

**FACTORS RELATED TO NEEDS IN PALLIATIVE CARE
AMONG PATIENTS WITH HEPATOCELLULAR CARCINOMA**


LE THI HIEN

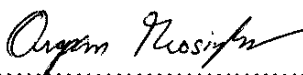
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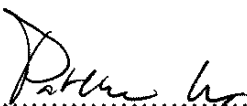
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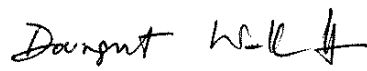
Thesis
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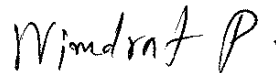
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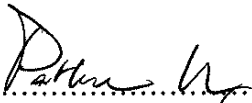
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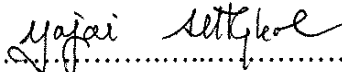
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FACTORS RELATED TO NEEDS IN PALLIATIVE CARE AMONG PATIENTS WITH HEPATOCELLULAR CARCINOMA

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THESIS ADVISORY COMMITTEE: WALLADA CHANRUANGVANICH, D.N.S.,
ORAPAN THOSINGHA, D.N.S.**ABSTRACT**

Patients with Hepatocellular carcinoma (HCC) in Vietnam have been increasing and they were more suffered from various symptoms which lead to increase needs in palliative care. This descriptive correlational research was to identify relationship between physical symptoms, anxiety-depression, social support and needs in palliative care among HCC patients. The Symptom Management Theory was utilized as a framework. The study conducted among 115 HCC patients with HCC at the Nuclear medicine and Oncology center in Hanoi, Vietnam. The data was using demographic questionnaire, Cohen-Hoberman Inventory of Physical Symptoms (CHIPS), Multidimensional Scale of Perceived Social Support, Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv), and Hopkins Symptom Checklist 25 (HSCL- 25). Spearman's rho was employed to test the relationship among all variables. The majority of the patients were male (74.8 %) and ages ranged from 22 to 80 years with the average age of 57.3 years (± 11.29 years). The patients suffered from physical symptoms with 40.9 % quite a bit, 39.1% little bothered and 6.1% extremely bothered. The mean scores of support from family, friends and significant others were 26.17 ± 3.10 , 23.07 ± 5.84 , and 10.03 ± 4.50 , respectively. The percentage of patients who had anxiety and depression were 56.5%. The highest prevalence of problem and need were in physical symptoms. (83.5%, 86.1%, respectively). Physical symptoms were high significant positively correlated with problems and needs in palliative care. ($r = .808$, $p = .000$; anxiety and depression had high positive correlation significantly with problems and needs in palliative care ($r = .886$, $p = .000$). Social support had low negative correlation significantly with problems and needs in palliative care ($r = -.219$, $p = .000$). So, this study recommended that nurses should assess and manage patients' symptoms, control their psychology and promote their social support. To improve palliative care, standard guidelines for symptom managements in palliative care should be developed and implemented. Moreover, further research should be conducted to test effectiveness of the guidelines.

KEY WORDS: NEEDS IN PALLIATIVE CARE / HEPATOCELLULAR
CARCINOMA / SOCIAL SUPPORT / PHYSICAL
SYMPTOMS / AXIETY AND DEPRESSION

88 pages

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LIST OF ABBREVIATIONS

CHIPS	Cohen-Hoberman Inventory of Physical Symptoms scale
HCC	Hepatocellular carcinoma
HSCL- 25	Hopkins Symptom Checklist 25
MSPSS	Multidimensional Scale Perceived Social Support
PNPC-sv	Problems and Needs in Palliative Care questionnaire-short version

CHAPTER I

INTRODUCTION

1.1 Background and significance of the study

Hepatocellular carcinoma is considered as the 5th common type of cancer in the world and the 3rd reason for the deaths in connection with cancer (Attwa & El-Etreby, 2015). Each year nearly one million deaths are caused by Hepatocellular carcinoma (HCC) (Teo & Fock, 2001). HCC occurs most commonly in Asia, in which the total about 80% of all cases is found in there (*Bosch et al., 2004*). The survival rate after five years is under five percent if the patients are diagnosed to be at advanced stage of HCC (Sun & Sarna, 2008). The HCC patients have a poor prognosis if they did not receive a specific treatment. The survival times of early and advanced stage HCC patients are 6-9 months and 1-2 months, respectively. Thus, HCC is an important health problem in Asia and the world (*Bosch et al., 2004*).

HCC patient rates are higher in males than females. The study conducted in 2000 has shown that the number of liver cancer cases in men was much higher than in women, specifically about two to four times (*Bosch et al., 2004*). Especially in Asian, where has high number of patients catching viral hepatitis. It is one of the most common reasons leading to HCC (Sun & Sarna, 2008). The HCC often appears in poor countries and less developed and associated with hepatitis infection. Vietnam is a country which has high rate of viral hepatitis infection that cause a huge public health problem. Recent studies have shown that incidence of current HBV infection (HBsAg+) ranges from 10% -20% in the whole population and 20% - 40% among HIV+ and injecting drug users patients (Nguyen, 2012). So that Vietnam is a country having the high rate of liver cancer which is the cause of mortality of many people.

According to Kudo and colleges' study (2015), they reported HCC is the most popular cancer in Asia, but recently, the rate has been increased rapidly in Western countries. Therefore, HCC is a global medical issue that urgently needs to be solved. The highest rate of HCC was reported in Eastern and South-Eastern Asia,

whereas Middle Eastern countries have moderate prevalence rate, and the lowest one was found in Central Asia and some parts of the Middle Eastern (Ashtari et.al.,2015).

The patients with HCC often suffer from a number of various symptoms as HCC is usually diagnosed in late stage despite the screening recommendations at-risk population (Tejeda-Maldonado et al., 2015). Prognosis of HCC is strongly correlated to disease stages when diagnostic. Patients who are diagnosed with HCC usually have multiple symptoms such as fatigue, weight loss, pain, ascites and jaundice (Sun & Sarna, 2008). HCC patients are often incapable of caring for themselves and they need special care from medical institutions or hospitals. Symptoms and signs of terminally ill HCC patients in hospice are very severe and should be managed appropriately (Lin et al., 2004). Until now, despite the fact that cancer treatments and aggressive symptom management are two important factors for improving physical functioning and quality of life of HCC patients (Sun & Sarna, 2008), their efficiency is still insufficient. The patients with terminal illness approaching the last dates of their lives suffer from physical distress which they concern most. Appropriate symptom management helps patients and their families maintain hope, connections with sociality, and optimism (Kumar. M& Panda, 2014). Therefore, providing quality palliative care is necessary to diminish the discomfort caused by HCC symptoms and improves the quality of life of HCC patients.

To supply effective palliative care practice, the identification of requirement referring to palliative care from patients is crucial. WHO has shown that palliative care is an access for bettering quality of life of patients and their families. The cancer patients often suffer from the problems related to life-threatening illness. The concept of palliative care consists of avoidance and reduction of suffering symptoms by early diagnosis, assessment and alleviation of pain and other physical, psychosocial and spiritual problems (WHO). Palliative care for terminally HCC patients and/or poor functional status focuses on comfort care and symptom control (Fitzmorris et al., 2015). It is estimated that from 15 to 20% patients with end stage of HCC have median survival length less than 3-4 months (Kumar et al., 2008; Paul et al., 2009). The treatment of HCC end stage is symptom management and no radical treatment. Patients with end stage or terminal HCC have a poor survival rate therefore they need palliative care including management of pain, nutritional and psychological

support (Kumar & Panda, 2014). One of the palliative care goals is supporting patients and their families in making difficult medical decisions especially when the outcomes are uncertain. When patients are diagnosed with a serious, and potentially life-danger disease, they have required palliative care since the diagnosis time to the end of life. Besides, it is necessary to choose a suitable therapy for curing disease or maintaining life (Kasl-Godley et al., 2014). Although the main purpose of palliative care is improving quality of life, it also can have positive effect on illness course or even if it is given early enough, it can help to lengthen the life (Temel et al., 2010). As such, palliative care is an important part in treatment process for HCC patients.

In Vietnam, hospitals or palliative care centers for patients, especially for advanced-stage-cancer patients are not really popular. This is because of the limitation of infrastructure and human resources, as well as the capacity of nurses on palliative care in public hospitals seem to be fairly restrictive. In the study of Ly Thuy Nguyen and colleagues (2014) in three oncology hospitals in the North of Vietnam, the results indicate that nurses' palliative care knowledge has low scores and it associated with pain and other symptom management as well as psychological and spiritual problems. With cancer patients who need palliative care, nurses have reflected discomfort attitudes on communicating about death and establishing therapeutic relationships. Therefore, improvement of knowledge and skills of palliative care for nurses who are working in oncology hospitals is necessarily required (Nguyen, Yates, & Osborne, 2014). Besides, research on HCC treatment and palliative care for patients anticipated dying is still limited in number (Hansen, Rosenkranz, Vaccaro, & Chang, 2015). In addition, the palliative care can reduce economic burdens for patients and their family. A study in United State of America indicated that the amounts of money for patients who receive palliative care at hospital are lower than other patients who are not under palliative care (Morrison et al., 2008).

