Report on current situation of palliative care service provision for cancer patients in Vietnam

Ha Noi, August 2010

STUDY ORGANIZATION

Funding agency:

HealthBridge Foundation of Canada

Research agency:

Research Center for Rural Population and Health

Key researchers:

Pham Thi Hoang Anh, MSc., HBV

Ngo Thi Thanh Thuy, MD., HBV

Trinh Huu Vach, Assoc. Prof., PhD., RCRPH

Nguyen Duc Hong, Assoc. Prof., PhD., CEHS

Nguyen Phi Yen, MD., National Cancer Hospital

Ms. Sarah Bales, MD., HBV

Luong Xuan Hien, Assoc. Prof., PhD., RCRPH

Le Van Bao, Assoc. Prof., PhD., Military Medical Academy

Nguyen Duc Thanh, PhD., RCRPH

Nguyen Thi Loan, MSc., RCRPH

Doan Trong Trung, MSc., RCRPH

Nguyen Van Thinh, MSc., RCRPH

Ngo Van Dong, MSc., RCRPH

Le Thi Tuyet, PhD., RCRPH

Tran Thanh Hue, MSc., RCRPH

Nguyen Phuong Ha, MPH., HBV

Vu Quang Thang, MSc., RCRPH

Le Xuan Hoan, MSc., RCRPH

Tran Thi Tham, MSc., RCRPH

Ngo Thi Nhu, PhD., RCRPH

Trinh Huu Hiep, BA., RCRPH

ACKNOWLEDGEMENT

The study on current situation of palliative care service provision for cancer patients in Ha Noi, Thua Thien Hue and HCM city was implemented by HealthBridge Foundation of Canada and Research Center for Rural Population and Health, Thai Binh Medical University.

First of all, we would like to express our sincere thanks to the HealthBridge Foundation of Canada in Viet Nam for its financial and technical support in this study, especially to Mrs. Pham Thi Hoang Anh, MD, MSc., Ngo Thi Thanh Thuy, MD. Nguyen Phi Yen, and Ms. Sarah Bales.

We would like to thank the Provincial Health Department, health agencies at provincial, district and communal levels in Ha Noi, Thua Thien Hue and HCM city for their enthusiastic support in data collection.

Many thanks to the health workers and inhabitants in the study sites as well as the patients and their caregivers who agreed to answer the survey questions.

Finally, we thank all the investigators and supervisors for their enthusiastic cooperation with our Center in implementation of this study.

Assoc. Prof., PhD. Trinh Huu Vach

Director of Research Center for Rural Population and Health,
Thai Binh Medical University

ACRONYMS AND ABBREVIATION

AIDS	Acquired Immune Deficiency Syndrome
CHC	Communal Health Center
Dist.	District
HCM	Ho Chi Minh
HIV	Human Immunodeficiency Virus
IDI	In-depth Interview
MOH	Ministry of Health
FGD	Focus Group Discussion
Prov.	Province
WHO	World Health Organization

TABLE OF CONTENTS

SUMMARY 10

1. INTRODUCTION 19

1.1. Palliative care and its role in cancer control 19

1.2. Needs for pain relief and palliative care in Vietnam 20

1.3. Palliative care in Vietnam 20

1.3. Reasons for study 22

2. STUDY SUBJECTS AND METHODOLOGY 24

2.1. STUDY SUBJECTS AND METHODOLOGY 24

2.1.1. Study subjects 24

2.1.1.1. Subjects for the quantitative study 24

2.1.1.2. Subjects for the qualitative research 24

2.1.2. Study time and study sites 24

2.2. STUDY METHODOLOGY 27

2.2.1. Study design 27

2.2.2. Sample size and sampling 27

2.2.3. Data collection 30

2.2.4. Data processing 31

2.3. ETHICAL ISSUES 31

2.4. STUDY LIMITATIONS 32

3.1. Implementation of and training on the Palliative care Guideline 33

3.1.1. Palliative care Guideline and some legal supporting documents 34

3.1.2. Implementation of Palliative care Guideline 42

3.1.3. Training on Palliative care Guideline 46

3.1.4. Supervision on Palliative care Guideline implementation 49

3.2. Needs for and accessibility to palliative care services 53

3.2.1. Needs of cancer patients for palliative care 54

3.2.2. Access of cancer patients to the services 57

3.2.3. Cost burden of palliative care services 68

3.3. Actual provision of palliative care services 70

3.3.1. Availability of palliative care services 71

3.3.2. Availability of painkiller 79

3.3.3. Knowledge on palliative care of health workers at district hospitals and CHCs 84
3.3.4. Referral of palliative care patients 89
3.4. Proposal for the community-based palliative care model 94
3.4.1. Needs for palliative care of cancer patients in community 95
3.4.2. Opinions on palliative care for cancer patients in community 98
3.4.3. Proposal for the community-based palliative care model for cancer patients 102
4. CONCLUSIONS AND RECOMMENDATIONS 104
4.1. CONCLUSIONS 104
4.2. RECOMMENDATIONS 106
REFERENCES 108
ANNEX 110

LIST OF TABLES

Table 1. Study sites 27
Table 2. Sample size 30
Table 3. Percentage of health facilities advertising Palliative care services 43
Table 4. Percentage of patients' relatives knowing about palliative care service facilities 44
Table 5. Percentage of health workers who were retrained in palliative care 47
Table 6. Needs for retraining in palliative care at health facilities 47
Table 7. Supervision and support of the upper level to the lower level in the last time 49
Table 8. Frequency of supervision 50
Table 9. Contents of the supervision of the upper level 51
Table 10. Satisfaction to supervision of the upper level 52
Table 11. Common symptoms of cancer 55
Table 12. Mood of the cancer patients 56
Table 13. Percentage of patients receiving pain relief in the last pain 57
Table 14. Percentage of patients receiving cancer therapy with pain relief by opioid drugs 57
Table 15. Percentage of patients receiving symptom treatment in the last treatment 58
Table 16. Frequency of counseling for the patients in treatment 59
Table 17. Satisfaction of patients on counseling services in treatment 60
Table 18. Percentage of patients receiving counseling services in treatment 61
Table 19. Satisfaction of patients on counseling services in the last treatment 62
Table 20. Frequency of psychological care services for patients 62
Table 21. Percentage of patients satisfying with psychological care services 63
Table 22. Forms of home-based palliative care services 64
Table 23. Percentage of patients' relatives having difficulties in care of patients 65
Table 24. Information sources for cancer patients' relatives 65
Table 25. Percentage of patients receiving spiritual support in end-of-life care 67
Table 26. Percentage of patients receiving pain relief in end-of-life care 67
Table 27. Percentage of patients receiving nursing care as defined in the end-of-life care instructions 68
Table 28. Economic condition of patients' families 68

Table 29. Funding sources for palliative care services 69
Table 30. Percentage of the health facilities having types of palliative care services 73
Table 31. Percentage of health facilities at all levels having types of palliative care services 76
Table 32. Percentage of health workers who met difficulties in palliative care for cancer patients 79
Table 33. Percentage of health facilities having painkillers 80
Table 34. Percentage of health facilities lacking opioid drugs for cancer patients 81
Table 35. Cases provided opioid drugs for patients 81
Table 36. Factors affecting the accessibility of patients to opioid drugs at health facilities 82
Table 37. Difficulties in managing the use of opioid drugs 83
Table 38. Percentage of health workers giving correct answer on concept of palliative care 84
Table 39. Percentage of health workers knowing about the time of palliative care for cancer patients 84
Table 40. Percentage of health workers knowing how to assess the pain intensity of cancer patients 85
Table 41. Percentage of health workers knowing about pain relief 86
Table 42. Contents that health workers at the grassroots level can help cancer patients 87
Table 43. Percentage of health workers knowing about the contents in the end-of-life care 88
Table 44. Percentage of health workers knowing about the rights of cancer patients 89
Table 45. Types of palliative care services for referred patients 90
Table 46. Reasons for referral of patients for palliative care 91
Table 47. Health facilities to which patients often referred for palliative care 91
Table 48. Reasons for referring patients to the community for palliative care 93
Table 49. Percentage of health facilities referring patients 93
Table 50. Percentage of patients referred by health facilities 94
Table 51. Reasons for not supporting oral morphine prescription for cancer patients treated at home 98
Table 52. Percentage of patients supported by unions/organizations and community 100
Table 53. Support types from branches and sectors 101
Table 54. Impacts of support to patients and their families 101

LIST OF FIGURES

Figure 1. Model of palliative care throughout the course of illness in the Palliative care Guideline for cancer and AIDS patients in Vietnam, 2006 35

Figure 2. Percentage of health facilities having palliative care documents 42

Figure 3. Sources of information on palliative care services 45

Figure 4. Percentage of health facilities having health workers trained in palliative care 46

Figure 5. Percentage of health facilities using checklists in supervision at lower levels 52

Figure 6. Types of cancer among the surveyed subjects 54

Figure 7. Pain intensity of patients in the last pain 56

Figure 8. Effectiveness of pain relief 58

Figure 9. Home-based care contents in the last treatment 64

Figure 10. Place of end-of-life care for patients who died 66

Figure 11. Reasons of patients for not having their end-of-life care at health facilities 66

Figure 12. Percentage of patients having and using health insurance in the last treatment 69

Figure 13. Percentage of health facilities providing palliative care services and having service-noticing boards 72

Figure 14. Percentage of health facilities having pain relief units or beds for palliative care 74

Figure 15. Places where patients treated their pain and other complications 77

Figure 16. Percentage of health workers who ever provided palliative care services for cancer and AIDS patients 78

Figure 17. Percentage of health facilities providing opioid drugs for cancer patients 79

Figure 18. Percentage of health workers giving correct answer on classification of pain intensity 86

Figure 19. Percentage of health facilities which received referred patients for palliative care 89

Figure 20. Health facilities from which patients were referred for palliative care 92

Figure 21. Capacity of patient beds at the National hospitals/Oncology Centers 95

Figure 22. Opinions of health workers and patients' relatives on the best facility for caring end-of-life cancer patients 96

Figure 23. Opinions of health workers on oral morphine prescription for cancer patients treated at home 98

Figure 24. Opinions of health workers on branches and sectors that should participate in end-of-life care for cancer patients 100

SUMMARY

According to WHO's estimate, there are 11 million people suffered from cancer annually and 6 million people died of this disease. In the Asia Pacific area, cancer is one of the three main causes of death in human. The rate of cancer morbidity is up to 100/100.000 people in China, Japan, Korea and Singapore [11],[15]. Palliative care is one of the important components in cancer prevention program, along with prevention, early detection, diagnosis and treatment aimed at reducing the incidence, mortality from cancer and improving the quality of life for cancer patients [16]. Thus, the Palliative care has oriented to cancer patients and their main caregivers. In Vietnam, the number of cancer patients has been increasing. As estimated in 2010, Vietnam has at least 126,307 new cancer cases, twice higher than that in 2000 (68,810 new cancer cases) [10]. In a presentation at the 15th National Workshop on Cancer Control in 2010 in Hanoi, Prof. PhD. Nguyen Ba Duc reported that about 55%-70% of cancer patients are diagnosed and cured in the late stage. In this stage, the pain symptoms appear in the most patients. The other symptoms, which are breathing difficulties, ulcer, constipation, etc., cause the patients to suffer pain, discomfort, and struggle in the last days of life. However, only a few patients have access to Palliative care services. The needs in pain relief and Palliative care of the cancer patients in particular, the persons who have life-threatening diseases in general are very big in Vietnam. The Palliative care Guideline for cancer and AIDS patients (herein after referred to as the Palliative care Guideline) was issued by Vietnam MOH in 2006.

A descriptive cross-sectional study combining both qualitative and quantitative methods was conducted from May to June 2010 in Ha Noi, Thua Thien Hue and HCM City to assess the Palliative care Guideline, needs of cancer patients in Palliative care and the current situation on palliative care services provision at all health levels. The quantitative interviewees were 410 main cancer patients' caregivers in the community, 360 health workers in the district hospitals, communal/ward health centers (CHCs) and 120 managers of the health facilities at all levels. The qualitative interviewees were the leaders of central hospitals/oncology centers, Palliative care specialists/cancer curing staff of the surveyed health facilities, related organizations, cancer patients and their main caregivers. Some main findings of the study are as follows:

Implementation and training on Palliative care Guideline:

Palliative care Guideline for cancer and AIDS patients was implemented in 2006 which ensured 10 general principles of WHO's Palliative care process and included all contents to ensure the comprehensiveness of the service. However, there should be a more detailed guidance for each level to better utilize the service.

Some legal documents related to Palliative care are the guidance on activities related to addictive drugs, the regulation on prescription of opioid drugs for cancer and AIDS patients in outpatient treatment, etc have created a legal framework in implementing the palliative care services at health facilities and in community. However, the requirements in the regulation are still very strict, which impose many difficulties for health facilities, health workers and outpatients. In addition, some issues are not consistent or not yet mentioned in the regulations such as list of essential drugs. For example, the communal levels are only allowed to use morphine in emergency cases, but not yet in Palliative care. Pain relief treatment and symptom treatment for cancer patients are not yet stipulated in the MOH's Decision on technical responsibility of the levels.

At the survey time, 90.9% of the National hospitals/Oncology centers had the guidance on palliative care, but only 15.8% of district hospitals and 6.7% CHCs had this document.

36.4% of the National hospitals/Oncology centers, 68.4% of the district hospitals and 72.2% of CHCs did not popularize the palliative care services. The palliative care services were mostly known in community via communication of the patients ever experiencing cancer examination and treatment (21.7%). The initiation in promoting the palliative care services at health facilities was still limited.

Nearly 20% of the interviewees knew that the palliative care services were available at the provincial hospitals; the district ones and CHCs accounted for 8.5% and 3.2% respectively.

All the surveyed National hospitals/Oncology centers had staffs who were trained on palliative care, but only 50% of the surveyed district hospitals and CHCs had staffs who were trained on palliative care. At the district hospitals that had staffs who were trained on palliative care, only 33% of doctors and 18% of assistant doctors who were providing the palliative care services were trained on palliative care.

At present, the supervision and support on palliative care for cancer patients are still very limited. Almost of the health facilities were only supervised on professional activities (examination and treatment in general) or palliative care for AIDS patients. The percentage of the health facilities received the supervision and support from the upper levels on palliative care was so low in both frequency and content.

Needs and accessibility to palliative care services:

Most of the cancer patients often suffered from pain caused by the disease (75.9%) along with other symptoms such as tiredness (78.8%), lack of sleep (55.1%), fever (40.7%), vomit/nausea and breathing difficulties (38.5%).

In the last time experiencing pain, 36.8% of the patients had severe pain, whereas 33.4% had moderate pain, 13.9% had mild pain and 15.9% had no pain. 27.9% of the patients who experienced severe pain, 25.6% experienced moderate pain and 62.3% experienced mild pain did not receive pain relief. Some common emotions patients experience during their cancer treatment were afraid of cancer and treatments (50.5%), concern about their future and family (47.5%), feared to die (31.5%), afraid of losing salary and poverty (25.9%) and losing desire to live (15.6%), etc.

24.2%-69.7% of the cancer patients had symptoms but not treated during the last treatment.

Over 1/3 of the respondents said that the patients were rarely or never counseled. The counseling they mostly received were on symptoms and their treatments (48.1%), nutrition (46.2%), nursing care level (45.7%). That rate was lower on treatment method (30.8%) and cancer consultancy (28.9%).

40.4% of the cancer patients at the central hospitals/oncology centers, 54.5% at the district hospitals, 27.3% at the private hospitals/clinics, and 100% at the CHCs rarely or never received the psychological support.

Only 15% of the respondents confirmed that the patients accessed palliative care services from public health facilities at home, while the rest bought drug by prescription for their treatments.

Regarding the difficulties cancer caregivers faced with, 46.4% of them gave out the reason of a lack of care giving skills, 31.4% lack of information.

86.1% of the dead patients were cared by their relatives even in pain relief at their end of life.

34.4% of the patients' families need to be supported to have their palliative care at the health facilities, 48.8% of the families could solve their own problems and 16.8% of the families did not have any difficulties in paying for treatment and palliative care.

82.7% of the surveyed patients had their health insurance card, in which 77.8% used their cards for the last treatment.

Current situation on provision of palliative care services:

100% of the National hospitals/Oncology centers, 94.7% of the district hospitals and 75.6% of the CHCs reported that they provided palliative care services for cancer patients, but only 72.7% of the National hospitals/Oncology centers, 15.8% of the district hospitals and 30% of the CHCs had the task assignment documents of palliative care service provision at their facilities.

Over 2/3 of the health facilities has been providing the services of counseling, pain relief, psychological support, but the services on relieving symptoms and complications were only implemented in 51.7% of the health facilities, and the end-of-life care was provided by only 36.7% of the health facilities.

81.8% of the National hospitals/Oncology centers had the pain relief units or beds for palliative care, while this percentage in the district hospitals and CHCs was relatively low (5.3% and 10% respectively).

Most of the surveyed cancer patients visited the National hospitals/Oncology centers for pain relief and other complication treatment (85.1%). However, only a small number of patients received these services in the provincial hospitals (26.6%), district hospitals (20.5%), private hospitals/clinics (13.7%), CHCs (9.5%).

Even in the National hospitals/Oncology centers, physicians mainly focused on pain relief and complication treatment, did not paid attention to all the other needs for patients and their families. Many reasons were given out to explain the lack of services' comprehensiveness besides the overloading patients such as the lack of staff or professional skills in psychological care.

All the central health facilities provided the opioid drugs for cancer patients. This percentage in the district hospitals and CHCs was 84.2% and 12.2% respectively.

The percentage of the National hospitals/Oncology centers having injecting and oral opioid drugs (100% and 90.9% respectively) was much higher than that in the district hospitals (57.9% and 31.6% respectively) and CHCs (11.1% and 1.1% respectively).

The patients' accessibility to opioid drugs at the health facilities was also affected by the limited number of drugs, reported by 71.1% of the health facilities with the highest percentage in CHCs (90.9%), and the lowest in the National hospitals/Oncology centers (54.5%). The patients' accessibility to opioid drugs at the health facilities was also affected by the "strict regulations in prescription" (39.5%; of which 45.5% at the National hospitals/Oncology centers, 50% at the district hospitals and 18.2% at CHCs).

45.5% of the doctors and 54.4% assistant doctors in the district hospitals, 30% of the doctors and 45% of the assistant doctors at the CHCs did not know about the concept of palliative care.

Over 2/3 of doctors and assistant doctors in the district hospitals and CHCs in this study did not know how to classify the pain intensity based on pain scale.

The percentage of health workers in the district hospitals and CHCs giving the correct answers about the time for pain relief (both medium and severe pain) was

very low; only 14.2% of the doctors and 24.7% assistant doctors said that the mild pain also needed to be cured.

The majority of health workers in the district hospitals and CHCs reported that they could provide psychosocial support for cancer patients (80-92% respectively), pain relief (62-77% respectively), counseling on nutrition regime (58-70% respectively), symptom treatment (39-58% respectively) and end-of-life support (16-29% respectively).

21.7% of the doctors and 24.2% of the assistant doctors at the CHCs could not state any contents of end-of-life care; this percentage in the district hospitals was 2.6% of the doctors and 2.9% of the assistant doctors. Conversely, only 3.9% of the doctors and 2.9% of the assistant doctors in the district hospitals, and 1.7% assistant doctors at the CHCs could tell all 7 contents in the end-of-life care.

90.9% of the National hospitals/Oncology centers and 73.7% of the district hospitals received the patients from the other places for palliative care, but only 26.7% of the CHCs received the patients from the upper level.

Among the health facilities that referred the cancer patients for palliative care, the most common support for cancer patients was "introduction paper" (86.5%), very few health facilities had "ambulance" and "health workers go with" (18% and 22.5% respectively).

Proposal for the community-based palliative care model:

Needs of palliative care (pain relief, symptom treatment, mental/spiritual support, etc) for cancer patients were very big. The accessibility of patients to palliative care services as well as the capacity of the health facilities in providing palliative care services provision was still very limited. Almost all of cancer patients and their main caregivers wanted to take care of patients during their end-of-life stage at home. Therefore, the need for a community-based palliative care for cancer patients has become more imperative.

The prescription regulation in outpatient treatment and the MOH's Circular on Guidance on activities related to addictive drugs issued in 2008 and 2010 were the legal documents, and created good conditions to implement the Palliative care Guideline in community.

81.4% of the interviewed health workers supported prescribing oral morphine for cancer patients at home.

The unions, social organizations and individuals have participated actively in caring and supporting cancer patients during the treatment as well as the end-of-life phase.

Although a community-based palliative care model for cancer patients has not been laid out in details, , it is proposed that this model is necessary to establish a multi-sector caring team for cancer patients. This team will be managed by the communal health with the participation of branches, unions, social individuals, donors under the direction of local authorities. The CHCs, as the core units and together with related ministries and mass unions to provide pain relief, complication treatment and mental/spiritual support for cancer patients and their relatives. A fund may be raised through the community people's contributions for palliative care activities.

Conclusions:

Palliative care Guideline:

The contents in the Palliative care Guideline for cancer and AIDS patients issued in 2006 were rather sufficient and easy to understand, but it must have more detailed instructions for each level for better application. Apart from the Palliative care Guideline, MOH has also issued some legal documents related to palliative care such as the guidance on addictive drugs related activities, the regulation on opioid drug prescription for the cancer and AIDS patients in outpatient treatment, etc. This has created the legal framework in the implementation of the palliative care services at the health facilities and in the community. However, the requirements in the regulation imposed many difficulties for the health facilities, health workers and outpatients when providing the palliative care services in the community.

There were other opinions that might not be consistent or not mentioned in the available regulations, for example, in the list of essential drugs, the communal level was only used the morphine in emergency cases, not allowed to use in pain relief. The pain relief and symptom treatment for the cancer patients have not been stipulated in the MOH's Decision of technical-level distribution.

The implementation of the palliative care according to the MOH's Palliative care Guideline for cancer and AIDS patients has been done in some provinces/cities. However, the original guidance document and training material based on the Palliative care Guideline were not available in many facilities. The percentage of the health facilities being supervised on palliative care by the upper level or supervised the lower level was still low in both frequency and content.

Needs and curent provision on palliative care services:

The needs of cancer patients and their relatives in the palliative care including pain relief, symptom treatment, psychological support were very big. Most of the cancer patients experienced in pain, lack of sleep, fever, vomiting/nausea, and breathing difficulties, along with the moods such as being afraid of the disease and treatments, worrying about future and family, fear of death, and losing desire to

live. However, the accessibility of the cancer patients to the palliative care services was not easy and regular.

According to the Palliative care Guideline, the palliative care services are provided at all levels, including pain relief, symptom treatment, psychosocial support, and end-of-life care. In fact, there are only some types of services are provided at the central and provincial levels. Even in the National hospitals/Oncology centers, the palliative care has just focused on pain relief and complication treatment, not yet to all the other needs for the patients. The reasons given to explain the lack of the comprehensiveness of the services are the lack of staff with qualification to provide psychology care for the patients.

Some CHCs have provided the pain relief and symptom treatment services for the cancer patients. It indicates that the palliative care providers who were trained by the home care program for the HIV/AIDS patients are totally capable of providing the palliative care services for cancer patients in community.

At present, the physical infrastructure for the palliative care services are still insufficient, because the hospitals do not have the specialized units in oncology or pain relief, except for some big hospitals/Oncology centers. Besides, the lack of painkillers with opioid at the health facilities and knowledge on palliative care of health workers in the district hospitals and CHCs are still limited.

Community-based palliative care model:

The needs of cancer patients in the palliative care (pain relief, symptom treatment, psychology/spirit support, etc) were very big, but the accessibility of the patients to the palliative care services as well as the satisfaction of the health facilities on these services were limited. In addition, most of cancer patients and their relatives wanted to carry out the end-of-life care at home. The community-based palliative care services for cancer patients have become more necessary.

The prescription regulation in outpatient treatment and the MOH's circular of Guidance on addictive drugs related activities issued in 2008 and 2010 were the legal framework for the cancer outpatients to access opioid drugs at home, and provided a legal basis for the Palliative care Guideline to be implemented in the community. 81.4% of the health workers at the surveyed health facilities supported allowing oral morphine prescription for cancer patients who were treated at home.

On the other hand, it is deeply rooted in the Vietnamese culture to help persons who face difficulties and misfortunes The unions, social organizations and individuals have been actively involved in the care and support for cancer patients during treatment as well as during end-of-life period.

Although a community-based palliative care model for cancer patients has not been laid out in details, , it is proposed that this model is necessary to establish a multi-sector caring team for cancer patients. This team will be managed by the communal health with the participation of branches, unions, social individuals, donors under the direction of local authorities. The CHCs, as the core units and together with related ministries and mass unions to provide pain relief, complication treatment and mental/spiritual support for cancer patients and their relatives. A fund may be raised through the community people's contributions for palliative care activities.

Recommendations:

In order to implement the palliative care services at the health facilities at all levels, apart from the introduction of the Palliative care Guideline, there should be an instructions in detail for the provincial/district/commune levels and private hospitals as defined in the Palliative care Guideline.

Provincial health departments should organize workshops with participation of some related agencies and sectors including the health insurance, pharmaceutical, finance, police, etc. to complete and build instructions on the implementation and supervision of painkiller supply for health facilities, and provide drugs for patients more appropriately, strictly and effectively. The health facilities, which have units for pain relief and palliative care and are allowed making strong painkillers prescriptions for outpatients, should assign doctors to register their signatures with the pharmacies providing strong painkiller and to make prescription as required in the prescription regulations.

The palliative care services at the district level, especially the communal/ward level, at the present, have just satisfied a part of needs of HIV/AIDS and cancer patients. It is necessary to implement the palliative care services at the district and communal level. MOH should have a program to implement the palliative care services at all levels in detail, including the documental guidance on palliative care contents for each level, policy for the implementation of palliative care, training on palliative care for health workers at all levels, and mass media communication.

Very few district hospitals and CHCs had the palliative care provision staffs who were trained on palliative care; the percentage of health workers at the health facilities that had staffs who were trained on palliative care was still low. Thus, it is urgent to improve the knowledge on palliative care for the health workers and strengthen the supervising and support from the upper level to ensure good practice on palliative care.

While the current conditions do not allow to have a separate infrastructure for palliative care services, they should be integrated into the internal/surgery examination and treatment departments of the provincial and district hospitals. It

is also important that the health workers will be trained on palliative care and be provided with the Palliative care Guideline appropriate for each level, and to concurrently set up groups of supervisors at each province/district to support the lower level. The community-based palliative care model can be assigned to CHCs' health workers with the participation of local associations and unions.

The communes/wards, depending on the specific conditions, need to have the policy for support and development of the palliative care services in community, encourage the participation of village health collaborators, mobilize and support the home-based palliative care for the patients.

In addition, the health facilities should have a strategy to advertise palliative care service at each locality to help the people to know about and access to the nearest palliative care service; contribute to reduce the overcrowding in the hospitals. Besides, this also reduces the economic burden as well as supports the psychology/spirit of the patients and their relatives.

1. INTRODUCTION

1.1. Palliative care and its role in cancer control

With chronic progression and bad prognosis in general, particularly with the invasion and metastasis, cancer affects adversely the vital functions of the human, affecting the physical, psychology and spirit of the patients at different levels depending on the types and stages of cancer. The disease also requires a prolonged treatment, a combination of many measures: surgery, radiation, chemicals. Many side effects and complications from the treatment can also cause pain or damage to the vital functions of the patients, especially during the advanced stage of the disease. Improving the quality of life for the cancer patients, thus, is a very important component in cancer control.

Palliative care aims to improve the quality of life of patients and their families as they have to face issues from a life threatening disease via preventing and reducing sufferings by early detection, accurate assessment, pain relief and addressing other physical, psychological and spiritual problems for the patients, etc… (WHO, 2002) [4],[12].

One of the principles of palliative care is that palliative care should be provided immediately after diagnosis and maintained throughout the course of disease. Palliative care is one of the important components in cancer prevention program, along with prevention, early detection, diagnosis and treatment aimed at reducing the incidence, mortality from cancer and improving the quality of life for cancer patients [11],[12],[16]. The comprehensive cancer prevention program needs to cover the entire population, while it should still seek and satisfy the needs of priority groups. Palliative care prioritizes the patients and their relatives.

The World Health Organization (WHO) and the International Committee for Addictive Drugs Control (INCB) have recommended that all countries must have a palliative care program. Here are five steps to achieve the quality of palliative care program [5],[12],[13].

- Accessing palliative care needs, gaps and obstacles;
- Building a guidance on palliative care to offer a standard model of care;
- Overcoming the barriers to access to essential medications on palliative care including reviewing and loosening the policies on management of the national management of addictive drugs in order to create favorable conditions in accessing essential medications for pain relief;

- Promoting education, training with certifications on palliative care for both formal and in-service medical students;
- Expanding palliative care services in the hospitals, at the end-of-life care centers as well as at home.

In fact, the Asia-Pacific countries have succeeded in establishing the National palliative care program are Australia, New Zealand, Japan, Taiwan, Thailand, Malaysia, Singapore and China, etc. In China, in the last decade, the National guidance on palliative care and access to opioid drugs was revised, and is now recognized as a national successful model in accessing palliative care in Asia. In Thailand, the National guidance on care and pain relief was revised and supplemented, and now is implemented nationwide. Singapore has built a complete National program on palliative care including the training for professional staff, ensuring better accessing to painkillers including morphine [11],[12].

1.2. Needs for pain relief and palliative care in Vietnam

As reported by the Ministry of Health (MOH), by 31 March 2010, the number of living HIV-infected persons in Vietnam is 164,197, of which 37,189 AIDS patients are still alive [6]. In addition, the cancer trends to increase. Each year in Viet Nam has 150,000 people diagnosed with cancer, and the percentage of cancer patients treated is very low, only about 10% [10]. At the present, an estimated 55-70% of the cancer patients are diagnosed and treated in the late stage. In this stage, the pain symptoms appear in the most patients. The other symptoms, which are breathing difficulties, ulcer, constipation, etc., cause the patients to suffer pain, discomfort, and struggle in their last days of life. These symptoms also cause psychological torment, distress to the families and relatives [1]. The fact shows that the symptoms of pain and sufferings from pain are common manifestations in cancer and AIDS patients and other life-threatening diseases in general. In our country, only a few patients have access to palliative care services. The needs in pain relief and palliative care of the cancer patients in particular, the persons who have life-threatening diseases in general are very big in Vietnam. For example, a study with 400 interviews of the patients who were examined and treated at the National Cancer Hospital on the needs of consultancy shows that: 91% of the patients reported that they needed a lot professional advice, 87.5% needed to be consulted about policy, 75.5% needed to be consulted on community relations [13].

