28	96.6	
	Total	29		
Q4.1. Paracetamol n=31	Yes	26	83.9	- use commonly - lack of medicine
	No	5	16.1	
	Total	31		
Q4.2. Paracetamol/Codeine n=28	Yes	15	53.6	- use commonly - lack of medicine
	No	13	46.4	
	Total	28		
Q5. Aspirin n=33[30]	Yes	28	84.8	
	No	5	15.2	
	Total	33		
Q6. Non-steroid analgesic: Ibuprofen, Mobic (Meloxicam, Felden (Piroxicam) n=28	Yes	22	78.6	- lack of supply - use commonly
	No	6	21.4	
	Total	28		
Q7. Cortico –steroids (prednisolone dexamethasone) n=28	Yes	21	75	- use commonly
	No	7	25	
	Total	28		
Q8. Benzodiazepines -Diazepam (seduxen) oral or injection mode; -Lorazepam (Ativan) oral or injection mode; n=27	Yes	15	55.6	- gov. management mechanism - use commonly - always out of stock
	No	12	44.4	
	Total	27		

---

[30] While 31 programs were included in the RSA, 33 program managers were interviewed, as two programs offered diverse enough services to warrant additional interviews.

Q9. Haloperidol oral or injection mode n=28	Yes	8	28.6	- always out of stock
	No	20	71.4	
	Total	28		
Q10. Anti-vomiting (Primperan) n=28	Yes	20	71.4	
	No	8	28.6	
	Total	28		
Q11. Anti-depressant: Amitriptyline N=27	Yes	4	14.8	- hardly use
	No	23	85.2	
	Total	27		
Q12. Anti-diarrheal (antibiotic, Loperamid, Smecta) n=29	Yes	29	100	- only stock in high season when there are many diarrhea patients - commonly used
	No			
	Total	29		
Q13. Anti-constipation (Forlax, Sorbitol, Microlax) n=28	Yes	22	78.6	- use commonly
	No	6	21.4	
	Total	28		
Q14. Chlorpromazine (for hiccup) n=28	Yes	13	46.4	- use hardly
	No	15	53.6	
	Total	28		
Q15. Anti-contraction (Spasmaverin, Atropin, Visceralgin, Spasfon) n=22	Yes	17	77.3	- use hardly
	No	5	22.7	
	Total	22		

Education and training

Most (81%) of the programs had offered training to their staff lasting less than seven days. Training content focused on home-based care, in-patient care, community care, psychological care, OI/TB treatment and end of life care. When asked what further training staff required, program managers said longer, more intensive in-service training was needed.

Data collection and information management

The majority (80%) of all programs stated that the used a standard data form to collect client information on the first visit. Client files were kept in health care facilities; 86% said they had a system to keep this information confidential. Pain is assessed by asking (54%), observing (42%) and examination (16%). Only one interviewee indicated that they used the WHO pain ladder to assess pain.

B. CURRENT STATUS OF OPIOID POLICIES AND PALLIATIVE CARE MEDICINE ACCESS IN VIET NAM

Through interviews with 27 health opinion leaders and the literature review, the following information was gathered regarding the availability of palliative care medicines including opioids.

AVAILABILITY OF PALLIATIVE CARE DRUGS

Opioids

Viet Nam is a signatory to the Single Convention on Narcotic Drugs of 1961 (signed Nov. 1997) and therefore part of the International Narcotics Control Board (INCB).

Opioids are classified as schedule A controlled medicines, and access to them is very limited. Oral morphine, while legal, is not widely available within most hospitals throughout Viet Nam. Parenteral morphine is more widely available in tertiary and provincial hospitals but limited quantities are available for prescription at any given time.

While oral and injectable forms of morphine are available for order by hospital managers in Viet Nam through the parastatal pharmaceutical company, Enterprise #2, sustained released morphine (lasting from eight to twelve hours) and other opioids such as fentanyl, a long-acting oral preparation (48-72 hours), are not readily available in Viet Nam. Fentanyl is found on the Viet Nam essential drugs list but not for use in general pain control; it is authorized only as a pre-operative medicine.

Enterprise #2 is the only pharmaceutical company in Viet Nam authorized by the Ministry of Health and regulated by the MoH Drug Administration to produce, order and distribute opioids. They currently produce short-acting oral and injectable forms of morphine. While the production capacity of Enterprise #2 is high, hospital orders for injectable and oral morphine in particular remain low.

The lack of oral morphine in hospital environments can be attributed to the fact that hospitals managers are often not well informed or trained in morphine and pain control, are not clear on what the law regarding opioid prescriptions entails and therefore, may fear legal repercussions for providing opioid analgesia. Because of these perceptions, doctors are likely less inclined to ask about pain and to prescribe morphine to patients in severe pain.

Analgesic combinations which include the weak opioids codeine and tramadol are available for sale in private pharmacies, but are less available in government hospitals.

However, codeine alone is not legally available and is not listed in the Viet Nam Essential Drugs List. Only the combination of codeine/paracetamol is authorized for production and use in Viet Nam. This limits the palliative care use of codeine because no more than 4mg of paracetamol can be taken in a 24-hour period. Codeine is a very effective and inexpensive medicine in controlling moderate pain.

Findings in palliative care program assessment and section 3b, further detail issues regarding the availability of palliative care medicines in programs and health care settings participating in the RSA.

Other palliative care medicines

The availability of other palliative care medicines is also highly limited. Certain anti-depressants essential for management of neuropathic pain and depression are difficult to find and are expensive. Medicines to manage breathlessness and anxiety are also generally not available. They are, however, legal and available for provincial and district hospitals to order.

PRESCRIPTION OF OPIOIDS

By law, morphine and other opioids in Viet Nam are classified as schedule A medicines; they are controlled and require a prescription from doctors only – nurses are not allowed to prescribe. Hospital managers must approve prescriptions made by doctors and limits are placed on the amount of opioid that can be made available to a client at any given time. All hospitals from the district level up are authorized to prescribe schedule A medicines such as morphine and codeine. In some cases, commune level health post staff are allowed to prescribe but special approval is required. Prescriptions are usually made for a 5-7 day period. However, according to the Viet Nam MoH Drug Administration, few opioid prescriptions are made in the vast majority of hospitals, including national level institutions.

In practice, opioid prescriptions are rarely made outside of the hospital and availability of oral morphine is extremely limited. For people with cancer and HIV/AIDS who are not able to afford hospitalization and/or who prefer to be cared for at home, they risk suffering from unrelieved pain and dyspnea if they remain home where opioids are not available. The lack of availability of opioids in the home setting creates a very difficult choice for patients and their loved ones.

REGULATORY PROCESS

The MoH Drug Administration (DA) is responsible for regulating pharmaceuticals. Hospital pharmacists order medicines from government-approved distributors. Generally the chief of the pharmacy unit in each hospital orders medicines based on previous prescription patterns. Since most doctors and pharmacists are not well trained in pain control and palliative care, repeated under-ordering of medicines for pain and palliative care is not surprising. Since the Drug Administration must report to the INCB annual estimates of opioid use, the DA may be reluctant to increase estimates of opioid need because of the concern that such an increase might attract scrutiny from the INCB.

Some hospitals in Viet Nam, misinterpreting regulations, have imposed greater restrictions on opioid prescriptions than the law requires. Hospitals mandate that all doctors and nurses return empty morphine ampoules to the chief pharmacist or otherwise be investigates for opioid diversion. Others discourage the use of morphine in patients by not ordering and stocking the medicine in the hospital pharmacy. The lack of updated training in palliative care among hospital management and senior clinicians may also result in an environment of limited use of opioids for treatment of pain.

OPIOID ACCESSIBILITY AND DRUG CONTROL BALANCE ANALYSIS

An essential element of the RSA was an analysis of the current balance in Viet Nam between the prevention of opioid diversion and opioid accessibility for pain control. Findings from the analysis strongly indicate that opioid use restrictions among health care workers are a major reason for inadequate pain control in people with life-limiting illnesses. The emphasis is far more on diversion prevention than on symptom relief and quality of care.

As referenced earlier, the International Narcotics Control Board (INCB) has recommended that all countries remove barriers to availability of opioids for palliative care services. The INCB has called on all governments to assess barriers to opioid use for medical purposes and to develop and implement a plan to remove barriers and facilitate availability of opioids for palliative care.