Available evidence indicated that palliative care has not been appropriately provided for HCC patients. The HCC patients coped with symptom experiences, treatment decisions, and unsatisfying information and unmet demand for palliative care (Hansen et al., 2015). The limitations of numbers and effectiveness of potent analgesics prevent HCC patients from receiving better palliative care (Ladep et al., 2014). A research of palliative care practice in 120 cancer centered hospitals, USA,

revealed that 23% of the centers offer palliative care, 37% provide hospice for inpatients, 75% report the median time of beginning palliative care to patients' death of 30 - 120 days. However, the research programs, palliative care fellowships, and mandatory rotations for oncology fellows were uncommon for advance education (Hui et al., 2010).

The patients diagnosed with HCC; which may have negative impacts on psychology of patients and their family. HCC patients suffer significantly from poor physical status, quality of life in all aspects and usually are exposed to anxiety and depression (Ryu et al., 2010). This is supported by a study which reported that HCC patients have the third highest reported psychological symptoms such as psychological distress or depression among patients with fourteen other forms of cancer (Zabora et al., 2001). It means psychological condition especially anxiety and depression have great negative impact to HCC patients. The fact that HCC patients have psychological problems requires palliative care to find out the need for assessment and treatment (Austin et al., 2011). However, research on the associations between anxiety and depression and patients' needs of palliative care is still limited on the number. Thus, there is a need of further research on this topic of interest.

Family and society play very important roles in providing care and support for cancer patients, especially HCC patients. There should be some changes in palliative care, for example letting family support during treatment process while enhancing the interaction between patients and medical staffs. This will help reduce the burden for hospital and meet the palliative care needs (Robinson et al., 2015). It is proved that the establishment of support group plays an important part in psychosocial service which helps cancer patients less stress full and more active. It is also a common type of social support (Brunet et al., 2014). For this reason, social support is very important for HCC patients in treatment process and improves palliative care.

According to literature review, the research on needs in palliative care among HCC patients in Vietnam is still limited. Thus, the researcher need to explore factors related to needs in palliative care in patients with HCC by identifying the relationships between physical symptoms, anxiety and depression, social support with needs in palliative care among HCC patients in hospital. The results of the study can provide the gap of knowledges between palliative care needs and its practices for HCC

patients. These knowledges can be used to develop nursing care and palliative care program in order to improve quality of care for HCC patients.

1.2 Research questions

1. What are needs in palliative care among HCC patients?
2. Does the physical symptoms; anxiety and depression; social support correlate with needs in palliative care among HCC patients?

1.3 Purpose of the study

1. To describe palliative care needs among HCC patients in The Nuclear medicine and Oncology center in Bach Mai Hospital.
2. To identify relationship between physical symptoms, anxiety and depression, social support with needs in palliative care among HCC patients.

1.4 Hypothesis

1. Physical symptoms are positively correlated with needs in palliative care for HCC patients.
2. Anxiety and depression are positively correlated with needs in palliative care for HCC patients.
3. Social support is negatively correlated with needs in palliative care for HCC patients.

1.5 Conceptual framework

The Symptom Management Theory was developed by Dodd and colleagues in 2001. Nursing Symptom Management Model is relying on the principle that effective symptom management should be mentioned in all three domains: Person, Environment and Health/ Illness. In the revised model, these recognized domains are

contextual variables affecting all 3 dimensions of the model: symptom experience, management strategies and outcomes. Symptom experience involves a person's feeling of a symptom, symptom meaning valuation and symptom reaction. The aims of symptom management strategies are to prevent or delay a bad effect through biomedical, professional and self-care strategies. Symptom outcomes are results of both above processes (Dodd et al., 2001).

According to the Symptom Management Theory, HCC patients who experience with very severe symptoms related to their health problems can be viewed as having symptom experiences or suffering with physical symptoms (Sun, & Sarna, 2008). This leads to the needs or requirements of palliative care which can be referred to the symptom management domain of this theory. The main factors found to be related to the needs of the patients in this health problem include the psychological factor and the sociological factor. Available evidence supports that patients' anxiety and depression as well as their perceived social support are important predictors of the need for palliative care among these patients. During treatment process, If the families and patients were enhanced the interaction to medical staffs this will help reduce the burden for hospital and meet the palliative care needs (Robinson et al., 2015). It is proved that the establishment of support group plays an important part in psychosocial service which helps cancer patients less stress full and more active. (Brunet et al., 2014)

In accordance with Dodd, person and environment factors influence symptom experiences. Symptom experiences have interaction with outcomes. Physical symptoms, anxiety and depression are derived from symptom experiences domain; social support is a factor of environment domain and need in palliative care is outcomes. Each domain can affect each other (Dodd et al., 2001). Therefore, the Symptom Management Theory can be used to guide the hypothesis that there is a correlation between physical symptom, anxiety and depression, social support and needs in palliative care among HCC patients.

The relationship between factors and outcome indicators are illustrated in the following conceptual framework:

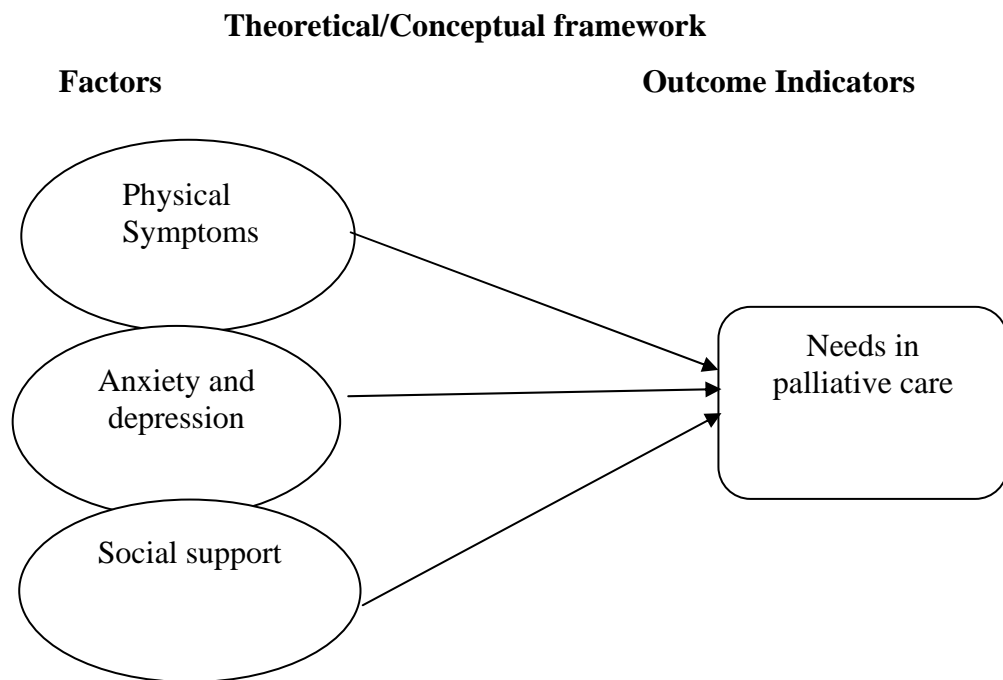


Figure 1.1 The research framework modified from Symptom Management Theory (Dodd et al, 2001)

1.6 Scope of the study

This study analyzes the relationship between physical symptoms, anxiety and depression, social support and needs in palliative care of 115 patients with HCC. The patients are 18 years or older being treated as inpatients at The Nuclear medicine and Oncology Center in Bach Mai Hospital from August to October, 2016.

1.7 Expected outcomes and benefits

1) Nurses can apply this knowledge for developing palliative care program to HCC patients.

2) Health care teams can use this knowledge to develop effective clinical practice guideline for HCC patients.

3) This knowledge can be used for the other research in areas of HCC study.

1.8 Definition of terms

The needs in palliative care: The needs in palliative care refers to a desire for receiving support in connection with an experienced problem. Problems relate to patients' health status and quality of health care for both patients and their family. It can be in need for further professional care (Osse et al., 2000). In this study, needs in palliative care will be measured by The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv) developed by Osse and colleges (2007). The scale was translated into Vietnamese which used back translation technique. This version consists of 33 items divided into eight parts including: carrying out daily activities, physical symptoms, self-reliance, social issues, psychological issues, spiritual issues, financial issues, information needs. There are two main purposes of these 33 questions. Firstly, they demonstrate the degree which patients actually experience a problem (Yes/ Sometimes/ No), and secondly, their need for professional support (Need more help than at present/ current level of help is sufficient/ No need). The higher scores are higher needs for more help.