1.3. Palliative care in Vietnam

The Vietnam National Plan for Cancer Prevention in the phase of 2008-2010 highlighted the issues of establishment and operation of pain relief and palliative care units at the existing cancer control facilities including Ha Noi, HCM city, Hai

Phong, Hai Duong, Quang Ninh, Thai Nguyen, Thanh Hoa, Thua Thien Hue, Khanh Hoa, Can Tho, Tien Giang, Kien Giang. The principal activities of the plan above are as follows:

- Setting up the units for pain relief and symptom care at the cancer control facilities.
- Assessing on the need in pain relief caused by cancer at the some health facilities in Vietnam.
- Professional training on pain relief and palliative care for staff at those units.
- Providing enough painkillers according to three-steps pain relief scale of WHO.
- Studying and applying the pain relief and symptom care methods for cancer patients.

Studying the supportive medications for radiotherapy, chemotherapy, etc. including Eastern and Western medicine to enhance resistance to disease and alleviate symptoms for the patients.

With the characteristics of cancer disease, the end-of-life cancer patients are mainly taken care at the community. The caring model at the grassroots level and community with the support of health workers at the community plays an important role. Therefore, the project *"Promoting evidence-based communication for improving cancer control in Vietnam"* has a special emphasis in building and deploying the end-of-life patients care model at the grassroots level.

The major activities includes

- Building the care model for end-of-life patients at the grassroots level.
- Deploying the model and assessing its effectiveness.
- Training for health staff at the grassroots level on knowledge and skills in deploying the model.
- Designing the guidance on end-of-life care for cancer patients at the grassroots level.

In 2005, the Curing Department-MOH in collaboration with international organizations conducted a rapid assessment on the palliative care situation in 5 provinces/citiesthat have the highest HIV infection rate in the country, which are Ha Noi , Hai Phong, Quang Ninh, HCM City and An Giang [5]. The assessment results show that the pain symptom was common in HIV-infected persons and

cancer patients, especially in the patients in the end-of-life phase. However, the pain relief measures were still limited. Surveys also show that the healthcare workers had limited access to essential drugs used in palliative care for pain relief and other symptoms. Heath care workers at the palliative care provision facilities have not been fully trained on theory and practice on palliative care. They did not know how to assess and treat the disease according to the present pain intensity (PPI) of WHO. The assessment results also indicate that the spiritual pain was found very common in cancer patients and HIV-infected persons. Leaders of some units in the health sector and some related governmental departments admitted that the palliative care services had been not available in our country and they completely supported the improvement, piloting, and scaling-up of some new approaching models, for examples the health workers who were trained in palliative care would be allowed to prescribe oral morphine for the patients with severe pain and cared at home. Some recommendations are proposed via the rapid assessment as follows: Building the National guidance on palliative care; Complete the National Policy of opioid drug management; Disseminate the policy and guidance; Conduct the educations, trainings with certificate award on palliative care as defined in the National guidance; Scale up the palliative care program at all levels; Support to develop the palliative care model including oral morphine supply at the community under the supervising of qualified health workers. By September 2010, the National Project on Cancer Prevention and Control has supported and advised to establish units for pain relief and symptom care at the existing cancer control facilities in Ha Noi, HCM City, Hai Phong, Hai Duong, Quang Ninh, Thai Nguyen, Thanh Hoa, Thua Thien Hue, Khanh Hoa, Can Tho, Tien Giang and Kien Giang [10].

1.3. Reasons for study

The project titled "*Promoting evidence-based communication for improving cancer control in Vietnam*" is a four-year project, from 12/2009 to 12/2013, funded by Atlantic Philanthropies. This project will be implemented directly by HealthBridge in close collaboration with National Cancer Institute, Vietnam Cancer Association, Vietnam Ministry of Health, National Occupational and Environmental Health Institute, Health Strategy and Policy Institute, World Health Organization, and other related ministries and association as well. The goal of the project is to reduce incidence and mortality from cancer and to improve quality of life for cancer victims. The specific objectives of the project are enhancing the community and policy makers' recognition of the need of cancer patients in palliative care including pain relief and physical symptoms, and improving the social support through improving psychological and spiritual support for cancer patients.

Palliative care Situation Analysis is one of components of baseline assessment for the project "*Promoting evidence-based communication for improving cancer control in Vietnam*" conducted by HealthBrigde. This research will bring out an overall

picture of palliative care in Cancer Control. The assessment results will be used for piloting an appropriate community-based palliative case model to be the foundation for expanding the palliative care system at all levels.

STUDY OBJECTIVES:

- To evaluate the comprehensiveness of Guideline on palliative care for Cancer and AIDS Patients in cancer care, level of implementation and identify problems/barriers during implementation.
- To assess cancer palliative care services at the national, provincial, and community level and the need of cancer patients in pain relief and palliative care.
- To provide recommendations for improving cancer palliative care services and to propose a feasible and sustainable model of cancer palliative care at the community level.

2. STUDY SUBJECTS AND METHODOLOGY

2.1. STUDY SUBJECTS AND METHODOLOGY

2.1.1. Study subjects

2.1.1.1. Subjects for the quantitative study

Cancer caregivers;

Directors/managers of the health facilities at all levels;

Palliative care providers in health facilities at the district and communal levels.

2.1.1.2. Subjects for the qualitative research

In-depth interviews with health workers:

At the central level: palliative care program managers of MOH, leaders of the National hospitals/Oncology centers, palliative care specialists, palliative care providers at the National hospitals/Oncology centers.

At the provincial level: leaders of HIV/AIDS control centers, managers of palliative care units from provincial HIV/AIDS control centers.

At the district level: leaders of internal medicine departments, palliative care providers at the district hospitals.

At the communal level: heads of CHCs.

In-depth interviews and FGDs at the community:

Cancer patients;

Cancer caregivers.

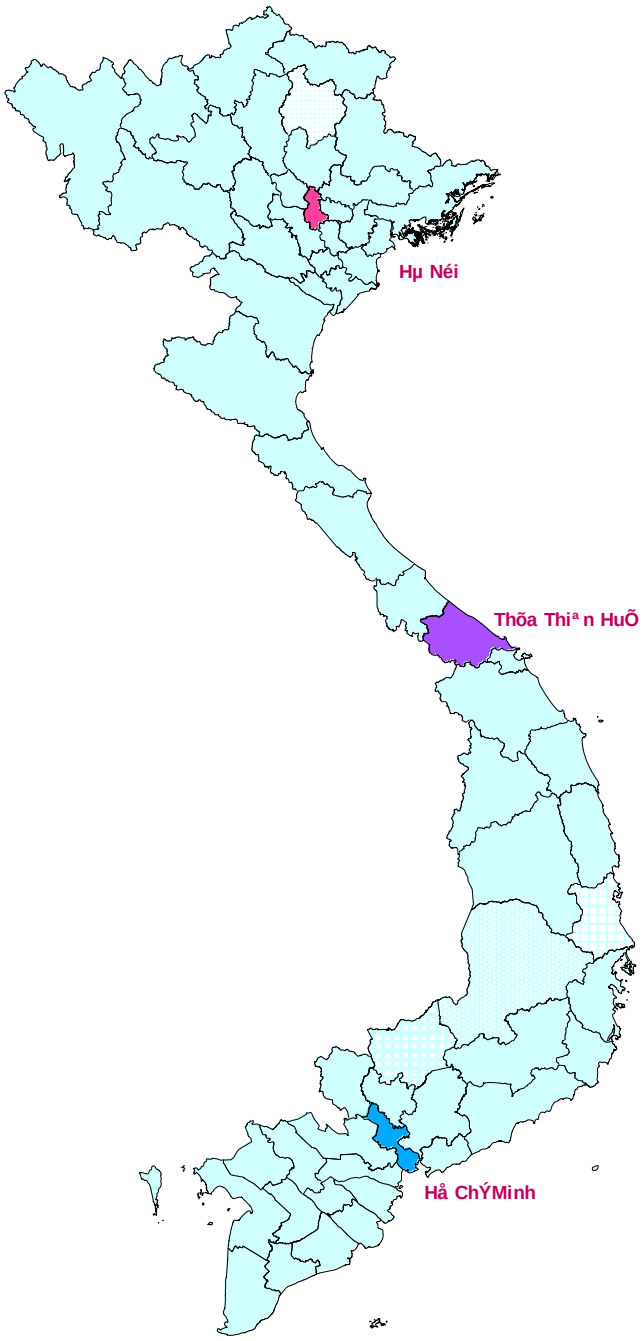
2.1.2. Study time and study sites

The study was conducted from May to June 2010.

Three big cities of Vietnam were chosen as study sites were Ha Noi, Hue and HCM City They are the provinces/cities having specialty hospitals, oncology departments at general hospitals and have implemented the units for pain relief and symptom

care at the some cancer control facilities. Those cities are considered to have numerous cases of cancer recorded. Some characteristics of the cities are described as follows:

Ha Noi is the capital of Vietnam, the largest and the second most populated city behind HCM City. Since expanding administrative border in 2008, Ha Noi has an area of 3,324.92 km^2 and a population of 6,448,837, of which 41.1% are urban population (according to the Census of Population and Housing conducted on 1/4/1999). The average population density was 1,979 persons per km^2. On population structure, according to the data on 1/4/1999, Ha Noi and Ha Tay residents were mostly the Kinh people (99.1%). at the present, Ha Noi has 29 district-level administrative units including 10 urban districts, 18 suburban districts, 1 town; 580 communal-level administrative units including 404 communes, 154 wards and 22 district towns.



At present, Ha Noi has specialized hospitals including the National Cancer hospital and Ha Noi Oncology hospital. Besides, it has the Oncology center at the Bach Mai hospital, Oncology departments at the Ha Noi Medical University, E hospital, Central Pediatric hospital, 198 hospital, 103 Military hospital, Institute of Nuclear Medicine and Military Oncology, Ear-nose-throat hospital, etc.

Among these cancer-related health facilities, the National Cancer hospital plays a key role in prevention, early detection, treatment and palliative care activities.
About the network of the cancer prevention task, The Ha Noi Oncology hospital has 250 outpatient beds and 250 inpatient ones, with sufficient facilities for surgical, internal medicine and radiation. The Oncology center at the Bach Mai

hospital, Oncology departments at the Ha Noi Medical University, E hospital, Central Pediatric hospital, 198 hospital, 103 Military hospital, Institute of Nuclear Medicine and Military Oncology, Ear-nose-throat hospital, etc. have beds and equipment for early detection, treatment and palliative care for cancer patients. The district health centers have participated in the communication on cancer prevention, screening, early detection to refer for treatment at the upper level; diagnosed some types of cancer that are common and easy to detect; and built the diagnostic cell unit in the testing department. The city hospitals have provided some services such as cancer prevention, screening, early detection, diagnosis and treatment of some cancer diseases in allowed capacity, care of end-of-life cancer patients. Each district and city health facility has 2-3 specialized staff providing cancer control services.

HCM City had the population of 7,162,86 by 1/4/2009 (8.34% of the Vietnam population), which consists of 1,812,086 households with an average of 3.95 persons per household. Male accounted for 47.97%, while female accounted for 52.03% of the population. The population density was 3,419 persons per km^2. The city population has a rapid increase with the growth rate of 3.54% per year. On population structure, the Kinh made up 92.91%, followed by the Hoa (6.69%) and the rest including the Cham, Khmer, etc. The city has recently 19 urban and 5 suburban districts. The total area of HCM City is 2,095.01 km^2 with over 322 communal-level administrative units including 259 wards, 58 communes and 5 district towns.

HCM City has Oncology Hospital, Oncology centers/departments at Cho Ray hospital, Thong Nhat hospital, Trieu An hospital; the Oncology units at Binh Dan hospital, Gia Dinh hospital, B115 hospital, Phu Tho hospital; and some district hospitals of Thu Duc and Cu Chi. These health facilities have participated in cancer prevention, early detection, treatment, and palliative care, in which, the City Cancer hospital plays a key role.

Thua Thien Hue is a coastal province in the North Central of Vietnam. The province borders Quang Tri province to the north, Da Nang City and Quang Nam province to the south, Laos to the west and the sea to the east. Thua Thien Hue is 654 km far from Ha Noi and 1,071 km far from HCM City. The province has an area of 5,053.990 km^2 with the population of 1,087,579 people (by 1/4/2010). The population density is approximately 215 persons per km^2. The province has 7 suburban districts, 1 town and 1 city, 151 communes/wards/district-towns.

The province has the Oncology center at the Hue Central hospital with the activities of prevention, early detection, treatment and palliative care.

Table 1. Study sites

City/province	Urban district	Suburban district	Total
Ha Noi	Dong Da, Long Bien and Hai Ba Trung	Dong Anh, Thuong Tin, Soc Son, Me Linh, Thanh Tri and Hoai Duc.	9 districts (30 communes/wards)
Thua Thien Hue	Hue	Huong Thuy, Phong Dien and Phu Vang	4 districts/cities (30 communes/wards)
HCM City	District 3, 5, 7, 8, Tan Binh and Thu Duc	Can Gio, Cu Chi	8 districts (30 communes/wards)
Total	10 urban districts	11 suburban districts	21 districts (30 communes/wards)

2.2. STUDY METHODOLOGY

2.2.1. Study design

The design of this study is descriptive cross-section, combining qualitative and quantitative methods.

2.2.2. Sample size and sampling

2.2.2.1. Sample size and sampling of cancer patient's relatives (in the quantitative study)

Sample size:

The sample size formula for intervention study was applied [12] to create a basis for the assessment of the interventions' effectiveness of the project in the end-of-life review. The sample size was calculated to expect that there was a difference in the percentage of cancer patients' caregivers who were satisfied with palliative care services before and after the intervention (assuming that this percentage would increase from 50%-60% after intervention). If there is a change after intervention as expected, the minimum sample size was 396 for the 95% confidence interval, 20% relative error and design effect equal to 1.3.

In fact, 410 cancer patients' caregivers at the community were interviewed.

Sampling:

Multi-stage sampling method was applied for the study, in detail as follows:

Selection of province: Actively select Ha Noi, Hue and HCM City.

Selection of districts: List all the districts (accompanied population) of each province, and then apply the probability-proportional-to-size (PPS) sampling method to select 30% of the districts.

Selection of communes: List all the communes/wards of each selected district, as PPS sampling method was applied later to select 30 communes. The sample size for each commune was 10 households.

At each commune/ward, list all cancer patients who died or are still living from the early December 2009 to June 2010. All the listed patients had to be confirmed that they were diagnosed with cancer by provincial or higher health facility. Then, systematically and randomly select 4 or 5 cancer patients until enough estimated sample size.

Cancer caregivers selected for this study were cancer patients' main caregivers since the diagnosis until the patients died or until the survey time. In addition, they must be healthy and conscious enough for answering the survey questions. During the data collection, in the case the main caregiver was not at home, if the investigator returned up to three times to finish the interview but could not meet him/her, or he/she refused the interview, the next one in the available list would be selected for replacement.

2.2.2.2. Sample size and sampling of health workers at the district hospitals and CHCs (in the quantitative study)

Sample size:

The sample size formula for intervention study was applied [12]. It was expected that there was a difference in the percentage of health workers who have good knowledge on cancer before and after the intervention (including early signs of common cancers, risk factors, cancer prevention and palliative care for cancer patients). To achieve the largest minimum sample size, it was assumed that this percentage was 50% and would increase to 65% at the end of the intervention. If there was a change after intervention as expected, the sample size was proved to be 174 for 5% probability threshold, 20% relative error and design effect equal to 1.3, which later rounded to 180 for each level. Thus, the total sample size for district and communal levels was 360.

In fact, 360 health workers were selected and interviewed, 132 of which were in Ha Noi, 132 in HCM city and 96 in Thua Thien Hue.

Sampling:

At communal level: In each selected commune/ward, select definitely leader of CHC and randomly one service provider for interviews. Therefore, the total sample size of health workers at the communal level was 180.

At district level: Except for the urban districts that have no hospitals, all the other district hospitals were chosen for knowledge study of the health workers on cancer. The total number of selected district hospitals was 19. Thus, the number of health workers in each hospital was 180/19 = 9-10 persons. In addition, a list of the health workers directly involved in health care in all clinical departments (except for para-clinical, administrative, organizational staff, etc. who had been not directly provided medical services) was also made for selection of 9 or 10 persons for interviews according to the systematically random method.

2.2.2.3. Sample size and sampling of directors/managers of health facilities (in the quantitative study)

The interviews were conducted with the managers of the studied health facilities which were 11 central hospitals/oncology centers, 19 district hospitals, 90 CHCs. One person per facility was chosen. Therefore, a total of 120 managers of the health facilities were selected and interviewed about the coverage and availability of palliative care services.

2.2.2.4. Sample size and sampling of health workers and cancer patients (in the qualitative study)

At the central level: Doing In-depth interviews with 1 palliative care program officer of MOH, 11 managers of the Central hospitals/oncology centers (1 interview each), 4 specialist palliative care providers at the 4 central hospitals, 11 medical health workers at the 11 Central hospitals/oncology centers (1 interview each). Doing 3 focus group discussions with cancer caregivers at the National Cancer Hospital, Hue Central Hospital and HCM Oncology Hospital (1 group discussion each).

At the provincial level: Doing in-depth interviews with 3 leaders of the HIV/AIDS control centers and 3 leaders of the palliative care units of the HIV/AIDS control centers.

At the district level: Doing in-depth interviews with 19 health workers of the internal medicine departments at the district hospitals (1 interview each). In each province/city, randomly select the leader of a district hospital and the manager of the internal medicine department at the district hospital for in-depth interviews. A total of 3 leader of district hospitals and 3 managers of the internal medicine departments at the district hospitals were selected for in-depth interviews.

At the communal level: In each province/city, randomly select an urban ward and a rural commune in the selected districts where the qualitative study was conducted for in-depth interviews with 1 leader of CHC, 1 cancer patient, and 1 caregiver. Do 3 focus group discussions with cancer patients' caregivers at the community (1 group discussion each).

The sample sizes for the study are as follows:

Table 2. Sample size

Study subjects	Number
Quantitative study	
• Cancer caregivers	410
• Leaders of the health facilities	120
• Health worker at the district and communal levels	360
In-depth interview	
• Palliative care program officers of MOH	1
• Manager of the National hospitals/Oncology centers	11
• Palliative care specialists	4
• Treatment staff	30
• Leaders of HIV/AIDS control centers, palliative care centers for HIV/AIDS patients, district hospitals, internal medicine departments of district hospitals	3 persons for each type
• Leaders of CHCs	6
• Cancer patients	17
• Cancer caregivers	6
Focus group discussion	
• Cancer caregivers at the hospitals	3 groups
• Cancer caregivers at the community	3 groups

2.2.3. Data collection

Preparation for data collection:

Designing and testing the survey tools: questionnaires, in-depth interview and group discussion guidelines were designed in accordance with each study subject group. They were tested in a pilot survey in Ha Noi, and then finalized before the survey.

A 3-day training course for investigators and supervisors was held in Ha Noi. The contents of the training consisted of introduction on survey tools, how to approach to the study subjects, sampling procedure, supervising and evaluation of data collection process.

Data collection:

Quantitative and qualitative surveys were simultaneously conducted in all the selected districts and provinces. The quantitative interviews were conducted with

cancer caregivers at their house, as well as health workers at the CHCs, district and central hospitals. The interviews had to ensure the science, privacy and acceptance of the study subjects.

The number of interviewees met the study sample size. The study subjects who refused the interviews or were not at home would be replaced by the next ones in the available list. On the other hand, the interviewers were supported by local health sector in organizing and guiding to find the study subjects.

Supervising and evaluation of the fieldwork:

The team leader concurrently holding the supervisor was responsible for data collection in the field. The quantitative and qualitative survey forms had to be checked to detect errors since the first day in the field. Findings and recommendations were summarized in the same day.

The Central program officers and the sponsors supervised and supervised closely throughout the field trip.

2.2.4. Data processing

Quantitative data:

Data entry: the data was entered by using the EpiData 3.2 software. In order to control the quality of the data, it had to be done twice at the Research Center for Rural Population and Health. Then, the data were analyzed by using the SPSS 17.0 software.

Data analysis: the data analysis specialists analyzed the data based on a data analysis strategy that was designed in advance. The result tables were presented by the percentages corresponding to the study contents.

Qualitative data:

Transcriptions of in-depth interviews and focus group discussions

Analysis by topics, quotation according to study objectives.

2.3. ETHICAL ISSUES

All the study subjects were voluntary to participate in this study. The importance of voluntary consent was emphasized in the training course before doing the fieldwork. The absolute confidentiality of the participants was also highlighted.

The facilitators had to explain for all the study subjects about the study objectives and contents before the interviews. In addition, the interviews would not be conducted without agreement.

Each member of the study team was required to sign an agreement on the confidentiality of the participants.

After finishing an interview, if the study subjects requested, the interviewers would consult and provide some essential information related to cancer prevention.

The data was only collected for study purposes, but not for any other purpose.

The study issues were relevant to current situation as well as accepted by the local authorities and health facilities. The study proposal was also approved by the Ethical Review Board of Ha Noi School of Public Health, MOH.

2.4. STUDY LIMITATIONS

The study was conducted in 3 provinces/cities where the health network in general and cancer prevention network in particular were better than those in the other provinces. All of these 3 provinces/cities have central-level health facilities providing palliative care services for cancer patients. Their lower-level direction and training activities were also paid more attention than those in the other localities. The evaluation results on the status of the system as well as the needs for palliative care of cancer patients, thus, were not representative for the general situation and tend to be more "optimistic" than the picture of the whole country.

The information were collected from the main caregivers rather than directly from the patients, so the needs of the patients was evaluated indirectly, especially the findings on the pain density and spiritual sufferings of the patients was not really accurate, depended on the level of interest and relationship between the patients and their main caregivers. However, in selection of the interviewees, the study teams tried to expose the criteria to select the persons who had the longest time in care of and closest relationship with the patients. In addition, cancer is a chronic disease with severe prognosis and unforgettable experiences to the patients and their relatives; therefore, we think that the patients and their relatives tend to remember more of what they experienced during the course of disease in comparison with the other diseases suffered in their life.

The interviews were done at the patients' home, after the patients came back from hospital; thus, the accuracy of the information depended on the recollecting capacity of the main caregivers and the length of time from the patients leaving the hospitals to the survey time. However, this is not a comparison study, so the impact is not so big to make bias in the study results.

The supervisors and investigators had not rich experiences and knowledge in cancer as well as palliative care for cancer patients; therefore, that made the interviews more objective, but on the other hand, it limited the development of in-depth interviews and focus group discussions.

3. FINDINGS AND DISCUSSIONS

3.1. Implementation of and training on the Palliative care Guideline

Main findings:

- Palliative care Guideline for cancer and AIDS patients was enforced in 2006 which ensured 10 general principles of WHO's palliative care process and included all contents to ensure the comprehensiveness of the service, but for easier to apply, there should be a more detailed guidance for each level.
- Some legal documents related to palliative care which are the guidance on activities related to addictive drugs, the regulation on prescription of opioid drugs for cancer and AIDS patients in outpatient treatment, etc have created legal framework in implementing the palliative care services at the health facilities and in community. However, the prescription regulation was so complicated that made many difficulties for the health facilities, health workers and outpatients. In addition, some issues are not yet consistent or not mentioned in the regulations such as list of essential drugs, so the communal level are only allowed to use morphine in emergency cases, not yet to use painkiller in palliative care. Pain relief treatment and symptom treatment for cancer patients are not yet stipulated in the MOH's regulation on technical distribution.
- At the survey time, 90.9% of the National hospitals/Oncology centers had the guidance on palliative care, but only 15.8% of the district hospitals and 6.7% CHCs had this document.
- 36.4% of the National hospitals/Oncology centers, 68.4% of the district hospitals and 72.2% of the CHCs did not popularize the palliative care services. The palliative care services were mostly known via the patients coming for cancer examination and treatment (21.7%). The initiative in popularizing the palliative care services at the health facilities was still limited.
- Nearly 20% of the interviewees knew that the palliative care services were available at the provincial hospitals, the district ones and CHCs were found 8.5% and 3.2% respectively.
- All the surveyed National hospitals/Oncology centers had staff who were trained on palliative care, but only 50% of the surveyed district hospitals and CHCs had staff who were trained on palliative care.
- At present, the supervising and supporting on palliative care for cancer patients are not yet implemented. Almost of the health facilities were only supervised on professional activities (examination and treatment in general) or palliative care for AIDS patients. The percentage of the health facilities received the upper levels' supervising and supporting on palliative care was so limited in both of frequency and content.

- The situation of not using checklists in palliative care supervising visits was quite popular, the reason was that the checklist forms for supervising and supporting on palliative care were not available. Out of the health facilities doing the supervising to the lower level, 50% of the National hospitals/Oncology centers, district hospitals and 70.8% of the CHCs did not use the checklists. For those using the checklists in the supervising visits, the percentage of sometime to use (23.3%) was found higher than the percentage of regular to use (10%).

3.1.1. Palliative care Guideline and some legal supporting documents

The palliative care guidance for cancer and AIDS patients (hereinafter referred as to the Palliative care Guideline) was enforced according to the Decision No. 3483/QD-BYT dated on June 15th 2006 of MOH. The MOH's Palliative care Guideline [4] includes 7 parts as follows:

Part I: Introduction to palliative care for cancer and AIDS patients: Concepts, principles and approaches.

Part II: Practice on palliative care: (1) pain control (concept, classification, causes, assessment and treatment in adults and children); (2) Symptom management (nausea and vomiting, diarrhea, constipation, mouth pain and pain on swallowing, dyspnea, cough, weakness/fatigue, fever, insomnia, agitation/delirium, depression/anxiety, pruritis, bed sores; (3) Psychosocial support for patients and caregivers.

Part III: Palliative care for those who are on antiretroviral (ARV) medications for AIDS: (1) Psychosocial support, (2) Adherence support, (3) Management of adverse effects (nausea and vomiting, nausea/vomiting accompanied by abdominal pain, fever, fever and rash, diarrhea, limb numbness, anemia, kidney stones/hematuria, nightmares/dizziness, jaundice, severe side effects).

Part IV: Palliative care for cancer patients, particularly for patients on radiation therapy, patients on chemotherapy, patients with surgery.

Part V: Pediatric palliative care: (1) introduction about the development stages of children, (2) symptom assessment, (3) treatment of some end-of-life symptoms, (4) bereavement in children.

Part VI: End-of-life care: (1) Emotional and spiritual support, (2) pain relief, (3) nursing care, (4) dying and bereavement care.

Part VII: Annexes: (1) List of analgesics in palliative care and common branded drugs (2) Management of opioid medications, (3) Brief pain inventory, (4) Psychological assessment, (5) Infection prevention when caring for HIV/AIDS patients at home and in the community, (6) Traditional medicine palliative care.

The MOH's Palliative care Guideline highlighted model of palliative care throughout the course of illness as follows:

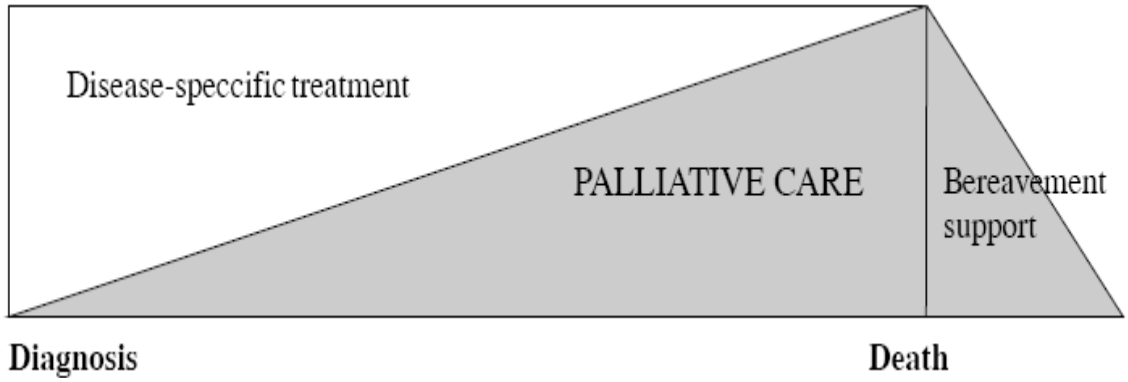


Figure 1. Model of palliative care throughout the course of illness in the Palliative care Guideline for cancer and AIDS patients in Vietnam, 2006

According to the MOH's palliative care model, the cancer patients need to focus much more on palliative care than disease-specific treatment right after diagnosis. Particularly to this model, MOH is also very interested in bereavement support for the patients' relatives (care and support of the dying). In fact, the palliative care model for cancer and AIDS patients in Vietnam is a standard model of WHO but it has increased the density of palliative care right after diagnosis. The reason is that, in Vietnam, the cancer detection is usually very late, so the patients have high demand in palliative care.

The contents in the Palliative care Guideline for cancer and AIDS patients in Vietnam have ensured 10 general principles in WHO's palliative care process, which are [4], [12]

- Provide palliative care services for all patients whose lives are threatened (HIV and cancer for example).
- Help patients to escape from pain and their uncomfortable symptoms.
- Strengthen the adherence support and reduce side effects of medications.
- Affirm life and regards dying as a normal process
- Neither hasten nor postpone death of patients.
- Integrate the psychological and spiritual aspects of care for patients.
- Offer support to help patients live as actively as possible until death, enhance the self-reliance as well as the skills and knowledge on self-care for patients and their families.

- Offer support to help patients' families cope during the patient's illness and in their own bereavement
- Consider patients as the center, work by multi-sector caring teams including professionals and non-professionals to address physical, psychosocial needs of patients and their families, even after the patients die.
- Improve the quality of life, contribute to a positive impact of disease process.
- Help patients to access early the other specific treatment methods (like radiation therapy) with the aim to prolong their life. Encourage, give spiritual support to patients to improve their knowledge on disease process, symptoms and side effects during treatment.