Results from the checklist for analysis of national drug control policy

The below WHO checklist was used to interview pinion leaders and to record findings from the literature review. It is clear that there remain a number of legal and policy barriers to the optimal access of opioids for pain control in Viet Nam.

Checklist

1. Have the authorities conducted an examination to determine if there are overly restrictive provisions in national, (and state, if applicable) drug control policies that impede prescribing dispensing or needed medical treatment of patients with narcotic drugs, or their availability and distribution for such purposes, and made the necessary adjustments?

-----X----Yes ---------No -------- Information not available

In part, the RSA serves as an analysis of opioid availability but necessary adjustments in the law to improve access to opioids have yet to be further analyzed and implemented.

2. Is there a provision in National Drug Policies that recognizes that narcotic drugs are absolutely necessary for the relief of pain and suffering?

---------Yes ---------No -----X---Information not available

3. Is there a provision in National Drug Policies that establishes that it is the Government’s obligation to make adequate provision to ensure the availability of narcotic drugs for medical and scientific purposes, including for the relief of pain and suffering?

---------Yes ---------No -----X---Information not available

4a. Has the government established administrative authority for implementing the obligation to ensure adequate availability of narcotic drugs for medical and scientific purposes, including licensing, estimates and statistics?

---------Yes ----X-----No --------Information not available

4b. Are adequate personnel (employees) available for the implementation of this responsibility?

---------Yes ---------No -----X---Information not available

5a. Does the authority have a method to estimate realistically the medical and scientific needs for narcotic drugs, including for the opioid analgesics which are needed for pain relief and palliative care?

---------Yes -----X----No --------Information not available

5b. Has the authority critically examined its method for assessing medical needs for narcotic drugs, as requested by the INCB?

---------Yes -----X----No --------Information not available

5c. Has the authority established a satisfactory system to collect information about medical need for opioid analgesics from relevant facilities?

---------Yes -----X----No --------Information not available

6. Does the authority furnish annual estimates to the INCB of need for narcotic drugs for the next year in a timely way?

-----X----Yes ---------No --------Information not available

7. If it appears that the medical need for opioid analgesics will exceed the estimated amount which has been approved and confirmed by the INCB, is it government policy to send a request for a supplementary estimate?

---------Yes ---------No ----X----Information not available

8. Does the authority submit to the INCB in a timely way the required annual statistical reports respecting production, manufacture, trade, use and stocks of narcotic drugs?

---------Yes ---------No ----X----Information not available

9a. Has the authority informed health professionals about the legal requirements for the use of narcotic drugs, and provided an opportunity to discuss mutual concerns

-----X----Yes ---------No --------Information not available

In part, information has been disseminated but there are no formal opportunities for health professionals to discuss their needs and concerns regarding legal requirements for the use of narcotic drugs with their hospital boards or the DA.

9b. Has the authority identified and addressed concerns of health care professionals about being investigated for prescribing opioids

---------Yes -----X----No --------Information not available

10. Is there cooperation between the authority and health care professionals to ensure the availability of opioid analgesics for medical and scientific purposes?

---------Yes -----X----No --------Information not available

11. Has the authority taken steps, in coordination with licensees, to ensure that there are no shortages of supply of opioid medications caused by inadequate procurement, manufacture and distribution systems?

---------Yes ---------No ----X----Information not available

12. Do national drug control policies provide for the licensing of an adequate number of individuals and entities to support a distribution system that will maximize physical access of clients to pain relief medications?

-----X----Yes ---------No --------Information not available

13a. Has the government established a national cancer control program to which it allocates resources?

-----X----Yes ---------No --------Information not available

13b. Has the government taken steps to ensure the practice of the WHO Analgesic Method (three-step ladder) for palliative pain relief by conducting education programs and by its inclusion in medical, pharmacy and nursing curriculum?

---------Yes -----X----No --------Information not available

14. Is there terminology in national drug control policy that could cause confusion between the medical use of opioids for pain and drug dependence?

---------Yes ---------No -----X---Information not available

15. Are there provisions in national drug policy that restrict the amount of drug prescribed or the duration of treatment?

-----X----Yes ---------No --------Information not available

16. Are there prescription provisions in national drug control policy that may unduly restrict physician and patient access to pain relief?

-----X----Yes ---------No --------Information not available

17. Is there a separate system for registration of drugs for use with HIV and AIDS and other chronic illnesses?

---------Yes ---------No ----X----Information not available

18. Is there a separate license required for practitioners to prescribe opioids and other essential drugs usually reserved for palliative care, e.g., phenobarbitone?

---------Yes -----X----No --------Information not available

However, only doctors at specific levels of the health care system are authorized to make prescriptions as outlined in the

Source: WHO. Achieving Balance in National Opioids Control Policy – Guidelines for Assessment. 2002. (with minor adaptations)

C. PALLIATIVE CARE NEEDS AND GAPS: RESULTS FROM INTERVIEWS WITH PEOPLE WITH HIV/AIDS AND CANCER AND THEIR CAREGIVERS

POPULATION INTERVIEWED

The rapid situation analysis included interviews with a total of 105 people with life-limiting illness: 66 people with HIV/AIDS and 39 people with cancer. An additional 106 PLHA participated in focus group discussions. Interviews were also conducted with 62 family caregivers and 37 bereaved caregivers. The majority of interviewees were male although nearly half of those with cancer were female (46%) while 37% with HIV/AIDS were female.

Table 5. PLHA and People with Cancer

Province	Number (n=104)	%
Hanoi	30	29
Hai Phong	22	21
Quang Ninh	10	10
HCMC	26	25
An Giang	16	15

The majority of PLHA (47%) and people with cancer (90%) were married; 36% of PLHA were single while 11% were separated or divorced.

Education levels among people with HIV/AIDS and people with cancer is also reflective of age differences among both populations and possibly socio-economic status; those with cancer had a higher level of education than people with HIV/AIDS.

Table 6. Highest Level of Education Completed

Education Level	People with Cancer (%)	PLHA (%)
None at all	0	8
Primary	5	20
Middle school	38	42
Secondary	33	17
College, University or higher	23	14

In terms of work, all people with cancer were employed with about a third (33%) employed in factories; 14% of PLHA were unemployed.

Table 7. Type of Work

Type of Work	People with Cancer (%)	PLHA (%)
Small business owner	8	0
Trader	8	8
Farmer	0	2
Student	5	6
Worker (factory)	33	2
Unemployed	0	14
Others	46	53

Palliative Care Experiences of PLHA, People with Cancer and Caregivers

"Sometimes, pain is not just physical but also psychological. Level of pain depends on how you cope with this pain." -FGD Interviewee

General Health:Just less than half (41%) of all interviewees indicated that their health was either poor or very poor. However, reported functional status was more limited among people with cancer than people with HIV/AIDS: 64% with cancer versus 26% of PLHA reported that they were no longer able to conduct their normal activities. Of these, none of the people with cancer were able to work while 6% of PLHA were still able to work.

Primary care provider: The primary caregivers reported by people with cancer and HIV/AIDS were different, likely due to the age differences of the two populations: 34% of PLHA said that their mother was the primary caregiver, 12% stated their wives and 8% their husbands. For people with cancer, the main caregiver was the spouse: wife (46%) and husband (24%).

Friends were also named as primary caregivers among 26% of people with HIV/AIDS.

Types of treatment sought: All of those with cancer reported currently receiving treatment and 72% of people with HIV/AIDS said they were currently receiving some form of treatment. Of those receiving treatment, the following breakdown between accessing western and traditional medicines were reported:

Interestingly, a quarter of people with cancer reported using a combination of western and traditional medicines whereas very few PLHA sought traditional medicines.

Table 8. Types of Medicines Used

Type of Medications Used	People with Cancer (%)	PLHA (%)
Western medicine only	74	90
Traditional medicine	0	2
Both Western and traditional	26	2
Don’t know/Can’t remember	0	6

Experiences with Pain and Pain Management

The majority of people with HIV/AIDS and cancer (75%) interviewed reported experiences with physical pain since diagnosis.

Of those, 53% who experienced pain felt it always or almost once a week and 57% also reported having very strong to severe pain the last time they were in pain.