Physical symptoms: Physical symptoms refer to bodily symptoms that cause bother or distress to the patients and the common physical symptoms in HCC patients consist of pain, fatigue, weight loss, and obstructive syndromes (Cohen, & Hoberman, 1983; Sun, & Sarna, 2008). In this study physical symptoms will be measured by Cohen-Hoberman Inventory of Physical Symptoms scale (CHIPS scale) (Cohen, & Hoberman, 1983). The scale was translated into Vietnamese using back translation technique. This scale composes of 33 items measuring how much that physical symptoms has bothered or distressed the patients for the last two weeks. Items are rated on a 5-levels scale from "not at all" to "extremely bothered". Total scores of physical symptoms from 0 to 132 and higher scores indicate extremely of physical symptoms.

Anxiety and depression: Anxiety refers to an uncomfortable feeling that people experience in terms of feelings, behaviors, thoughts, and physical sensation. It is a general term for several disorders that cause nervousness, fear, apprehension, and worrying (Medical news today, 2015). Depression refer to an illness that involves the body, mood, and thoughts and that affects the way a person eats, sleeps, feels about himself or herself, and thinks about thing (Medicine net, 2014). In this study anxiety

and depression will be measured by Hopkins Symptom Checklist 25 (HSCL- 25). The HSCL- 25 was originally designed by Parloff, Kelman, and Frank at Johns Hopkins University and developed by Rickels (Parloff et al. 1954). The scale was translated into Vietnamese using back translation technique. It consists of 25 items: part I of the HSCL-25 has 10 items for anxiety symptoms; part II has 15 items for depression symptoms. The scale for each question includes four categories of response (“not at all”, “a little”, “quite a bit”, “extremely” rate 1 to 4, respectively). The scores of 2 parts are calculated: the total score is the average of all 25 items and higher scores indicate higher symptoms. Individuals with average score greater than 1.75 are considered symptomatic.

Social support: Social support is a compound construction in three main aspects: psychological, informational, and instrumental support (Thoits, 1986). In this study, social support of HCC patients will be measured by the Multi-Dimensional Support Scale (Winefield, Winefield, & Tiggemann, 1992). The scale was translated into Vietnamese using back translation technique. It is composed of 12 items. The items which refer to the source of social support are divided in to three groups, namely family (Fam), friends (Fri) or significant other (SO). The score of each question is from 1 to 7 ((1) Very strongly disagree, (2) strongly disagree, (3) mildly disagree, (4) neutral, (5) mildly agree, (6) strongly agree, (7) very strongly agree. Total scores of social supports from 12 to 84 and high scores indicate better social support.

CHAPTER II

LITERATURE REVIEW

This chapter provides a literature review of factors associated with needs in palliative care among patients with Hepatocellular carcinoma (HCC) patients. The contents enhance the understanding concerning needs in palliative care among patients with HCC based on symptom management theory. The chapter will start by providing information related to patients with HCC, including the incidence, the pathophysiology and impacts of the disease on patient outcomes. This is followed by the discussion of palliative care needs among patients with HCC. The symptom management theory used to guide the development of a conceptual framework for this study will also be described. Lastly, the factors related to the needs of palliative care among HCC patients will be addressed.

2.1 Patients with Hepatocellular carcinoma (HCC)

2.1.1 Incidence of HCC

2.1.2 Pathophysiology of HCC

2.1.3 Impact of HCC

2.2 Needs in palliative care among patients with HCC

2.2.1 The concept of palliative care

2.2.2 Needs in palliative care among HCC patients

2.3 Symptom management theory as a conceptual framework to explain needs among HCC patients

2.3.1 Symptom management theory

2.3.2 Symptom management theory and the HCC patients

2.4 Factors associated with needs among HCC patients

2.4.1 Physical symptom its association with needs among HCC patients.

2.4.2 Anxiety and depression its association needs in palliative care among HCC patients

2.4.3 Social support and its association needs in palliative care among HCC patients

2.5. Conclusion

2.1 Patients with Hepatocellular carcinoma (HCC)

2.1.1 Incidence of HCC

Hepatocellular carcinoma (HCC) is a significant cause of cancer-related deaths in the world because it is the fifth most typical cancer and especially the third most important cause for men. The increasing number of new HCC cases each year is nearly the number of deaths caused by this cancer. The hepatocellular carcinoma (HCC) expansion is powerfully influenced by various regions, for instance; 5 to 15 cases in Western Europe and USA while 40 cases in Asia and Japan per 100,000 per year (McGlynn, 2011). Hepatocellular carcinoma (HCC) is the most rapid increasing tumor in the USA, and its prognosis stays low with a 5-year survival rate about 12% (Vilarinho & Taddei, 2015). Incidence for HCC in males is higher than in females Asia, where there is tremendously high viral hepatitis (Sun & Sarna, 2008). It often happens in poor countries and less developed and related to hepatitis infection. According to Kudo and colleagues study (2015), they reported that HCC is most common in Asia, but now rate is rising faster in the Western countries.

It can be said that HCC is a global health issue that urgently needs to be addressed. The highest rate of HCC was reported in Eastern and South-Eastern Asia, whereas Middle Eastern countries have moderate prevalence rate, and the lowest one was witnessed in Central Asia and some part of the Middle Eastern (Ashtari et.al, 2015). Vietnam is also a country having high rate of liver cancer, there is also the cause of mortality of very many people.

From these proofs, we can see that HCC rate is more and more increasing not only in Vietnam but also in other countries in the world. HCC can cause enormous damage to human as well as economy especially in poor and under-developed countries. Vietnam is one of the countries that have the highest HCC rate in the world,

so we need to have government's policies to support HCC patients and restrict the development of this disease.

2.1.2 Pathophysiology of HCC

Liver is the biggest organ in human body. There are a number of liver's important functions; for example: providing bile to assist with dissolving fat; changing sugar and fat into energy; saving nutrients; supplying protein for the blood; helping the blood to clot; producing other necessary chemicals for the body; destroying unhealthy elements such as alcohol and drug, and giving up waste matters (Biomedicine, 2002)

Hepatocellular carcinoma is the same with any other cancers; it grows up when there is a genetic mutation in cells that causes the higher rate of cell replication than apoptosis. Particularly, chronic infections of hepatitis B and/or C can increase the progress of HCC constantly causing the immune system to greatly affect the liver cells, some of which are disrupted by the hepatitis virus or outside factors (Chien-Jen et al, 2006). An applicable hypothesis now is carcinogenesis is caused by mistakes during repair which follows constant cycle of damage. Chronic hepatitis B and/ or C causes HCC through the stage of cirrhosis. The viral genome attacks infected cells can directly make a non-cirrhotic liver to develop HCC. Besides, the constant use of a plenty of ethyl alcohol can bring the same effect. Alcoholism, chronic hepatitis B and Generally cause cirrhosis of liver cells. The building up of toxin as well as aflatoxin from *Aspergillus* in the liver leads to carcinogenesis of hepatocellular cancer. According to Wikipedia, 2005, there are relatively high rates of hepatocellular carcinoma in some countries like China and Africa because of the combination of the high rate between aflatoxin and hepatitis B

The signs and symptoms of HCC depend on the stage of disease. In the first stages of liver cancer, symptoms are often not apparent but in the late stages often have some symptoms such as abdominal pain, back pain, weight loss, anemia, jaundice, itching, appetite loss, fever, fatigue, sickness and nausea, etc.

Liver is an especially important organ in human's body because it is directly related to the body's metabolism. The development of pathology of HCC is associated with hepatitis virus infection particularly B and C hepatitis viruses. Furthermore, living environment and eating habit seem to be a huge influence. The restriction

of developing of HCC in treatment process is connected to stages of disease. Therefore, disease detecting at late and serious stages is leading the limitation in successful treatment.

2.1.3 Impact of HCC

HCC is a more and more important public health matter in the world. It creates impacts in many aspects such as economic, health status of patients, psychology and social issues. Following reported of Mishra and colleagues (2013), median charges at the time of discharge increased from \$29,466 per case (2005) to \$31,656 per case (2009). Total HCC charges in USA rose from \$1.0 - \$2.0 billion (2009) of the US nationwide inpatient patients. The number of inpatient cases and the inpatient charges associated with HCC continued to increase sharply (Mishra et al., 2013). It means that HCC have affected to family and social economics.