Almost all of the surveyed health facilities which had Palliative care Guideline for cancer and AIDS patients reported that the content of the guidance was quite sufficient (100% Central hospitals/oncology centers, 100% district hospitals, 85% CHCs), easy to understand (100% Central hospitals/oncology centers, 100% district hospitals, 95% CHCs) and easy to apply (87.5% Central hospitals/oncology centers, 100% district hospitals, 95% CHCs). The in-depth interviews also show that "*This guidance is sufficient on regulation, enough to satisfy. The palliative care department of Ha Noi Oncology hospital has applied correctly according to this guidance effectively. There is no difficulties in applying this guidance*" (IDI, a curing staff, Oncology hospital, Ha Noi). "*The guidance help us to have more documents to orient clearly the treatment methods. The difficulty is the difference among levels, so the treatment is also different*" (IDI, a curing staff, Tu Du hospital, HCM city). However, there were many difficulties during the implementation of the Palliative care Guideline. For example, there were no clear regulations on implementation mechanism of the Palliative care Guideline for the health facilities at all levels. The implementation of the service depended on the opinions and enthusiasm of the managers at the grassroots level. Because the palliative care services were closely related to the opioid drugs management, management regulation, and prescription complications; many managers were afraid of implementing this service. However, according to a leader of the Department of Examination and Treatment Management, MOH "*The consistency and comprehensiveness as recommended by WHO are highlighted quite clearly in the Palliative care Guideline of MOH, especially in the 2nd edition (being revised and printed). In the 2nd edition, the training program on psychological care is built and the regulation of prescription was revised that the medicine provision was changed from one week to one month, divided into 4 times, required to have confirmation of the locality that the patient is still alive*" (IDI, a staff of Department of Examination and Treatment Management, MOH).

In conclusion, the contents of the MOH's guidance highlighted quite sufficiently contents for palliative care. The guidance also ensured 10 general principles

according to WHO's palliative care process and included the comprehensiveness of the service. The document included all essential factors of palliative care, including the diagnosis and pain relief or treatment of other symptoms, psychological support, spiritual care and end-of-life care, counseling and care of patients' relatives.

After the Palliative care Guideline for cancer and AIDS patients was issued according to the Decision No. 3483/QD-BYT in 2006, some other legal documents related to the implementation of the Palliative care Guideline were also issued.

The regulation of prescription in outpatient treatment was issued by MOH according to the Decision No. 04/2008/QD-BYT dated on 1/2/2008. This Regulation described in detail the contents enclosed forms to effectively manage the supply and use of opioid drugs, as follows [2]. About the management, the prescription regulation pointed out strict requirements to prevent the dispersion of opiods in the society.

- The requirements of opioid drug prescription for cancer and AIDS patients:

  - The medical examination and treatment facilities annually register the signatures of the persons who are permitted in addictive drug prescription to addictive drug provision facilities;

  - Doing drug prescription in the form "N" for the drug provision facilities to file the prescription, concurrently doing registration for treatment of chronic diseases or examination registration to follow the treatment and guide patients to take drugs;

  - Health facilities appointed to diagnose cancer and AIDS patients provide chronic disease treatment books (with indication of opioid drugs) for the patients as a basis in opioid drug prescription at lower health levels;

  - Opioid drug dose is defined according to the patients' need. The time for each drug indication is not exceeded one (01) month, but at the same time, physicians have to make 3 prescriptions for 3 treatment times, each prescription does not exceed ten (10) days (the starting and ending date of the treatment are specified). Ones who make drug prescription have to guide patients' relatives about: the 2nd and 3rd drug prescriptions for the patients will be valuable only when enclosed the CHCs' confirmation that the patient is still alive; the time for buying or receiving drugs is 01 day before that treatment course (if on holidays, it should be bought a day before);

- The end-of-life cancer and AIDS patients staying at home will be permitted to receive examination, treatment and opioid prescription via home visits of physicians from CHCs, each prescription does not exceed 07 days;

- The opioid drug prescription makers require patients' relatives engage to use the opioid drugs for the right purposes and have to be responsible under the law if they use the drug for the wrong purpose.

- Requirements to validate the drug prescription in term of time

  - A drug prescription is valid within 05 days after the prescription day at all the legal pharmacies in the whole country;

  - Buying or receiving drugs has to follow the treatment dates in the prescription. Buying or receiving opioid drugs in the 2nd and 3rd prescription for cancer and AIDS patients have to be done 01 day before each treatment course (if on holidays, it should be bought a day before) only at pharmacies having the signature registration of drug prescription makers or at the pharmacy department of the hospital where the prescription was made (if the locality has drug stores selling addictive drugs).

  - Requirements for facilities selling prescription-based addictive drugs: the Provincial Health Department is responsible for directing facilities selling addictive drugs for outpatients. In areas having no facilities selling addictive drugs, the pharmacy department of the hospital has to provide (at the price it bought) for the outpatients to ensure the sufficient drug supply for the patients.

- Regulations for persons providing prescription-based addictive drugs:

  - Each time of drug provision does not exceed ten (10) days. The time of selling prescription-based addictive drugs is as mentioned above;

  - The drug providers takes note on the expired date of the drugs on the prescriptions (to follow the time filing the prescriptions) that has full signature, name, address, ID number of the buyer. The confirmation of patients' alive status of CHC enclosed the 2nd and 3rd prescription;

  - Make a record for returning addictive drugs the patients did not use from their relative. There will be copies of the record (one kept at the drug provision facility; one kept by the patients' relative). The re-turned drugs are kept separately, managed and treated correctly according to the Regulation of addictive drugs management.

- Regulations on filing addictive drug documents:

  - Medical examination and treatment facilities file the drug prescription counterfoils "N" for 02 years since the day the last page of the drug prescription book "N" is used; and also file the agreement of the cancer and AIDS patients' relatives on opioid drug use for 02 years since the day the last page is used in that year;

  - Addictive drug provision facilities file the drug prescription "N" as defined in the Regulation on addictive drug management;

  - When the time for filing documents (drug prescription counterfoils "N", drug prescriptions "N", agreements of cancer and AIDS patients' relatives on addictive drug use) is over, the facilities will establish a Council for destroying these documents according to the Regulation on addictive drug management.

The requirements and regulations mentioned above were very good for the management, but imposed many difficulties on the health facilities and outpatients. A leader of a district hospital reported that "*Our hospital provides the painkiller but the Regulation on opioid drug use is very strict, so the doctors do not have enough authority to write the prescription. The drug management process is strict so it is very difficult to have drugs when treating at the community. If the patients need drugs, they must go to the hospital for treatment to get drugs, it wastes a lot of time of patients and their caregivers*" (IDI - a leader, Dist. 8 hospital, HCM City). For outpatients, it was very difficult for them to buy the opioid drugs at pharmacies. As defined, only some pharmacies are assigned to sell the drug with hospital doctors' signature registration. In fact, only the National Cancer hospital did that, still many hospitals did not assign their doctors to prescribe, did not register their doctors' signatures to the assigned pharmacies, so they could not prescribe for the outpatients. For example, Cho Ray and Bach Mai hospitals did not prescribe for the outpatients. Besides, there are some difficulties in management of the opioid drug use: "*Health workers cannot control the drug use of the patients because they thought that morphine can satisfy addiction, that the market price of morphine is high leads to sell the drug for making money. Moreover, although many cancer patients do not come to the hospital, we still have to make prescription. We make an appointment at every 10 days to provide the drug, the patients did not come because they live far from the hospital. The lower level can't do it, so we have to do all*" (IDI - a palliative care specialist, National Cancer hospital, Ha Noi). However, the MOH's regulation on drug prescription for outpatient treatment has initiated and facilitated Palliative care Guideline to be done in the community.

A legal document related to palliative care issued most recently by MOH is the Circular No. 10/2010/TT-BYT dated on 29th April 2010 "Guidance on activities

related to addictive drugs" The Article 14 guide on retail sale of addictive drug products for outpatients. The retail sale contents in this Circular regulated as follows [8]:

- Provincial/city health departments under management of the upper level respond for organizing and directing the addictive drug providers to satisfy the demand for outpatients in the localities.

- Addictive drug provision facilities have to meet the standards of good practice (GPP);

- Pharmacy owners who are university pharmacists will directly manage and sell retail addictive drugs.

- Addictive drugs must be stored separately in a cabinet with good lock, avoiding loss. If the amount of addictive drugs is small, they may be stored in the same cabinet of psychotropic drugs and substances but in different boxes to avoid mistakes;

- Purchasing and selling retail addictive drug products has to follow the regulations defined in the Drug prescription regulations for outpatients.

Thus, although there are many difficulties in implementing and applying, the Circular on guidance of activities related to addictive drugs is still a premise for cancer outpatients to have opioid drugs when they treat at home. It also means that the Palliative care Guideline is feasible to be follow at community.

After the National Assembly passed the Health Insurance Law (on November 14, 2008) and the Law was officially applied (on July 1, 2010), MOH issued the program No.527/Ctr-BYT dated June 18, 2009 on improving the quality of examination and treatment at the medical facilities for patients having health insurance cards to make people believe and actively use health insurance, step by step to make all people have and use health insurance. The program No.527/CTr-BYT has four specific objectives as follows: enhancing the spirit, attitude of health workers in serving patients; improving the administrative procedure; decreasing inconvenience in reception; doing medical examination and treatment, and paying hospital fees for the patients who use health insurance cards; increasing the quality of health services in hospitals and health facilities, ensuring the interests of patients having health insurance cards; preventing the abuse of drug, laboratory tests to save medical resources and hospital cost. This program is not directly related to the Palliative care Guideline, but implemented effectively, it will have positive impact in implementation of the Palliative care Guideline at health facilities [7].

On February 1, 2008, MOH issued the list of key drugs used at health facilities according to the Decision No.05/2008/QD-BYT that replaces the Decision No. 03/2005/QD-BYT dated January 24, 2005 on issuing the list of essential drugs used at health facilities and the Decision No.33/2006/QD-BYT dated October 24, 2006 on issuance of the list of radioactive substances and radioactive tracers in diagnosis and treatment. In the list of essential drugs used at all levels, the injectable morphine (hydrochloride) and oral morphine sulfate are only used by health facilities at the central, provincial and district levels. In particular, the injectable morphine used in emergency, all the four levels are allowed to use [9]. Thus, at the communal level, the morphine drug is only used in emergency cases, not in palliative care. This regulation is an obstacle to doing palliative care at the grassroots health facilities.

At present, the Decision on promulgating the Regulation on delineation of technical levels according to the Decision No. 23/2005/QD-BYT is still valid to apply. The technique list in medical examination and treatment is arranged according to the specialties; the medium technical level division for all levels, from the communal, district and provincial levels to the central level. According to the technical category in oncology examination and treatment, the communal level is not allowed to make any of those techniques, evenly the district level is also permitted to do a few simple techniques [3]. The palliative care and symptom treatment for cancer patients are not yet mentioned in this Decision. It is also a barrier in implementing the Palliative care Guideline at the grassroots health facilities.

In conclusion, together with the Decision to issue the Palliative care Guideline for cancer and AIDS patients, MOH also issued some legal documents related to the palliative care implementation such as guidance related to addictive drugs, list of essential drugs, opioid drug prescription for cancer and AIDS patients in outpatient treatment, etc. The decisions and regulations mentioned above have made a legal framework in the implementation of palliative care services at health facilities and in community. However, most of the health facilities having pain relief units have not yet implemented the prescription regulations because the requirements in regulations are too strict, so very few outpatients could buy the opioid drugs at pharmacies. The regulation on the use of morphine in the list at the health facilities still hindered the comprehensiveness of the implementation of palliative care at the grassroots health facilities.

3.1.2. Implementation of Palliative care Guideline

3.1.4.1. Dissemination of Palliative care Guidance and Advertisement of palliative care services

MOH of Vietnam issued the Palliative care Guideline for cancer and AIDS patients according to the Decision No. 3483/QD-BYT dated June 15, 2006. The Article 2 and Article 3 in the Decision for cancer and AIDS patients highlighted that "The Palliative care Guideline is applied at all public and private health facilities and used to instruct for palliative care of cancer and AIDS patients at family and community" [5]. The study results on availability of documents on palliative care at the 120 health facilities (11 National hospitals/Oncology centers, 19 district hospitals, 90 CHCs) are presented in the Figure below:

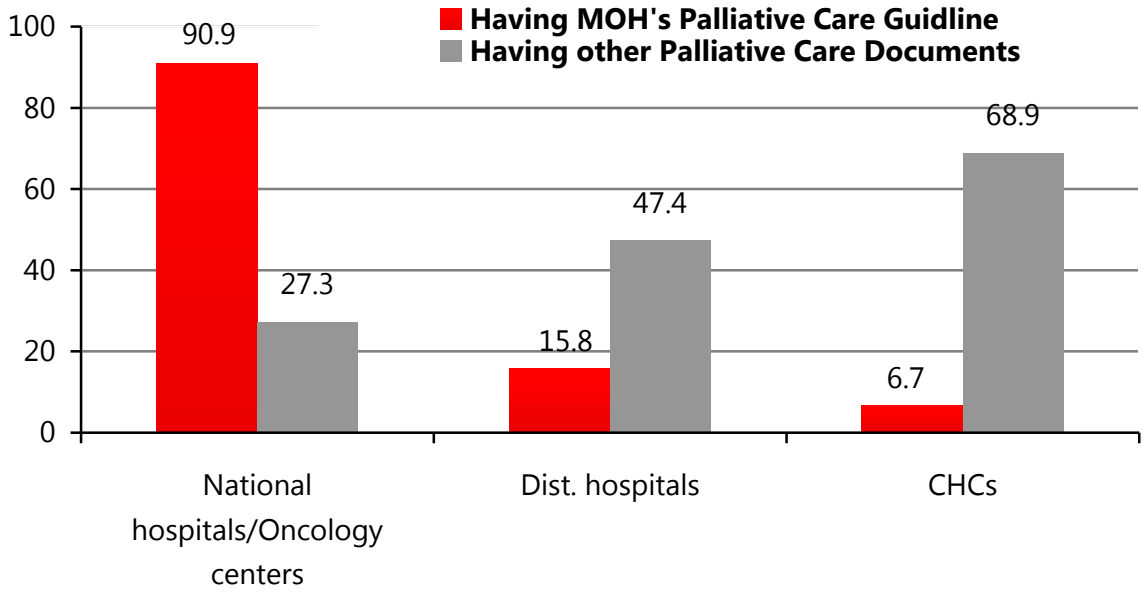


Figure 2. Percentage of health facilities having palliative care documents

90.9% of the National hospitals/Oncology centers reported that they had the MOH's Palliative care Guideline, but only 15.8% of the district hospitals and 6.7% of the CHCs has this document. However, 68.9% of the CHCs and 47.4% of the district hospitals had other guidance documents provided by the HIV/AIDS control program. Thus, although the MOH's Palliative care Guideline for cancer and AIDS patients was issued since 2006, until the survey time (6-7/2010) very few district health facilities and CHCs had it available. Some in-depth interviews also show some opinions of interviewees: "*I have never known about the MOH's Palliative care Guideline*" (IDI - a curing staff, General hospital, Dong Anh dist., Ha Noi). "*I have ever seen this document but don't know about its contents*" (IDI - a leader of Duc Giang hospital, Long Bien dist., Ha Noi). Especially in Thua Thien Hue province,

almost all of the health workers did not know about the MOH's Palliative care Guideline "*I totally did not know about the MOH's Palliative care Guideline, we only know about some guidance documents for HIV/AIDS patients. However, they are simple. The health department also doesn't have any guidance*" (IDI - a leader of HIV/AIDS control center, Thua Thien Hue). "*I have been working here for over 10 years but I have never seen the MOH's Palliative care Guideline*" (IDI - a leader of hospital, Hue city, Thua Thien Hue). *I and many doctors at the hospital have never heard about or seen the MOH's Palliative care Guideline. Now I just hear about the concept of palliative care, I think palliative care is care for cancer patients to reduce their pain*" (IDI - a leader of hospital, Phu Vang dist., Thua Thien Hue).

Thus, the Palliative care Guideline for cancer and AIDS patients currently is a basis to create good conditions for education and training programs for health workers as well as public health improvement at the present, this document also pays an important role in improving the balance between drug management and availability of painkiller/drug for other symptoms. However, in fact, this guidance has just been applied in the National Cancer Hospital, Oncology centers, Cancer department of hospitals, some regional hospitals and provincial hospitals.

Table 3. Percentage of health facilities advertising Palliative care services

Promoting forms	National host./Oncology center		Dist. hospital		CHC		Total	
	n	%	n	%	n	%	n	%
TV/radio/book/magazine	6	54.5	0	0.0	1	1.1	7	5.8
Internet	4	36.4	0	0.0	0	0.0	4	3.3
Leaflet, handbook	2	18.2	2	10.5	11	12.2	15	12.5
Posters, banners	0	0.0	2	10.5	2	2.2	4	3.3
Communal/ward loudspeaker	1	9.1	1	5.3	14	15.6	16	13.3
Patients who come for cancer examination and treatment	6	54.5	5	26.3	15	16.7	26	21.7
Other	0	0.0	2	10.5	7	7.8	9	7.5
Not promoting	4	36.4	13	68.4	65	72.2	82	68.3
n	11		19		90		120	

The advertisement of palliative care services has not been paid much attention. 36.4% of the National hospitals/Oncology centers, 68.4% district hospitals and 72.2% CHCs under the survey did not advertise the palliative care services. Main reason is that the patients who came for cancer examination and treatment self-communicated to the community (21.7%). The initiative of service advertisement at the health facilities was still limited. The palliative care service advertisement channel that was applied the most was the communal/ward loudspeaker system (13.3%); leaflets, handbooks (12.5%); TV/radio/book/magazine (5.8%, most at the National hospitals/Oncology centers-54.4%).... The following opinions show clearly

the level of the palliative care service advertisement at the health facilities "*The palliative care service advertisement is not yet paid attention, MOH only encourages hospitals to self-advertisement*" (IDI - a palliative care specialist, Management-Examination and Treatment Bureau, MOH). However, at public hospitals, this work was not done well "*There is no advertisement, the hospital still has have a lot of patients, it is not a problem*" (IDI - a palliative care specialist, Management-Examination and Treatment Bureau, MOH). "*There have been no advertisement applied because in fact the services are not yet comprehensive. The K hospital has palliative care services and also introduces to refer the patients to the K hospital if the patients have comprehensive palliative care needs*" (IDI - a curing staff, National Pediatric hospital, Ha Noi). "*At present, the capacity of palliative care services provision is available at leading hospitals. We only organize several times of training for lower levels, especially for staff in charge in community health care. Because the health workers are at many positions, so, after trained they could not disseminate knowledge they got for the other CHCs' health workers*" (IDI - a curing staff, Cho Ray hospital, HCM City). Some health facilities such as Ha Noi Oncology hospital, Cho Ray hospital, etc. had some advertisement forms for palliative care services, but it was still desultory and not effective.

Table 4. Percentage of patients' relatives knowing about palliative care service facilities

Services	National hospital/Oncology center	Prov. hospital	Dist. hospital	CHC	Private hospital/clinic	Home-based service	Don't know
Pain relief	65.6	19.5	8.5	3.2	7.1	4.1	31.2
Symptom management	52.2	16.6	5.1	3.2	3.9	2.0	45.1
Psychology support	37.6	11.0	5.6	3.2	3.9	2.2	58.3
End-of-life care	16.8	4.6	2.0	0.7	1.2	2.4	81.7

The percentage of caregivers who knew about the palliative care service facilities was still low. Palliative care services of National hospitals/Oncology centers found at a not high percentage are pain relief (65.6%), symptom management (52.2%), psychology support (37.6%), end-of-life care (16.8%). The percentage of

respondents who knew about palliative care service facilities such as provincial hospitals, district hospitals, CHCs, public hospitals/clinics was very low (less than 20% for provincial hospitals, around 8.5% and 3.2% for district hospitals and CHCs respectively). Thus, information on palliative care services for people in need is also still limited, not yet mentioning people in community. Up to 81.7% of the interviewees did not know about end-of-life service provision facilities, 58.3% did not know where patients could receive psychological support, and 31.2% did not know any facilities for provision of pain relief services. Some opinions of patients: "*I came to this hospital by the referral of a doctor. When having sign of menorrhagia, I went to a private clinic but the symptom was not alleviated. I didn't know where I should go to examine. Before treated here (HCM Oncology hospital), I went to a lot of health facilities*" (IDI - a cancer patient, Oncology hospital, HCM City). "*I think that the advertisement of palliative care services needs to be strengthened because people who live in the rural area don't know anything about it. When I told about my disease to some others, they said that I had miscarriage and needed to rest only. Health facilities providing cancer treatment services should advertise widely to the people*" (IDI - a cancer patient, Oncology hospital, HCM City).

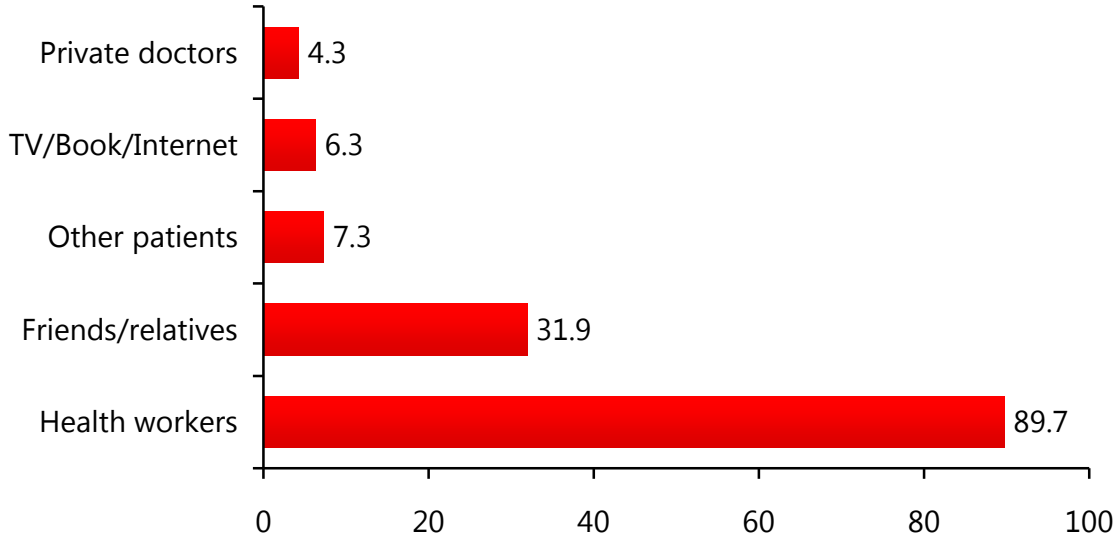


Figure 3. Sources of information on palliative care services

Information sources on palliative care services that the interviewees (cancer patients' relatives) received were health workers (89.7%) and friends/relatives (31.9%). Very few respondents accessed to information on palliative care services from the other sources including TV/radio/magazine, etc. In conclusion, palliative care services were not yet advertised widely. A cancer patient said that "*When having abnormal signs and not yet detected as cancer, I worried very much. I also accessed internet for information but it was not available for all. I called for consultation all day but failed. Sometimes I wanted to ask but my relatives didn't know and doctors were too busy to answer. Since hospitalization in Bach Mai*

hospital the doctors have been very enthusiastic and explained very carefully" (IDI - a cancer patient, Oncology center, Bach Mai hospital, Ha Noi).

3.1.3. Training on Palliative care Guideline

In order to implement the Palliative care Guideline for cancer and AIDS patients, the first is to train for health workers at health facilities at all levels. The survey findings show that

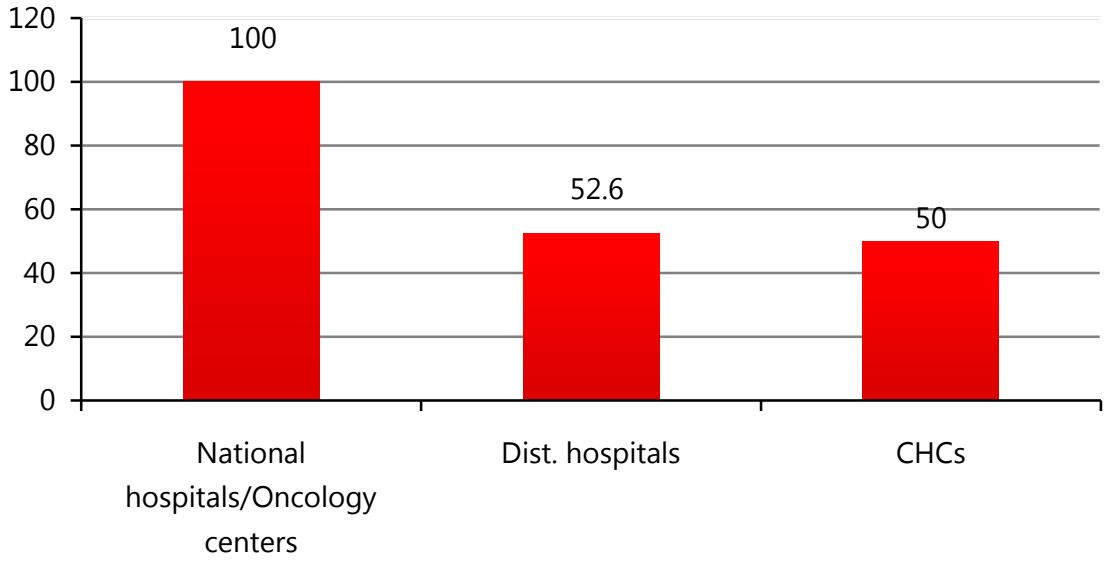


Figure 4. Percentage of health facilities having health workers trained in palliative care

All the National hospitals/Oncology centers under the survey reported that their health workers were trained in palliative care (for cancer and AIDS patients). For district hospitals and CHCs, only over 50% of the health facilities reported that their staff were trained in palliative care. According to the preliminary report on results of implementation of the National Project on Cancer Control in the phase 2008-2010 [10], the project held 1-2 training courses on symptom care for the doctors working at the oncology departments each year. Ha Noi and HCM City are the areas having a lot of cancer prevention and control units, so the implementation of palliative care could be done better than the other localities.

Some in-depth interviews also show that for the health facilities providing palliative care, almost all of their health workers were assigned to provide palliative care services they were trained in. Training courses for trainers (TOT) at all provinces/cities were conducted with the expectation that after being trained provincial trainers will re-train for local service providers. However, because of limited budget, the number of training courses was limited and did not yet cover all contents; besides, there have been needs for additional training and re-training.

At the health facilities where their staff were trained in palliative care the number of health workers who were trained in palliative care was counted. The average number of doctors, nurses among the total number of doctors, nurses working in palliative care is presented in the table below:

Table 5. Percentage of health workers who were retrained in palliative care

Health facilities	Doctor (Average)	Assistant doctor (Average)
National hospital/Oncology center	14,00/21,36 (65%)	17,27/18,91 (91%)
Dist. hospital	12,50/37,40 (33%)	15,17/82,83 (18%)
CHC	1/1,39 (72%)	2,08/3,13 (66%)

At health facilities having staff trained in palliative care, about 2/3 of doctors at the National hospitals/Oncology centers and CHCs were trained in this field. However, only about 1/3 of doctors in the surveyed districts were trained in palliative care.

Similarly, almost all of the assistant doctors at the National hospitals/Oncology centers and CHCs were trained in palliative care, but this percentage was only 18% at the district hospitals.

Some health facilities conducted the training courses on palliative care rather well for health workers who are working at the Oncology departments: "*Most of health workers were trained at the hospital. The trainings were conducted regularly and in many times to enable the participation of health workers. All doctors, assistant doctors and hospital orderlies in this department were trained in the contents defined in the Palliative care Guideline*" (IDI - a curing staff, National Gynecological/Obstetric Hospital, Ha Noi).

Table 6. Needs for retraining in palliative care at health facilities

Needs for training	National hospital/Oncology center		Dist. hospital		CHC		Total	
	n	%	n	%	n	%	n	%
Training for health workers who are not yet trained in palliative care	9	81.8	16	84.2	81	90.0	106	88.3
Re-training for health workers who were trained in palliative care	10	90.9	11	57.9	44	48.9	65	54.2
Other	0	0.0	1	5.3	2	2.2	3	2.5
No need	0	0.0	1	5.3	2	2.2	3	2.5
N	11		19		90		120	

Almost all of the surveyed health facilities had needs for training in palliative care (81.8-90% of the health facilities) for those who have not been trained and re-training for those who were trained (48.9-90.9% of the health facilities).

According to the interviewed health workers, there have been many difficulties in implementing the Palliative care Guideline. For example, there was no clear regulation on a clear mechanism to implement the Palliative care Guideline at the medical service provision facilities at all levels. The development of the services depended on the opinions and enthusiasm of the leaders at the grassroots level. Due to the palliative care services closely related to the opioid drug management, complicated mechanism of the management and prescription, many managers hesitated to provide this service. A leader of a district hospital said that: "*Our hospital provides painkiller but the regulation on management of opioid drugs is too difficult to follow, so the doctors do not have enough authority to write the prescription. The drug management process is so strict that it is very difficult to access in the community. If the patients have a need for a drug, they must go to the hospital for treatment, it wastes time of the patients and their caregivers*" (IDI - a leader, Dist. 8 hospital, HCM City).

The implementation of the Palliative care Guideline for cancer patients was not well carried out at all levels. Therefore, the curing staff's accessibility to the guideline was still limited. "*Palliative care is a new concept, so the policy makers and managers of the health department at all levels have not been aware of it*" (IDI, a palliative care specialist, Management-Examination and Treatment Bureau, MOH).

The human resource and physical infrastructure for palliative care at the some National hospitals did not yet satisfy the actual needs, and the main reason was due to the overload of patients. A lot of the National general hospitals have not yet had palliative care departments. For the provincial level, the palliative care work was significantly difficult, the palliative care services were integrated into the tasks of the internal medicine department, health workers were not yet trained in palliative care, so the effectiveness of provision of the palliative care for patients was still limited. "*At present, the physical infrastructure for the palliative care is very poor, there is no Pain relief or palliative care department, except in some big hospitals and Oncology centers. No investment in human resource, no long-term plan for this work. For the provincial hospital, this work is integrated into the tasks of the internal medicine department, physicians have no specialty, so the effectiveness of the implementation is very low*" (IDI, a palliative care specialist, Management-Examination and Treatment Bureau, MOH).