Respondents were asked to rank the pain they’d experienced last on a scale of zero to 10 with zero representing no pain and 10 the worst pain they could possibly imagine. Pain reported is classified into the WHO staging of mild, moderate and severe pain. Pain described by the interviewees fell into the following categories:

Graph 1. People with HIV/AIDS and cancer who reported ever being in pain since diagnosis

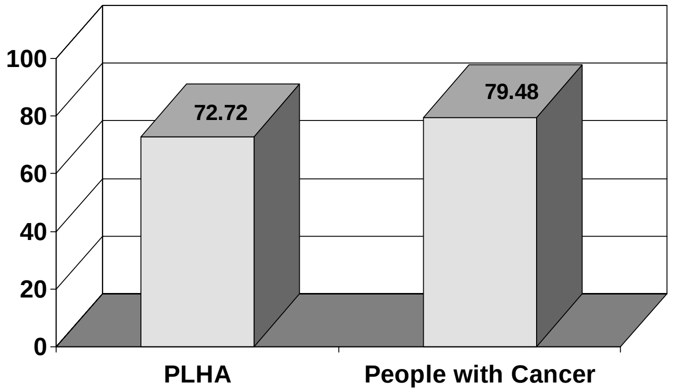


Table 9a. Pain Severity by WHO Scale Before Treatment

Severity of pain	People with Cancer (%)	PLHA (%)
Mild (1-3)	16	13
Moderate (4-6)	19	35
Severe (7-10)	65	52

Respondents were then asked to describe the level of pain they experienced, if any, after they had sough treatment for the pain. Note that not all interviewees reported receiving any treatment for pain: 70% of people with cancer said they received treatment while only 46% of PLHA stated that they received medicines for pain.

Table 9b. Pain Severity by WHO Scale After Treatment

Severity of Pain	People with Cancer (%)	PLHA (%)
No pain (0)	23	16
Mild (1-3)	50	51
Moderate (4-6)	23	31
Severe (7-10)	4	11

While pain was addressed to a certain extent both among people with HIV/AIDS and cancer, this finding indicates that pain was still present after treatment for the majority of people with cancer and HIV/AIDS: 77% of people with cancer and 84% of PLHA remained in pain despite treatment. Among people with HIV/AIDS, just less than half were still in moderate to severe pain after treatment.

Despite 70% of people with cancer and 46% of PLHA saying they received medicines for pain, few listed medicines which are used to treat pain. Forty-five individuals with cancer and HIV/AIDS reported being in severe pain, yet only three received morphine and four, codeine with paracetamol. Only 17 out of the total of 79 individuals who said they had experienced any level of pain reported receiving paracetamol.

Severe pain was sited as a common problem among PLHA focus group discussion participants. Pain described was most commonly related to herpes zoster, peripheral neuropathy, odynaphagia, headache and physical malaise.

Participants in focus group discussions described the following experiences with pain:

“My friend had an extremely bad headache, sometimes it was incredibly painful, crazily painful, he took analgesics but it did not relieve the pain. He writhes in bed and cries but nothing works.”

"I have a little trouble in my two toes and I hardly go to sleep, I have to moan at night because of extremely stabbing pain from the head downward, it is a nerve disease I think."

"When I was diagnosed oral thrush, I was so painful, it hurt to swallow."

"I got extremely horrible headache and could not sleep, even I took sleeping pills."

Significantly, in interviews with bereaved caregivers, reports of pain were higher: 81% bereaved caregivers of people with HIV/AIDS and cancer said that the person they were caring for experienced pain in the last stages of life. Of those, 83% reported the person they were caring for experienced pain all the time or almost everyday.

Pain health seeking and treatment

Most PLHA and people with cancer (46%) sought treatment at a government health facility. The rest either self-medicated (35%), went to the HIV outpatient clinic (11%) or received support from a home-care team (8%).

People with cancer and HIV interviewed reported mixed experiences with pain relief. For more mild pain, people said that they were able to access adequate pain relief medicines and care. Those with severe pain reported persistent pain and difficulty in accessing pain relief from health care providers.

Under-addressed Pain: When PLHA in focus groups referred to physical pain they had experienced in the past, they also mentioned that the pain persisted despite care provided by health care workers.

"My sister had terrible pain in her last days. She looked very pale after coughing. I see nobody mentioned about morphine prescription to her."

"My husband was staying in hospital without taken care of as they know he is HIV positive. Even though I know there is a medicine to treat esophageal candidiasis but doctor don't prescribed for him. Even when he was in pain they don't pay attention to him."

"It very much depends on the health care doctor at different hospitals. For example, I had oral fungus, pneumonia, and pain in the chest but when I went to see a doctor in Gia Lam he just gave me some pain relief. It could only help me for a half hour."

Addressed Pain: A few focus group participants felt they received adequate pain treatment from their health care providers.

"When I was painful, I came to doctor to have prescription, often it helps to reduce the pain."

"Prescription by doctors in commune health station, district health center, provincial hospital or other health care center often help me to reduce my pain."

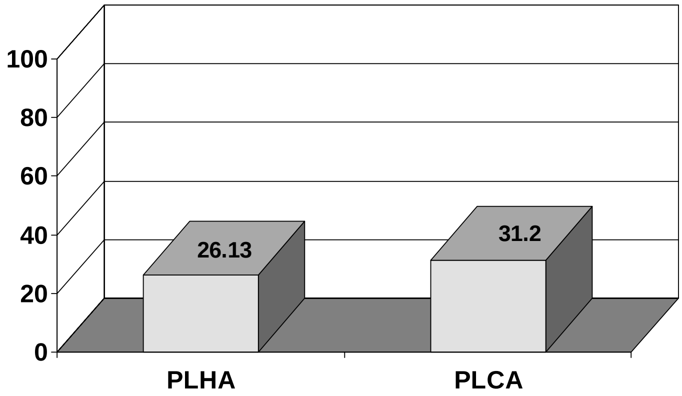
Family pain treatment strategies

A few interviewees said that they sought opium and heroin to treat their family members with HIV when they could not access morphine from a doctor. One family caregiver reported giving heroin to manage pain in their loved one. Participants in the focus groups said the following:

"In end of life care, family often gives opium to patient to prolong their life as much as possible."

"Heroin has very good effect in reducing the pain."

Graph 2. Pain Relief Need



Pain relief needs and recommendations

From about a quarter to a third of PLHA and people with cancer stated one of their major needs as pain relief:

Focus group participants expressed support for increased access to pain medicines for severe pain, particularly morphine, and offered suggestions on how to manage these prescribed medicines.

"One of good ways to monitor medicine use is through support group. They know who is having pain in their group and have connection with commune health center to get drug for those pain persons under close monitoring of commune health station."

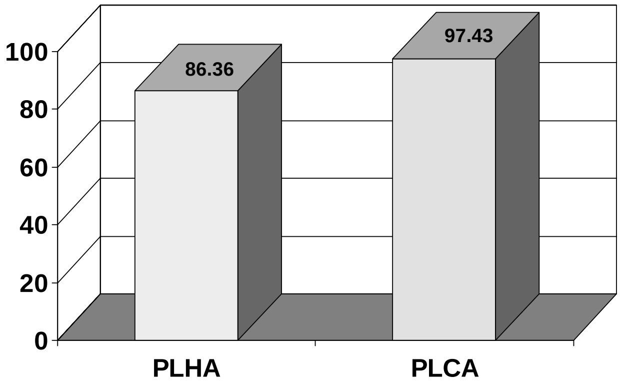
"I think there should be a policy which defines that morphine will be prescribed at the terminal stage."

"I have never seen any prescription of morphine for AIDS patients even though I think it would be very essential."

Experiences with Other Symptoms and Symptom Management

Distressing symptoms were prevalent among PLHA and people with cancer: 90% of people with HIV and cancer interviewed experienced symptoms which caused physical discomfort since having their disease.

Graph 3. Percentage experiencing physical discomfort due to symptoms



Interviewees were asked to rank the level of discomfort related to their symptoms the last time they experienced them, 54% said their discomfort was severe.

As with pain, RSA respondents were asked to rank the level of discomfort caused by symptom the last time they'd experienced them. A scale of 0 to 10 was used with 0 representing no discomfort and 10 the worst discomfort they could possibly imagine. Discomfort was then grouped as mild, moderate and severe pain.

Table 10a. Symptom Discomfort Before Treatment

Symptom discomfort severity	People with Cancer (%)	PLHA (%)
Mild (1-3)	5	11
Moderate (4-6)	34	37
Severe (7-10)	61	49

Ninety-five per cent of both people with HIV/AIDS and people with cancer stated that they care they sought partially or completely addressed the discomfort caused by the symptom.