HCC also have an impact on physical and psychological health of patients. The results from the study by Fan & Eiser (2012) demonstrated the effect of this disease. HCC is in connection with physical symptoms, psychosocial stress, and other negative changes as well. HCC is a chronic disease and unable to cure, so patients always suffer from various unpleasant symptoms although they can be controlled (Fan & Eiser, 2012). It makes the patients lose their ability to do their activity in everyday lives. Besides the patients suffer from depression about malignant disease leads to fatigue and even more difficult to return to normal life.

The most significant effects are caused by hospital burdens such as stay in hospital for a long time and bed occupancy, increased workload on health care professions, increased hospital mortality rates and higher re-admission rates. The number of new HCC cases seen at Tulane, USA, increased by 300%, paralleling reported national trends (Tangutur et al., 2011). Patients with HCC as well as other types of patients are increasing, but the development of infrastructure and human resources are not enough for it. It leads to the burden of disease to hospitals and other health care facilities.

Detecting HCC is a significant life event of patients and their family. It affects directly to the physical and mental health as well as their family's economy.

HCC is a dramatic impact for not only patients and their family but also for the whole society.

2.2 Needs in palliative care among patients with HCC

2.2.1 The concept of palliative care

Palliative care is an effective method and is referred a lot in improvement of treatment quality for patients. There are a plenty of definitions of palliative care, however; it is normally mentioned as follow.

Palliative care is considered as an active care of patients who are suffering from advanced stages of disease. Palliative care helps manage pain and other symptoms as well as provide psychological, social and spiritual support for patients. The aim of palliative care is to bring patients and their families the best quality of life. Palliative care should be provided as soon as possible for patients because it has the direct connection with treatment process of patients.

Palliative care is care provided for patients from diagnosis to death about all aspects of physical, psychological, social, and spiritual health (Quest, Marco & Derse, 2009). It is such a wide concept and it is very helpful for patients at any stages of illness. The quality of life for patient and their family will be improved considerably if they receive an appropriate support care (National Consensus Project for Quality Palliative Care, 2009; World Health Organization, 2007; Kasl-Godley, King, & Quill, 2014). To provide patients with the best and most effective palliative care, it's necessary to have a team of professionals including, physicians, nurses and other health experts to work collaboratively.

Palliative care aims attention at alleviating symptoms, pain, physical and mental problems of a serious illness patients. Its purpose is to improve the life quality of the patient as well as their family become better. It is not only essential in managing symptoms of the patient's illness condition, but also concentrates in providing better quality of life (Onyeka, 2010).

Palliative care is considered as an extremely necessary and helpful care for patients. It's a whole health care for patients that helps improve their quality of life. It is useful for cancer patients who are in need in palliative care.

2.2.2 Needs in palliative care among HCC patients

Hepatocellular carcinoma (HCC) is one of the most serious diseases. It is the third dangerous cancer causing death and most of the patients do not receive effective treatment method such as liver transplantation. The patients who are in their advanced or progressive stage which occur from metastasis of disease always come to the hospital with physical pain. Patients may suffer with many symptoms including fatigue, with instability, loss of appetite, as well as exhaustion and drowsiness. Moreover, there are 15-20% of terminal stage HCC patients with median survival of less than 3-4 months (Kumar et al, 2008; Chalamalasetty, et al., 2009). So, the management is only symptomatic and there is no specific medicine or treatment to cure the disease. Patients with end stage or terminal HCC have a poor survival should accept palliative care including control of pain, nutrition and psychological encouragement (Kumar & Panda, 2014). For terminally HCC patients and/or poor functional status, palliative care focuses on comfort care and symptom control (Fitzmorris, Shoreibah, Anand, & Singal, 2015).

HCC patients have a lot of problems in all aspects physically, psychologically and socially. So that assessment patient's need is an important step for taking care process. The good evaluation will help us make a plan for effective patient care.

In this study, needs in palliative care was assessed by The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv). It was developed by Osse, Bart H. P and colleges (2007) with 33 items. The validity and reliability were established with it item responded; it interned consistency, and with it correlated with the original PNPC and with European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 and COOP/WONCA quality-of-life measures. In this study, used eight dimensions of the PNPC-sv, addressing in total 33 topics: carrying out daily activities (3 terms), physical symptoms (12 terms), self-reliance (4 terms), social issues (5 terms), psychological issues (5 terms), spiritual

issues (4 terms), financial issues (2 terms), and information needs (1 terms). For these 33 topics, patients can first indicate the degree to which they actually experience a problem (Yes/Sometimes/No), and second; their need for professional support (Need more help than at present/current level of help is sufficient/No need). The higher scores are higher needs for more help.

The PNPC-sv is a concise, patient-centered tool that helps to identify the problems affecting the patient's quality of life and needs for care. It identifies prevalent needs for care and appears reliable of Cronbach's $\alpha > 0.70$ (Osse et al., 2007).

2.3 Symptom management theory as a conceptual framework to explain needs among HCC patients

2.3.1 Symptom Management Theory

Symptom Management Theory was developed by Dodd and colleagues in the year 2001. It consists of many aspects which have the conceptualized relationship to each other in both the original and revised model. The relationships among these aspects were revised based on the study and discoveries and on further definitions by the professors and students of the UCSF Symptom Management Center. The UCSF Symptom Management Theory is a deductive, middle range theory described symptom management as a several aspects taking place in the domains of nursing (Humphreys et al., 2008). The model is relied on programs of research working with adult patients (Dodd et al., 2001). In this final model, the three significant domains are person, health/illness and environment influenced all three dimensions of 1) symptom experience, 2) management strategies and 3) outcomes.

Symptom experience includes an individual's perception of a symptom, evaluation of the meaning of a symptom and response to a symptom; Symptom management strategies is the goal of symptom management is to avert or delay a negative outcome through biomedical, professional and self-care strategies; Symptom outcomes is the outcomes emerged from symptom management strategies as same as from the symptom experience (Dodd et al., 2001).

There are 6 stated assumptions within the theory addressing the nature of symptoms, the focus of symptom management strategies, and relationships within the model. These six assumptions were updated in the 2001 as follow: 1) the gold standard for the research of symptoms which is relied on the perception of the individual experiencing and reporting the symptoms. 2) the symptoms that are not experienced by an individual to apply this model of symptom management. The individual may be vulnerable for the symptoms development because of the situation determinants such as a working danger. So, Intervention strategies should be started before the patient experiences the symptoms. 3) unutterable patients may experience symptoms and the interpretation by the parents or caregiver is assumed to be accurate for purposes of intervening. 4) all of the disturbing symptoms must be controlled. 5) the management tactics may be focused on an individual, a group, a family, or the work environment. 6) the symptom management is a dynamic system that is adjusted by individual outcomes and the influences of the nursing domains of person, health/illness, or environment (Dodd, et al., 2001).

This theory is perfectly suitable for the research to find out the factors that influence the need in palliative care for HCC patients because the symptom management is one of the most important aspects for improving the effectiveness of palliative care. Consequently, The Symptom Management Theory is used as a conceptual framework for this study.

2.3.2 Symptom Management Theory and the HCC patients

According to the Symptom Management Theory, it is important to establish interventions and action plans that will be helpful for HCC patients in decreasing their symptom burden. The symptom experience component in symptom management theory is the most specifically and totally described and is considered as the very first part of the symptom management process. This dimension consists three aspects including the individual's perception, evaluation, and response to a symptom. Bidirectional arrows are used to describe the relationships among these aspects. These relationships are recognized when they happen repetitively and at the same time (Humphreys et al., 2008). It covers all aspects of HCC's symptoms. Therefore, the Symptom Management Theory is a particularly useful conceptual guide for the present

study to explain the relationships among the selected factors including physical symptoms, anxiety, depression and social support.

The HCC patients are experiencing a number of burdens; for example: physical, psychological, social, spiritual, existential, medical, financial and social difficulties (Sun & Sarna, 2008). Consequently, hostile management of disease and treatment-related symptoms is particularly effect to the functional status and quality of life for HCC patients. Nurses can provide care of HCC patients through several strategies like using the guidelines for patients' common cancer-related symptoms as tools for symptom management. The palliative care guideline should rely on patient needs and preferences, physical status, and disease condition. Moreover, the symptom management program can be best given in a cooperative environment including the skills of physician, nurses and other health care professionals.

HCC is a disease that occurs silently, patients often detected at later stages. Therefore, they have to go through a lot of symptoms. Treatment in advanced stages often does not get effective treatment. So, controlling patients' symptoms leads to improving patients' quality of life.