"There is no separate training guidance for assistant doctors, main caregivers of patients with home-based care. The opioid drugs are not yet used much at the grassroots level because of the hesitation in seeking the drugs, complication in use, and management of the drugs. Thus, doctors and assistant doctors are not yet

enthusiastic on the palliative care work for end-of-life patients, they should have reasonable financial support" (IDI - a palliative care specialist, Oncology hospital, HCM City).

3.1.4. Supervision on Palliative care Guideline implementation

MOH has not yet supervised the implementation of the Palliative care Guideline at service provision facilities at all levels. "*Although MOH issued the legal documents; monitoring and evaluation on implementation at the grassroots level is insufficient. There is a lack of direction, supervision and encouragement so this work doesn't come into effect*" (IDI - a palliative care specialist, K hospital, Ha Noi). As presented in the above section, the palliative care for cancer patients has just been provided at the specialty hospitals, Oncology centers and Oncology centers of general hospitals at some provinces/cites. Thus, almost all of the health facilities have not yet been supervised on palliative care by the upper level: *"There is no supervision. There were only some cooperation, exchange and workshops (only cooperation and exchange, rarely training)"* (IDI - a curing staff, National Pediatric hospital, Ha Noi).

In-depth interviews at all the surveyed sites show that at the present, the supervision and support in palliative care for cancer patients were not yet done. Most of the health facilities were only supervised on the professional activities (examination and treatment in general) or palliative care for AIDS patients from the upper level. "*The specialty units of the provincial health department have supervised palliative care for HIV/AIDS patients in periodic once each quarter, but totally not for palliative care for cancer patients*" (IDI - a leader of Phu Vang hospital, Thua Thien Hue).

The answers to the question "*When was the last supervision by the upper level at your facility*?" and the question "*When was the last time your facility supervised and supported the lower level*?" are presented in the table below:

Table 7. Supervision and support of the upper level to the lower level in the last time

Point of time of supervision	National hospital/Oncology center		Dist. hospital		CHC		Total	
	Supervised	Supervising	Supervised	Supervising	Supervised	Supervising	Supervised	Supervising
< 3 months	0.0	27.3	5.3	10.5	12.2	14.4	10.0	15.0
3-<6 months	18.2	27.3	15.8	5.3	12.2	16.7	13.3	15.8
6-<12 months	18.2	0.0	26.3	5.3	30.0	20.0	28.3	15.8
≥12 months	0.0	0.0	5.3	10.5	6.7	2.2	5.8	3.3
Never supervised	63.6	45.5	47.4	52.6	38.9	17.8	42.5	25.8
Not appropriate		0.0		15.8		28.9		24.2
n	11	11	19	19	90	90	120	120

Very few health facilities were supervised on palliative care (including palliative care or AIDS patients). Conversely, still 47.4% of the district hospitals and 38.9% of the CHCs have never been supervised and supported on palliative care. 63.6% of the National hospitals/Oncology centers have never been supervised and supported by the upper level, it is reasonable that because they are the highest-level health facilities. Only four Oncology centers (26.4%) under the administrative management of provinces/cities were still supervised and supported by cancer specialty hospitals. The last time health facilities received supervision and support from the upper level was mostly from 6 to <12 months before (28.3%), 3 to <6 months before (13.3%) and <3 months before (10%).

The supervision and support on palliative care to the lower level is still limited. Still 45.5% of the National hospitals/Oncology centers, 47.4% of the district hospitals and 16.7% of the CHCs have never supervised and supported the lower level (village health workers) on palliative care. 15.8% of the district hospitals and 28.9% of the CHCs reported that the supervision and support for the lower level were not appropriate. It is not exact, because the CHCs are one of the health facilities to provide the palliative care services for cancer and AIDS patients; the village health workers could provide the palliative care services for patients with home-based care, especially in the end-of-life phase. According to the health facilities, the last time for supervision and support of the lower level was divided equally into 3 levels: from 6 to <12 months (15.8%), from 3 to <6 months (15.8%) and <3 months (15%).

Table 8. Frequency of supervision

Frequency	National hospital/Oncology center		Dist. hospital		CHC		Total	
	Supervised	Supervising	Supervised	Supervising	Supervised	Supervising	Supervised	Supervising
<3 months	0.0	16.7	0.0	33.3	20.0	29.2	15.9	28.3
3-<6 months	25.0	66.7	40.0	33.3	32.7	31.3	33.3	35.0
6-<12 months	50.0	16.7	50.0	33.3	45.5	37.5	46.4	35.0
≥12 months	25.0	0.0	10.0	0.0	1.8	2.1	4.3	1.7
n	4	6	10	6	55	48	69	60

At the health facilities that were supervised and supported, the most popular frequency of supervision and support by the upper level on palliative care was once a year (from 6 to <12 months: 46.4%), followed by once per a half of year (from 3 to <6 months: 33.3%), once per quarter (<3 months: 15.9%) and a few health facilities received supervision and support once per more than 12 months (4.3%).

According to the survey health facilities, the frequency of supervision and support on palliative care to the lower level (CHCs supervised and supported the village health workers) was divided equally into 3 levels: once per year (from 6 to <12 months: 35%), once per a half of year (from 3 to <6 months: 35%), and once per quarter (<3 months: 28.3%).

Table 9. Contents of the supervision of the upper level

Contents	National hospital/Oncology center		Dist. hospital		CHC		Total	
	Supervised	Supervising	Supervised	Supervising	Supervised	Supervising	Supervised	Supervising
Pain relief	50.0	100.0	70.0	66.7	16.4	14.6	26.1	28.3
Symptom treatment	25.0	100.0	60.0	50.0	23.6	20.8	29.0	31.7
Counseling skills	25.0	66.7	20.0	50.0	74.5	52.1	63.8	53.3
Patients' psychology support skills	25.0	66.7	50.0	66.7	54.5	52.1	52.2	55.0
End-of-life care guidance	25.0	83.3	20.0	33.3	23.6	22.9	23.2	30.0
Other	50.0	0.0	40.0	16.7	36.4	16.7	37.7	15.0
No support		0.0		0.0		25.0		20.0
n	4	6	10	6	55	25	69	60

The most popular supervision contents of the upper level were the counseling skills (63.8%), followed by patients' psychology support skills (52.2%), symptom treatment (29%), pain relief (26.1%), end-of-life care guidance (23.2%) and the others (37.7%, including finance support-14.5%, checking general work -18.8%, and no support-4.3%). The counseling contents were appropriate to the conditions and ability of each level, for example the two most common contents to the district hospitals were pain relief and symptom treatment, that for CHCs was counseling skill.

The most popular contents the surveyed health facilities supported the lower level were the counseling skill (53.3%) and patients' psychology support skill (55%), followed by symptom/complication treatment (31.7%), end-of-life care guidance (30%), pain relief (28.3%) and others (15%). Of the CHCs 25% did not give any support for village health workers on palliative care. For example, the Tu Du hospital, HCM City had "*a timetable of supportive examination for the lower level once every 3 months and once every 6 months. There are some additional times for charity. The cancer patients are always examined and tested periodically. The hospital also supports their staff to help the lower level.*" (IDI, a curing staff, Tu Du hospital, HCM City). Or that "*The National Pediatric hospital supports the lower level in providing training materials; chemicals (not yet providing painkiller) in case the patients have health insurance cards (children aged under 6); and next is providing drugs for occasional infection complication treatment, blood transfusion; referral of patients (the mild patients will be referred back to the provincial level and provided with chemicals to continue treatment at the provincial hospital)*" (IDI, a curing staff, National Pediatric hospital, Ha Noi).

Table 10. Satisfaction to supervision of the upper level

Satisfaction level	National hospital/Oncology center		Dist. hospital		CHC		Total	
	n	%	n	%	n	%	n	%
Too unsatisfied	0	0.0	0	0.0	1	1.8	1	1.4
Unsatisfied	0	0.0	0	0.0	0	0.0	0	0.0
Moderate	2	50.0	6	60.0	33	60.0	41	59.4
Satisfied	2	50.0	4	40.0	20	36.4	26	37.7
Very satisfied	0	0.0	0	0.0	1	1.8	1	1.4
n	4		10		55		69	

The quality of supervision and support of the upper level was not good. According to the supervised health facilities, the satisfaction level to the supervision and support of the upper level found the most was the moderate level (59.4%) and one CHC was still too unsatisfied. Only 37.7% of the health facilities were satisfied with the supervision and support of the upper level; only one CHC was very satisfied.

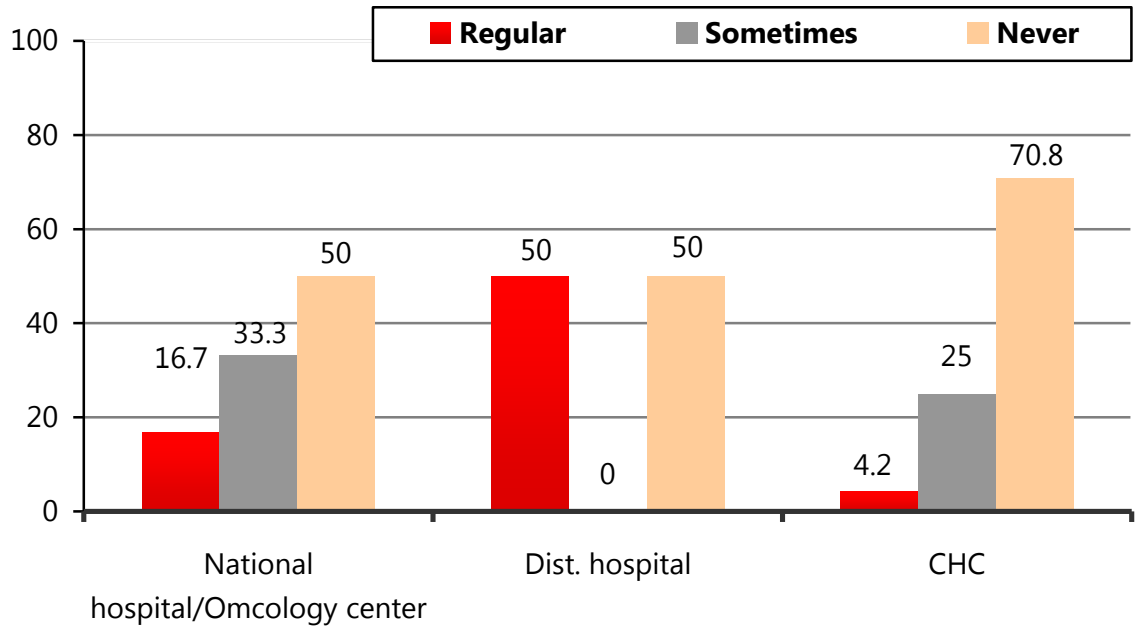


Figure 5. Percentage of health facilities using checklists in supervision at lower levels

The situation of not using checklists in the palliative care supervision was very popular because there is no forms of checklist (checklists used in palliative care supervision is being designed by the K hospital). Among the health facilities supervised the lower level, 50% of the National hospitals/Oncology centers, 50% of the district hospitals and 70.8% of the CHCs did not use checklists. The percentage of the health facilities that sometimes used checklists in supervision was 23.3%, higher than the percentage of those that regularly used (10%).

3.2. Needs for and accessibility to palliative care services

Main findings:

- Most of the cancer patients often suffered pain in disease (75.9%) along with other symptoms such as tiredness (78.8%), lack of sleep (55.1%), fever (40.7%), vomit/nausea and breathing difficulties (38.5%).
- 36.8% of the patients had severe pain, whereas 33.4% had moderate pain, 13.9% had mild pain and 15.9% had no pain during the most recent experience of pain.
- Some popular moods of patients during their cancer treatment were described as being afraid of cancer and treatments (50.5%), concerning about their future and family (47.5%), fearing to die (31.5%), being afraid of losing salary and poverty (25.9%) and losing desire to live (15.6%), etc.
- In the last pain, 27.9% of the patients in severe pain, 25.6% in moderate pain and 62.3% in mild pain did not receive pain relief.
- 24.2%-69.7% of the cancer patients had symptoms but not treated during the last treatment.
- Over 1/3 of the respondents said that the patients rarely or never be counseled, mostly on symptoms and their treatments (48.1%), nutrition (46.2%), nursing care level (45.7%), lower on the treatment method (30.8%) and cancer consultancy (28.9%).
- 40.4% of the patients at the central hospitals/oncology centers, 54.5% at the district hospitals, 27.3% at the private hospitals/clinics, and 100% at the CHCs rarely or never been received any psychological support.
- Only 15% of the respondents confirmed that the patients accessed palliative care services from public health facilities at home, while most of the rest bought drug by prescription for their treatments.
- Regarding the difficulties cancer caregivers faced with, 46.4% of them gave out the reason of a lack of caring skills, 31.4% lack of information.
- 86.1% of the dead patients were taken care of by their relatives even in pain relief at the end of life.
- 34.4% of the patients' families need to be supported to have their palliative care at the health facilities, 48.8% of the families could solve their own problems and 16.8% of the families didn't have any difficulties in paying for treatment and palliative care.
- 82.7% of the surveyed patients had their health insurance card, in which 77.8% used their cards for the last treatment.

3.2.1. Needs of cancer patients for palliative care

Results of 410 interviews with cancer patients' caregivers show that 54.9% of the patients were female, the remaining were male; most of them aged 45 and over (84.6%), but still 2.4% were under 15 years old; the rural patients accounted for 58.3% and the rest were urban civilians; 38.5% of the patients have died since December 2009, 31.5% were currently being treated at home, 17.1% were being treated in central hospitals/oncology centers, 4.2% were undergoing treatment in provincial, district or private hospitals, while 8.8% of them have finished their treatments or survived the illness, etc.

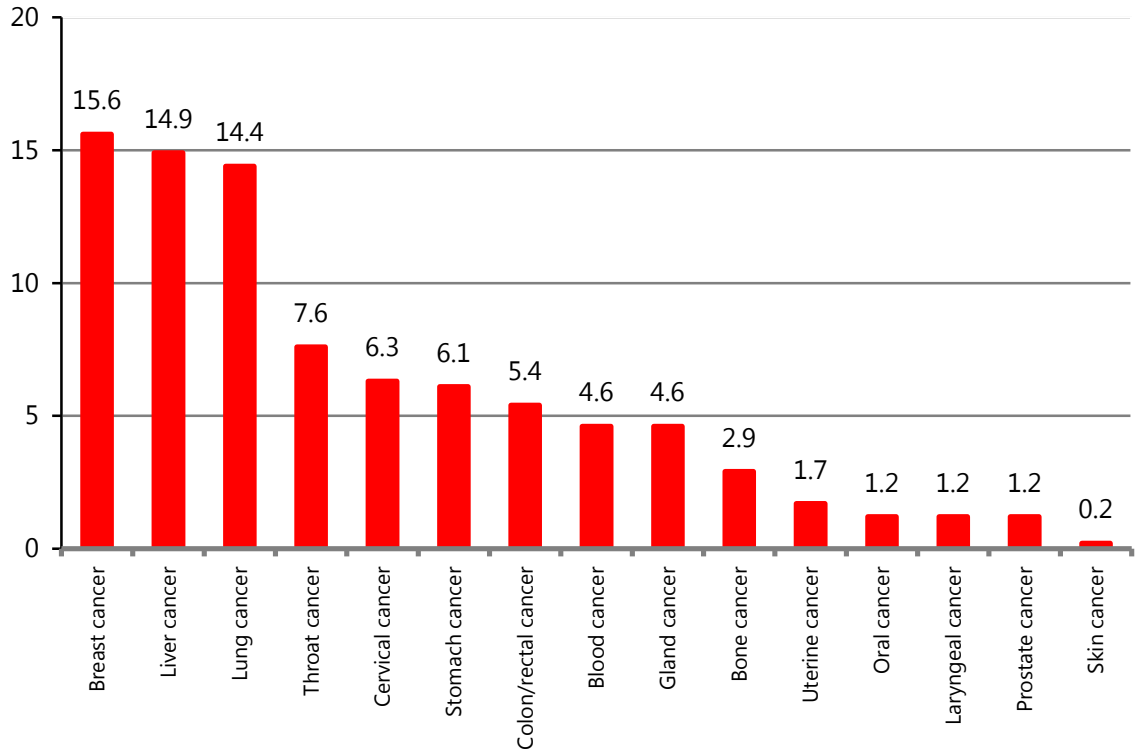


Figure 6. Types of cancer among the surveyed subjects

Types of cancer identified in the survey were quite diversified. Most of cases were the breast cancer (15.6%), liver cancer (14.9%) and lung cancer (14.4%); followed by throat cancer (7.6%), cervical cancer (6.3%), stomach cancer (6.1%), colon/rectal cancer (5.4%), blood cancer and gland cancer (both 4.6%), bone cancer (2.9%), uterine cancer (1.7%), prostate cancer, laryngeal cancer and oral cancer (all 1.2%) and skin cancer (0.2%). The other types of cancers accounted for 12%.

Table 11. Common symptoms of cancer

Symptoms	In the disease process		In the last treatment	
	n	%	n	%
Pain	311	75.9	297	72.6
Fever	167	40.7	161	39.4
Vomit/nausea	158	38.5	140	34.2
Diarrhea	68	16.6	72	17.6
Constipation	77	18.8	66	16.1
Cough	114	27.8	109	26.7
Breathing difficulties	158	38.5	164	40.1
Tiredness	323	78.8	325	79.5
Itchy	29	7.1	29	7.1
Ulcer	15	3.7	28	6.8
Lack of sleep	226	55.1	216	52.8
Too excited	17	4.1	17	4.2
Depression	90	22.0	61	14.9
Other	132	32.2		
Don't remember	2	0.5		

From the surveyed cases, the two most common symptoms of cancer in the disease process and in the last treatment were pain (75.9% and 72.6% respectively) and tiredness (78.8% and 79.5% respectively). A patient's husband said: *"She had throat cancer so she had pain while swallowing, sometimes she had no spittle, or eat without feeling. When she had pain, she shouted out loudly."* (FGD, cancer patients' caregivers (a man aged 50), Thuy Phuong commune, Huong Thuy district, Thua Thien Hue province). The second most common symptom was the lack of sleep (55.1% and 52.8% respectively), fever (40.7% and 39.4% respectively), vomit/nausea (38.5% and 34.2% respectively) and breathing difficulties (38.5% and 40.1% respectively). Thus, the needs in palliative care (pain relief, symptom treatment, spiritual support, etc.) for cancer patients are very big.

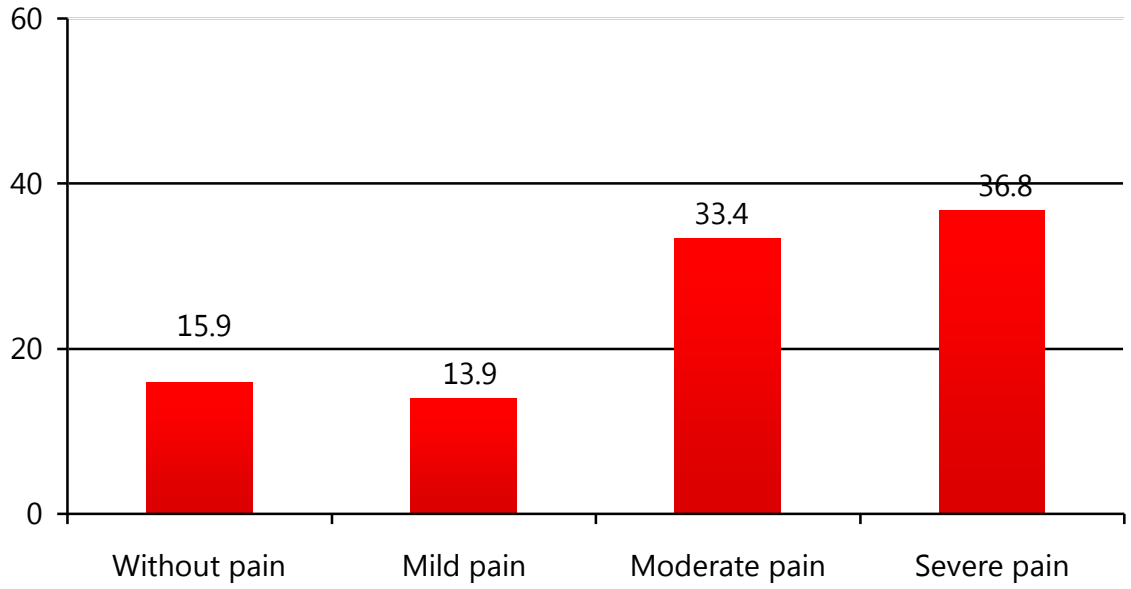


Figure 7. Pain intensity of patients in the last pain

Among the surveyed cases, 36.8% of the patients had severe pain, 33.4% had moderate pain, 13.9% had mild pain and 15.9% had no pain. It clearly shows needs for pain relief of cancer patients.

Most of the patients have experienced fear, worry about the disease at the time of examination and treatment. The most common states of mind of the patients during their diseases were: afraid of the disease and treatments (50.5%), worry about future and family (47.6%), fear of death (31.5%), afraid of losing salary and poverty (25.9%), losing desire to live (15,6%), etc. Most of the health workers also said that the cancer patients and their families had to face with health and mental problems, as well as their routine which enormously affected their quality of life. A doctor said: *"Some patients felt so sad, sorrowful, even puzzled after they knew about their cancer. Those problems affected their quality of life very much, leading to gauntness, tiredness and pains. Some fell like they were powerless; thus*

Table 12. Mood of the cancer patients

Mood	n	%
Afraid of the disease and treatments	207	50.5
Lose desire to live	64	15.6
Fear of death	129	31.5
Guilt and punishment feeling	1	0.2
Feel lonely	20	4.9
Worry about future and family	195	47.6
Afraid of losing salary and poverty	106	25.9
Afraid of losing position	4	1.0
Calm, accepting the fact	202	49.3
Other	10	2.4
Don't answer	9	2.2

their families felt worried, tired and faced with the financial difficulties, etc." (IDI, a palliative care specialist, Hue central hospital, Thua Thien Hue province).

Regardless of the type of cancer and cancer's stage of patients, the most common symptoms in the disease process were the pain, lack of sleep, fever, vomit/nausea, and breathing difficulties, along with the moods such as be afraid of the disease and treatment, worrying about future and family, fear of death, and losing living desire. It indicates that the needs of cancer patients in care, spiritual support since the diagnosis and throughout the treatment are very big and need to be paid attention.

3.2.2. Access of cancer patients to the services

3.2.3.1. Access to and use of pain relief service

Table 13. Percentage of patients receiving pain relief in the last pain

Pain intensity	Physician treatment		Self treatment		No treatment		n
	n	%	n	%	n	%	
Mild pain	26	37.7	22	31.9	21	30.4	69
Moderate pain	90	74.4	24	19.8	7	5.8	121
Severe pain	106	72.1	39	26.5	2	1.4	147
n							337

In the last pain, there was still a number of patients not supported with pain relief It is easy to see that the service was still limited. For example, the percentages of patients having moderate and severe pain receiving painkillers were 74.4% and 72.1% respectively; that percentage in the patients having mild pain was lower, accounting for over 1/3 of the cases. Thus, it indicates that when the patients had mild pain, very few of them received pain relief from their relatives and health workers.

Table 14. Percentage of patients receiving cancer therapy with pain relief by opioid drugs

Cancer therapy	Treated with opioid drugs (either injection or oral)	
	n	%
Chemotherapy	31	23.5
Radiotherapy	10	7.6
Surgery	15	11.4
(Only) symptom cure	104	78.8
Other	1	0.8
n	132	

Most of the patients had their pain treated with opioid drugs either orally or through injection (78.8%). There were only 23.5% of them having chemotherapies, 11.4% having surgeries and 7.6% having radiotherapies.

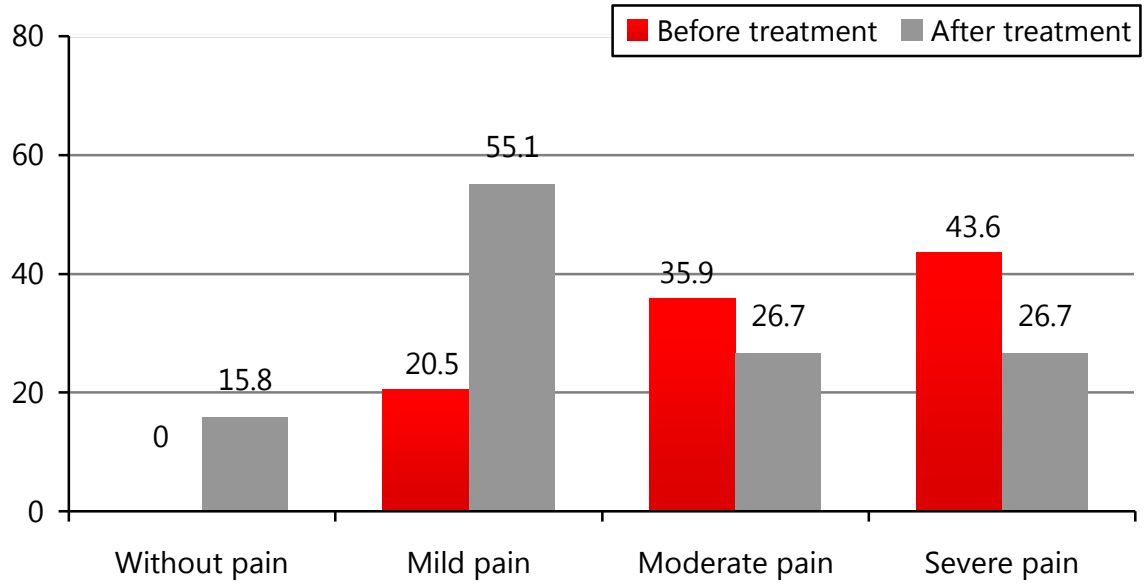


Figure 8. Effectiveness of pain relief

The effectiveness of pain relief was highlighted through a comparison of pain intensity before and after treatment. Before treatment, the percentages of patients having severe, moderate and mild pain were 43.6%, 35.9% and 20.5%, respectively. Those percentages were 26.7% in both severe and moderate pain groups and 55.1% in mild pain group after treatment.

3.2.3.2. Access to and use of symptom treatment service

Table 15. Percentage of patients receiving symptom treatment in the last treatment

Symptoms	Have symptoms		Informed to health workers		Treated by health workers		Good effectiveness		Satisfied	
	n	%	n	%	n	%	n	%	n	%
Pain	297	72.6	229	77.1	220	74.1	104	46.8	111	50.0
Fever	161	39.4	123	76.4	122	75.8	86	70.5	82	67.2
Vomit/nausea	140	34.2	84	60.0	77	55.0	49	62.0	47	59.5
Diarrhea	72	17.6	41	56.9	38	52.8	30	76.9	26	66.7
Constipation	66	16.1	21	31.8	20	30.3	11	52.4	13	61.9
Cough	109	26.7	75	68.8	74	67.9	29	39.2	26	35.1
Breathing difficulties	164	40.1	113	68.9	107	65.2	27	25.2	27	25.2
Tiredness	325	79.5	163	50.2	143	44.0	46	31.9	46	31.9
Itchy	29	7.1	16	55.2	15	51.7	7	46.7	5	33.3
Ulcer	28	6.8	14	50.0	14	50.0	4	28.6	7	50.0
Lack of sleep	216	52.8	111	51.4	100	46.3	30	30.0	26	26.0
Too excited	17	4.2	9	52.9	8	47.1	4	50.0	4	50.0

Depression	61	14.9	38	62.3	31	50.8	7	21.2	4	12.1

In the last treatment, among symptoms, beside the tiredness, there was a high percentage of patients having pain (72.6%), followed by lack of sleep (52.8%), breathing difficulties (40.1%), fever (39.4%), vomit/nausea (34.2%), cough (26.7%), diarrhea (17.6%), constipation (16.1%) and depression (14.9%), etc. If a patient had a symptom, he/she would tend to see doctor, mostly when he/she had pain (77.1%) and fever (76.4%), while rarely seeing doctor when he/she had constipation (31.8%). However, there were 24.2 to 69.7% of patients having symptoms/complications were not treated, mostly in the case of constipation (69.7%) and lowest in the case of fever or pain (24.2% and 25.9% respectively). These results show that apart from the symptoms of pain and fever, the patients tended to be resigned themselves to the other symptoms, and the care of health workers also focused more on these two symptoms.

The percentage of the patients satisfying with their pain relief was relatively low, making up 50% of the surveyed subjects. It is indicated that half of the patients having pain were not certainly treated with pain relief. For other symptoms, the percentage of effective symptom treatment mostly approximately 1/3 of the patients who treated. This percentage was found highest in the case of diarrhea (76.9%), fever (70.5%) and vomit/nausea (62%) and lowest in depression (21.2%), and breathing difficulties (25.2%). The satisfaction level of the patients and their relatives was directly proportional to treatment effectiveness.

3.2.3.3. Access to and use of counseling services

Table 16. Frequency of counseling for the patients in treatment

Content of counsel	Regular		Sometimes		Rarely		Never		n
	n	%	n	%	n	%	n	%	
Disease	124	30.3	167	40.8	44	10.8	74	18.1	409
Treatment method	125	30.6	158	38.6	61	14.9	65	15.9	409
Symptom treatment	98	24.0	114	27.9	77	18.8	120	29.3	409
Nutrition	106	25.9	114	27.9	79	19.3	110	26.9	409
Nursing care level	107	26.2	115	28.1	76	18.6	111	27.1	409

No more than 1/3 of the respondents were regularly counseled, mostly on the topics of cancer and treatment method (30.3% and 30.6% respectively), and lowest on symptoms and treatment (24%). In contrast, over 1/3 of the patients rarely or never be counseled. This percentage was highest in symptoms and treatment (48.1%), nutrition (46.2%), nursing care level (45.7%) and lowest in treatment method (30.8%) and cancer counsel (28.9%). Therefore, the consultancy for cancer patients during their treatments has not regularly conducted. A patient said that "*The doctor only gave drugs, did not consult anymore on psychology, even on the*

health problems or symptoms, I only receive the consultancy from my husband and relatives" (IDI, a cancer patient, Dist. 15, Tan Binh ward, HCM City).