Table 10b. Symptom Discomfort After Treatment

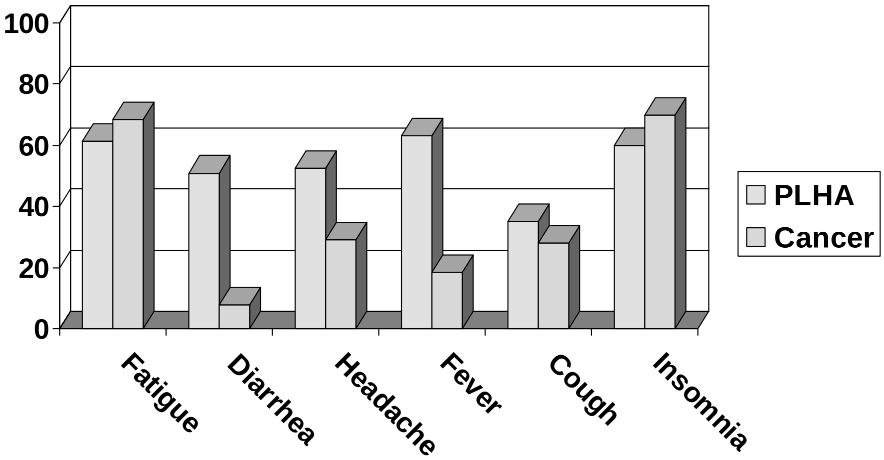
Symptom discomfort severity	People with Cancer (%)	PLHA (%)
Mild (1-3)	5	11
Moderate (4-6)	34	37
Severe (7-10)	61	49

Symptoms among RSA respondents were under-addressed. Symptom discomfort decreased after treatment but approximately 50% of participants with HIV/AIDS and cancer report that they are still experiencing moderate to severe distress from symptoms.

Types of symptoms experienced

PLHA and people with cancer reported fatigue and insomnia with near equal frequency. Symptoms associated with HIV and opportunistic infections were of course much more prevalent in PLHA than people with cancer.

Graph 4. Symptom Prevalence



Other symptoms which were experienced by people with HIV/AIDS and cancer included:

- Lack of appetite (cancer: 68% and PLHA: 51%)
- Weight loss (cancer: 61% and PLHA: 58%)
- Itchiness (cancer: 0% and PLHA: 49%)
- Abdominal discomfort (cancer: 32% and PLHA: 40%)
- Bone/joint aches (cancer: 39% and PLHA: 23%)
- Vomiting (cancer: 32% and PLHA: 21%)
- Forgetfulness (cancer: 29% and PLHA: 18)
- Difficulty swallowing (cancer: 29% and PLHA: 14%)
- Numbness and tingling (cancer: 16% and PLHA: 18%)
- Hiccups (cancer: 16% and PLHA: 9%)

Typical to the different etiologies of cancers and HIV, the prevalence of symptoms between people with either disease was generally different. However, similarities were seen with fatigue, insomnia, weight loss, abdominal discomfort and numbness and tingling.

These results compare with international research on prevalence on symptoms among people with AIDS.

Common Symptoms in AIDS	Range (%)
Fatigue	48-77
Weight loss/anorexia	31-91
Pain	29-76
Insomnia	21-50
Cough	19-36
Nausea/ vomiting	17-43
Dyspnea/ respiratory symptoms	15-48
Diarrhea	11-32
Constipation	10-29

Source: Krakauer, E., Based on several published descriptive studies of patients with AIDS, predominantly in patients with late-stage disease, Europe and North America, 1990-2002.

Focus group participants described their and their loved ones experiences with distressing symptoms:

"My husband could not sleep while lying on the bed; he had to sleep while sitting because he breathed very hardly. He died after one night of terrible dyspnea."

"I am itching all around day, this is terrible feeling. I have rash and abscess everywhere in my body."

"He suffered from lung tuberculosis, coughed, vomited, felt uncomfortable, emaciated…"

"I coughed, the more I coughed, the more I itched, it spread out with many small spot like scabies. It was awful itching."

"I felt so uncomfortable; I wanted to eat but could not eat anything."

"I usually felt so tired, I did not want to and sometimes could not do anything."

"I could not swallow, it made me crazy."

Impact of symptoms on functional status

Respondents were asked to comment on the impact which symptoms had on their ability to do the things they normally do when they are not experiencing symptoms. Sixty-four per cent of people with cancer and 26% of people with HIV/AIDS stated that the symptoms interfered with their ability to do the following things:

Table 11. Impact of Symptoms on Functional Status

Activities not able to do due to symptoms	People with Cancer (%)	PLHA (%)
Lift my head in bed	0	12
Sit up in bed	8	12
Standup	12	18
Walk around slowly	24	18
Walk around normally	40	53
Go to the toilet myself	20	18
Do household chores slowly	64	35
Do household chores as normal	76	65
Do my normal work	100	94

This is an indication of the impact of symptoms on the ability of respondents to perform normal daily activities, as well as an indicator of the level of support needed by caregivers to move in bed, sit-up, get out of bed, go to the toilet, etc.

Symptom health seeking and treatment

For those who reported physical symptoms, many sought health care services from the government system (Cancer: 58% and HIV: 39%) and some PLHA (18%) went the HIV outpatient clinic (OPC) for treatment. However, more people with HIV self-medicated rather than seek medical services: 40% of people with HIV self-medicated whereas only 26% of people with cancer did.

The majority of PLHA and people with cancer (74%) who indicated that they had experienced severe symptoms the last time they had them said that they were partially relieved by treatment; reduced to mild or moderate symptoms from severe.

Focus group participants commented on the desire to self-treat due to stigma and discrimination among health care workers as well as the cost of services.

"Some people like me will choose to stay at home with self-treatment. We do not want to go the health setting because we felt stigma and discrimination from health care providers."

"Whenever having a health problem, you should go to see the doctor. However, some of my friends always buy drugs for treatment and stay at home as they see the complication of going to health service."

"The local health system was blamed a lot as you need money to get into hospitals. Those people at the end stage have to sell everything, even their house and land, for treatment."

"Most of families are facing difficulties to access hospital as they don't have money. They need to have at least 500,000 or 1 million (dong) to go. They can not afford it so they stay at home and only when they become severe, they go to see the doctor."

Caregiving location preferences

Participants were asked when they felt sick the last time they experienced a symptom where they wanted their care. The responses given by people with HIV/AIDS and people with cancer were quite different. The majority of people with cancer (67%) reported that they would prefer to receive care in the hospital, while 26% of PLHA said they would want to be cared for in the hospital. PLHA (55%) indicated that they wanted to receive care in the home environment and 27% of people with cancer said the same. A few individuals indicated they would prefer care in a private clinic and hospice.

Table 12. Where people with cancer and HIV/AIDS

Care location preferences	People with Cancer (%)	PLHA (%)
At my home	26	55%
At the government hospital	67	27%
At a private clinic/hospital	3	3
At a hospice	3	2
At 06 center	0	5
Do not mind where	3	3
Other	0	6

Interviewees were not specifically asked to differentiate between where they would prefer care when experiencing an acute versus chronic symptom or end-of-life care.

However, the fact that more people with cancer wanted to be cared for in the hospital than PLHA may be related to fear of being discriminated against by health care workers as indicated by the quotations in the previous section. These issues are further highlighted in the stigma and discrimination section.

Care service and information needs

When asked that types of services were needed, 50% of people with cancer and 34% of PLHA said they needed support from home-based care teams. Other service needs included:

- Pain control (47% People with cancer; 38% PLHA)
- Symptom care (45% People with cancer; 26% PLHA)
- Access to ART (68%)
- Join PLHA support group (25%)

In terms of information needs, 50% of participants with cancer and 35% with HIV/AIDS indicated they wanted more information on nutrition. And 52% of PLHA wanted more information on how to take ART.