2.4 Factors associated with needs in palliative care among HCC patients

2.4.1 Physical symptoms and its association with needs in palliative care among HCC patients.

The previous researches have shown that HCC patients are often detected at later stages, and limited the effective treatments like transplantation or curative ablation. Meanwhile, they usually suffer from a lot of physical symptoms; for example, anorexia, fatigue, ascites, nausea/vomiting, pruritus and constipation. Therefore, palliative care is an absolutely necessity and helpful method for them.

The patients in the severe symptom group had considerably poor functional status and quality of life (Ryu et al., 2010). Symptom management in terminal stage HCC includes management of those aforementioned symptoms (Kumar & Panda, 2014). Pain in HCC can be caused from disease and treatment. Both are very

common and significant cause of morbidity. The pain of HCC tends to be most prominent in the right upper quadrant and described as deep, aching, sharp or stabbing. The HCC patients should be used to assess pain and, recognize its often-transient nature and need to be reassessed frequently (Kumar & Panda, 2014).

Weight loss and malnutrition is a common symptom in HCC patients, especially in terminal stage. It is known that patients without weight loss and muscle wasting have higher clinical outcomes than patients with these symptoms. Nutritional status evaluation is important to recognize the risk of reducing quality of life or functional status in patients with HCC. Prognostic nutritional index has been found to be independently related to general survival in HCC patients. Added to this in the late stage, anorexia is a typical symptom of the primary metabolic cachexia syndrome called anorexia-cachexia syndrome (Del, Fabbro, Dalal, & Bruera, 2006). Therefore, it is necessary to supply nutrients to improve the nutritional status and also quality of life. Since, quality of life is certainly the most important criteria in patients with terminal cancer in general and is mainly dependent on nutritional status (Ravasco, Monteiro-Grillo, Vidal, & Camilo, 2004).

Nausea and vomiting could be occurred from either chemotherapy or radiation therapy or could occurred from the disease process. Pruritus can range in severity from mild, to moderate and lead to sleep disturbance. The ascites caused by an imbalance between influx and efflux of fluid from the peritoneal cavity. When ascites occurred, many symptoms can be found such as increased intra-abdominal pressure, abdominal wall discomfort, dyspnea, anorexia, early satiety, nausea and vomiting, fatigue, esophageal reflux, pain, and peripheral edema (Kumar & Panda, 2014). The best supportive care is recommended for patients who lack the hepatic reserve to tolerate therapy (Vilarinho & Taddei, 2015). In addition, palliative care and symptom managements must be applied to improve symptoms, survival times and the quality of life (Paul, Manjunatha, & Acharya, 2009). Moreover, a common and distressing symptom is fatigue. Thus, education for continuing home care should advise the proper sleep hygiene and energy conservation tips for the patients. Particularly important is careful medication review that may identify adverse effects escalated fatigue (Kumar & Panda, 2014).

Physical symptoms are the bodily symptoms that cause bother or distress to the patients. These symptoms can greatly affected the quality of life of patients. The needs in palliative care for HCC patients derived from the discomfort that caused by the symptoms such as pain, nausea, vomiting, diarrhea so on. Therefore, the physical symptoms relate to the needs of palliative care among HCC patients

In this study physical symptoms will be measured by Cohen-Hoberman Inventory of Physical Symptoms scale (CHIPS scale) (Cohen, & Hoberman, 1983). This scale composes of 33 items measuring how much that physical symptoms has bothered or distressed the patients for the last two weeks. Items are rated on a 5-levels scale from "not at all" to "extremely bothered". Total scores of physical symptoms from 0 to 132 and higher scores indicate extremely of physical symptoms.

2.4.2 Anxiety and depression and their association with needs in palliative care among HCC patients

Anxiety and depression were very common symptoms of HCC patients since diagnosis that can cause psychological problems of the patients (Hong, & Tian, 2014; Kumar & Panda, 2014). Because HCC cancer is very severe disease, the Of greater concern is the will to live that may fluctuate at the end of life as a result of distress and grief, the physical decline taken by the illness, and spiritual, family, and personality issues. As the result of Akechi's study showed that the cancer patients were consulted for psychiatric evaluation (35%), sleep disorders (19%), anxiety or fear (18%). For other psychological problems, the majority issues were adjustment disorders (34%) followed by delirium (17%) (Akechi et al., 2001). Moreover, depressive and major depression symptoms were reported up to 58% and 38%, respectively (Massie, 2004). However, anxiety and depression always underestimated and these problems effected immune systems and resulted in the patients' survival rate (Williams & Dale, 2006). It means that anxiety and depression are a matter of concern and needs to be assessed together with the needs in palliative care among HCC patients.

In this study anxiety and depression will be measured by Hopkins Symptom Checklist 25 (HSCL- 25). The HSCL- 25 was originally designed by Parloff, Kelman, and Frank at Johns Hopkins University and developed by Rickels

(Parloff et al. 1954). It consists of 25 items: part I of the HSCL-25 has 10 items for anxiety symptoms; part II has 15 items for depression symptoms. The scale for each question includes four categories of response (“not at all”, “a little”, “quite a bit”, “extremely” rate 1 to 4, respectively). The scores of 2 parts are calculated: the total score is the average of all 25 items and higher scores indicate higher symptoms. Individuals with average score greater than 1.75 are considered symptomatic.

2.4.3 Social support and its association with needs in palliative care among HCC patients

Social support refers to the availability of emotional, practical, and informational support from family and friends, and health care providers in relation to the present oncology treatment as patients received. Furthermore, social support is conceptualized as instrumental support including financial, emotional or appraisal support, informational, companionship, and self-esteem support (Chida & Vedhara, 2009). As such family and society has a very important role for patients, especially HCC patients. Change environmental in patient care such as enabling family to stay and improving the physical environment as well as the social relationship between patients and health professionals may be a more realistic approach for decrease the burden of hospitalizations for patients with palliative care needs (Robinson, Gott, Gardiner, & Ingleton, 2015).

The result of lacking social support cause weak fighting spirit of cancer patients. (Grassi, Rosti, Lasalvia, & Marangolo, 1993). The research which was carried out in Chinese Medical Institution reported that effective social and psychological supports would be extremely useful for the improvement of cancer patients' quality of life. It has also shown that cancer patients should have received more care and attention from family and society (Li, Yang, Liu, & Wang, 2016). So, social support is an important aspect in palliative care. If the patients received a good social support, the psychological burden should reduce as well as improve fighting spirit of cancer patients.

In this study, social support of HCC patients will be measured by the Multi-Dimensional Support Scale (Winefield, Winefield, & Tiggemann, 1992). It is composed of 12 items. The items which refer to the source of social support are

divided in to three groups, namely family (Fam), friends (Fri) or significant other (SO). The score of each question is from 1 to 7 ((1) Very strongly disagree, (2) strongly disagree, (3) mildly disagree, (4) neutral, (5) mildly agree, (6) strongly agree, (7) very strongly agree. Total scores of social supports from 12 to 84 and high scores indicate better social support.

2.5 Conclusion

According to the literature review it can be concluded that HCC patients are ones who suffered with a variety of severe symptoms interfering their daily lives and reducing their quality of life. Those symptoms came from the process of disease itself couple with the variety of treatment modalities including radiation therapy and chemotherapy. Providing palliative care is required for this group of patients as it provides them with comfort, holistic, comprehensive and more focused on patients' genuine needs. Employing symptom management model, the phenomena of patients with HCC is clearly explained. While the physical symptoms refer to patient's symptom experiences and patients level of anxiety and depression and the support by the society refer to factors related to symptom management or palliative care. This provides the researcher with clear understanding with these phenomena and will assist the researcher to conduct research to confirm the relationship among these variables. It can be expected that knowledges gain from this study can be used to improve the quality of care among patients with HCC and thus enhance outcomes of treatments.

CHAPTER III

METHODOLOGY

In this chapter included study design, population and sample of the study, studied instruments and their validity and reliability, data collection procedure, human right protection, data analysis.

3.1 Study design

The study was a descriptive correlational study research aimed to study relationships between physical symptoms, anxiety and depression, social support and needs in palliative care for HCC patients. Data were collected from patient hospital records and interviewed patients by questionnaires.

3.2 Population and sample of the study

The population of this study included patients age of 18 years and above, both males and females, who were diagnosed HCC and received treatments in The Nuclear medicine and Oncology center in Bach Mai hospital during the data collection period. The samples were selected according to the criteria as follow:

The inclusion criteria:

- 1) Know that they were diagnosed of HCC
- 2) Able to verbally communicate with the researcher in Vietnamese language.

The exclusion criteria:

- 1) Patients in dying stage with unstable vital sign
- 2) Incomplete fill out questionnaire

Termination criteria:

1) Had poor condition during the interview process such as severe pain, dyspnea or shortness of breath, unconsciousness and unstable vital sign.