Table 17. Satisfaction of patients on counseling services in treatment

Counseling contents	Too unsatisfied		Unsatisfied		Moderate		Satisfied		Very satisfied		n
	n	%	n	%	n	%	n	%	n	%	
Disease	1	0.3	11	3.3	153	45.7	152	45.4	18	5.4	335
Treatment method	2	0.6	15	4.4	152	44.2	153	44.5	22	6.4	334
Symptoms and how to treat	1	0.3	3	1.0	126	43.6	142	49.1	17	5.9	289
Nutrition	0	0.0	5	1.7	102	34.0	174	58.0	19	6.3	300
Nursing care level	0	0.0	4	1.3	101	33.9	173	58.1	20	6.7	298

The percentages of patients satisfied with the counseling services in all contents were found the highest at the satisfied level (44.5%-58.1%) and moderate level (33.9%-45.7%). 5-7% of the respondents were very satisfied, 1-4% were unsatisfied and a few were too unsatisfied. Thus, most of the surveyed patients were pleased with the service they received. Some patients and relations said: *"My family was so satisfied with the services of the hospital which were so adequate and professional. My mom received pain relief, symptom care and psychological care. They provided good services; especially the doctors took care of patients' mentality, making them fell better"* (FGD, patients' relatives (a woman aged 49), Oncology hospital, HCM City).

"The doctors cared of the disease and explained about it in detail. If there was anything that I don't understand, I could ask them easily. Here they hold a talk or a conversation once every week for cancer patients and their relatives, but I occasionally joined it" (IDI, a patient, E Hospital, Ha Noi).

"I was pleased with the services here. Actually, I hope that he would have a better treatment condition, but the services in this hospital could not meet the ideal. However, the doctors and nurses were very ready to help us" (IDI, a patient's relative, National Pediatric hospital, Ha Noi).

Otherwise, also a patient said that "*I wish that the doctors could tell me about the disease, I have no money to go to the hospital, but if I go to hospital, doctors might not consult and when being asked they would shout and say that there are still a lot of patients, so I don't ask more*" (IDI - a cancer patient, Dist. 15, Tan Binh ward, HCM City).

Table 18. Percentage of patients receiving counseling services in treatment

Counseling contents	National hospital/Oncology center	Prov. hospital	Dist. hospital	CHC	Private hospital/clinic	Home	Herbalist	Other
Disease	63.9	40.5	63.6	0.0	72.7	48.5	72.7	63.6
Treatment method	63.6	56.8	63.6	0.0	81.8	42.4	81.8	81.8
Symptom treatment	46.8	37.8	45.5	0.0	36.4	28.8	27.3	63.6
Nutrition	53.9	56.8	72.7	0.0	54.5	36.4	27.3	63.6
Nursing care level	52.5	54.1	72.7	0.0	45.5	34.8	27.3	63.6
n	280	37	11	2	11	66	11	11

During the last treatment, according to the patients' relatives, none of the 2 patients at the CHCs were counseled. The percentages of patients receiving doctor's advices on the disease were the highest in the private hospitals/clinics and herbalists' (72.7% and 81.8% respectively), followed by national hospital/oncology centers and district hospitals (both over 63%). The percentages of patients counseled on symptom treatment, nutrition and nursing care level were high in the district hospitals and national hospital/oncology centers. A patient said: *"The information and counseling services in the provincial hospital are both limited; almost no information consulted. In contrast, in Tu Du hospital, the doctors were pleased to give me advices, let me know about the disease, risk factors, treatment, and how to care of myself for a good health"* (IDI, a patient, Tu Du hospital, HCM City).

The results also show that the private health system seemed to pay more attention on counseling for the patient than that the public health system does. This can be explained by two possibilities: the competitiveness led health workers of private health facilities to care more comprehensively for insurance of a better service quality; while in the public health system, the overload of patients limited health workers' consultancy.

Table 19. Satisfaction of patients on counseling services in the last treatment

Counseling contents	Too unsatisfied		Unsatisfied		Moderate		Satisfied		Very satisfied		n
	n	%	n	%	n	%	n	%	n	%	
Disease	1	0.4	6	2.5	114	46.7	112	45.9	11	4.5	244
Treatment method	1	0.4	9	3.6	107	43.1	119	48.0	12	4.8	248
Symptoms and how to treat	0	0.0	3	1.7	74	42.0	89	50.6	10	5.7	176
Nutrition	0	0.0	4	1.9	51	24.2	139	65.9	17	8.1	211
Nursing care level	1	0.5	4	2.0	49	24.0	133	65.2	17	8.3	204

The most common level of satisfaction of patients to the counseling issues in the last treatment was the satisfied level (45.9%-65.9%) and moderate (24%-46.7%). There were 5%-8% of the patients satisfied, even as 2%-4% of them were unsatisfied, and only one person was too unsatisfied. Therefore, most of the patients were satisfied with the counseling service. In-depth interviews show that many of the patients at the hospitals had mental and psychological problems but, then, they felt gradually better. Some patients said: *"It's not denied that I worried at the first, but during the time being treated here, they gave me much advice. During my radiotherapy, I was so tired and could not eat but doctors helped me how to act well"* (IDI, a patient, Cho Ray hospital, HCM City). *"Since the first time I was diagnosed with cancer, my family and I felt like despairing. I thought I would die. But after I went to Tu Du hospital and consulted I felt better and tried to be healthy to face with the disease"* (IDI, a cancer patient, Tu Du hospital, HCM City).

3.2.3.4. Access to and use of psychological care service

Table 20. Frequency of psychological care services for patients

Health facility	Regularly		Sometimes		Rarely		Never		Total
	n	%	n	%	n	%	n	%	
National hospital/oncology center	48	17.1	119	42.5	36	12.9	77	27.5	280
Prov. hospital	10	27.0	8	21.6	5	13.5	14	37.8	37
Dist. hospital	3	27.3	2	18.2	2	18.2	4	36.4	11
CHC	0	0.0	0	0.0	1	50.0	1	50.0	2
Private hospital/clinic	4	36.4	4	36.4	0	0.0	3	27.3	11
At home	8	12.1	21	31.8	15	22.7	22	33.3	66
Herbalist	0	0.0	4	36.4	0	0.0	7	63.6	11
Other	3	27.3	5	45.5	1	9.1	2	18.2	11

According to patients' relatives, the percentage of patients regularly received psychological care in their treatment was very low in all health facilities (17.1% at the national hospitals/oncology centers, 27% at the provincial level, 27.3% at the

district level, 36.4% in private hospitals/clinics). Contrary to that, the proportions of patients rarely or never supported on spiritual issue were relatively high (making up 40.4% at the national hospitals/oncology centers, 41.3% at the provincial hospitals, 54.5% at the district hospitals, 27.3% at the private hospitals/clinics, 54% of the patients at home and 100% of the patients at the CHCs). Some patients disclosed their feelings: *"Pain relief services were provided to us but the doctors were too busy to take care of our feelings. Indeed, people with cancer, in general, need for mental care because they have to face with many problems in the disease. Without spiritual supports, cancer patients could feel lonely and left behind"* (FGD, patients' relatives (a woman aged 34), Oncology hospital, HCM City).

Table 21. Percentage of patients satisfying with psychological care services

Health facility	Too unsatisfied		Unsatisfied		Moderate		Satisfied		Very satisfied		Total
	n	%	n	%	n	%	n	%	n	%	
National hospital/oncology center	2	1.0	5	2.5	69	34.0	120	59.1	7	3.4	203
Prov. hospital	0	0.0	0	0.0	6	26.1	13	56.5	4	17.4	23
Dist. hospital	0	0.0	0	0.0	2	28.6	5	71.4	0	0.0	7
CHC	0	0.0	0	0.0	0	0.0	1	100.0	0	0.0	1
Private hospital/clinic	0	0.0	0	0.0	3	37.5	4	50.0	1	12.5	8
At home	0	0.0	0	0.0	22	50.0	21	47.7	1	2.3	44
Herbalist	0	0.0	0	0.0	3	75.0	1	25.0	0	0.0	4
Other	0	0.0	0	0.0	2	22.2	6	66.7	1	11.1	9

The majority of patients who received spiritual support were in satisfied or moderate feeling. The head of a district hospital said: *"Psychological care for cancer patients is fine. This is because most of patients don't have their treatment here, except for some end-of-life patients. We have tried best to provide counseling and psychological care services as we can. But we still have difficulties because of the limited awareness of health workers on cancer"* (IDI, a leader of Dist. 3 hospital, HCM City).

3.2.3.5. Home-based palliative care service

The answers of the question "What was the purpose of home treatment in the last time?" are presented in the figure below:

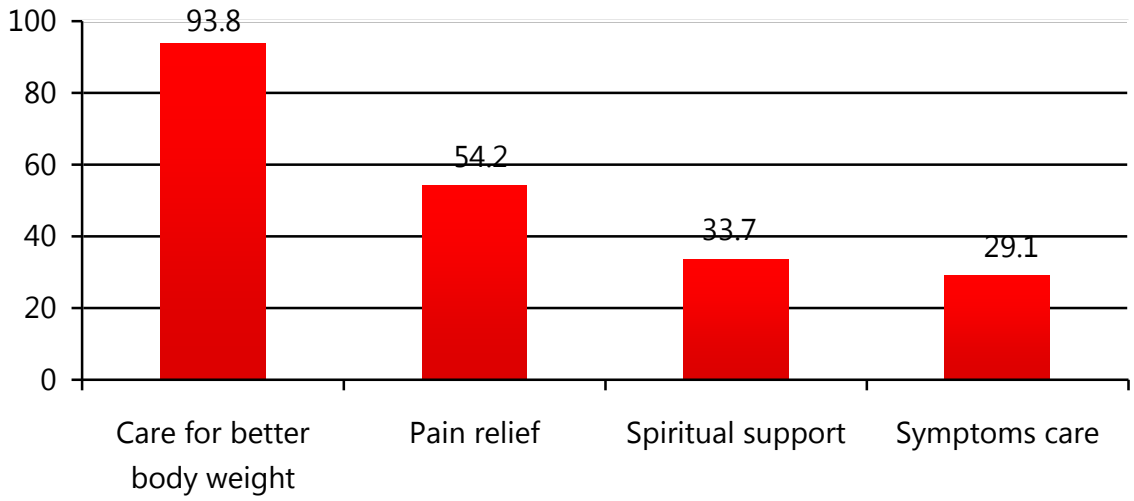


Figure 9. Home-based care contents in the last treatment

Among the patients cared at home, according to their main caregivers, the purposes of home-based care in the last treatment was for better body weight (93.8%), pain relief (54.2%), spiritual support (33.7%) and symptom care (29.1%).

Table 22. Forms of home-based palliative care services

Form	Urban		Rural		Total	
	n	%	n	%	n	%
Home care services by public health facility	23	23.0	23	11.2	46	15.0
Home care services by private hospital/clinic	13	13.0	9	4.4	22	7.2
Buy prescription drug for treatment	63	63.0	165	80.1	228	74.5
Buy non-prescription drug for treatment	8	8.0	16	7.8	24	7.8
Take oriental medicine	27	27.0	75	36.4	102	33.3
Other	16	16.0	21	10.2	37	12.1
n	100		206		306	

The most common form of home-based palliative care services was the buying prescribed drug for treatment (74.5%), higher in the rural area than the urban area (80.1% vs. 63%). The second most common one was the taking oriental medicine (33.3%l), in particular, that percentage in the rural area was higher than that in urban area (36.4% vs. 27%). It's proved that home-based palliative care was still limited. 15% of the respondents received services provided by public health facilities. This percentage was different between urban (23%) and rural areas (11.2%). The percentage of patients receiving palliative care services from private hospitals/clinics was quite low (7.2%). A patient said: *"When I came to the CHC, asking them for protein transfusion, they comforted as well as encouraged me to be brave. I know they did their best. They will visit my home when I need"* (FGD, patients' relatives (a woman aged 41), Hiep Binh Chanh commune, Thu Duc dist., HCM City).

Table 23. Percentage of patients' relatives having difficulties in care of patients

Difficulty	Urban		Rural		Total	
	n	%	n	%	n	%
Lack of information	31	31.0	65	31.6	96	31.4
Inadequate of caring skills	47	47.0	95	46.1	142	46.4
Lack of essential equipment	7	7.0	16	7.8	23	7.5
Difficult to buy opioid drugs	13	13.0	14	6.8	27	8.8
No spiritual supports	4	4.0	6	2.9	10	3.3
No home-based care services	14	14.0	23	11.2	37	12.1
No money	49	49.0	118	57.3	167	54.6
Other	3	3.0	4	1.9	7	2.3
No difficulties	29	29.0	51	24.8	80	26.1
n	100		206		306	

Beside difficulties in economics (54.6% had no money), the most common difficulties in care for patients at home were inadequacy of skills in care of patients (46.4%) and lack of information (31.4%).

"*Now I don't have anyone who can give me advice. I wish I had someone to talk, to help me to not worry, not being sad. I also need someone know about drugs to cure*". (IDI, a patient, ward 15, Tan Binh dist., HCM City).

Some caregivers said that: *"It is hard for patients to access the home-based palliative care services. The painkillers were so expensive. Health workers at the CHC just help me inject, but I have to pay for all medicine."* (FGD, patients' relatives (a woman aged 37), Thuy Phuong comm., Huong Thuy dist., Thua Thien Hue province).

Table 24. Information sources for cancer patients' relatives

Information sources	Pain relief		Symptom care		Spiritual support		End-of-life care	
	n	%	n	%	n	%	n	%
Health workers	187	61.1	158	51.6	119	38.9	51	16.7
Documents from health facilities	5	1.6	6	2.0	4	1.3	0	0.0
Other	4	1.3	5	1.6	27	8.8	8	2.6
Don't receive	117	38.2	144	47.1	163	53.3	247	80.7
n=306								

The information on care for patients' relatives was mainly provided by health workers. 61.1% of the cancer caregivers were advised on pain relief, 51.6% of them were advised on symptom care, 38.9% of them were advised on spiritual support, and 16.7% of them were advised on end-of-life care for patients. However, the proportions of caregivers did not receive the information on these above 4 issues were still high (38.2%; 47.1%; 53.3% and 80.7% respectively).

1.2.3.6. End-of-life care service

End-of-life care is a form of care and support for patients having an end-stage disease. This is one of the most essential components of palliative care for cancer patients with highly humanitarian and profound social significance. In this stage of the disease, patients are no longer capable of being treated by specific therapies. Hence, they need pain relief as well as supports on psychological problems and nursing care at the end of their life [4],[14].

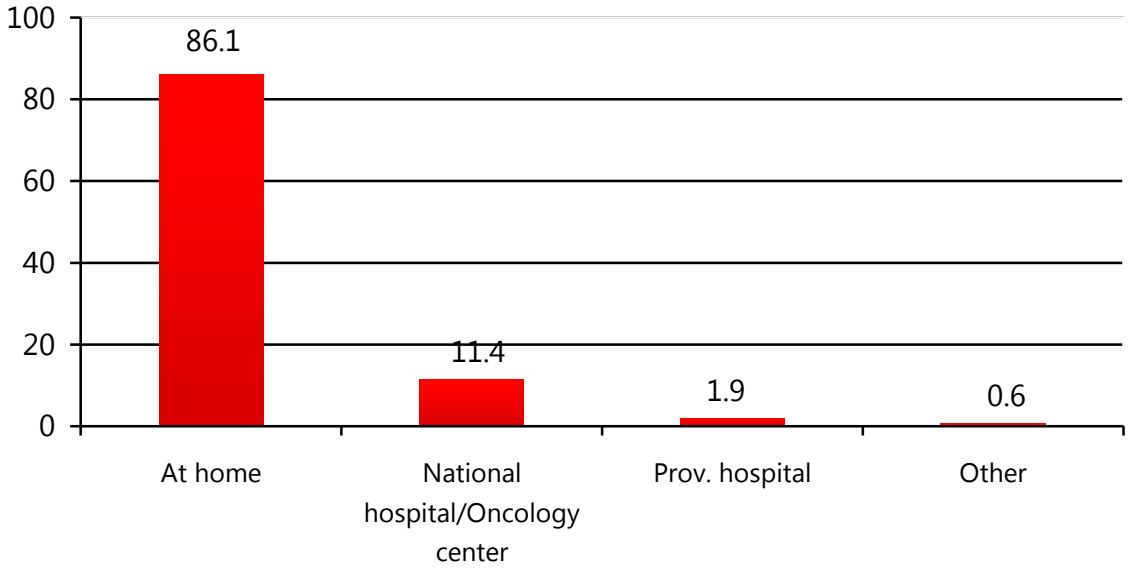


Figure 10. Place of end-of-life care for patients who died

When asking the cancer patients' caregivers, 86.1% of the dead patients were end-of-life cared at home. The rest were taken care at the National hospitals/Oncology centers.

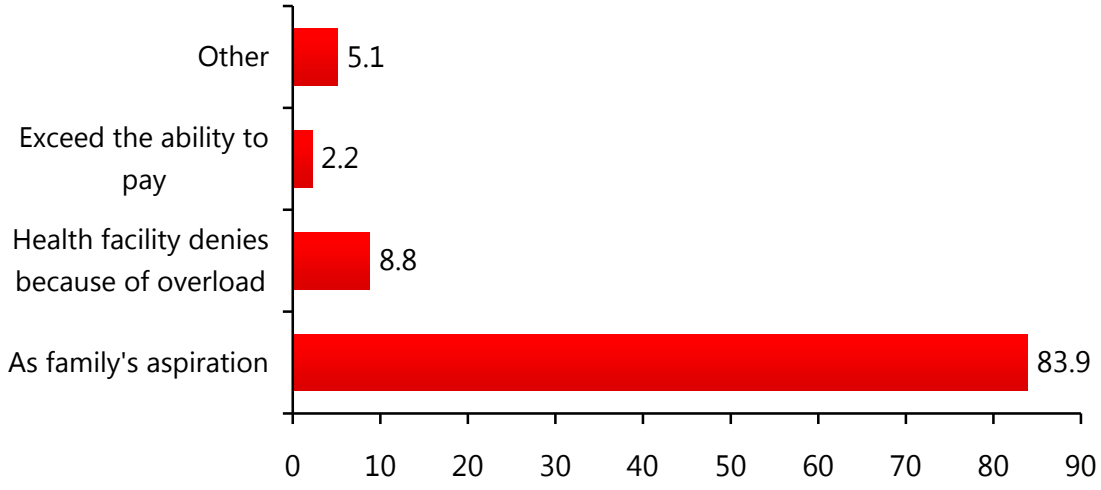


Figure 11. Reasons of patients for not having their end-of-life care at health facilities

For most of Vietnamese people, it is desirable to die at home, so most of cancer caregivers did not have their end-of-life care in health facilities because of their family's aspiration (83.9%). There was a small percentage of patients that were not taken care of due to the denial of the health facilities (8.8%). Results of qualitative interviews health workers, patients and cancer caregivers show that palliative care was mainly conducted in the community: *"To me, it's the best for terminal cancer patients cared at home. There are caregivers at home; also, it is traditional in Hue that people select to die at home."* (IDI, a leader of Hue hospital, Thue Thien Hue province).

"At the end-stage, it is better to take care of them at home, buy medicine and inject at home. Going to a CHC is a waste." (FGD, cancer patients' caregivers (a woman aged 56), KII hospital, Ha Noi).

Table 25. Percentage of patients receiving spiritual support in end-of-life care

Care contents	n	%
Often sympathize with patients	148	94.9
Help patients complete their incomplete activities	57	59.4
Respect patients' decision on end-of-life care place	98	89.9
Respect patients' decision on burial place	78	82.1

Most of the patients were supported on their spirit at the end-stage. The most common form of support was the frequent sympathy with the patient (94.9%), followed by the respecting the patient's decision on end-of-life care place (89.9%), respecting the patients' decision on the burial place (82.1%) and helping the patients complete their incomplete activities (59.4%).

Table 26. Percentage of patients receiving pain relief in end-of-life care

Pain relief treatment	n	%
Respect patients' complaints on pain	131	97.0
Do massage/hot compress	115	82.1
Use painkiller periodically	121	92.4
Guide cancer caregivers on care for patients	78	55.7
Guide cancer caregivers on drug use	94	66.7

Most of the patients were relieved of pain at the end-stage of the disease, the most common contents were the respect of patient's complaints on their pain (97%), followed by using painkiller periodically (92.4%), massage/hot compress (82.1%). However, the percentages of cancer caregivers introduced on drug use and patient care were not high (66.7% and 55.7% respectively).

Table 27. Percentage of patients receiving nursing care as defined in the end-of-life care instructions

Nursing care	n	%
Eat liquid food in a lot of meals per day	139	97.2
Regularly care the body	138	92.0
Apply anti-ulcer of skin/mucus membrane	73	81.1
Regularly change the lying position, once per 2 hours	85	71.4
Support respiratory system when difficult to breath	74	69.8
Prevent danger for pull-brained patients	139	97.2
Informs the patient's family to visit them at the end of their life	138	92.0

The percentage of patients taking nursing care as defined in the end-of-life care instructions was relatively high. That percentage was found the highest in eating liquid food in many meals in a day and prevention of danger for pull-brained patients (both 97.2%), and the lowest in respiratory care in breathing difficulties (69.8%) and regular change of lying position once per 2 hours (71.4%).

3.2.3. Cost burden of palliative care services

Table 28. Economic condition of patients' families

Economic condition	Urban		Rural		Total	
	n	%	n	%	n	%
Have no difficulties in examination and treatment fees	38	22.2	31	13.0	69	16.8
Have difficulties but can solve by themselves	87	50.9	113	47.3	200	48.8
Have many difficulties, need supports to go to hospital	46	26.9	95	39.7	141	34.4

Regarding the ability of patients' families in payment for palliative care services, it is indicated that 34.4% of the patients' families had a lot of supports to go to hospital, especially in rural areas (39.7%), and lower in urban areas (26.9%); 48.4% of the families could solve their economic problems; and only 16.8% of the families had no difficulties in paying for the services. Some ideas from in-depth interviews and focus group discussions were as follows: *"The diagnosis has prolonged so my family and I have spent too much money. Now I am feeling so tired and worried"* (IDI, a patient, Oncology hospital, HCM City). *"I'm the bread-winner of my family, I have kids in school and the treatment is also costly. Every time of therapy either radiotherapy or chemotherapy I had to bring with me about 11 million dongs. It was in case of using my health insurance card, if not, it would be much more expensive. I have spent about 100 million dongs a year. I could only pay half, the rest were borrowed"* (IDI, a patient, Cho Ray hospital, HCM City). *"I think the cancer patients have to bear a lot of problems. Particularly, the poor in the rural area is easily becoming out of money, or in debt. The fees for treatment at the central level and*

relatives' accommodation are considerable. It's the most concerned issue of a rural patient go to city for treatment" (FGD, cancer caregivers (a man aged 42), Oncology hospital, HCM City).

It is proved that health insurance plays a very important role in payment for health services including palliative care. Among the surveyed patients, the percentages of patients having insurance cards and using it in the last treatment are described as follows:

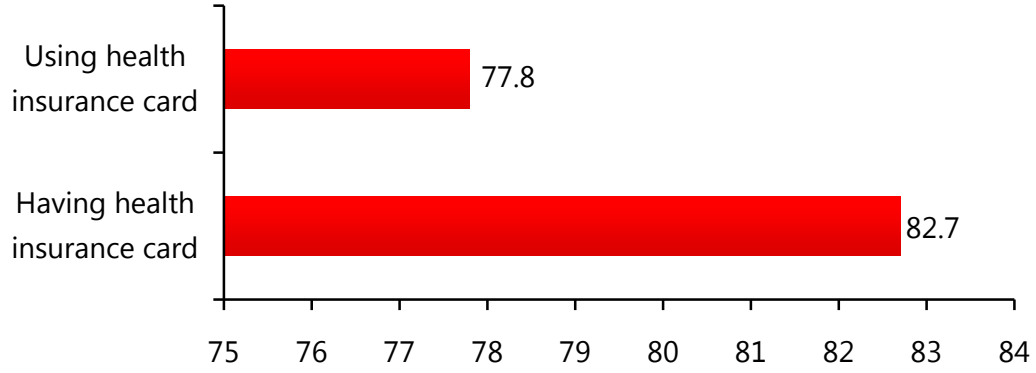


Figure 12. Percentage of patients having and using health insurance in the last treatment

Among the surveyed patients, 82.7% had health insurance and 77.8% used their cards in their last treatment. A patient said: *"I've had no difficulties in my treatment. However, now we have some economic difficulties due to the chemotherapy. Sometimes, my family had to borrow some money. Currently, the regular medicine is 100% free of charge, chemotherapy is discounted 50%"* (IDI, a patient, Central hospital for Tuberculosis and Lung disease, Ha Noi). Nevertheless, health insurance sometimes was a barrier to patients' access to palliative care. A cancer caregiver reported: *"My husband is in a severe illness. I asked them to refer him but they did not allow. After he was diagnosed with cancer, we showed the examination results to them but they didn't let us move his health insurance. They said we could be referred, but not move the health insurance. Then, I had to handle it via relationship."* (FGD, cancer caregivers (a woman aged 65), KII hospital, Ha Noi).

Table 29. Funding sources for palliative care services

Funding source	Urban		Rural		Total	
	n	%	n	%	n	%
Money available at family	114	66.7	164	68.6	278	67.8
Money borrowed	79	46.2	148	61.9	227	55.4
Money from selling some properties	10	5.8	10	4.2	20	4.9
Money from selling house/flat	11	6.4	7	2.9	18	4.4
Money from support of relatives	90	52.6	94	39.3	184	44.9
Money from individuals/charitable organization	12	7.0	18	7.5	30	7.3
Other	1	0.6	0	0.0	1	0.2

n	171		239		410	

According to cancer patients' caregivers, the money for payment for palliative care services were "available at family" (66.7%), followed by "borrowed" (55.4%) and "support of relatives" (44.9%). Some cancer patients' families had to sell their properties, even land (9.3%) to pay the cost. Some ideas show that *"We have no money. We had to borrow some money to pay for the surgery. If my children don't give me money, I will have to borrow again. It will be 80 thousand dongs per month of interest for each million dong. Generally, it's hard for me to borrow someone money without paying interest"* (IDI, a cancer patient, hospital of Can Gio district, HCM City). *"Many ones had to sell or mortgage their house/land. My family had to borrow at the interest of 30%-40% per year."* (FGD, cancer patients (a man aged 50), Thuy Phuong commune, Huong Thuy district, Thua Thien Hue province).

3.3. Current provision of palliative care services

Main findings:

- 100% of the National hospitals/Oncology centers, 94.7% of the district hospitals and 75.6% of the CHCs reported that they provided the palliative care services for cancer patients, but only 72.7% of the National hospitals/Oncology centers, 15.8% of the district hospitals and 30% of the CHCs had the task assignment documents of palliative care service provision at their facilities.
- Over 2/3 of the health facilities has been providing the services of counseling, pain relief, psychological support, but the symptom and complication cure were only implemented in 51.7% of the health facilities, and the end-of-life care was done in only 36.7% of the health facilities.
- 81.8% of the National hospitals/Oncology centers had the pain relief units or beds for palliative care, while this rare in the district hospitals and CHCs was relatively low (5.3% and 10% respectively).
- Most of surveyed cancer patients accessed the pain and other complication treatment in the National hospitals/Oncology centers (85.1%). However, only a small number of patients received these services in the provincial hospitals (26.6%), district hospitals (20.5%), private hospitals/clinics (13.7%), CHCs (9.5%), etc.
- Even at the National hospitals/Oncology centers, it mainly focused on pain and complication treatment, but not on all the other needs for patients and their families.
- All surveyed National hospitals/Oncology centers provided opioid drugs; this percentage in the district hospital and CHCs was 84.2% and 12.2% respectively.

- The percentage of the National hospitals/Oncology centers where the injectable and oral opioid drugs were available (100% and 90.9% respectively) was much higher than that in the district hospitals (57.9% and 31.6% correlatively) and the CHCs (11.1% and 1.1% respectively).
- The patients' accessibility to opioid drugs at the health facilities was also affected by the limited number of drugs, reported by 71.1% of the health facilities with the highest percentage in CHCs (90.9%), and the lowest in the National hospitals/Oncology centers (54.5%).
- 45.5% of the doctors and 54.4% assistant doctors in the district hospitals, 30% of the doctors and 45% of the assistant doctors at the CHCs did not know about the concept of palliative care.
- Over 2/3 of doctors and assistant doctors in the district hospitals and CHCs in this study did not know how to classify the pain intensity in scale.
- The percentage of health workers in the district hospitals and CHCs giving the correct answers about the time for pain relief (both medium and severe pain) was very low; only 14.2% of the doctors and 24.7% assistant doctors said that the mild pain also needed to be cured.
- The percentage of district and communal health workers knowing about the professional supports for cancer patients was not high as expected, particularly only 16%-29% respectively reported the end-of-life support.
- 21.7% of the doctors and 24.2% of the assistant doctors at the CHCs could not tell any contents of end-of-life care; this percentages in the district hospitals were 2.6% of the doctors and 2.9% of the assistant doctors.
- 90.9% of the National hospitals/Oncology centers and 73.7% of the district hospitals received the patients from the other places for palliative care, but only 26.7% of the CHCs received the patients from the upper level.
- Among the health facilities that referred the cancer patients for palliative care, the most common support for cancer patients was "introduction paper" (86.5%), very few health facilities had "ambulance" and "health workers go with" (18% and 22.5% respectively).