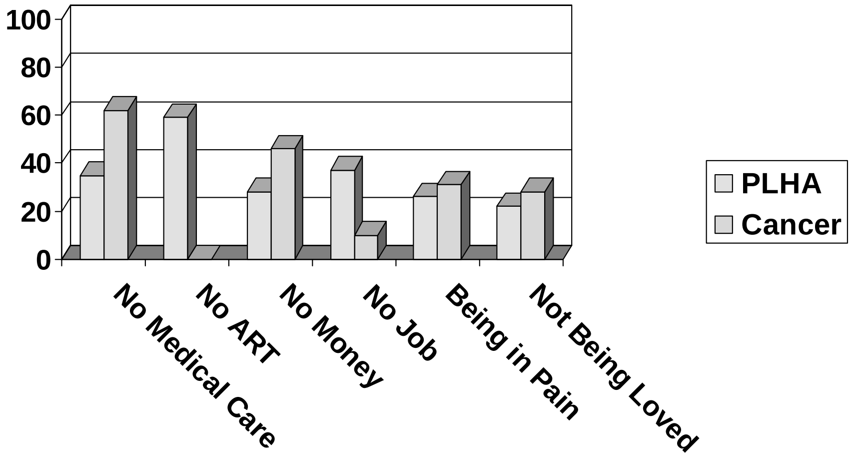
Emotional Wellbeing

The PLHA and people with cancer interviewed both reported significant emotional suffering at the time of interview: 48% felt completely or mostly dissatisfied with their life; and, strikingly, 79% of people with HIV and 87% of those with cancer said that they were either unhappy or very unhappy. It is clear that emotional support needs of those interviewed are substantial.

“When I knew my HIV (+) status, I was shocked and wanted to die immediately, I was self-isolated and self-discriminated.”

A number of fears were sited by people with HIV and cancers, including the worries that they would not be loved, would not get the medical treatment they needed and about the future of their children.

Graph 5. Greatest Fears



Emotional support experiences and needs

Respondents were asked if they had anyone who offered them emotional or spiritual support. Almost all people with cancer 97% stated that they had some form of assistance; however, 23% of PLHA said they had no one who provided them with support.

Spouses were the primary emotional supporters (74%) of respondents with cancer, while 59% of PLHA turned to their parents for care.

In focus group discussions, participants cited PLHA groups as being a great source of support.

"I participated in one support group consisted of people with the same status as me, I found myself released and life is more meaningful to continue"

"I found sympathy and felt relief while talking with people like me in support group."

Not surprisingly, about one-third (30%) of people with HIV/AIDS and cancer reported needing emotional support and counseling services.

Experiences with Stigma and Discrimination

Just less than half of people with HIV/AIDS interviewed (45%) stated that they had experienced stigma and discrimination in the past. The greatest level of stigma and discrimination reported was among neighbors: 59% of individuals interviewed said they felt discriminated by them. Family members were also cited as being common sources of stigma and discrimination. Reported stigma and discrimination among health care workers was lower, at 24.14%.

However, in focus group discussions participants shared many stories of discrimination experienced in the health care setting. These experiences include:

"Most of doctors stigmatize HIV infected people. They often don't take care of us. Sometime they ask us to wait for a very long time until they have no patient left to examine".

"I knew I was HIV positive when my arms were broken. They talked to each other quietly and look at me scary. I see that most of the infected coming to hospital have been stigmatized, even by health care workers".

"The HIV test result was given to me in a crowded room. I feel socked and wanted to have a seat for a while but they did not allow me. I dare not to go to that hospital as I feel myself discriminated."

"Even the doctors know about HIV but still discriminate the infected people like me. I see doctors in Bach Mai are more enthusiastic than doctors at lower level."

Family caregivers of PLHA and people with cancer also reported experiences with stigma and discrimination: 18% said that they felt stigmatized because they were caring for someone with HIV and/or cancer.

A few focus group participants also expressed self-stigma through the following comments:

"I am not young and I try to hide my HIV status because HIV is a social evil. I did some thing wrong and I have to accept punishment from God"

"I dare not do anything even playing with my children with the fear of transmitting to them."

Table 13. Religious Affiliation

Religion	People with Cancer (%)	PLHA (%)
Buddhist	13	32
Christian - Catholic	8	9
Protestant	5	0
Cao Dai	0	2
Other	3	5
None	72	53

Spiritual Wellbeing

Most of the people with cancer (72%) stated that they were not religious; 13% were Buddhist, 8% Christian and 5% Protestant. Among PLHA respondents, 32% were Buddhist, 9% Christian and 53% were not affiliated with a religion.

When respondents were asked how they coped with physical discomfort, 5% of people with cancer and 6% PLHA said they went to a place of worship for support. Eighteen per cent of people with cancer and 9% of PLHA also stated that they feared death.

When asked about spiritual support needs, 31% of people with HIV and 37% with cancer reported they needed spiritual counseling.

Socio-economic Wellbeing

During focus group discussions and interviews with program managers, financial constraints were named several times as a barrier to accessing health care services. As established by the 2005 UNDP report, households affected by HIV/AIDS spend 13 times more on health care expenses than average households. This is compounded by the fact that most PLHA are young and less able to contribute economically to their household and the fact that caregivers, in many cases mothers, spend significant time every day providing care, time that would otherwise have gone to work.

Among the greatest fears listed by respondents, lack of money or having a job ranked as most significant after concerns regarding access to health care and ART; 56% of family caregivers listed their primary worry as not having enough money.

People with HIV and cancer reported they needed the following services:

- 27% Assistance with finding a job
- 15% Legal advice
- 15% Care and support for children

Experiences of Caregivers

Interviews with family caregivers clearly indicate that they are tired, worried, sad and struggling economically. More than 50% of caregivers reported concerns related to limited economic resources; 33% stated that they were worried about the future and 21% reported that caregiving made them sad.

"I witness him from the day of his illness till the day he passed away. His family member called me at midnight as they didn't know what to do. They did not dare to bathe him. I then helped him and showed his family members how to bathe him."

Time spent caregiving

Family caregivers (64%) indicated they were spending more than 10 hours a day providing care to their family member with HIV or cancer. Bereaved caregivers (44%)

said they provided care 20-24 hours a day. These are substantial periods of time to spend caring for a family member and have an impact upon the ability of the caregiver to work or do the other activities normally conducted as part of the household.

Caregiver worries and needs

The primary concern among family caregivers was not having enough money (56%). Caregivers also said they were in general worried about the future (33%) and that caregiving made them sad (21%). In addition, 30% of family caregivers expressed feeling stressed because they did not know how to provide care.

Family members also named the following worries related to caregiving:

- Need to travel long distances for medicine
- Do not know how to prevent HIV transmission
- Shortage of money
- The wellbeing of their children
- The sick individual is irritated and has a temper
- Complications in caring for a person of a different gender
- Don't feel healthy enough to be a caregiver
- Worry about parents

Support to caregivers

The majority (76%) of bereaved caregivers reported receiving support from various sources. Most (93%) said that their extended family offered support. After that the most common source of support was from friends (32%), neighbors (25%), the women's union (21%), PLHA support groups (14%) and home-based care (11%).

Training needs

Family caregivers reported being unsure of what to do to manage pain and symptoms in the home. Essential skills building needs of family members include knowing how to provide around the clock pain medicines for family members in chronic pain.

"Morphine can't be bought without doctor's prescription. I gave it to my husband only when he was painful. I did not give it to him around the clock."

Opinion Leaders' and Health Care Workers' Perceptions of and Experiences with Palliative Care

Overall, 27 health opinion leaders – hospital managers and unit chiefs – were interviewed. Of these, 13 were from the national level, two provincial, six district, four community leaders and two program managers. In addition, six policy opinion leaders were interviewed. These included people in provincial and national leadership positions in the ministry of health and other sectors.

Health and Policy Leaders' Perceptions of Palliative Care and Palliative Care Needs

The majority of health leaders interviewed (85%) felt that palliative care services in Viet Nam were inadequate. Reasons cited for these limitations include: lack of training and knowledge in palliative care, no guidelines for pain management and no department for pain management within healthcare services.

Leaders described essential palliative health care services as including health care and medicines, psychological and social support, and nutrition care.

However, 70% were concerned about diversion of opioids should they be made more available throughout the health care system. Other reasons included worries regarding addiction to opioids.

Still, these leaders felt that the provision of oral morphine by trained and authorized health personnel to people with life-limiting illnesses in the home should be piloted. 100% of policy leaders stated that oral morphine should be available to people with cancer and HIV/AIDS in the home, administered under the supervision of a nurse, other trained health workers or family members.

Health Care Worker Palliative Care Policies and Practices

Of the 76 health care workers interviewed, 65% said they had been trained in some aspect of palliative care, however, only 43% reported having been trained in the identification and treatment of pain. Only 26% could identify the correct strategy in managing pain: providing pain medicine regularly, around the clock, to prevent breakthrough of pain.