Sample size

The determination of sample size was done by using G*power 3.1.9.2 program to calculate sample size for correlational design (Faul, Erdfelder, Buchner, & Lang, 2009). Three parameters require including 1) the level of significance $\alpha = 0.05$, 2) the power of the statistical test (Power $1 - \beta = 0.80$) and 3) the effect size. Because there was limited study about these variables, the researcher will select medium effect size for this study (ES = 0.25). Based on G*power 3.1.9.2, sample size should be at 115 HCC patients.

3.3 Setting

The research conducted at The Nuclear medicine and Oncology center in Bach Mai Hospital. For the first comprehensive general hospital of Vietnam, Bach Mai Hospital established in 1911. With nearly 2000 beds, 2 Institutes, 8 Centers, 21 Clinical departments, 6 Paraclinical departments, 9 Functional departments, 1 Nursing college school. Accordingly, The Nuclear medicine and Oncology center was a public center which had a 400 beds capacity for about 1500 inpatients per year, and it had an out-patient department that provided health check-ups and medical consultations in both oncology and general areas. With approximately 40 medical physicians, 80 nurses and a number of administrative staff, the center provided treatment and caring for most common cancer and tumor diseases, such as liver cancer, lung cancer, breast cancer, thyroid cancer, colon cancer. Daily healthcare services were provided by the oncologists and nurses from 7:30 a.m.- 4:30 p.m. at the inpatient departments. These services included patient examination, treatment and nursing care for cancer patients. The researcher collected data by herself from 11.00 am to 5.00 pm from Monday to Friday until the sample reached the target of the studied sample size. For each sample the researcher spent 30 to 40 minutes on interviewing and collected some data from their patients' records.

3.4 Instruments

The instruments used for data collection included 4 parts as follows:

Part 1 Demographic and medical information

The demographic part consisted of 10 items including name, age, weight, height, gender, occupation, level of education, marital status, payment method, income. The medical information part has 5 items including disease diagnosis, date of treatment, duration of illness, stage of disease, treatment method.

Part 2 Physical symptoms

In this study, physical symptoms were measured by Cohen-Hoberman Inventory of Physical Symptoms scale (Cohen & Hoberman, 1983). The scale was translated into Vietnamese using back translation technique. This scale composed of 33 items. Each item is rated for how much that problem bothered or distressed the individual during the past two weeks. Items are rated on a 5-point scale from "not at all" to "extremely". Total scores of physical symptoms from 0 to 132 and high scores indicate extremely of physical symptoms. Total scores divided to 4 groups: less than 33 scores was not bothered, 33-66 was a little to be bothered, 67-99 scores was quite a bit bothered and higher 99 scores was extremely bothered.

Part 3 Anxiety and depression

Hopkins Symptom Checklist 25 (HSCL- 25) was measured anxiety and depression. The HSCL- 25 was originally designed by Parloff, Kelman, and Frank at Johns Hopkins University and developed by Rickels (Parloff et al. 1954). The scale was translated into Vietnamese using back translation technique. It consisted of 25 items: part I of the HSCL-25 has 10 items for anxiety symptoms; part II had 15 items for depression symptoms. The scale for each question included four categories of response ("not at all", "a little", "quite a bit", "extremely" rate 1 to 4, respectively). The scores of 2 parts were calculated: the total score was the average of all 25 items and the higher scores indicated higher symptoms. Individuals with average score greater than 1.75 were considered symptomatic.

Part 4 Social support

The Multidimensional Scale Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1998). This scale used to measurement perception of social support as it offered from special person, family and friends. The scale was translated

into Vietnamese using back translation technique. It composed of 12 items. The score of each item ranges from 1 to 7: (1) if you very strongly disagree, (2) if you strongly disagree, (3) if you mildly disagree, (4) if you were neutral, (5) if you mildly agree, (6) if you strongly agree, (7) if you very strongly agree. Total scores of social supports ranged from 12 to 84 with higher scores indicated better social support. The study of Somjaiwong showed the Cronbach's α of SSQ was 0.81 in liver cancer patients (Somjaiwong, 2011).

Part 5 Problems and needs in palliative care

The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv) was measured problems and needs in palliative care. It was developed by Osse, Bart H. P and colleges (2007) with 33 items. The scale was translated into Vietnamese using back translation technique. In this study, used eight dimensions of the PNPC-sv, addressing in total 33 topics: carrying out daily activities (3 terms), physical symptoms (12 terms), self-reliance (4 terms), social issues (5 terms), psychological issues (5 terms), spiritual issues (4 terms), financial issues (2 terms), and information needs (1 terms). For these 33 topics, patients could first indicate the degree to which they actually experience a problem (Yes/Sometimes/No), and second; their needs for professional support (Need more help than at present/current level of help is sufficient/No need). The higher scores were higher needs for more help. The PNPC-sv was a patient-centered tool that helped to explore the problems affecting the patient's quality of life and needed for care. The PNPC-sv appeared reliable of Cronbach's $\alpha > 0.70$ (Osse et al., 2007).

3.5 Validity and Reliability of Measurement

3.5.1 Instrument Validity

To use instrument in this research, all scales were verified by 3 experts include 1) oncology doctor, 2) oncology nurse, 3) oncology nursing instructors. The content validity was inspected with CVI of .90 and the linguistic changing was applied for clearly understanding. After verifying by experts, these scales were used with 30 samples to assure their understanding of the contents.

3.5.2. Instrument Reliability

Vietnamese versions of HSCL- 25, MSPSS, PNPC-sv and CHIPS were tested for internal consistency reliability before conducting the actual data collection. The questionnaires and scales were tried out on 30 HCC patients before using with 115 patients at The Nuclear medicine and Oncology center in Bach Mai hospital. Then, the reliability was tested by Cronbach's alpha method. The result showed that Cronbach's alpha of 30 patients and 115 patients for each scale were MSPSS of 0.75 and 0.88, HSCL- 25 of 0.90 and 0.98, CHIPS of 0.89 and 0.94, and PNPC-sv of 0.91 and 0.97.

3.6 Data collection

1) First of all the researcher submitted research proposals to obtain the ethical approval from institutional Review Board of Nursing Faculty Mahidol University and Vietnam National University.

2) After getting the approval and receiving the permission for data collection, the researcher met the director of Bach Mai Hospital, the director of The Nuclear medicine and Oncology center and the head nurse of the center in order to explain the purpose for data collection. The head nurse introduced the researcher to the target population.

3) Then, the researcher approached potential patients to confirm their eligibility based on the inclusion and exclusion criteria. Patients were informed the purposes of the study and provided the consent forms. Patients gave time to decide their participation in the study.

4) After the consent forms were signed, patients were asked to complete the questionnaires had 121 items which include: 1) demographic data questionnaire, 2) CHIPS scale, 3) Multidimensional Scale of Perceived Social Support, 4) The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv), 5) Hopkins Symptom Checklist 25 (HSCL- 25). Selecting patients after three days to seven days admitted hospital. The time used for complete this data collection is about 30-40 minutes. Interviewing time was arranged from 11.00 am to 5.00 pm from Monday to

Friday to minimize the interruptions of patients' treatment and caring which were mostly conducted between 7.30 am to 11.00 am.

5) After finished questionnaire, researcher checked all data again for complete

6) During interviewed or used questionnaire, all of the patients wanted to participant in this study and had not unstable condition for example severe pain, dyspnea and shortness of breath, unconsciousness or unstable vital sign. They could complete all 5 questionnaires.

3.7 Protection of human rights

This study was conducted based on the protection of human rights. The participants were asked to participate in the study. The researcher explained the purpose of the study, the research procedure, benefit, risks, types of questionnaire, length of time for completing questionnaire, and the right to refuse participation in the study anytime. The participants who agreed to participate were informed and assured that the data would be kept confidentially and would be reported only as a group data. Informed consent was signed by all participants.

3.7.1 Submitting the research proposal to get approval from Mahidol University and started the data collection process after received approval from Ethical Committee of Research with Human Subjects of the hospital.

3.7.2 The researcher introduced herself the participants, inform the patients about the research objective and all data collection process. The patients were informed that they had right to refuse to join in the research process. During anytime throughout the research process, patients had their own right to with draw from the research project at any time and would not influence their treatment or caring process. After patients clearly understood and agreed join in the research process, they were invited to sign their name in the consent form.

3.7.3 This research was not caused any risk to the patient's physical health. The data collection process might take time about 30 - 45 minutes. Although the patients did not get any benefit from this research but the results were benefited for other patients who had the same health care problem as the sample.

3.7.4 All contents were kept confidential, only the researcher and the research team were able to get access to the data. Any content related to data that was presented in the thesis or any publication was anonymous. In case of ones who with drawn themselves from the research, all data were deleted from the database and were not used as any part of the research.