3.3.1. Availability of palliative care services

In 120 surveyed health facilities (including 11 National hospitals/Oncology centers, 19 district hospitals and 9 CHCs), the percentage of the health facilities providing the palliative care for cancer patients and having the task assignment documents is presented in the figure below:

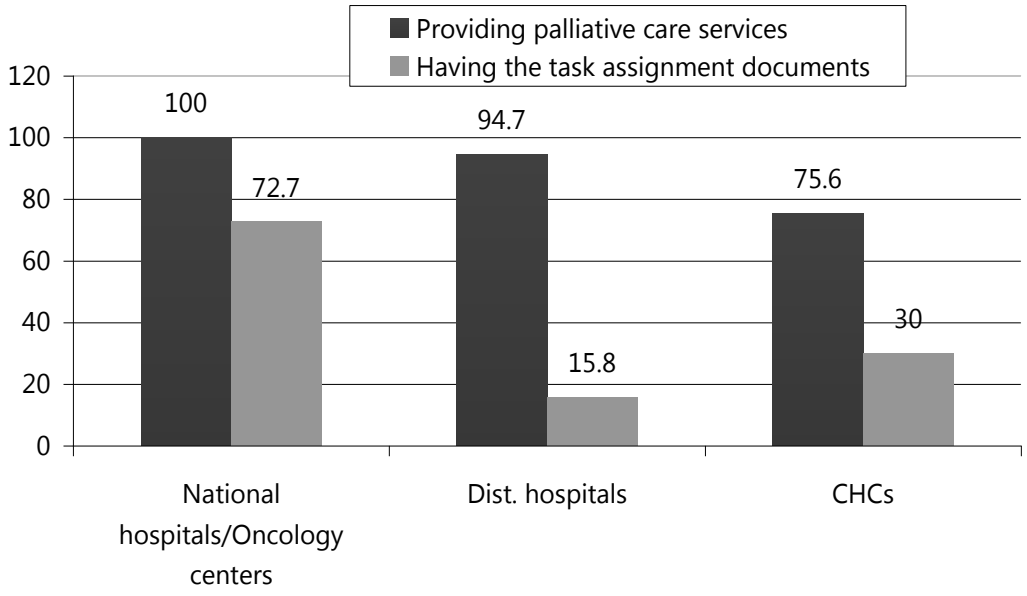


Figure 13. Percentage of health facilities providing palliative care services and having service-noticing boards

Most of the surveyed health facilities at all levels provided palliative care services for cancer patients (100% of the National hospitals/Oncology centers, 94.7% of the district hospitals and 75.6% of the CHCs). However, only 72.7% National hospitals/Oncology centers, 15.8% district hospitals and 30% of the CHCs confirmed that they had the task assignment documents on palliative care services provision. Although the majority of health workers said that they provided palliative care services for cancer patients, the health facilities that had the task assignment documents provided the palliative care services were much lower, especially in the district hospitals and CHCs. Some leaders of the district hospitals said: *"Now, in Hue city, the palliative care network is not available at the communal level. The hospital has also not conducted any training courses for health workers because there is no agreement from the upper level and we also have no adequate manpower and equipment."* (IDI - a leader of Phu Vang hospital, Thua Thien Hue); *"I think that the palliative care is not adequate and consistent at the moment. It may due to a lack of physical infrastructure, the limitation of drug provision and the lack of health workers' professional skills."* (IDI - a leader of Long Bien hospital, Ha Noi).

Table 30. Percentage of the health facilities having types of palliative care services

Palliative care services	National hospitals/Oncology centers		District hospitals		CHCs		Total	
	n	%	n	%	n	%	n	%
Pain relief	11	100.0	15	78.9	65	72.2	91	75.8
Symptoms/complications cure	11	100.0	14	73.7	37	41.1	62	51.7
Patients' psychology/spirit support	11	100.0	17	89.5	60	66.7	88	73.3
Patient relatives' psychology/spirit support	10	90.9	17	89.5	54	60.0	81	67.5
Counseling	11	100.0	17	89.5	77	85.6	105	87.5
End-of-life care	9	81.8	12	63.2	23	25.6	44	36.7
Other	0	0.0	0	0.0	1	1.1	1	0.8
n	11		19		90		120	

According to the interviewed health workers, some palliative care services have been implemented in most of the health facilities. The service that has been implemented the most was "counseling" (87.5%), followed by "pain relief" (75.8%), "Patients' psychology/spirit support " and "Patient relatives' psychology/spirit support" (73.3% and 67.5% respectively). However, the "symptoms/complications cure" and "end-of-life care" were done at the 51.7% and 36.7% of the health facilities respectively.

The results also show that the percentage of the National hospitals/Oncology centers providing the palliative care services was remarkably higher than in the district hospitals and CHCs. The National hospitals/Oncology centers supplied the palliative care services quite adequately. However, the CHCs mainly focused on counseling (85.6%), pain relief (72.2%), but not on symptom/complication care (41.1%) and end-of-life care (25.6%). Thus, the palliative care was interrupted and also incomplete at the communal level.

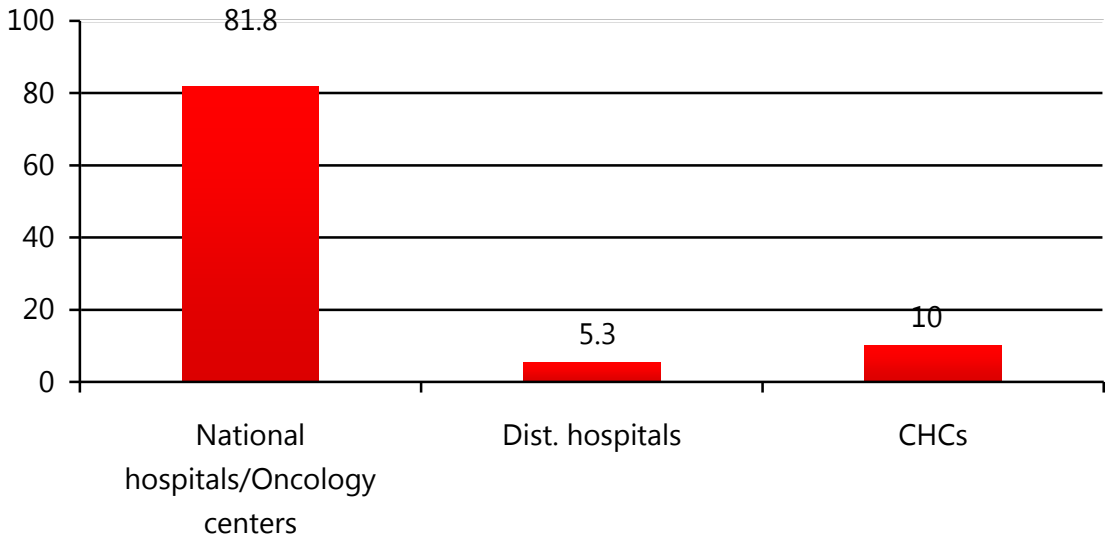


Figure 14. Health facilities having pain relief units or beds for palliative care

The above figure shows quite clearly a picture of the distribution of palliative care services in the health facilities at all levels. While most of the National hospitals/Oncology centers had pain relief units or beds for the palliative care (81.8%) with the average of beds of 15.09±15.25, this percentage in the district hospitals and CHCs was only 5.3% and 10% respectively. It indicates that most of the district hospitals and CHCs did not provide the palliative care services for cancer patients.

In fact, most patients came to the National hospitals/Oncology centers to access the palliative care services, that created a serious overloading for the health facilities. Consequently, it led to the incomprehensiveness of the services at the highest technical level. There was a big number of patients needed to be examined and prescribed every day, but the health workers did not have enough time to provide a full and comprehensive service. Thus, the quality of the services were adversely affected. The in-depth interviews with the leaders and curing staff in the health facilities at all levels also presented many evidences for the lack of the comprehensiveness of the palliative care services. Even in the National hospitals/Oncology centers, they mainly focused on pain relief and complication treatment, but not paid attention to all the other needs for patients and their families. Many reasons were given out to explain the lack of services' comprehensiveness besides the overloading such as the lack of staff or professional skills in psychological care, and the lack of multi-sector caring team, etc.

"This hospital has been implementing pain and complication treatment, psychological care for patients and their families. However, there are some limitations in psychological support for patients and their families because the

hospital has no psychologists" (IDI - a palliative care specialist, Oncology hospital, HCM City).

"*The pain and symptom treatments were available. There is a lack of comprehensive psychology support, even if any, it will be very simple. The patients almost died at home, their families and the community supported the patient at that time. About the patients who died in hospital, they were also relatively well supported. However, their relatives still played the main roles*". (IDI - a curing staff, National Cancer Hospital, Ha Noi).

'There is not a well-trained team for palliative care, a standard regimen in pain relief for cancer children. The medical supplies for children have also not been paid attention to (currently we have to subdivide the medical supplies for adults to use instead). The hospital is often overloaded; there are many other issues to be focused on the palliative care" (IDI - a curing staff, National Hospital of Pediatrics, Ha Noi).

"*This hospital does not have enough staff and psychosocial consultants for cancer patients. Medical doctors take most of this task; therefore, they do not have enough experiences and incapable of providing a comprehensive psychosocial support . The hospital is also often overloaded, we lack of beds for patients*" (IDI - a palliative care specialist, Hue Central Hospital, Thua Thien Hue province).

Most of the leaders and cancer curing doctors in the hospitals at all levels were not satisfied with the current palliative care activities: "*Generally I'm not satisfied with the palliative care services at the district hospitals, because only a few services were done in conjunction with other specialties such as pain relief, common diseases treatment. Even if a patient has strong pain, the doctors will encourage him/her, they also have no professional advices*" (IDI - Phu Vang district hospital, Thua Thien Hue province).

The unavailability of palliative care services along with the lack of facilities and qualified staff prevented the patients from accessing the comprehensive palliative care services. Even the patients who were in the hospitals were not timely and comprehensively cured.

The survey results clearly v the inconsistency of the services through the analysis of availability and coverage of the services at all levels. Besides, the in-depth interviews with the health workers also reflected the lack of continuous services. Only a few district hospitals deployed the palliative care services. In HCM City, only Thu Duc hospital had an oncology faculty and developed the palliative care services. Many hospitals reported that they had their staff trained in palliative care, however, the hospitals were not qualified to conduct the services.

"*The palliative care services are not available at the district level. We wish we could establish a department for pain relief, but do not have the human resource and*

mechanism. At the present, some end-of-life cancer patients are being treated in the hospital. The doctors examine comprehensively and counsel on spot" (IDI - a leader of dist. 8 Hospital, HCM City).

Table 31. Percentage of health facilities at all levels having types of palliative care services

Types	National hospitals/Oncology centers		District hospitals		CHCs		Total	
	n	%	n	%	n	%	n	%
Inpatient	11	100	15	78.9	5	5.6	31	25.8
Outpatient	10	90.9	12	63.2	31	34.4	53	44.2
Mobile	5	45.5	4	21.1	75	83.3	84	70.0
No service	0	0	1	5.3	1	1.1	2	1.7
n	11		19		90		120	

About the palliative care forms, according to the MOH's model, the Oncology centers and the Oncology departments in the hospitals should be developed in all three forms for inpatient, outpatient and home-based care. However, at the present, the health facilities providing palliative care services have only focused on inpatient and outpatient care. In the National hospitals/Oncology centers, the main forms were found for the inpatient and outpatient care (100% and 90.9% respectively). The mobile services (home-based care) were still limited. Although there were 5 out of 11 National hospitals/Oncology centers reported that they provided mobile services, most of them were spontaneous without well-structured mobile teams. "*Most of the patients asked the doctors to go to their houses as a type of private health services*" (IDI - a palliative care specialist, National Cancer Hospital, Ha Noi). At the district hospitals and CHCs, they mainly provided home care services to serve AIDS patients in the localities, it is a responsibility of CHCs in HIV/AIDS prevention program; thus, the percentage of CHCs having staff providing home- based care for AIDS patients was very high (83.3%). The community-based palliative care model for end-of-life cancer patients was still less developed due to a lack of finance and implementation plans in detail.

According to some interviewed health workers, the home-based palliative care services for cancer patients have not yet implemented because "*There is not enough manpower to provide the palliative care for patients and their families. The counseling service for patients and their families takes a lot of time but there is no more fee for health workers*" (IDI - a palliative care specialist, Oncology hospital, HCM City)

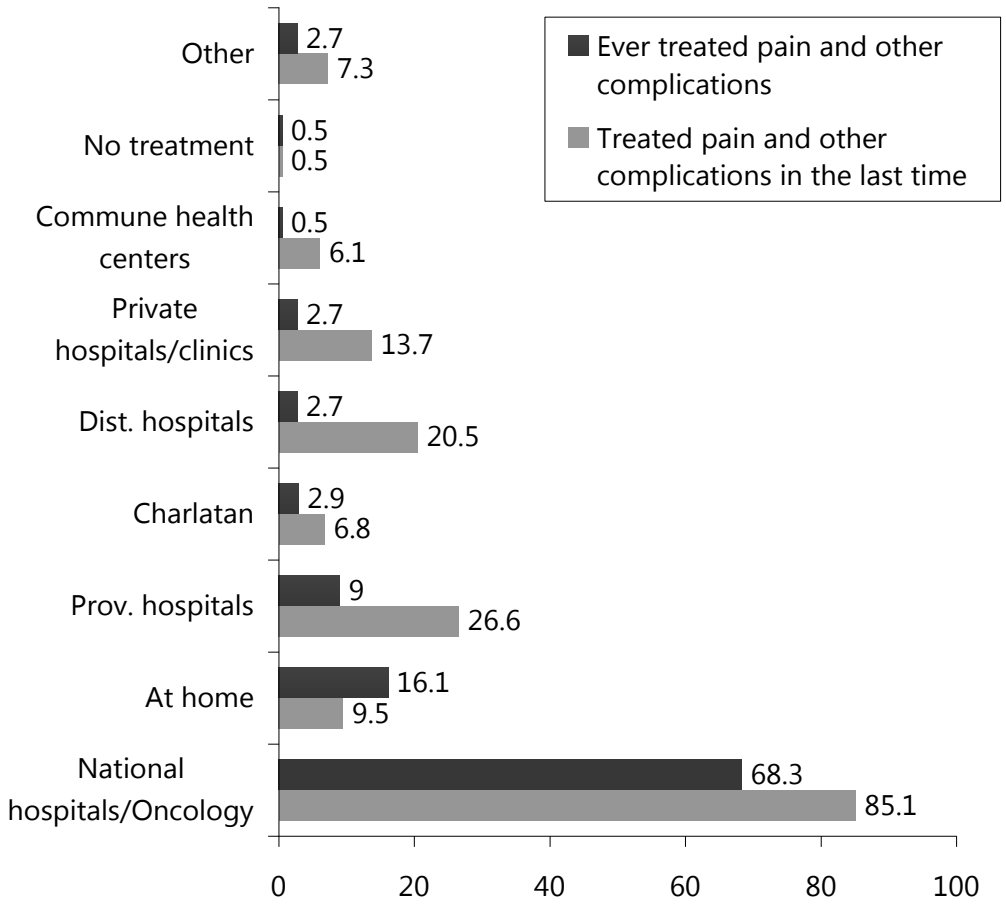


Figure 15. Places where patients treated their pain and other complications

When the pain/symptoms caused by cancer appeared, most of the surveyed cancer patients went to the National hospitals/Oncology centers for the palliative care services (85.1%). Only a few patients received pain relief and other symptom treatment in the provincial hospitals (26.6%), district hospitals (20.5%), private hospitals/clinics (13.7%), and CHCs (9.5%). Once again, the survey results show the disparity of the services in the entire system. Most patients accessed the national hospitals, while a small number of them visited the province or district hospitals. The services were not nearly available in the lower-level health facilities and community, including provincial hospitals.

Among the interviewed cancer patients, 68.3% accessed the last pain relief at the National hospitals/Oncology centers , 16.1% did at home; and very few patients did at the provincial, district and communal levels. This shows a gap of palliative care in the health facilities from the provincial level to lower.

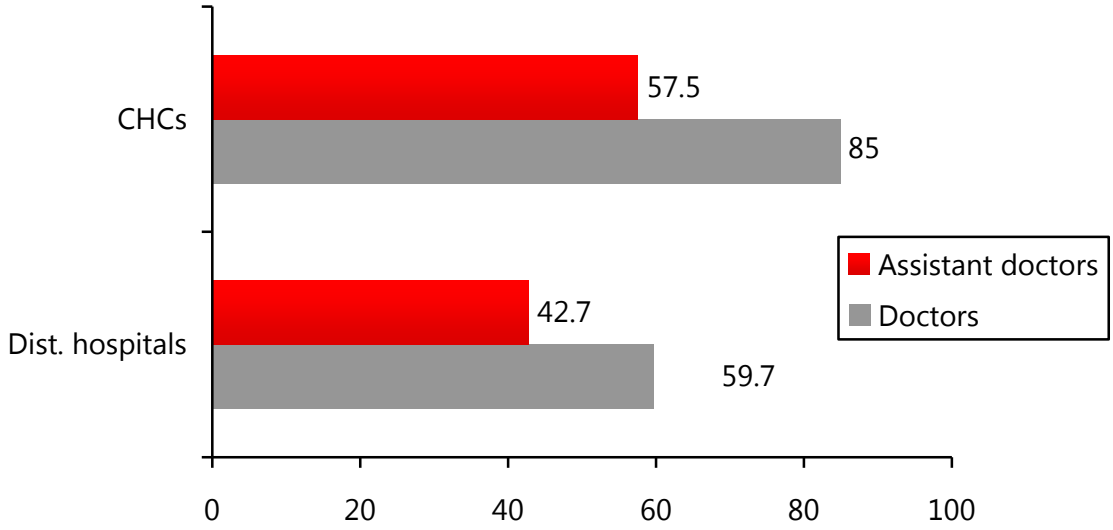


Figure 16. Percentage of health workers who ever provided palliative care services for cancer and AIDS patients

Among the interviewees, the percentage of doctors and assistant doctors at the CHCs ever providing the palliative care services for cancer and AIDS patients (85% and 57.5% respectively) was higher than in the district hospitals (59.7% and 42.7% respectively).

In fact, the in-depth interviews also show that the palliative care for cancer patients were mainly located at the central level, while very limited at the grassroots level. The services such as pain relief, psychological support or complication treatment mostly focused on HIV/AIDS patients. The main palliative care services for cancer patients in the district hospitals or clinics were the injection and transfusion on demands.

"*The palliative care is done, but it is mostly for HIV/AIDS patients and we just do according to health task such as examination and if a patient is probably with cancer, he will be sent to the higher level. When the seriously ill patient returns home, the CHC staff come and inject or give him/her common painkiller that the CHC has. We counsel them on drug use, care, spirit care, but only when the patients ask. In addition, the CHC staff don't know a lot, so we only tell a little*" (IDI - a head of CHC, Phong Son commune, Phong Dien district, Thua Thien Hue province).

"*After coming back from the upper level health facility, if the patient have any symptoms and complications, they can come to CHC for transfusion, injections or we will sell drugs on patients' demand. The patients can buy drugs at the private pharmacies, clinics and then ask the CHC staff for injection/transfusion*" (IDI - a head of CHC, Tan Phu Trung commune, Cu Chi district, HCM City).

Table 32. Percentage of health workers who met difficulties in palliative care for cancer patients

Difficulties	District hospitals				CHCs			
	Doctors		Assistant doctors		Doctors		Assistant doctors	
	n	%	n	%	n	%	n	%
No guide documents	28	60.9	20	45.5	15	29.4	25	36.2
Inappropriate document	6	13.0	7	15.9	7	13.7	7	10.1
Lack of painkillers	13	28.3	3	6.8	27	52.9	32	46.4
Lack of staff/untrained staff	12	26.1	11	25.0	26	51.0	28	40.6
Other	12	26.1	12	27.3	10	19.6	3	4.3
No difficulties	5	10.9	11	25.0	6	11.8	14	20.3
n	46		44		51		69	

According to the doctors and assistant doctors who have ever provided the palliative care services for cancer patients, the difficulties that they have met the most were "no guide document" (29-61% respectively), followed by "lack of staff/untrained staff" (25-51% respectively), "lack of painkillers" (7-53% respectively), "inappropriate document" (10-16% respectively). Whereas, still 11-25% of the health workers at the district and communal levels did not meet any difficulties in the palliative care services for cancer patients.

3.3.2. Availability of painkiller

The availability of opioid drugs in the health facilities at all levels are presented in the figure below:

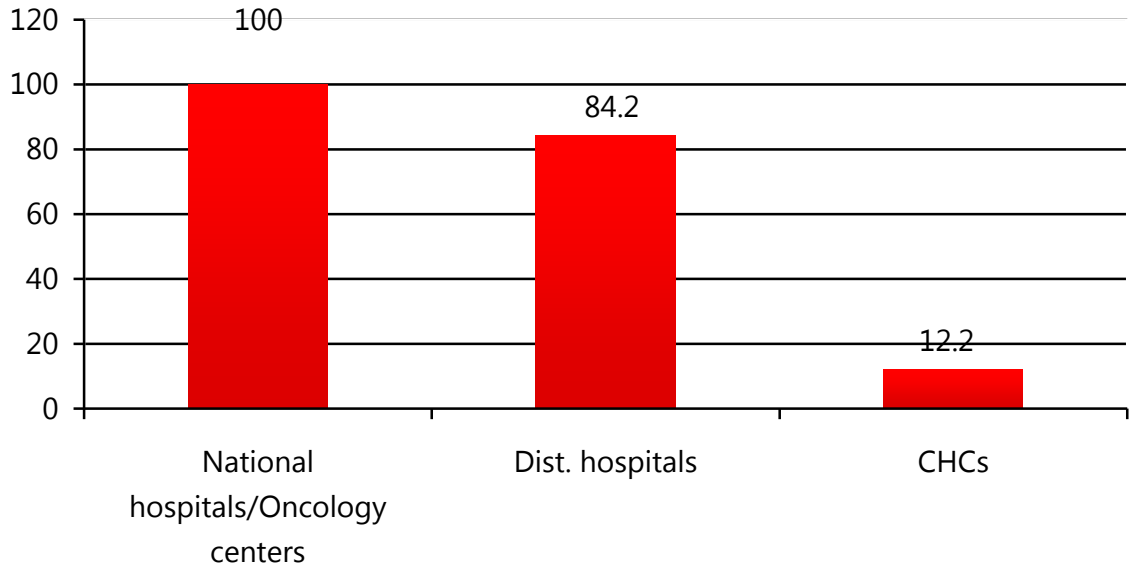


Figure 17. Percentage of health facilities providing opioid drugs for cancer patients

The Palliative care Guideline only presents how to use the opioid drugs with the unwanted side effects that are not regulated for the levels. However, the opioid drugs can't be avoided in pain relief. The survey results show that all the central health facilities provided the opioid drugs for cancer patients. This percentage in the district hospitals and CHCs was 84.2% and 12.2% respectively. It indirectly indicates that nearly 90% of the CHCs had no pain relief service for cancer patients. It also means that the palliative care at the CHCs is incomprehensive.

Table 33. Percentage of health facilities having painkillers

Types of drugs	National hospitals/Oncology centers		District hospitals		CHCs		Total	
	Oral	Injecting	Oral	Injecting	Oral	Injecting	Oral	Injecting
Opioid drugs	90.9	100.0	31.6	57.9	1.1	11.1	14.2	26.7
Opioid-like effect drugs	54.5	63.6	31.6	42.1	1.1	0.0	10.8	12.5
Non-opioid drugs	90.9	81.8	47.4	42.1	11.1	3.3	24.2	16.7
Painkillers	90.9	90.9	63.2	42.1	8.9	1.1	25.0	15.8
n	11		19		90		120	

In general, the percentage of the health facilities having injecting and oral opioid drugs was very low (26.7% and 14.2% respectively). The opioid-like effect drugs, non-opioid drugs and other painkiller were hardly available at the health facilities, similar to the opioid drugs. According to the WHO's Palliative care Guideline, the regulations of pain relief with drugs were to give priority in oral drug use except the case where the patients could not drink or had severe pain that needed to be treated quickly. However, at the surveyed health facilities, the injecting opioid drugs were more available than the oral ones.

In particular, the percentages of the National hospitals/Oncology centers having injecting and oral opioid drugs (100% and 90.9% respectively) were much higher than that in the district hospitals (57.9% and 31.6% respectively) and CHCs (11.1% and 1.1% respectively). It means that the health facilities at the district and communal levels did not implement the palliative care services for cancer patients, and that the palliative care services in many district hospitals and CHCs were not comprehensive.

Table 34. Percentage of health facilities lacking opioid drugs for cancer patients

Frequency	National hospitals/Oncology centers		District hospitals		CHCs		Total	
	n	%	n	%	n	%	n	%
Not available	0	0.0	3	15.8	79	87.8	82	68.3
Often	0	0.0	0	0.0	1	1.1	1	0.8
Sometimes	2	18.2	5	26.3	2	2.2	9	7.5
Seldom	2	18.2	3	15.8	3	3.3	8	6.7
Never	7	63.6	8	42.1	5	5.6	20	16.7
n	11		19		90		120	

Among the surveyed health facilities, only 16.7% of them reported that the opioid drugs were available for cancer patients, found the highest in the National hospitals/Oncology centers (63.6%), followed by the district hospitals (42.1%) and the lowest at the CHCs (5.6%). Conversely, 88.9% of the CHCs and 15.8% of the district hospitals had no or frequently lacked opioid drugs. It indicates that the palliative care services for cancer patients were not comprehensive and consistent.

Table 35. Cases provided opioid drugs for patients

Indication	National hospitals/Oncology centers		District hospitals		CHCs		Total	
	n	%	n	%	n	%	n	%
Surgery	8	72.7	5	31.3	0	0.0	13	34.2
Radiotherapy	7	63.6	0	0.0	0	0.0	7	18.4
Chemotherapy	9	81.8	1	6.3	1	9.1	11	28.9
Inpatient	10	90.9	11	68.8	1	9.1	22	57.9
Outpatient	9	81.8	7	43.8	0	0.0	16	42.1
Patients treated at home	5	45.5	4	25.0	1	9.1	10	26.3
AIDS patients	2	18.2	5	31.3	0	0.0	7	18.4
Others (emergency)	0	0.0	1	6.3	9	81.8	10	26.3
n	11		16		11		38	

The survey results at the facilities providing the opioid drugs show that the opioid drugs were mainly provided for cancer patients in the National hospitals/Oncology centers. Except the purpose of pain relief after surgery, radiotherapy, chemotherapy or inpatient treatment (from 63.6%-90.9%), the percentage of the National hospitals/Oncology centers providing the opioid drugs for home-based patients and outpatients was rather high (81.8% and 45.5% respectively). At the district hospitals, the opioid drugs were mainly provided for cancer patients after surgery or inpatient treatment (31.3% and 68.8% respectively). The district hospitals providing the opioid drugs for outpatient and home-based treatments were made up low percentages (43.8% and 25% respectively). At the CHCs, the opioid drugs were mostly used for emergency cases (81.8%).

With the question "*What affects the accessibility of patients to opioid drugs in the health facilities?*", the answers are presented as follows:

Table 36. Factors affecting the accessibility of patients to opioid drugs at health facilities

Factors	National hospitals/Oncology centers		District hospitals		CHCs		Total	
	n	%	n	%	n	%	n	%
Limited supply of opioid drugs	6	54.5	11	68.8	10	90.9	27	71.1
Inadequately planned	1	9.1	2	12.5	0	0.0	3	7.9
Lack of staff who can prescribe opioid drugs	0	0.0	1	6.3	1	9.1	2	5.3
Strict regulations in prescription	5	45.5	8	50.0	2	18.2	15	39.5
Others	2	18.2	3	18.8	0	0.0	5	13.2
n	11		16		11		38	

According to the health facilities that provided the palliative care, the factors affecting the accessibility to opioid drugs first were “limited supply of opioid drugs” (71.1%), the highest percentage was found in the CHCs (90.9%), followed by the district hospitals (68.8%) and the lowest in the National hospitals/Oncology centers (54.5%). The second was "strict regulations in prescription" (39.5%; of which 45.5% found at the National hospitals/Oncology centers, 50% at the district hospitals and 18.2% at the CHCs). Some health facilities reported that the other factors were “ inadequately planned at the facilities” (7.9%), as well as “limited staff of prescribing opioid drugs” (5.3%).

Table 37. Difficulties in managing the use of opioid drugs

Difficulties	National hospitals/Oncology centers		District hospitals		CHCs		Total	
	n	%	n	%	n	%	n	%
Patients could sell drug or use for other purposes	2	18.2	5	26.3	2	2.2	9	7.5
Health staff could sell drug or use for other purposes	2	18.2	0	0.0	1	1.1	3	2.5
Complicated approval, administration	3	27.3	4	21.1	10	11.1	17	14.2
Difficult in collecting of drug bottles after used	3	27.3	5	26.3	5	5.6	13	10.8
Limited dose of opioid drug in prescription	3	27.3	3	15.8	5	5.6	11	9.2
Other	0	0.0	3	15.8	53	58.9	56	46.7
No difficulty	5	45.5	5	26.3	21	23.3	31	25.8
n	11		19		90		120	

25.8% of the surveyed health facilities (including 45.5% of the National hospitals/Oncology centers, 26.3% of the district hospitals and 23.3% of the CHCs) reported that there was no difficulty in managing the use of opioid drugs. "*In my opinion, the HCM City National Oncology hospital has sufficient opioid drugs for patients and a correct examination process in accordance with the MOH's regulations in prescribing addictive drugs. We believe that the use and the management of opioid drugs in the hospital are good and many cancer patients have been treated with opioid drugs*" (IDI - a palliative care specialist, National Oncology Hospital, HCM City).

Except 46.7% of the health facilities (mainly CHCs accounting for 58.9%) having no drugs (other difficulty), the difficulties that the health facilities have met in managing and using the opioid drugs were "approval procedures, complicated management regulations" (14.2%), as a following opinion *"Our hospital provides the painkiller but the regulation of opioid drugs is very difficult, so the doctors are not enough powerful to do the prescription"* (IDI - a leader, Dist. 8 hospital, HCM City).

For the outpatients, it is very difficult to buy the opioid drugs at the pharmacies. As defined, only some certain pharmacies with the doctors' signature registrations in prescription are allowed to sell the opioid drugs for clients. However, at the present, only the National Cancer Hospital has done so, still many hospitals have not registered the doctors' signatures with the appointed pharmacies. For example, Cho Ray and Bach Mai hospitals haven't prescribed for the outpatients.

3.3.3. Knowledge on palliative care of health workers at district hospitals and CHCs

Table 38. Percentage of health workers giving correct answer on concept of palliative care

Concept	Dist. level				Comm. level			
	Doctor		Assistant doctor		Doctor		Assistant doctor	
	n	%	n	%	n	%	n	%
Prevention, detection and treatment of pain	25	32.5	28	27.2	35	58.3	43	35.8
Prevention, detection and treatment of symptoms	27	35.1	20	19.4	26	43.3	41	34.2
Counseling/support of psychology for patients	35	45.5	31	30.1	35	58.3	55	45.8
Counseling/support of psychology for patients' relatives	25	32.5	23	22.3	33	55.0	47	39.2
Know all the above 4 contents	12	15.6	3	2.9	18	30.0	25	20.8
Other	1	1.3	2	1.9	0	0.0	2	1.7
Don't know	35	45.5	56	54.4	18	30.0	54	45.0
n	77		103		60		120	

In general, the knowledge on palliative care of health workers at the district and communal levels was still limited. The percentage of those did not know about any content of palliative care's concept was found around 50% at the district level, including doctors and assistant doctors (45.5% and 54.4% respectively). Similarly at the communal level, the percentage of doctors and assistant doctors who did not know about any content of palliative care's concept was 30% and 45% respectively. Nearly 1/3 of interviewees told al 4 contents of the palliative care's concept. The percentage of doctors and assistant doctors at the CHCs who could tell about all 4 contents (30% and 20.8% respectively) was higher than that at the district level (15.6% and 2.9% respectively).