Medications for palliative care

There is a very wide range of availability of essential palliative care medicines in health care settings. In all health facilities interviewed paracetamol, anti-diarrheals and anti-constipations were available. However, other vital medicines were not readily available, these include medicines to manage moderate and severe pain, breathlessness and depression -- all medicines which are the crux of basic palliative care to people with life-limiting illnesses.

When asked whether or not oral morphine had ever been available in the hospital, 5.63% responded yes, with 2.70% saying that it was available now at their workplace. Injection form of morphine was more available but very far from sufficient in hospitals providing care to people with HIV/AIDS and cancer: only 57.89% of health care workers said it was currently available in their hospital. Codeine was even more limited to only 12.16% of institutions interviewed.

Table 14. Palliative Medicines Available in Health Care Setting

Medicines	Is this		%	At any time in the last six months did you run out of this medication?	%	Has this medication ever been available in your workplace?	%
Q1. Morphine (oral form)	Yes	2	2.7	2		4	5.6
	No	71	94.7	2		67	94.4
	Total	**75**	**100.0**	**4**		**71**	**100.0**

Q2. Morphine (injectable form)	Yes	44	57.9	2	4.5	0	0.0
	No	32	42.1	42	95.5	32	100.0
	Total	**76**	**100.0**	**44**	**100.0**	**32**	**100.0**
Q3. Codeine	Yes	9	12.2	1		0	0.0
(tablet or liquid)	No	65	87.8	8		62	100.0
	Total	**74**	**100.0**	**9**		**62**	**100.0**
Q4. Paracetamol	Yes	75	98.7	7	9.3	0	
	No	1	1.3	68	90.7	1	
	Total	**76**	**100.0**	**75**	**100.0**	**1**	
Q5. Aspirin	Yes	41	53.9	5	12.2	12	35.3
	No	35	46.1	36	87.8	22	64.7
	Total	**76**	**100.0**	**41**	**100.0**	**34**	**100.0**
Q6. Ibuprofen	Yes	58	76.3	3	5.2	0	0.0
	No	17	22.4	55	94.8	16	100.0
	Total	**76**	**100.0**	**58**	**100.0**	**16**	**100.0**
Q7. Cortico –steroids (prednisolone dexamethasone)	Yes	69	90.8	69	90.8	5	7.2
	No	7	9.2	7	9.2	64	92.8
	Total	**76**	**100.0**	**76**	**100.0**	**69**	**100.0**
Q8. Benzodiazepines, Diazepam	Yes	56	73.7	5	8.9	3	15.0
	No	20	26.3	51	91.1	17	85.0
	Total	**76**	**100.0**	**56**	**100.0**	**20**	**100.0**
Q9. Haloperidol(oral or injection mode)	Yes	25	36.2	3	12.0	0	0.0
	No	44	63.8	22	88.0	42	100.0
	Total	**69**	**100.0**	**25**	**100.0**	**42**	**100.0**
Q10. Anti-omiting(e.g. primperan)	Yes	59	79.7	5	8.5	2	14.3
	No	15	20.3	54	91.5	12	85.7
	Total	**74**	**100.0**	**59**	**100.0**	**14**	**100.0**
Q11. Anti-depressant(e.g. amitriptyline)	Yes	16	24.2	1	6.3	7	14.6
	No	50	75.8	15	93.8	41	85.4
	Total	**66**	**100.0**	**16**	**100.0**	**48**	**100.0**
Q12. Anti-iarrheal	Yes	76	100.0	8	10.5	68	90.7
(e.g. loperamide, smecta)	No	0	0.0	68	89.5	7	9.3
	Total	**76**	**100.0**	**76**	**100.0**	**75**	**100.0**

Q13. Anti-constipation(e.g. sorbital, forlax)	Yes	68	90.7	7	10.3	1	2.2
	No	7	9.3	61	89.7	44	97.8
	Total	**75**	**100.0**	**68**	**100.0**	**45**	**100.0**
Q14. Chlorpromazine (for hiccups)	Yes	23	33.3	1	2.2	1	2.2
	No	46	66.7	41	91.1	44	97.8
	Total	**69**	**100.0**	**45**	**100.0**	**45**	**100.0**

Policies and procedures

Just over half of health care workers (57%) interviewed indicated that their hospital had a policy on pain relief and opioid use for pain relief. Estimates of opioid need were the responsibility of the pharmacist (27%); doctor (27%) and nurse (12%).

Opioid prescriptions were almost always (95%) made by doctors including the section chief or hospital director.

Concerns with opioids

Among health care workers interviewed, 21% said they experienced some form of difficulty in managing opioids. Problems included:

- Worried that clients will sell or otherwise misuse opioids (64%)
- Strict management and regulations and complication approval procedures for accessing opioids (25%)
- The fragile morphine vial is difficult to collect once used and returned to the hospital (25%)
- Limit in amount of opioids that can be prescribed at any one time (18%)
- Running out of stock (9%)
- Worry that the medicines will be used illegally (9%)

Annual opioid prescriptions

Total number of opioid prescriptions made were low. In a year, 34% of health care workers said they did not prescribe opioids to any of their clients. Five per cent reported providing opioids to two clients in a year; the same percentage prescribed to 20-60 clients in a year

Only 41% of doctors interviewed had ever prescribed opioids for pain control.

Perspectives on home palliative care

Health care workers were asked, “Many people who are chronically ill prefer to be cared for at home, do you think it would be possible to prescribe oral morphine to be administered by nurse or other trained health worker in the home environment?” The majority, 52%, agreed that oral morphine should be made available to people with life-limiting illnesses in severe pain who opt to receive care in the home.

Symptom care

The most common symptoms cared for by health care workers included: diarrhea (23%); fatigue (22%); headache (10%); fever (7%); coughing (7%); rash (5%) and abdominal discomfort/pain (3%) and insomnia (3%).

The majority of health care workers (59%) did not feel that they have adequate medicines/ supplies to manage these symptoms.

SECTION 5

RECOMMENDATIONS AND NEXT STEPS

Physical pain, other distressing symptoms, and emotional distress are prevalent among people with HIV/AIDS and cancer in Viet Nam. Yet treatment is generally inadequate or unavailable. Reasons for this include:

- Health practitioners have not received adequate training in palliative care
- Some essential pain medicines, particularly morphine (parenteral and oral), are not readily or consistently available to people in pain.
- There are currently no national guidelines on palliative care or opioid availability for people with life-limiting illnesses such as HIV and cancer.
- Emotional support services are not readily available.
- Coverage of community and institution-based palliative care programs is still very limited
- Stigma and discrimination and cost are significant barriers to accessing existing palliative care programs

Policy makers, health care workers, family caregivers and people with HIV/AIDS and cancer all recognize that measures to address pain and suffering are not adequate in Viet Nam and that several actions need to be taken to improve palliative care.

Based on the above findings, key recommendations are:

DEVELOP NATIONAL PALLIATIVE CARE GUIDELINES

The findings from the RSA clearly indicate that palliative care guidelines are needed in order to set standards and norms for palliative care practice for people with life-limiting illnesses, including adults and children with HIV/AIDS and cancer. These guidelines should be developed as soon as possible to provide much needed guidance in palliative care to leaders, health care providers and communities. The guidelines should cover all the essential elements of palliative care including symptom and pain identification and control, psychosocial support, spiritual and end-of-life care and counseling, and care of caregivers.

COMPLETE NATIONAL OPIOID CONTROL POLICY

Without greatly increased availability of opioid analgesics, especially oral morphine clear and parameters for health care workers regarding the use of opioids, Viet Nam will not be able to achieve quality palliative care for people with HIV/AIDS and cancer. Moderate to severe pain can only be reduced or altogether eliminated by opioids, medicines which are inexpensive, rarely cause side-effects that cannot be easily managed and do not lead to dependence in the vast majority of patients. Therefore, national guidance specifying the handling and prescription of opioids in pain control so as to maximize availability for pain control and minimize diversion is essential.

In addition, the following opioids should be approved for use and made available in Viet Nam, ideally through local production:

- Codeine (not compounded with other medications)
- Long-acting morphine
- Fentanyl should also be classified as an analgesic on the Viet Nam Essential Drugs List

DISSEMINATE GUIDELINES AND POLICIES

Once guidelines and policies are developed, they will need to be widely disseminated among leaders, hospital managers, health care workers and home-based care services. Hospital administrators and provincial and district leaders will need to be aware of the new guidelines so they can update and improve their palliative care practices accordingly.