3.7.5 If the participants had further questions or require more explanation in regard to the research, they were informed to feel free to ask the researcher at any time throughout the research process.

3.8 Data analysis

1. Quantitative data were analyzed using computer programs .
2. All data were analyzed using descriptive in terms of frequency, percentage, mean and standard deviation and range were used to describe general information and studied variables, including physical symptom, anxiety and depression, social support, problem and need in palliative care.
3. The variables were tested for their normal distribution according to the assumption of the Pearson Product-Moment correlation coefficient. However, all studied variables did not show normal distribution so Spearman's rho was employed to test correlation among the variables.

CHAPTER IV

RESULTS

The purpose of this research is to study the relationship between physical symptoms, anxiety and depression, and social support with needs in palliative care among HCC patients.

The samples were 115 patients recruited from The Nuclear medicine and Oncology center in Bach Mai Hospital, Vietnam from August to October, 2016. Data were obtained by interviewing patients and from the patients' records. The results gave as follow:

- 1) General demographic of HCC patients.
- 2) Medical information
- 3) Physical symptoms, anxiety and depression, social support and needs in palliative care.
- 4) The correlation between physical symptoms, anxiety and depression, social support and needs in palliative care among HCC patients.

4.1 General demographic of HCC patients

Table 4.1 showed demographic data of 115 samples. The majority of patients were male (74.8 %) and most of them were married (92.2%). The average age was 57.3 (SD = 11.29) and age range from 22 to 80 years (table 4.1).

The education level was mainly in secondary school (34.8%) and high school (30.4%) while in primary school and two-year certificate levels were low (1.7% and 2.6%). The education level in college and bachelor degree was 13.9% and 16.5% (table 4.1).

Most of the patients were retired (38.3%) and farmers (21.7%). They mostly lived in cities (42.6%) and rural areas (53.0%). Meanwhile the number of patients who lived in mountainous areas was very low – about 4.3%. The average

monthly income of patients' was 147.7 USD (SD = 95.26) and families' was 304.2 USD (SD= 190.70). All of patients had government insurance (100%) (table 4.1).

The amount of the patient who were living with less than 3 people were 74.8% while living with more than 4 people were 25.2% (table 4.1).

Table 4.1. General demographic of HCC patients (n =115)

Characteristics	Number (n =136)	Percentage (%)
Gender		
Male	86	74.8
Female	29	25.2
Age)years(
≤ 25	2	1.7
26-45	14	12.2
46- 70	88	76.5
≥71	11	9.6
Min :22		
Max :80		
Mean ± SD :57.38 ± 11.29		
Marries		
Married	106	92.2
Single	2	1.7
Separated	3	2.6
Widowed	1	0.9
Divorced	3	2.6
Educational Level		
Primary school	2	1.7
Secondary school	40	34.8
High school	35	30.4
Two-year certificate	3	2.6
College	16	13.9
Bachelor degree	19	16.5

Table 4.1 .General demographic of HCC patients (n =115)

Characteristics	Number (n =136)	Percentage (%)
Occupation		
Farmer	25	21.7
Home worker	6	5.2
Professional	5	4.3
Salesperson	11	9.6
Industrial worker	6	5.2
Retired	44	38.3
Other job	16	13.9
Location of residence		
City	49	42.6
Rural	61	53.0
Mountain	5	4.3
Patient income (USD)		
0 to 100 USD	39	33.9
101 to 300 USD	67	58.3
≥ 301 USD	9	7.8
Min :0		
Max :440.53 USD		
Mean ± SD :147.7 ± 95.26		
Family income (USD)		
0 to 100 USD	12	10.4
101 to 300 USD	43	37.4
301 to 500 USD	51	44.3
≥ 301 USD	9	7.8
Min :8.81		
Max :1321.59 USD		
Mean ± SD:304.2 ± 190.7		
Insurance		
Yes	115	100.0
No	0	0
Number of people live together		
Min :0		
Max :7		
Mean ± SD:2.7 ± 1.4		
0 to 3 person	86	74.8
≥ 4 people	29	25.2

4.2 Medical information

The ratio of participants admitted in hospital less than one week was highest (35.7%). The proportion of patients who stayed from one to two weeks was a little less about 28.7% and those who stayed from two to four weeks were least (23.5%) (table 4.2).

Of the patients enrolled, 33.9% were underweight, 52.2% were normal weight, 9.6% of patients were classified as overweight, and 4.3% were obese. Almost all participants had advanced stage of disease with stage4:80.9% and stage 3:17.4% (table 4.2).

There are three main treatment methods for all participants such as chemotherapy (23.5%), palliative treatment (33.9%) and combination (palliative and chemotherapy) (28.7%) (table 4.2).

Table 4.2 : Medical information (n =115)

Information	Number (n =115)	Percentage (%)
Duration of treatment(day)		
< 7 days	41	35.7
8-14 days	33	28.7
15-28 days	27	23.5
>29 days	14	12.2
Min :1		
Max :60		
Mean± SD:13.99± 12.24		
Weight (kg)		
Min :40		
Max :80		
Mean ± SD :52.48 ± 7.21		
Height (cm)		
Min :140		
Max :180		
Mean ± SD :162.26 ± 7.41		

Table 4.2 : Medical information (n =115)

Information	Number (n =115)	Percentage (%)
BMI		
<18.5	39	33.9
18.5-22.9	60	52.2
23-24.9	11	9.6
≥25	5	4.3
Min :14.51		
Max :28.69		
Mean ± SD :19.94 ± 2.51		
Stage of disease		
Stage 1	1	0.9
Stage 2	1	0.9
Stage 3	20	17.4
Stage 4	93	80.9
Treatment method		
Liver resection	1	0.9
Chemoembolisation (TACE or TOCE)	14	12.2
Chemotherapy	27	23.5
Radiotherapy	1	0.9
Palliative treatment	39	33.9
Combination (Palliative and chemotherapy)	33	28.7

4.3 Physical symptoms of samples

The patients who were extremely bothered with physical symptoms were low (6.1%). The participants had a little bothered were 39.1% and quite a bit were 40.9 %. The mean scores of physical symptoms were $64.11 \pm 2.5.44$. The participants who had not suffered from physical symptoms were 13.9% (table 4.3).

Table 4.3 Physical symptoms of HCC patients

Physical symptom	Number	Percentage
< 33	16	13.9
33 - 66	45	39.1
67 - 99	47	40.9
> 99	7	6.1
Min :13		
Max :110		
Mean \pm SD :64.11 \pm 2.5.44		

4.4 Social support of samples

The result was mentioned in 3 subscale groups which had been expected: 1) perceived support from family, 2) friends, and 3) a significant other. The mean and standard deviations of the three groups of MSPSS and total scale are presented in table 4.4 The mean scores that was represented for family were 26.17 ± 3.10 ; friends 23.07 ± 5.84 ; significant other 10.03 ± 4.50 . And the mean of total items in MSPSS were 59.28 ± 10.08 (table 4.4).

Table 4.4 Multidimensional scale of Perceived Social Support item and subscale mean and standard deviation

MSPSS items	Min	Max	Mean \pm SD
Significant other (SO)	4.00	25.00	10.03 \pm 4.50
Family (Fam)	17.00	28.00	26.17 \pm 3.10
Friends (Fri)	4.00	28.00	23.07 \pm 5.84
Total	2.00	78.00	59.28 \pm 10.08

4.5 Anxiety and depression of samples

The percentage of samples that suffered from anxiety with considered symptomatic was 56.5%. The mean score of Anxiety was 2.15 ± 0.89 . Besides, the results also showed that the proportion of patients had depression symptoms were quite high with 60.9%. The mean score of depression was 2.29 ± 0.89 .

Overall, the result showed that the percentage of patients who had anxiety and depression (56.5%) were higher than the non-symptomatic patients (43.5%). With the mean scores of anxiety and depression were 2.24 ± 0.88 (table 4.5).

Table 4.5 Anxiety and depression of HCC patients

Characteristics	Number	Percentage
Anxiety		
< 1.75 non-symptomatic	50	43.5
> 1.75 considered symptomatic	65	56.5
Min = 1.0		
Max = 3.7		
Mean \pm SD = 2.15 ± 0.89		
Depression		
< 1.75 non-symptomatic	45	39.1
> 1.75 considered symptomatic	70	60.9
Min = 1.13		
Max = 3.73		
Mean \pm SD = 2.29 ± 0.89		
Anxiety and Depression		
< 1.75 non-symptomatic	50	43.5
> 1.75 considered symptomatic	65	56.5
Min = 1.12		
Max = 3.64		
Mean \pm SD = 2.24 ± 0.88		

4.6 Problems and needs in palliative care of samples

The patients' major problems were physical symptoms (83.5%), following by psychological issues (65.2%) and daily activities (36.5%) (table 4.6).