Table 39. Percentage of health workers knowing about the time of palliative care for cancer patients

Time	Dist. level				Comm. level			
	Doctor		Assistant doctor		Doctor		Assistant doctor	
	n	%	n	%	n	%	n	%
Since the diagnosis	65	84.4	83	80.6	49	81.7	89	74.2
When patients begin pain	8	10.4	11	10.7	6	10.0	15	12.5
End-of-life stage	2	2.6	5	4.9	4	6.7	15	12.5
Don't know	2	2.6	4	3.9	1	1.7	1	0.8
n	77		103		60		120	

According to the Palliative care Guideline, the palliative care must be started immediately after the diagnosis. Moreover, 74-84% of the doctors and assistant

doctors in the district hospitals and CHCs gave the correct answer, the rest gave the incorrect answers such as "when patients begin pain" and "end-of-life stage". Especially, some interviewed health workers in the district hospitals and CHCs did not know about the time of palliative care for cancer patients.

Table 40. Percentage of health workers knowing how to assess the pain intensity of cancer patients

Pain classification	Dist. level				Comm. level			
	Doctor		Assistant doctor		Doctor		Assistant doctor	
	n	%	n	%	n	%	n	%
Ask about pain history	46	59.7	49	47.6	39	65.0	49	40.8
Classify pain types	31	40.3	35	34.0	14	23.3	20	16.7
Identify pain causes	21	27.3	15	14.6	6	10.0	11	9.2
Classify pain intensity in scale	11	14.3	7	6.8	2	3.3	2	1.7
Know all the 4 contents above	0	0.0	0	0.0	0	0.0	0	0.0
Other (massage, acupuncture, compresses, etc)	15	19.5	28	27.2	5	8.3	18	15.0
Don't know	5	6.5	12	11.7	8	13.3	44	36.7
n	77		103		60		120	

Pain is an unpleasant feeling due to existing or potential tissue damage, or it is described as actual tissue damage that a person is suffering. In order to classify the pain intensity in scale, the doctors need to ask about pain history, classify pain types, identify pain causes and classify pain intensity in scale. The survey findings show that except about 60% of the doctors and 40% of the assistant doctors in the district hospitals and CHCs asked about pain history, the percentage of health workers reporting the rest three contents was lower, the lowest was "classify pain intensity in scale" (nearly 15% of the doctors or assistant doctors reported). Particularly, still some doctors, assistant doctors in the district hospitals and CHCs did not know how to assess the pain intensity of cancer patients, the most was found in assistant doctors at the CHCs (36.7%). Noticeably, no doctor or assistant doctor reported all 4 contents to assess the pain intensity of cancer patients.

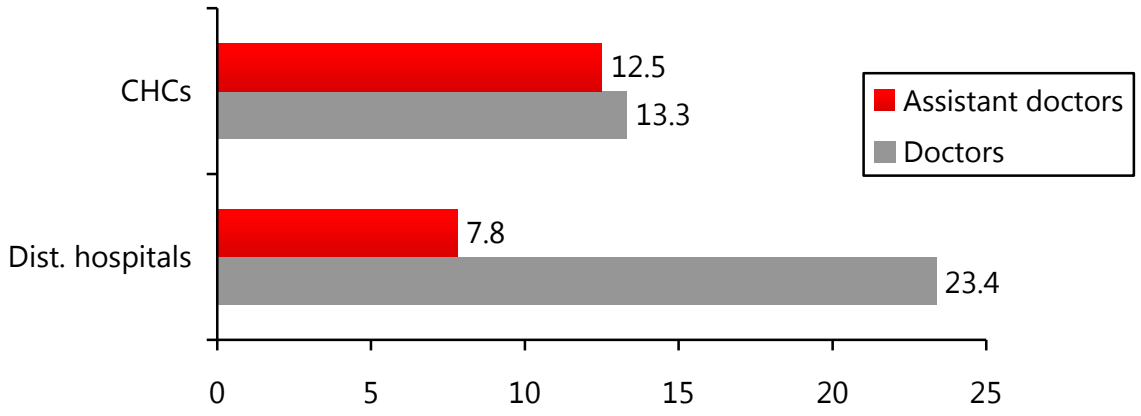


Figure 18. Percentage of health workers giving correct answer on classification of pain intensity

In the MOH's Palliative care Guideline for cancer and AIDS patients, the classification of pain intensity in scale included 4 levels (*no pain: 0 points, mild pain: 1-3 points, medium pain: 4-6 points, and severe pain: 7-10 points*) [4]. The percentage of health workers giving the correct answer on the pain intensity in scale was very low (8-23% of the doctors and assistant doctors in the district hospitals and CHCs gave the correct answers). Conversely, more than 2/3 of doctors, assistant doctors in the district hospitals and CHCs did not know how to classify the pain intensity in scale. It indicates that the skill of health workers at the grassroots level in classification of pain intensity was very weak.

Table 41. Percentage of health workers knowing about pain relief

Pain relief	Dist. level				Comm. level			
	Doctor		Assistant doctor		Doctor		Assistant doctor	
	n	%	n	%	n	%	n	%
Time for pain relief								
• Mild pain	19	24.7	25	24.3	11	18.3	17	14.2
• Medium pain	39	50.6	36	35.0	18	30.0	31	25.8
• Severe pain	15	19.5	33	32.0	31	51.7	69	57.5
• Unknown	4	5.2	9	8.7	0	0.0	3	2.5
Pain relief for mild level								
• Non-opioid drugs	15	19.5	19	18.4	20	33.3	27	22.5
• Painkiller	48	62.3	54	52.4	41	68.3	73	60.8
• Other drugs	15	19.5	17	16.5	1	1.7	8	6.7
• Unknown	5	6.5	21	20.4	4	6.7	17	14.2
Pain relief for medium level								
• Opioid drugs	32	41.6	20	19.4	14	23.3	27	22.5
• Painkiller	43	55.8	63	61.2	48	80.0	85	70.8
• Other drugs	7	9.1	5	4.9	0	0.0	5	4.2
• Unknown	5	6.5	28	27.2	2	3.3	10	8.3
Pain relief for severe level								
• Strong opioid drugs	70	90.9	77	74.8	56	93.3	94	78.3
• Painkiller	22	28.6	28	27.2	36	60.0	50	41.7
• Other drugs	3	3.9	6	5.8	0	0.0	5	4.2
• Unknown	3	3.9	18	17.5	1	1.7	8	6.7
n	77		103		60		120	

According to the MOH's Palliative care Guideline for cancer and AIDS patients, the patients should be treated to reduce pain and improve their quality of life in all

stages of the disease. The results of the survey show that the percentage of health workers in the district hospitals and CHCs giving a correct answer on the time to treat pain for patients, including mild pain, medium pain and severe pain was very low. The percentage of those who reported that the mild pain needed to be treated accounted for only 14.2%-24.7% respectively. Thus, many doctors and assistant doctors in the district hospitals and CHCs could not understand the regulations in the Palliative care Guideline.

According to the MOH's Palliative care Guideline for cancer and AIDS patients, if the patients have mild pain, they need to use non-opioid drugs and more painkiller; if the patients have medium pain, they need to use opioid drugs combining non-opioid drugs and more painkiller; if the patients have severe pain, they need to use strong opioid drugs combining with non-opioid drugs and more painkiller.

The survey results also show that most of the interviewed health workers gave the answers rather appropriately according to the Guidance. Using painkiller for mild and medium pain, and strong opioid drugs for severe pain. However, still some interviewed health workers did not know how to use the medications in pain relief, found the most in assistant doctors at the district hospitals (17.5%-27.2%), followed by assistant doctors at the CHCs (6.7%-14.2%), doctors at the district hospitals (3.9%-6.5%) and the least was found in doctors at the CHCs (1.7%-6.7%)

Table 42. Contents that health workers at the grassroots level can help cancer patients

Contents	Dist. level				Comm. level			
	Doctor		Assistant doctor		Doctor		Assistant doctor	
	n	%	n	%	n	%	n	%
Pain relief	58	75.3	64	62.1	46	76.7	77	64.2
Symptom treatment	44	57.1	40	38.8	35	58.3	57	47.5
Psychosocial support	71	92.2	86	83.5	53	88.3	96	80.0
Counseling on nutrition care	54	70.1	64	62.1	35	58.3	73	60.8
End-of-life support	22	28.6	17	16.5	10	16.7	24	20.0
Other	7	9.1	4	3.9	3	5.0	4	3.3
n	77		103		60		120	

The majority of health workers in the district hospitals and CHCs reported that they could provide psychosocial support for cancer patients (80-92% respectively), pain relief (62-77% respectively), counseling on nutrition care (58-70% respectively), symptom treatment (39-58% respectively) and end-of-life support (16-29% respectively). These contents are suitable with the condition and capacity of the health facilities at the grassroots level, but not all of the interviewed health workers were aware of it.

Table 43. Percentage of health workers knowing about the contents in the end-of-life care

Contents	Dist. level				Comm. level			
	Doctor		Assistant doctor		Doctor		Assistant doctor	
	n	%	n	%	n	%	n	%
Help for the patients and their relatives to be calm	67	87.0	88	85.4	36	60.0	72	60.0
Respect the patient's decision	34	44.2	24	23.3	2	3.3	14	11.7
Support the patient's beliefs	13	16.9	11	10.7	3	5.0	6	5.0
Use pain relief regularly and appropriately	47	61.0	54	52.4	21	35.0	34	28.3
Introduce cancer caregivers about using painkiller	39	50.6	37	35.9	21	35.0	35	29.2
Guide the nursing care	50	64.9	58	56.3	34	56.7	62	51.7
Care/Guide the patient's family to care for patient after dying	20	26.0	24	23.3	13	21.7	29	24.2
Know all above 7 contents	3	3.9	3	2.9	0	0.0	2	1.7
Other	1	1.3	4	3.9	0	0.0	3	2.5
Don't know	2	2.6	3	2.9	13	21.7	29	24.2
n	77		103		60		120	

When the medical measures are no longer effective to help cancer patients avoid their death, the care will aim to help them die in a natural, untroubled and quiet way. The main contents of end-of-life care included the support in spirit, sentiment, psychology, nursing care for the patients, their caregivers and families.

The survey results show that the majority of health workers in the district hospitals and CHCs reported about the content "Help for the patients and their relatives to be calm" (60-87% respectively), the other contents were found at lower percentages. Especially, still more than 21.7% of the doctors and 24.2% of the assistant doctor at the CHCs could not name any contents, these percentages in the district hospitals were 2.6% of the doctors and 2.9% of the assistant doctors. Conversely, only 3.9% of the doctors and 2.9% of the assistant doctors in the district hospitals, and 1.7% assistant doctors at the CHCs could name all 7 contents in the end-of-life care.

Table 44. Percentage of health workers knowing about the rights of cancer patients

Rights	Dist. level				Comm. level			
	Doctor		Assistant doctor		Doctor		Assistant doctor	
	n	%	n	%	n	%	n	%
To access appropriate and good health care services	65	84.4	85	82.5	53	88.3	84	70.0
To privacy and confidentiality	39	50.6	39	37.9	18	30.0	39	32.5
To be treated with respect and dignity	39	50.6	42	40.8	10	16.7	28	23.3
To involve an advocate of their choice	44	57.1	40	38.8	25	41.7	41	34.2
To be informed about the medical record and hospital fee	24	31.2	23	22.3	13	21.7	24	20.0
To refuse being cared and may check out the health facility	16	20.8	21	20.4	12	20.0	17	14.2
To be protected by Law when having no/limited personal ability or at the adolescent age	13	16.9	7	6.8	6	10.0	14	11.7
Other	4	5.2	7	6.8	1	1.7	3	2.5
Don't know	7	9.1	12	11.7	3	5.0	27	22.5
n	77		103		60		120	

The awareness of health workers in the district and communal levels on the rights of cancer patients was very limited. The rights that the health workers in the district hospitals and CHCs reporting the most were "To access appropriate and good health care services" (70-88% respectively). The other rights were found in the lower percentages, the lowest was "To be protected by Law when having no/limited personal ability or at the adolescent age" (around 10%).

3.3.4. Referral of palliative care patients

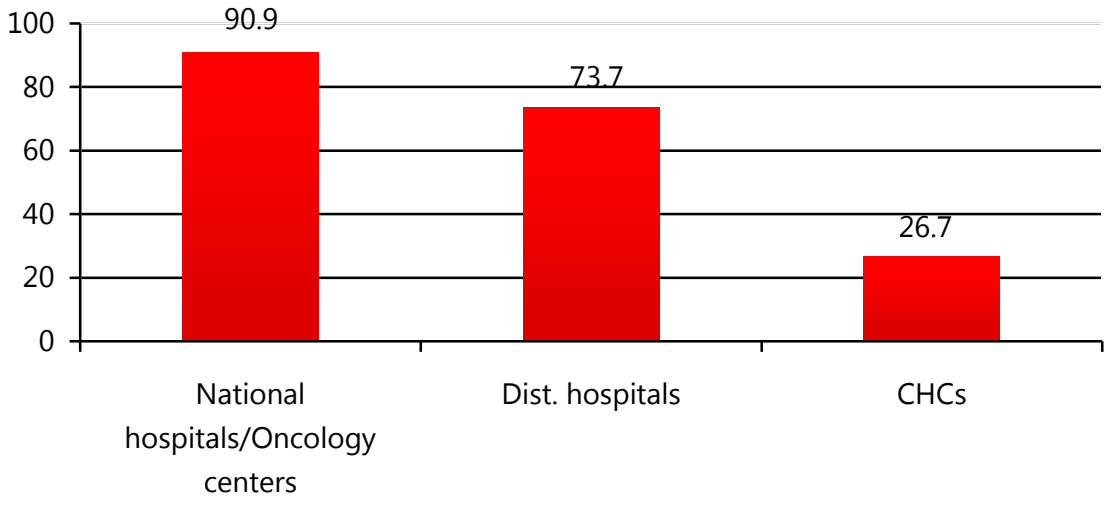


Figure 19. Percentage of health facilities which received referred patients for palliative care

90.9% of the National hospitals/Oncology centers and 73.7% of the district hospitals under the survey received the palliative care patients from the other places. However, only 26.7% of the CHCs received the palliative care patients from the upper level.

The lack of the continuity in the palliative care services were expressed very clearly when analyzing the activity of referral for the palliative care patients. Because the services were not available at the lower level, most of cancer patients were referred to the central-level hospitals. Therefore, the health workers at the central level have had difficulty in the decision of referral for the patients. "*We often have to refer the patients to their locality and make the outpatient prescription for them, if there is a problem, we will make distance counseling via phone or let the patients be back to the hospital. Some provinces manage and prescribe for the cancer outpatients such as Thai Nguyen, Bac Giang, etc.. If the patients live in those provinces, we will refer to the province*" (IDI - a palliative care specialist, National Cancer Hospital, Ha Noi). *"When referring the patients to the lower level, because the painkillers are only provided within one month, the patients can not get painkillers from the district level, so they have to return to the Ha Noi Oncology hospital*" (IDI - a curing staff, National Cancer Hospital, Ha Noi).

Table 45. Types of palliative care services for referred patients

Health facilities	Pain relief by using drug		Symptom treatment by internal medicine		Symptom treatment by surgery		Complications control		Other needs of palliative care	
	n	%	n	%	n	%	n	%	n	%
National hospitals/Oncology centers (n=10)	9	90.0	9	90.0	8	80.0	10	100.0	0	0.0
District hospitals ((n=14)	12	85.7	11	78.6	5	35.7	5	35.7	2	14.3
CHCs (n=24)	16	66.7	12	50.0	2	8.3	6	25.0	13	54.2
Total (n=48)	37	77.1	32	66.7	15	31.3	21	43.8	15	31.3

The findings from the survey show that most of cancer patients who were referred to the National hospitals/Oncology centers wanted to access all the palliative care services including pain relief by using drug, symptom treatment by internal medicine, symptom treatment by surgery and complications control. For the district hospitals, the patients who were referred wanted to access the services of pain relief by using drug and symptom treatment by internal medicine. For the CHCs, besides the patients wanted to access the services of pain relief by using drug and symptom treatment by internal medicine, up to 54.2% of the CHCs reported that the referred patients wanted to receive counseling and support in psychology.

Table 46. Reasons for referral of patients for palliative care

Health facilities	Overload		Complicated cases		Stable treatment		Wishes of patients		Other	
	n	%	n	%	n	%	n	%	n	%
National hospitals/Oncology centers (n=8)	3	37.5	2	25.0	4	50.0	7	87.5	1	12.5
District hospitals ((n=16)	0	0.0	14	87.5	3	18.8	14	87.5	1	6.3
CHCs (n=65)	0	0.0	57	87.7	10	15.4	51	78.5	0	0.0
Total (n=89)	3	3.4	73	82.0	17	19.1	72	80.9	2	2.2

Among the health facilities that referred the palliative care for cancer patients, the common reasons of referral at all the 3 levels were "according to the wishes of patients and their families" (80.9%). Apart from the reason "according to the wishes of patients and their families", nearly 88% of the district hospitals and CHCs reported the reason "Complicated cases". Particularly for the National hospitals/Oncology centers, except the reason "according to the wishes of patients and their families", 50% of the health facilities reported the reason "treatment cases were stable but still needed medical care staff". Besides, 37.5% of the National hospitals/Oncology centers had to refer the patients due to the reason "overload".

Table 47. Health facilities to which patients often referred for palliative care

Health facilities	National hospitals/Oncology centers		Provincial hospitals		District hospitals		Private hospitals/clinics		Other	
	n	%	n	%	n	%	n	%	n	%
National hospitals/Oncology centers (n=8)	7	87.5	2	25.0	0	0.0	0	0.0	1	12.5
District hospitals ((n=16)	16	100.0	9	56.3	0	0.0	0	0.0	0	0.0
CHCs (n=65)	53	81.5	20	30.8	43	66.2	1	1.5	3	4.6
Total (n=89)	76	85.4	31	34.8	43	48.3	1	1.1	4	4.5

Among the health facilities where referred the patients, most of those including CHCs often selected the National hospitals/Oncology centers for referral of the palliative care patients. Only 56.3% of the district hospitals often referred the palliative care patients to the provincial hospitals and 66.2% of the CHCs referred to the district hospitals. Therefore, many palliative care patients skipped the level in referral.

One of the reasons for that the lower-level health facilities referred palliative care patients right to the central level was that the palliative care services were not available. "*The palliative care network for the cancer patients in my province is not*

available. Because this work is new, so we have not yet deployed. Maybe the Oncology department in Hue Central Hospital has implemented some services such as pain relief or symptom treatment" (IDI - a leader of Hue hospital, Thua Thien Hue). The disruption of the palliative care services were found in the grassroots level (district hospitals and CHCs). "*Most of CHCs don't know about the concept of palliative care. Because they have never been accessed to and trained in, or provided training materials on this activity*" (IDI - a leader of Phong Dien hospital, Thua Thien Hue).

Among the 410 interviewed cancer patients' main caregivers, 256 patients (62.4%) had been referred for palliative care services. The facilities that referred the patients to the nearest palliative care services are presented in the figure below:

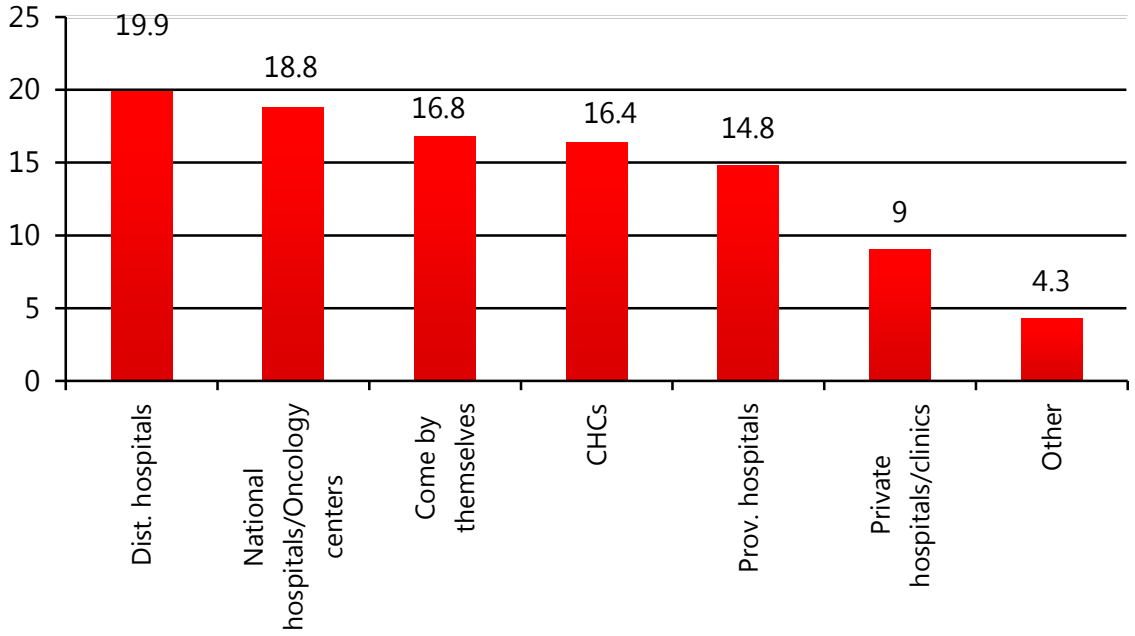


Figure 20. Health facilities from which patients were referred for palliative care

Out of the patients referred, 19.9% were referred from district hospitals to the facilities where they were being provided with palliative care at the survey time, 18.8% were referred from National hospitals/Oncology centers, 16.4% were referred from CHCs, 14.8% were referred from provincial hospitals, 9% were referred from private hospitals/clinics and 16.8% came to the palliative care facilities by themselves. Thus, the percentage of health facilities at all levels, from the National hospitals/Oncology centers to the CHCs, referring patients to the closest level for palliative care services was not much different (around 14.8% and 19.9%).

Table 48. Reasons for referring patients to the community for palliative care

Health facilities	End-of-life patients		Wishes of patients and their families		Other		No referral	
	n	%	n	%	n	%	n	%
National hospitals/Oncology centers (n=8)	5	62.5	7	87.5	0	0.0	1	12.5
District hospitals ((n=16)	5	31.3	9	56.3	1	6.3	6	37.5
CHCs (n=65)	12	18.5	12	18.5	1	1.5	46	70.8
Total (n=89)	22	24.7	28	31.5	2	2.2	53	59.6

Among the health facilities that referred the patients who had needs in palliative care, reasons why most of the National hospitals/Oncology centers referring palliative care patients to the community mentioned the most were "end-of-life patients" (62.5%) and "according to the wishes of patients and their families" (87.5%). Conversely, 70.8% of the CHCs, 37.5% of the district hospitals and 12.5% of the National hospitals/Oncology centers did not have palliative care patients to refer to the community. Thus, due to many different reasons, the percentage of cancer patients referred to the community was rather high. In addition, until death, the patients were still cared for for another period of time, so the need for palliative care services in the community are very big.

Table 49. Percentage of health facilities referring patients

Health facilities	Ambulance		Health workers go with		Introduction paper		Consulting referral		Other		No support	
	n	%	n	%	n	%	n	%	n	%	n	%
National hospitals/Oncology centers (n=8)	3	37.5	2	25.0	5	62.5	6	75.0	1	12.5	0	0.0
District hospitals ((n=16)	10	62.5	8	50.0	13	81.3	11	68.8	0	0.0	0	0.0
CHCs (n=65)	3	4.6	10	15.4	59	90.8	27	41.5	0	0.0	4	6.2
Total (n=89)	16	18.0	20	22.5	77	86.5	44	49.4	1	1.1	4	4.5

For the health facilities that referred cancer patients, the most common supporting forms in referral of patients were "introduction paper" (86.5%), very few health facilities supported "ambulances" and had "health workers go with" (18% and 22.5% respectively). The percentage of health facilities that supported the "ambulances" and had "health workers go with" was found highest at the district hospitals (62.5% and 50% respectively). The in-depth interviews also show that the most common form of referral of cancer patients at health facilities was

"introduction paper" and there were no feedbacks from the patients after the referral. "*We only have the introduction paper for patients to refer. If the patients want to stay in hospital for treatment of another disease, we will transfer their clinical records to the upper level. If the patients want to refer, we do not have any support, the family member will transport the patient by themselves*" (IDI - a leader of Hue Central Hospital, Thua Thien Hue).

Table 50. Percentage of patients referred by health facilities

Health facilities	Ambulance		Health workers go with		Introduction paper		Consulting referral		Other		No support		Total
National hospitals/Oncology centers	0	0.0	1	2.1	39	81.3	15	31.3	2	4.2	4	8.3	48
Provincial hospitals	2	5.3	1	2.6	30	78.9	11	28.9	1	2.6	4	10.5	38
District hospitals	4	7.8	2	3.9	46	90.2	18	35.3	0	0.0	1	2.0	51
CHCs	1	2.4	2	4.8	40	95.2	37	88.1	0	0.0	0	0.0	42
Private hospitals/clinics	0	0.0	1	4.3	15	65.2	18	78.3	0	0.0	0	0.0	23
Other	0	0.0	0	0.0	5	45.5	8	72.7	2	18.2	0	0.0	11

According to the main caregivers of patients referred, most of the health facilities only provided an introduction paper when referring the patient. Besides, the health facilities also counseled on referral for many patients, mostly at the CHCs (88.1%) and at the private hospitals/clinics (78.3%), the least at the provincial hospitals (28.9%). Very few patients were supported with "ambulance" and had "health workers go with" when referring.

3.4. Proposal for the community-based palliative care model

Main findings:

- Needs for palliative care (pain relief, symptom treatment, mental/spiritual support, etc) for cancer patients were very considerable. The accessibility of patients to palliative care services as well as the capacity of the health facilities in palliative care service provision was still very limited. Almost all of cancer patients and their main caregivers wanted to take care of end-of-life patients at home. Therefore, the community-based palliative care for cancer patients has been increasing.
- The prescription regulation in outpatient treatment and the MOH's Circular on Guidance of activities related to addictive drugs issued in 2008 and 2010 were legal documents that created good conditions to implement the Palliative care Guideline in community.
- 81.4% of the interviewed health workers supported the opinion of oral morphine prescription for cancer patients at home.

- The unions, social organizations and individuals have participated actively in caring and supporting cancer patients during the treatment as well as the end-of-life phase.
- Although it is not specific, a community-based palliative care model for cancer patients is proposed as that it is necessary to establish a multi-sector caring team for cancer patients. This team will be managed by the communal health with the participation of related ministries, unions, social individuals, donors under the direction of local authorities. The CHCs will be implementing the services and act as core units along with related ministries and sectors to provide pain relief, complication treatment and mental/spiritual support for cancer patients and their relatives. A fund may be raised through the people's contributions for palliative care activities.

3.4.1. Needs for palliative care of cancer patients in community

As presented above, the needs of palliative care (palliative relief, symptom treatment, mental/spiritual support) for cancer patients are very considerable. Most of cancer patients had to suffer from pain in the disease (75.9%) together with other symptoms such as tiredness (78.8%), insomnia (55.1%), fever (40.7%), vomit/nausea and breathing difficulties (38.5%). In the disease, the patients and their relatives met some difficulties in health, mentality and personal activities; and these difficulties affected their lives. The common moods of cancer patients are as follows: be frightened illness and cure intervention (50.5%), be worried about their future and their family's future (47.6%), fear of death (31.5%), fear of losing income and of poor (25.9%), decrease in desire to live (15.6%), etc.

The needs of cancer patients on palliative care are very big, but the accessibility of patients to palliative care services as well as the capacity of the health facilities in palliative care services provision was very limited. For the service of pain relief and other uncomfortable signs treatment, most of the interviewed patients visited the National hospitals/Oncology Centers (85.1%). Only few patients visited the provincial hospitals (26.6%), district hospitals (20.5%), private hospitals/clinics (13.7%), CHCs (9.5%), etc. The cancer patients mostly went to the National hospitals/Oncology centers that created overcrowding. The figure above shows an overcrowding at the National

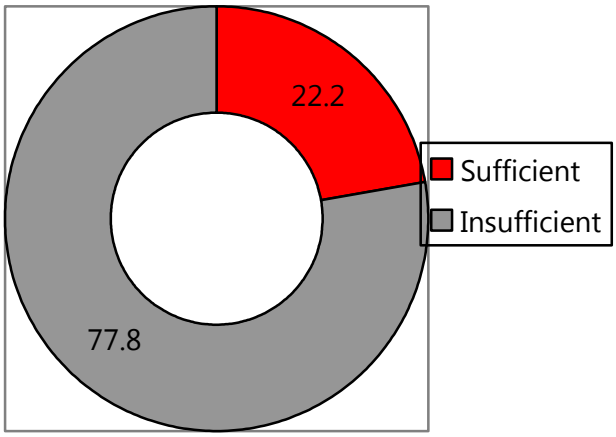


Figure 21. Capacity of patient beds at the National hospitals/Oncology Centers

hospitals/Oncology centers; it is presented via the percentage of hospitals lacked beds for palliative care (77.8%). The survey findings at Tam Hiep branch of the K hospital also show that many patients had to rent accommodation near the hospital for convenient treatment, due to beds were not available here.

Apart from the lack/interruption of palliative care services at the grassroots level, the overcrowding at the central level led to incomprehensiveness in palliative care services. So many patients need to be tested and prescribed on the same day.The health workers did not have enough time to provide a full and comprehensive service, they only focused on pain relief and complication treatment and have not yet paid attention to all other needs of patients and their relatives. For this reason, the quality of services was affected.