UPGRADE AND EXPAND AVAILABILITY OF PALLIATIVE CARE EDUCATION, TRAINING AND CERTIFICATION IN ACCORDANCE WITH NATIONAL GUIDELINES

In-service training and certification should be provided in a step-wise fashion, starting first with cancer and HIV/AIDS care providers and then extending to other health care providers who do not provide care solely for PLHA and people with cancer.

In addition, palliative care training needs to be a part of basic education for nurses, pharmacists, doctors, social workers and psychologists. In order to develop a basic palliative care education curriculum for clinicians, an assessment would need to be undertaken for students of nursing, medicine, pharmacy, social work and psychology.

SCALE-UP NATIONAL, PROVINCIAL AND LOCAL PALLIATIVE CARE PROGRAMS, SUPPORT DEVELOPMENT OF MODEL PALLIATIVE CARE PROGRAMS, INCLUDING COMMUNITY PROVISION OF ORAL MORPHINE BY TRAINED HEALTH WORKERS.

Both the availability and quality of palliative care services urgently need to be improved, particularly in areas of high HIV and cancer prevalence. In order to do this, the following actions should be taken:

- Priority should be given to incorporating palliative care within current cancer and HIV care and treatment programs including HIV outpatient clinics and 09 centers at central, regional, provincial and district hospitals. Staff at these facilities will need to be trained and equipped to assess and treat pain and other distressing symptoms. Palliative care and pain control centers should be establish in each cancer hospital with a complete range of pain control medicines including morphine and beds to accommodate local need.
- Coverage and quality of community and home-based care programs need to be extended so they are able to reach more people with HIV/AIDS and cancer with palliative care including

pain control. Current home-based care and hospice service providers need to be better trained and equipped with essential palliative care medicines.

- Provision of oral morphine at the community and home based care level, prescribed and monitored by trained and certified health care workers should be piloted in a few high HIV and cancer prevalence settings. As many people with cancer and HIV/AIDS prefer to be cared for in the home, such programs could vastly reduce suffering and enhance quality of life. Pilot programs could be conducted in high HIV and cancer prevalence provinces in the north and south. Based on lessons learned, a nationwide program of community administered oral morphine could be considered, as has been done in several other countries.
- Determination of quality standards of palliative care services which are based on national palliative care guidelines and international best practice. Palliative care programs in the community, hospices and hospitals should develop operational plans and standard operational procedures which include quality standards and rules for maximizing both availability and safe handling of opioids.

As much as possible, palliative care services and access to palliative care medicines should be offered at low or no cost for people with life-limiting illness. The RSA and a number of other research studies in Viet Nam reveal that people with chronic illness require multiple hospital admissions, medicine prescriptions, laboratory tests and clinical procedures, and outpatient clinic visits, are unable to afford the associated costs of chronic care. By minimizing or waiving the cost of palliative care services, people with cancer and HIV/AIDS will be able to live and die in greater peace and comfort.

ANNEX 1

RAPID SITUATION ANALYSIS DATA COLLECTION PROTOCOL

PROTOCOL FOR RAPID SITUATION ANALYSIS OF PALLIATIVE CARE IN VIỆT NAM FINAL AUGUST 2005

Rationale for the Rapid Situation Analysis

While palliative care as a concept is relatively new to Việt Nam, many public, private and charity facilities do provide basic palliative care to people with chronic life-limiting illnesses and disabilities across the country. Little is known though regarding the scope of these services, and how capable these services are of providing comprehensive palliative care, including the management of pain through use of a range of analgesic and adjuvant medicines.

In Huế, Hồ Chí Minh City and Hà Nội, there are facilities providing more comprehensive palliative care services to people with HIV and cancer. The pain management center at the national cancer institute in Hà Nội, which has been in operation for just over one year, provides pain care for a limited number of cancer patients. Mai Hoà hospice in Củ Chi outside of Ho Chi Minh City provides comprehensive palliative care services to adults and children with HIV. In Huế, the provincial hospital manages a palliative care service in the oncology ward and in-patient services for PLHA; these are services are linked to a home-based care program run by the government, and Buddhist and Christian nuns. There are also hundreds of home-based care programs providing care to people with HIV and AIDS in Việt Nam; however, the quality and scope of these programs is unknown.

Comprehensive palliative care in this analysis is defined as palliative care which is provided by staff trained in the principles and practice of palliative care, with access to the full range of drugs required to provide pain and symptom management and either providing, or with access to, the equally important services needed to provide emotional psychological social and spiritual support.

As there are no overall national guidelines in palliative care, no standard has been established in the level and type of care which should be available to people with chronic illness and disabilities; however, the national cancer program has developed specific palliative care guidelines for cancer patients in select facilities.

For people with HIV and AIDS, very little is known about their palliative care needs. Several qualitative research studies have been done looking at the overall needs of people with HIV and AIDS, but not on their experiences with physical, psychological and existential pain.

The purpose of conducting the rapid situation analysis of palliative care is to:

- Provide an overview of existing palliative care related laws, policies, trainings and guidance
- Describe the range of palliative services available in Việt Nam, including coverage and scope in select provinces
- Identify successful or promising models for palliative care provision
- Identify palliative care needs and gaps among people with chronic illness and family/household caregivers
- Better understand the palliative care training and supply needs of health care workers at the national, provincial, district and commune levels
- Define current laws and practices in use of opioids in pain management
- Outline opinions and perspectives of national and provincial leaders in palliative care needs, gaps and use of opioids in pain management
- Provide the background from which to develop national palliative care guidelines which address the primary needs and gaps related to palliative care in Việt Nam

Methodology

The rapid situation analysis (RSA) will consist of a combination of qualitative and quantitative data collection methods and a literature review. Both key informant interviews using structured questionnaires and focus groups discussions using discussion guides will be used in the rapid situation analysis. In addition a comprehensive literature review of palliative care related laws, regulations, policies, trainings, guidance etc. will be conducted to guide the data collection process and provide background for the development of national palliative care guidelines.

Selection of key informants will be based on intentional and convenience sampling and is no way meant to be random or representational. This is not a national survey, rather it is a rapid situation analysis of current palliative care services, needs, policies and laws to provide background from which to develop national palliative care guidelines.

RSA Locations

The RSA will be conducted in five high HIV prevalence provinces:

- Hà Nội
- Hải Phòng
- Quảng Ninh
- Hồ Chí Minh City
- An Giang

In addition, select national level key informant interviews with policy makers will also be conducted.

Table 1. Site Overviews

Province	Population Size (Est.)	HIV Prevalence (2003 HSS) %	Cancer Data (not available)	Hospitals Per Province
Hà Nội	4, 071,000	IDU: 30.5 SW: 15	0	43 hospital
Hải Phòng	1,500,000	IDU: 60.5 SW: 5.94	0	22
Quảng Ninh	1,029,900	IDU: 54.3 SW: 3.25	0	20
HCMC	5,700,000	IDU: 54.8 SW: 10.5	0	32
An Giang	2,146,800	IDU: 26.3 SW: 14.14	0	12

Table 2. 2004 Projections and Estimates

Number of total HIV by cluster	2005
HCMC	50,199
Mekong River Delta	61,316
South East	27,623
High Plateau	5,527
Central Coast	7,082
Red River Delta	25,826
North East Coast	21,208
North East	20,015
North Plateau	5,982
North West	21,353
Ha Noi	17,339
Total	**263,470**

Prevalence of HIV by cluster (age 15-49)	2005
HCMC	1.250
Mekong River Delta	0.543

South East	0.595
High Plateau	0.203
Central Coast	0.125
Red River Delta	0.352
North East Coast	1.150
North East	0.572
North Plateau	0.198
North West	0.380
Ha Noi	0.860
Total	**0.510**

RSA Participants

Approximately 70 individuals will be interviewed in each site. Key informant interviews and FGDs will be conducted with:

- PLHA and people with cancer (n=150; 100 PLHA/50 cancer; 30% of PLHA Female; 30% of PLHA non-IDU/ Cancer 50% F)
- Family caregivers of PLHA and people with cancer (n=75; 30 HIV/20 cancer; 25 HIV or cancer)
- Healthcare workers involved in care for PLHA and people with cancer (n=75)
- Program managers of palliative care services for PLHA and people with cancer (n=25+)
- National and provincial leaders who are knowledgeable or influential in palliative care issues (n=25-50)

Interview Respondents by Location and Sizes

See province tables

RSA Data Collection Tools

A combination of surveys will be used in the palliative care situation analysis:

1. Interview guide for health opinion leaders key informant interviews
2. Interview guide for policy opinion leaders key informant interviews
3. Palliative care program questionnaire
4. PLHA and persons with cancer questionnaire
5. Family caregiver of PLHA or PWC questionnaire
6. PLHA focus group discussion (FGD) guide
7. Family caregiver bereavement questionnaire
8. Health care worker questionnaire

ANNEX 2: DATA COLLECTION SCHEDULE

RSA TIMELINE

	July 05		August 05					September 05			
Activity	**18-22**	**25-29**	**1-5**	**8-12**	**15-19**	**22-26**	**29-2**	**5-9**	**11-15**	**18-22**	**25-29**
Hold consultation meeting with national govt, donor and NGO reps	X										
Finalize study protocol	X										
Finalize data collection tools (questionnaires and checklists)		X	X								
Train data collectors[1] and fine tune data collection tools [31]			X	X							
Pre-test and modify questionnaires as appropriate			X	X							
Conduct 3-4 key national policy maker in-depth interviews			X	X							
Finalize literature review			X								
Conduct interviews and FGDs/collect data in the field				X	X	X					
o Hà Nội				X			X				
o HCMC/Hải Phòng					X						
o An Giang/Quảng Ninh						X					
Finalize database for data entry							X				
Data entry								X	X	X	X
Analyze data and compile draft report										X	X
Prepare detailed timeline of next steps in using the situation analysis to draft the national palliative care guidelines							X	X			

---

[31] Data collection teams will be trained for two days, while pre-testing will be done in a day

ANNEX 3:

RSA DATA COLLECTION TEAM

	Name	**Working Position and Place**
1	Dr. Vương Ánh Dương	Therapy department - MOH
2	Dr. Lê Văn Khảm	Therapy department - MOH
3	Dr. Nguyễn Quốc Thái	National Institute for Clinical Research in tropical medicine
4	Dr. Nguyễn Sơn Hà	Bảo Việt Insurance
5	Dr. Đỗ Thị Phương	CHRU- Hanoi Medical University
6	Dr. Bùi Tiến Hưng	CHRU- Hanoi Medical University
7	Dr. Trần Quốc Tuấn	CHRU- Hanoi Medical University
8	Dr. Nguyễn Phi Yến	K hospital
9	Ms. Nguyễn Minh Thu	POLICY Project
10	Dr. Trương Jeanne Darc	POLICY Project
11	Ms. Huỳnh Như Thanh Huyền	POLICY Project
12	Dr. Đỗ Duy Cường	FHI
13	Dr. Ngô Đức Thọ	Nurse Association
14	Dr. Nguyễn Thị Huỳnh	VAAC-MOH
15	Dr. Nguyễn Phương Hiền	Traditional medicine department-Hanoi Medical University
16	Dr. Bùi Văn Hào	Hanoi Medical University
17	Mr. Đỗ Đăng Đông	Bright Futures
18	Dr. Phạm T. Hiền	K hospital
19	Dr. Đỗ Minh Hoa	CHRU- Hanoi Medical University
20	Dr. Nguyễn Thuỳ Hương	CHRU- Hanoi Medical University
21	Dr. Phạm Duy Hưng	Hanoi Medical University
22	Dr. Trương Lê Vân Ngọc	Therapy department - MOH
23	Dr. Dương Trường Thuỷ	POLICY Project

ANNEX 4:

REFERENCES

Coughlan, Marie. Protocol for Rapid Appraisal of Palliative care in South Africa. Washington, DC: FHI, 2004.

Coughlan, Marie. Rapid Appraisal of Palliative Care and Community and Home based Care in Abidjan, Cote D'Ivoire: Summary Report. Washington, DC: FHI, 2005.

Harding R, Higginson I. J. Palliative Care in Sub-Saharan Africa: An Appraisal. The Diana, Princess of Wales Memorial Fund, King's College: London, 2004.

Health Canada. Canadian Strategy on Palliative and End-of-Life Care: Progress Report of the Coordinating Committee. Health Canada: Ottawa.

International Narcotics Control Board. Availability of Opiates for Medical Needs. New York: UN, 1996.

International Observatory on End of Life Care. Opioid Availability and Consumption in South Africa. www.eolc-observatory.net/global_analysis/southafrica_opioid_pf.htm

Joranson DE. New international efforts to ensure availability of opioids for medical purposes. Journal of Pain and Symptom Management. 1996;12:285-286.

MoH Viet Nam, General Department of Preventive Medicine and HIV/AIDS Control. HIV/AIDS Estimates and Projections 2005-2010, MoH: Hanoi, 2005.

MoH Kenya National AIDS/STD Control Programme. National Home-Based Care Programme and Service Guidelines. Ministry of Health: Nairobi, 2002.

MoH Vietnam. Health Statistics Yearbook 2003: HSID. Planning and Finance Department, MoH: Hanoi, 2003.

MoH Vietnam. Essential Drug List. Drug Administration: Hanoi, January 24, 2005.

Nguyen Tran Hien, Nguyen Thanh Long & Trinh Quan Huan. "HIV/AIDS epidemic in Vietnam: Evolution and responses." AIDS Education and Prevention, (2005) 16 Suppl A, 137-154.

Official Gazette: Decision No. 36/2004/TTg of March 17, 2004 approving the National Strategy on HIV/AIDS Prevention and Control in Vietnam till 2010 with a vision to 2020.

O'Neill J., Selwyn, Peter A., Schietinger, Helen. A Clinical Guide to Supportive and Palliative Care for HIV/AIDS. HRSA, HIV/AIDS Bureau: Washington, DC, 2003.

President's Emergency Plan for AIDS Relief. HIV/AIDS Palliative Care Guidance #1 for the United States Government In-country Staff and Implementing Partners. US Department of State, Office of the Global AIDS Coordinator, Washington, DC, 2006.

Quality End-of-Life Care Coalition of Canada. Framework for a National Strategy on Palliative and End-of-Life Care. Quality End-of-Life Care Coalition of Canada: Ottawa, 2005.

Spence D, Merriman A and Binagwaho."Palliative Care in Africa and the Caribbean" Public Library of Science. (2004) Volume 1, Issue 1.

Statistical Yearbook 2003. General Statistics Office: Hanoi, 2004.

Than Nien. Lack of Prompt Medical Attention Leads to High Cancer Death Rate. Vietnam Economy: Hanoi

UNAIDS. AIDS Palliative Care: UNAIDS Technical Update. UNAIDS: Geneva, Switzerland, 2000.

UNAIDS. 2004. UNAIDS at Country Level. Progress Report. UNAIDS: Geneva, Switzerland, 2004.

UN Country Team Vietnam. Millennium Development Goals 2003. UNCT: Hanoi, 2003.

UN Country Team Vietnam. User Fees, Financial Autonomy and Access to Social Services in Viet Nam. United Nations, Discussion Paper No. 6, Hanoi, 2005.

UN Development Programme and Australian Agency for International Development. Impact of HIV/AIDS on household vulnerability and poverty in Viet Nam: Report of UNDP-AusAID supported project – VIE/98/006. UNDP: Hanoi, 2005

Vietnam Social Security (VSS). Statistics yearbook 2002.

Vietnam Development Gateway. Cancer on the Rise in Children. VDG: Hanoi, July 21, 2005.

WHO. Achieving balance in National Opioids Control Policy: Guidelines for Assessment. Geneva: WHO, 2000.

WHO. A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients in Sub-Saharan Africa: WHO, Geneva, 2004.

WHO. National Cancer Control Programmes: Policies and Managerial Guidelines. 2nd ed. WHO, Geneva, 2002.

WHO. Palliative Care: Symptom management and end-of-life care. Geneva: WHO

WHO. Palliative Care Guidelines. Geneva: WHO

WHO/WPRO. Vietnam Health Situation

Zhang H. People’s Republic of China: “Status of Cancer Pain and Palliative Care”. Journal of Pain & Symptom Management, (1996) Volume 12(2):124-126.

Printed under Publishing Permit No: 23-2006/CXB/212 - 271/YH issued Sep 12rd 2006by the Publishing Department.
1200 copies in Vietnam, 300 copies in English in A4 size

Design and printed by Luck House Graphics

OFFICE OF THE UNITED STATES GLOBAL AIDS COORDINATOR

fhi Family Health International

USAID FROM THE AMERICAN PEOPLE

HEALTH POLICY INITIATIVE