Other reasons for the incomprehensiveness in palliative care services were that the providers were insufficient, the staff were unspecialized in care of patient's psychology, there was no multi-sector caring teams, etc. "*...But I still wish the patients like me often get consultancy on cancer prevention methods and reasonable nutrition, drug and daily activities after the treatment?*" (IDI, a cancer patient, Central Hospital for Tuberculosis and Lung disease, Ha Noi).

In addition, most of cancer patients and their relatives wanted to take care of end-of-life patients at home. Therefore, it is necessary to deploy the community-based palliative care services.

The below figure presents the answers of health workers and patients' families to the question "*According to you, where should the end-of-life cancer patients be cared?*":

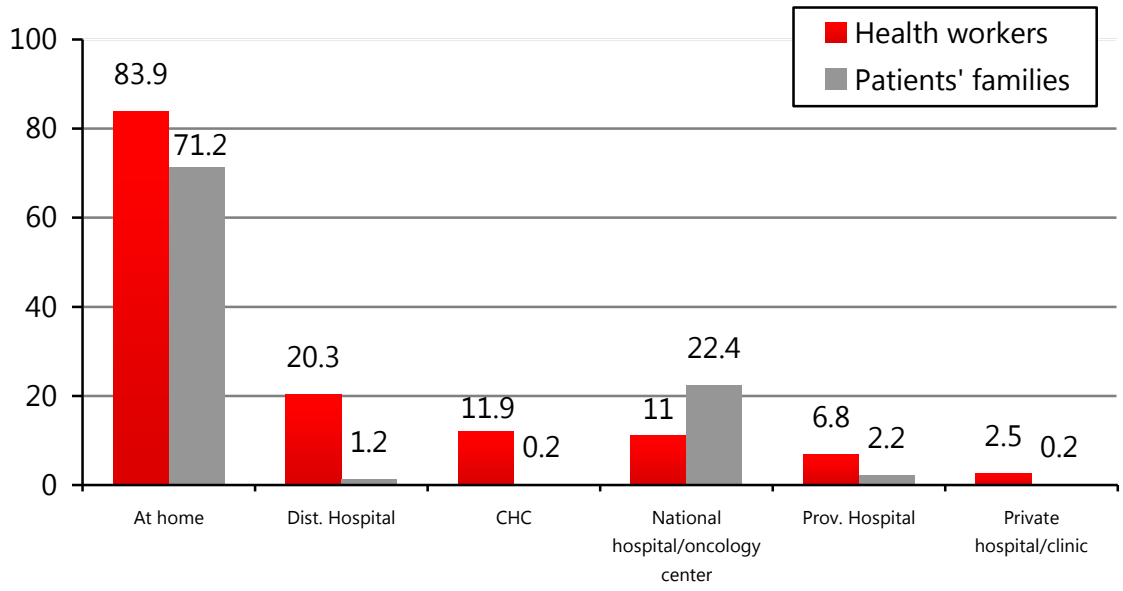


Figure 22. Opinions of health workers and patients' relatives on the best facility for caring end-of-life cancer patients

Almost all of health workers at the surveyed health facilities reported that the best place for caring end-of-life cancer patients was at home (83.9%). A low percentage of health workers reported that the best place for caring end-of-life cancer patients was at the health facility, found the most at the district hospitals (20.3%), followed by at the National hospitals/Oncology centers (11%), at the CHCs (11.9%), at the provincial hospitals (6.8%) and private hospitals /clinics (2.5%). According to a health worker "*The needs of end-of-life cancer patients in palliative care are very big, but the hospital is not able to provide the service due to lack of manpower, lack of psychological counseling ability and lack of para-clinical test equipment*" (IDI, a leader of the hospital, Phong Dien dist., Thua Thien Hue).

Similarly, the cancer patients' caregivers reported that the best place for caring end-of-life cancer patients was at home (71.2%), followed by National hospitals/Oncology centers (22.4%). The percentage of those telling that the provincial or district hospitals, CHCs or private hospitals/clinics were the best places was lower than that of health workers. A cancer caregiver said: "*It is better to be at home because of crowded hospitals, difficult traveling and many difficulties, especially finance. More adequate conditions and easier eating are found at home. If there is any complication, we will take my uncle to the hospital, but our house is near the CHC, so we can visit it for blood transfusion*" (IDI, a cancer caregiver, Ward 15, Tan Binh dist., HCM City).

In fact, the interviews with the dead cancer patients' caregivers show that 86.1% of the cancer patients' were taken end-of-life care at home, and a remaining 11.4% were done at the National hospital/Oncology center. Thus, the palliative care for end-of-life cancer patients at home was not only the need but also the desire and sentiment of most Vietnamese people. However, there is currently no organization or individual to take care of cancer patients in community, apart from the families' members. "*After the treatment from the hospital, the cancer patients don't receive any professional care in the community apart from the instructions in the drug prescription. There are some cancer patients who are homeless, have no health insurance cards, and when coming back home from the hospital, they don't receive any support from the community*" (IDI, a leader, Dist. 7 hospital, HCM City). On the other hand, "*Mainly it is simple health care of upper-level doctors when making drug prescriptions for continuous treatment at home, they advise about nutrition, painkiller, and mental care. It is the best if the cancer patients access the opioid drug provision place when coming back community from the hospitals*" (IDI, a curing staff, Oncology hospital, Ha Noi).

3.4.2. Opinions on palliative care for cancer patients in community

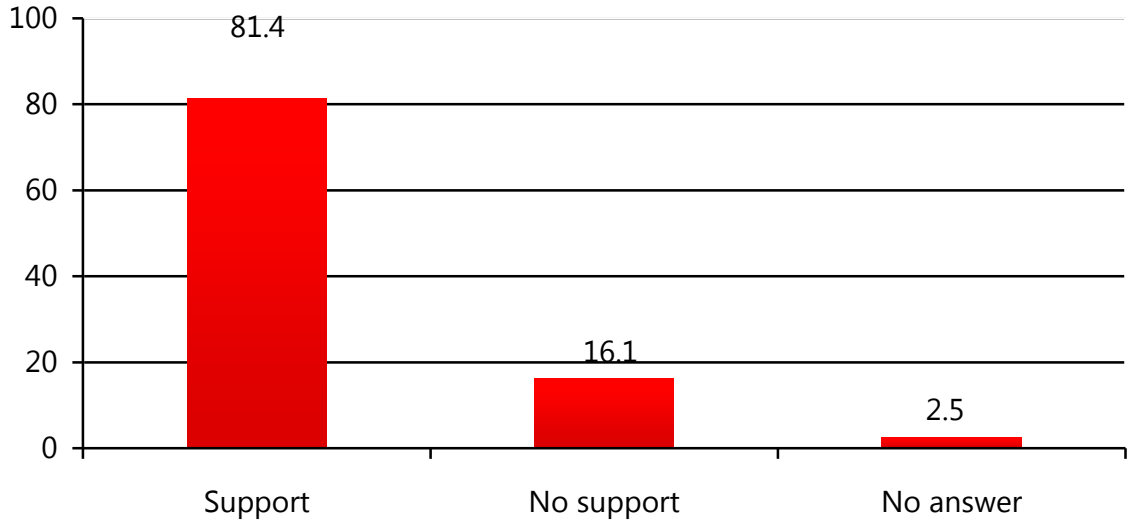


Figure 23. Opinions of health workers on oral morphine prescription for cancer patients treated at home

81.4% of the health workers at the surveyed health facilities supported the opinion on the oral morphine prescription for cancer patients who were treated at home. As presented in the section above, the prescription regulation for outpatient treatment and the MOH's Circular of Guidance on addictive drug related activities issued in 2008-2010 was legal document, created good conditions for the patients to access the opioid drugs at home. It also means that the Palliative care Guideline has a basis to implement the palliative care in community. However, still 16.1% of the interviewed health workers did not support the oral morphine prescription for cancer patients who were treated at home. The reasons are presented in the figure below:

Table 51. Reasons for not supporting oral morphine prescription for cancer patients treated at home

Reasons	n	%
Oral morphine used for other purposes	12	63.2
Lack of oral morphine	4	21.1
Lack of health workers, health workers could not provide palliative care at home	12	63.2
Impossible to supervise palliative care of the health facilities at the lower levels	3	15.8
Other	3	15.8
n	19	

Among the health workers who did not support to make the oral morphine prescription for cancer treatment at home, only a few reported about the lack of oral morphine (21.1%); most of them said that the oral morphine might be used for other purposes and because the lack of health workers who could implement palliative care at home (at the same percentage, 63.2%). Strictly implementing the prescription regulations for outpatients and the MOH's Circular of Guidance on addictive drug related activities can minimize the wrong-purpose use of oral morphine. Establishing and operating well the multi-sector caring team will overcome the lack of health workers or avoid the overloaded work of health workers who are not able to implement the patient care services at home.

Almost all of the interviewed health workers reported that it was very necessary to implement the palliative care for cancer patients in community. "*It is very necessary to provide the palliative care services (pain relief, psychology support) for cancer patients in community. So, it will reduce a burden of patient overcrowding for our department, and this needs to be done because the patients are very painful in body, if there is no consultancy, sympathy and sharing of the family members, the patients are very miserable*" (IDI - a curing staff, Cho Ray hospital, HCM City). "*For me, it is very necessary to implement the palliative care services for cancer patients in community to reduce the number of patients for the upper level, and especially the patients who are homeless* " (IDI - a leader, Dist. 7 hospital, HCM City). "*For me, it is very necessary to implement the palliative care services for cancer patients in community because it brings many benefits to the patients. At the present, the cancer patients are only taken care of like other patients while the end-of-life cancer patients have to suffer from a lot of pain, so they need to be cared specially*" (IDI - a leader, Cu Chi hospital, HCM City). Some health workers proposed in detail more "*In order to implement this model, it must deploy many comprehensive measures such as the staff must have qualification and be trained methodically. It is necessary to pilot to learn lessons before implementing this service on a large scale*" (IDI - a leader, Dist. 8 hospital, HCM City).

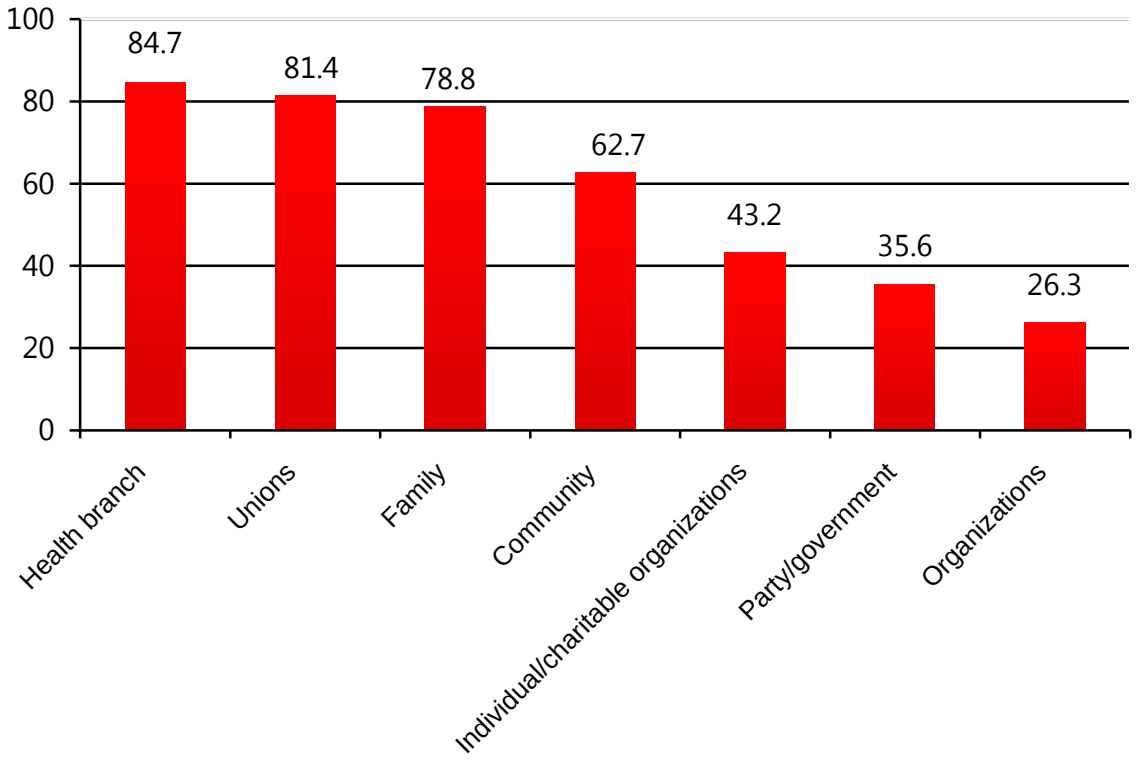


Figure 24. Opinions of health workers on branches and sectors that should participate in end-of-life care for cancer patients

According to the health workers at the surveyed health facilities, the branches and sectors that should participate in end-of-life care for cancer patients were the health branch (84.7%), unions (81.4%), family (78.8%), community (62.7%), individual/charitable organizations (43.2%).

According to the cancer patients' main caregivers, during the treatment, apart from the family, the percentage of patients receiving the interest of unions was found the most (65.9%), followed by individual/charitable organizations (42.2%), party/government (17.1%), offices of patients or their relatives (11.5%), etc. However, 20.7% of the patients did not receive any support.

Table 52. Percentage of patients supported by unions/organizations and community

Branches and sectors	n	%
Health branch	39	9.5
Unions	270	65.9
Party/government	70	17.1
Organizations	47	11.5
Individual/charitable organizations	173	42.2
Other	16	3.9
Don't receive	85	20.7
n	410	

Table 53. Support types from branches and sectors

Forms	n	%
Give money	161	49.2
Give present	241	73.7
Encourage and support patients' spirit	303	92.7
Encourage and support patient relatives' spirit	254	77.7
Counsel and care of patients	17	5.2
Care/treat	12	3.7
Give funeral support	8	2.4
Other	5	1.5
n	327	

The most common forms of support from the branches, sectors, unions and individuals for cancer patients were "Encourage and support patients' spirit" (927%), "Encourage and support patient relatives' spirit" (77.7%), "give present" (73.7%), and "give money" (49.2%).

The support from the branches, sectors, unions and individuals actively affected the patients and their relatives, in detail: "support and improve patients' psychology" (92%), "support and improve patient relatives' psychology" (82.3%) and "share a burden of finance" (30.6%).

Table 54. Impacts of support to patients and their families

Impacts	n	%
Share a burden of finance	100	30.6
Support and improve patients' psychology	301	92.0
Support and improve patient relatives' psychology	269	82.3
Enhance skills of patient care	18	5.5
Give pain relief	14	4.3
Improve status of complications	3	0.9
n	327	

3.4.3. Proposal for the community-based palliative care model for cancer patients

Through the interviews with the leaders of the health facilities, health workers, cancer patients and their main caregivers, many ideas were reported, a community-based palliative care for cancer patients was established. That was to establish a multi-sector caring team for cancer patients. This team will be managed by communal health with the participation of branches, unions, social individuals, donors under the direction of local authorities. The CHCs will be implementing the services and act as core units along with branches and sectors to provide pain relief, complication treatment and mental/spiritual support for cancer patients and their relatives. A fund may be raised through people's contributions for palliative care activities.

The community-based palliative care model for cancer patients was recorded through the ideas as follows: "*It is necessary to establish a multi-sector caring team for cancer patients. A fund may be raised through people's contributions to support patients' spirit and to care for them. It is the best if this team is managed by the health branch. But it must have the direction from the upper level with the participation of people's committee and government, and the health branch will be the implementing and care unit together with the other branches and sectors*" (FGD - cancer patients' main caregivers (women aged 41), Thu Duc Dist., HCM City).

"*The palliative care must be implemented from the community with the assistance of health branch, especially the qualified health workers. The hospital plays a bridge to help the people to early examine and detect cancer and take the treatment*" (IDI - a leader of Hue hospital, Thua Thien Hue).

"*For me, the local health branch should be responsible to supervise, support and help the patients, if the hospital has the Oncology department, It is necessary to combine with the local health workers. at the present, this model can be done because the cancer disease like the others is under the management from upper level to lower level*" (IDI - a leader of Cu Chi hospital, HCM City).

"*The end-of-life patients are very painful, so they can't come to the hospital for treatment because of far distance. It is necessary to establish a palliative care program to support the cancer patients at the CHCs. The health workers can visit the patients' houses or the patients can come to CHCs, but the health workers must be trained in palliative care, and the drugs and finance must be provided (can manage the morphine drugs at the CHCs) according to the toxic drug management regulation*" (IDI - a head of CHC, Tan Phu Trung comm., Cu Chi dist., HCM City).

"I think, apart from the diagnosis and treatment at the hospital, the cancer patients need to be cared in community such as being injected by CHC, encouraged and supported in spirit. The most important factor of cancer patients is their spirit and belief. For example, when a cancer patient comes home from the hospital, he/she needs to be cared and shared by his/her relatives. In addition, the CHC may consult more on patient care for the patients' caregivers. However, I find that this work is not yet done by the local health, so the patients have to depend on the upper-level hospitals. I think the CHC can provide pain relief and spiritual support for the patients. In fact, this issue is very necessary but the locality has not yet done" (FGD - main patients' caregivers (a woman aged 34), National Cancer hospital, HCM City).

"In my opinion, It is necessary to establish a center for palliative care including the mobile teams (like the 115 emergency team). The mobile teams can provide home care for the end-of-life patients. When implementing this model, it must manage the opioid drugs very strictly. The staff of the center should have responsibility and awareness in management of the opioid drugs'' quality " (IDI - a curing staff, Central Pediatric hospital, Ha Noi).

"*We should establish centers for palliative care at the district hospitals and train for one or two staff from each CHC to provide the palliative care services for the cancer patients in community*" (IDI - a leader of Hoai Duc dist., Ha Noi).

"First of all, It is necessary to quickly establish a network of local health and guide them on palliative care. When the cancer patients have needs, they would access the service immediately. The network also help the patients know about the correct place for examination and treatment" *(*IDI, a main caregiver, National Cancer hospital, Ha Noi).

In order to operate the palliative care teams in community, the service providers must be trained carefully to do the palliative care techniques (pain relief, symptom treatment, psychology care for the patients and their caregivers, end-of-life care) depending on the ability of each service provider. Apart from the practice on palliative care, the service providers of the palliative care teams must also guide onpalliative care techniques for the patients' caregivers.

4. CONCLUSIONS AND RECOMMENDATIONS

4.1. CONCLUSIONS

4.1.1. Palliative care Guideline:

The contents in the Palliative care Guideline for cancer and AIDS patients issued in 2006 were rather sufficient and easy to understand, but for better application, it must have more detailed instructions for each level. Apart from the Palliative care Guideline, MOH has also issued some legal documents related to palliative care such as the guidance on addictive drugs related activities, the regulation on opioid drug prescription for the cancer and AIDS patients in outpatient treatment, etc. This has created the legal framework for the implementation of the palliative care services at the health facilities and in the community. However, the requirements in the regulation imposed many difficulties for the health facilities, health workers and outpatients when providing the palliative care services in the community.

There were other opinions that might not be consistent or not mentioned in the available regulations, for example, in the list of essential drugs, the communal level was only used the morphine in emergency cases, not allowed to use in pain relief. The pain relief and symptom treatment for the cancer patients have not been stipulated in the MOH's Decision of technical-level distribution.

The implementation of the palliative care according to the MOH's Palliative care Guideline for cancer and AIDS patients has been done in some provinces/cities. However, the original guidance document and training material based on the Palliative care Guideline were not available in many facilities. The percentage of the health facilities that were supervised on palliative care by the upper level or supervised the lower level was still low in both frequency and content.

4.1.2. Needs and actual provision on palliative care services:

The needs of cancer patients and their relatives for palliative care including pain relief, symptom treatment, psychology support were very big. Most of the cancer patients were found in pain, lack of sleep, fever, vomit/nausea, and breathing difficulties, along with a mood swing such as being afraid of the disease and treatments, worrying about future and family, fearing of death, and losing living desire. However, the accessibility of the cancer patients to palliative care services were not easy and regular.

According to the Palliative care Guideline, the palliative care services are provided at all levels, including pain relief, symptom treatment, psychosocial support, and end-of-life care. In fact, there are some types of services in the central and provincial levels. Even in the National hospitals/Oncology centers, the palliative care has just focused on pain relief and complication treatment, not yet paid attention to all the other needs for the patients. The reasons given to explain the incomprehensiveness of the services are the lack of staff, qualification and psychological care for the patients.

Some CHCs have provided the pain relief and symptom treatment services for the cancer patients. It indicates that the palliative care providers who were trained by the home care program for the HIV/AIDS patients are totally able to provide the palliative care services for cancer patients in community.

At present, the physical infrastructure for the palliative care services is still insufficient, because many hospitals do not have the specialized units in oncology or pain relief, except for some big hospitals/Oncology centers. Besides, the lack of painkillers with opioid at the health facilities and knowledge on palliative care of health workers in the district hospitals and CHCs were still limited.

4.1.3. Community-based palliative care model:

The needs of cancer patients in the palliative care (pain relief, symptom treatment, psychology/spirit support, etc) were very big, but the accessibility of the patients to palliative care services as well as the satisfaction of the health facilities on these services were limited. In addition, most of cancer patients and their relatives wanted to do the end-of-life care at home. The community-based palliative care services for cancer patients have become more imperative.

The prescription regulation in outpatient treatment and the MOH's circular of Guidance on addictive drugs related activities issued in 2008 and 2010 were the legal framework for the cancer outpatients to access to the opioid drugs at home, it also means that the Palliative care Guideline has a basis to be implemented in community. Therefore, 81.4% of the health workers at the surveyed health facilities supported oral morphine prescription for cancer patients to be treated at home.

On the other hand, it is deeply rooted in the Vietnamese culture to help the persons who face difficulties and misfortunes. The unions, social organizations and individuals have been actively involved in care and support for the cancer patients during their treatment as well as end-of-life care.

Although it is not specific, a community-based palliative care model for cancer patients is proposed as that it is necessary to establish a multi-sector caring team for cancer patients. This team will be managed by the communal health with the participation of branches, unions, social individuals, donors under the direction of local authorities. The CHCs will be implementing the services and act as core units along with branches and sectors to provide pain relief, complication treatment and mental/spiritual support for cancer patients and their relatives. A fund may be raised through people's contributions for palliative care activities.

4.2. RECOMMENDATIONS

In order to implement the palliative care services at the health facilities at all levels, apart from the introduction of the Palliative care Guideline, there should be the instructions in detail for the provincial/district/commune levels and private hospitals as defined in the Palliative care Guideline.

Provincial health departments should organize workshops with participation of some related braches and sectors including the health insurance, pharmaceutical, finance, police, etc. to complete and build instructions on the implementation and supervision of painkiller supply for health facilities, and provide drugs for patients more appropriately, strictly and effectively. The health facilities, which have units for pain relief and palliative care and are allowed making strong painkillers prescriptions for outpatients, should assign doctors to register their signatures with the pharmacies providing strong painkiller and make prescription as required in the prescription regulations.

The palliative care services at the district level, especially the communal/ward level, at the present, have just satisfied a part of the needs in HIV/AIDS patients. It is necessary to implement the palliative care services at the district and communal level. MOH should have a program to implement the palliative care services at all levels in detail, including the documental guidance on palliative care contents for each level, policy for the implementation of palliative care, training on palliative care for health workers at all levels, and mass media communication.

Because health workers have been only trained on palliative care for HIV/AIDS patients, they need to have knowledge on palliative care for cancer patients and be supervised/supported from the upper level to ensure a good practice on it.

While the current conditions are not able to separate the physical infrastructure for palliative care services, they could be integrated into the internal/surgery examination and treatment departments of the provincial and district hospitals, but the health workers need to be trained on palliative care and be provided with the Palliative care Guideline appropriate for each level, concurrently set up groups of supervisors at each province/district to support the lower level. The community-based palliative care model can be assigned to CHCs' health workers with the participation of local associations and unions.

The communes/wards, depending on the specific conditions, need to have the policy for support and development of the palliative care services in community, encourage the participation of village health collaborators, mobilize and support the home-based palliative care for patients.

In addition, the health facilities should have a strategy on palliative care service advertisement at each locality to help people know about and access to the closest palliative care services; contribute to reduce the overcrowding in the hospitals. Besides, this also reduces the economic burden as well as supports the psychology/spirit of the patients and their relatives.

REFERENCES

1. National Cancer Hospital (2008), National project on Cancer Control in 2008-2010.

2. MOH (2008), Decision on Stipulation of the prescription regulation in outpatient treatment, No. 04/2008/QD-BYT, Feb 01st 2008.

3. MOH (2005), Decision on promulgating the Regulation on delineation of technical levels and a list of techniques in medical examination and treatment, No.23/2005/QD-BYT, August 30th 2005.

4. MOH (2006), Palliative care Guideline for cancer and AIDS patients, Medical Publishing House, Ha Noi.

5. MOH (2006), palliative care in Vietnam-Analysis results of rapid assessment in 5 provinces/cities.

6. MOH (2010), Report on the HIV/AIDS infection, Quarter I/2010, No. 4402/BYT-AIDS, July 05th 2010, http://www.vaac.gov.vn/Desktop.aspx/Noi-dung/Tinh hinh dich_nhiem_HIVAIDS_toan_quoc_Quy I 2010/, 10/08/2010.

7. MOH (2009), Programme No.527/CTr-BYT: "Enhancing the quality in examination and treatment at the health facilities due to the goal to satisfy the health insurance used patients, create a belief to the people to actively participate in health insurance, towards to universal health insurance", June 18th 2009.

8. MOH (2010), Circular of Guidance on addictive drugs related activities, No.10/2010/TT-BYT, April 29th 2010.

9. MOH (2008), Decision on Stipulation of the list of essential drugs at the health facilities, No. 05/2008/QD-BYT, Feb 01st 2008.

10. Nguyen Ba Duc and co-workers, Preliminary report on the implementation of the National project on Cancer Control in 2008-2010. National 15th workshop in Cancer Control (Oct 7-8th 2010), Vietnam Oncology Magazine, No. 01-2010.

11. Trinh Thi Ngoc, Pham Thanh Thuy & Do Duy Cuong, palliative care-the essential need of cancer and AIDS patients, http://bachmai.gov.vn/index.php?option=com_content&task=view&id=409&Itemid=33, accessed on 02/08/2010.

12. PATHFINDER USA (2000), A Guide to Supervising and Evaluating Adolescent Reproductive Health Programs, Focus on young adults.

13. Vu Thi Phuong and co-workers, Survey on the needs of cancer patients in consulting at the National Cancer Hospital. National 15th workshop in Cancer Control (Oct 7-8th 2010), Vietnam Oncology Magazine, No. 01-2010.

14. WHO (2006), Cancer Control: Knowledge into Action, WHO Guide for Effective Programmes: Planning, Geneva.

15. WHO (2007), Cancer Control: Knowledge into Action, WHO Guide for Effective Programmes: palliative care, Geneva.

16. WHO (2000), Achieving balance in National opioid drug Control Policy: Guidelines for Assessment, Geneva.

17. WHO (2004), palliative care: Symptom management and end-of-life care, Geneva.

18. WHO (2007), Cancer Control: Knowledge into Action, WHO Guide for Effective Programmes: Prevention, Geneva.

19. WHO (2002), National Cancer Control Programmes: Policies and Managerial Guidelines, Geneva.

ANNEX

List of the surveyed provinces/districts/communes

Number	Province	District	Commune
1	**THUA THIEN HUE**	1. Phong Dien	
			1. Phong Dien
			2. Phong Xuan
			3. Phong Hoa
			4. Phong Son
			5. Phong My
			6. Phong Thu
			7. Phong Hien
			8. Phong Chuong
		2. Hue	
			1. An Cuu
			2. An Tay
			3. Thuan Loc
			4. Thuan Thanh
			5. Phu Hiep
			6. Phu Hoa
			7. Thuy Bieu
			8. Thuy Xuan
		3. Huong Thuy	
			1. Phu Bai
			2. Thuy Van
			3. Thuy Thanh
			4. Thuy Bang
			5. Thuy Phuong
			6. Thuy Phu
		4. Phu Vang	
			1. Phu Vang
			2. Phu Ho
			3. Phu Luong
			4. Phu My
			5. Phu An
			6. Phu Da
			7. Vinh Phu
			8. Vinh Hai

Number	Province	District	Commune
2	**HA NOI**	1. Dong Da	
			1. Trung Liet
			2. Nam Dong
			3. Cat Linh
		2. Hai Ba Trung	
			1. Nguyen Du
			2. Pho Hue
			3. Bach Dang
		3. Long Bien	
			1. Long Bien
			2. Thach Ban
			3. Bo De
		4. Me Linh	
			1. Quang Minh
			2. Tien Phong
			3. Tam Dong
		5. Dong Anh	
			1. Dong Anh
			2. Vinh Ngoc
			3. Hai Boi
			4. Tien Duong
		6. Thuong Tin	
			1. Thuong Tin
			2. Quat Dong
			3. Thang Loi
			4. Van Binh
		7. Thanh Tri	
			1. Van Dien
			2. Ta Thanh Oanh
			3. Huu Hoa
		8. Hoai Duc	
			1. Tram Troi
			2. An Thuong
			3. An Khanh
		9. Soc Son	
			1. Soc Son
			2. Phu Linh
			3. Nam Son
			4. Mai Dinh

Number	Province	District	Commune
3	**HO CHI MINH CITY**	1. Dist. 3	
			1. Ward 1
			2. Ward 7
			3. Ward 12
		2. Dist. 5	
			1. Ward 3
			2. Ward 9
			3. Ward 14
		3. Dist. 7	
			1. Binh Thuan
			2. Tan Hung
			3. Tan Phong
		4. Thu Duc	
			1. Hiep Binh Chanh
			2. Hiep Binh Phuoc
			3. Linh Xuan
			4. Linh Trung
		5. Dist. 8	
			1. Ward 2
			2. Ward 8
			3. Ward 11
			4. Ward 12
			5. Ward 16
		6. Tan Binh	
			1. Ward 3
			2. Ward 6
			3. Ward 10
			4. Ward 13
			5. Ward 15
		7. Can Gio	
			1. Can Thanh
			2. An Thoi Dong
			3. Tam Thon Hiep
		8. Cu Chi	
			1. Phuoc Vinh An
			2. Phu Hoa Dong
			3. Tan Thanh Dong
			4. Tan Phu Trung