The needs in palliative care were mostly in physical symptoms (86.1%) and psychological issues (67.8%), following by daily activities (47.8%) (table 4.6).

The highest level of problems was mild problems (46.1%), following moderate problems (27.8%) and lowest was high problems (26.1%) (table 4.7).

The highest level of needs was mild needs (47.0%), following high needs (36.5%) and lowest was moderate needs (16.5%) (table 4.7)

Table 4.6 Problems and needs among HCC patients by number and percentage

Dimension	Problems aspect			Need for care aspect		
	Yes (%)	Some times (%)	No (%)	Yes, more (%)	As Much As now (%)	No (%)
1 .Daily Activities	36.5	26.1	37.4	47.8	12.2	40.0
2 .Physical symptoms	83.5	15.6	0.9	86.1	12.2	1.7
3 .Autonomy	18.3	53.9	27.8	21.7	46.1	32.2
4. Social issues	33.0	64.4	2.6	39.1	60.0	0.9
5 .Psychological issues	65.2	32.2	2.6	67.8	28.7	3.5
6 .Spiritual issues	18.3	59.1	22.6	17.4	51.3	31.3
7 .Financial problems	20.0	16.5	63.5	16.5	13.9	69.6
8 .Need of information	33.0	30.4	36.5	32.2	14.8	53.0

Table 4.7 The level of the problems and needs among HCC patients

Characteristics	Number	Percentage
Problems in palliative care		
33 - 55 mild problems	53	46.1
56 - 77 moderate problems	32	27.8
78 - 99 high problems	30	26.1
Min = 1.0		
Max = 3.0		
Mean \pm SD = 1.80 \pm 0.83		
Needs in palliative care		
33 - 55 mild needs	54	47.0
56 - 77 moderate needs	19	16.5
78 - 99 high needs	42	36.5
Min = 1.0		
Max = 3.0		
Mean \pm SD = 1.89 \pm 0.91		

4.7 Correlation between Physical symptom, Anxiety and depression, Social support and Problems and needs in palliative care among HCC patients

Before using Pearson's Product Moment correlation, all of the variables was tested for their distribution. The result showed that there were not normal distribution. Therefore, Spearman's rho was employed to test all variables' correlation with problems and needs in palliative care.

The result showed that physical symptoms were significant positive high correlate with problems and needs in palliative care at $r = .775$, $p = .000$; anxiety and depression had significantly high positive correlation with problems and needs in palliative care ($r = .828$, $p = .000$). Social support had significantly low negative correlation with problems and needs in palliative care ($r = -.307$, $p = .000$) (table 4.7).

Table 4.8 Correlation between Physical symptom, Anxiety and depression, Social support and Problems and needs in palliative care among HCC patients

Variables	1	2	3	4
1. Physical symptoms	1			
2. Anxiety and depression	.847**	1		
3. Social support	-.129	-.142	1	
4. Need in palliative care	.775**	.828**	-.307**	1

** p < 0.01

CHAPTER V

DISCUSSION

This descriptive research is to study the relationship between physical symptoms, anxiety-depression, social support and needs in palliative care among HCC patients. The study findings can be discussed based on the study objectives and hypotheses as follows:

- General demographic and medical information
- Problems and needs in palliative care among HCC patients
- The correlation between physical symptoms, anxiety and depression, social support with needs in palliative care among HCC patients.

5.1 General demographic and medical information

This study included 115 in patients with HCC who were treated in The Nuclear medicine and Oncology in Bach Mai Hospital. During data collection, there were no adverse so that all participants throughout the study with no attrition. In this study, the findings revealed that the mean age of patients with HCC was 57.38 years (± 11.29), with ages ranging from 22 to 80 years old. It the same in one study was conducted in China (2013) has 155 HCC patients showed average age of the participants was 53.25 (± 10.33 ; range 22 - 77) (Wenting et al., 2013). The number of people who were less than 45 years old and suffered HCC were 16 %. The proportion of male patients with HCC (74.8%) was much higher than females' (25.2%). Therefore, the research results showed the rate of HCC in men was higher than in women and the incidence occurred among young people is quite high. It seemed to be the same as in study conducted by Bosch et al (2004) the rate of HCC in men were higher than women in 2-4 times, HCC usually founds for those who are at the age of between 35 and 65, when people were working the most effectively (Bosch et al.,

2004). According to another research that was conducted by Greten et al. (2005), the HCC patients had the male to female ratio was 3.8: 1.

The participants consisted of 115 patients with 92.2% were married and live with their family. Almost all of the patients in this study lived in cities and rural areas. The personal average income was 147.7 USD and the family average income was 304.2 USD. It seemed to be normal in Viet Nam. The number of patients who were from the mountainous areas was less than the number of patients from cities and rural areas because of the geographic distance, low education level as well as average income. All of the HCC patients had government insurance which helped them in paying for treatment fees. This thanked for the policy of Vietnam Government required all citizens had insurance. The more numbers of people who were living with HCC patients, the more spiritual and financial support they gave.

The HCC patients often come to hospital to follow treatment schedule. Therefore, their length of stay in hospital which was less than one week was the highest (35.7%). However, the long time in hospital was pretty high (one to two weeks was 28.7%, two to four weeks were 23.5% and more than four weeks were 12.2%). This showed that the patients had many problems and needed much more support and medical care.

More than half of the HCC patients in this study had normal weight (52.2%) and very little of them were overweight and obese. However, the thing that we needed to worry the most was the high number of patients who were underweight (33.9%). Remaining the nutrition and normal weight are very necessary for the effective treatment.

Almost all the HCC patients were detected at late stages with stage 3: (17.4%) and stage 4 (80.9%). In another research conducted by Cahill and Braccia in 2004, the researchers reported that the amount of HCC patients in late stages were particularly high about 80% of all the patients (Cahill & Braccia, 2004). As the result of it, the patients have to suffer from a lot of negative symptoms; for example: pain, weight loss, loss of appetite and jaundice. Moreover, they also have to underline the more serious syndromes like cirrhosis and portal hypertension. Therefore, in order to find out an effective treatment is extremely tough (Park et al., 2015). Being detected at the later stages leads to lack of opportunities for patients to receive effective treatment

methods. The curative treatments for early stage liver cancer mainly involve partial liver resection and liver transplantation. Regretfully, most patients were found in late stage without the opportunity for operation (Cheng et al., 2016). As a result of this, three treatment methods which were chemotherapy 23.5%, palliative treatment 33.9 % and combination treatment (palliative and chemotherapy) 28.7%. These treatment methods could help them reduce symptoms and improve quality of life. On the other hand, these treatment methods have their own side effects which can cause some problems for patients. For example, chemotherapy can cause falling hair, nausea; vomiting and so on. Therefore, assess the problems and the needs to care for liver cancer patients are a really necessary.

5.2 Needs in palliative care among HCC patients

Palliative care is a needs which is necessary for cancer patients, especially for patients with HCC because The HCC patients have high malignant condition and suffered a lot symptoms. Detection of primary liver cancer is a major event in the lives of patients and their families. Palliative care refers both physical factors and morale of patients and their families.

When assessing the needs of palliative care for patients with liver cancer, the researchers used the questionnaire assess both problems and needs. The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv) developed by Osse, Bart H. P and colleges (2007) was used for assessed needs in palliative care among HCC patients in this study. This study showed the high prevalence of problems in carrying out daily activities was 36.5% and physical symptoms of 83.5% because HCC disease usually were detected in advanced stage. These problems could make more psychological problems (65.2%), social problems (33.0%) and financial problems (20.0%) even they have some financial support from the government for treatment process. However, they might spend more money for another thing and needed support and information form nurses or health personal (33.0%). In addition, physical and psychological problems could cause to lower self-reliance (18.3%). Beside, the spiritual problem was not high (18.3%). It can because most of Vietnamese

culture had not belief about god or ghost so spiritual belief and hope might not be high impacted to this group.

According to these patient problems, the needs of HCC patients were high in physical symptoms (86.1%) and psychological symptoms (67.8%). Several domains showed quite more problems such as carrying out daily activities (47.8%) and information needs (32.2%), social issues (39.1%), and self-reliance (21.7%) while spiritual issues (17.4%) and financial issues (16.5%) had quite low problem. These finding similar to a review from 94 articles of Harrison et al. (2009), the prevalence of unmet need was 57%. Incident of unmet need covered all aspects and at all time points. The patients needed more help in the domain of activities of daily living (1–73%), physical (7–89%), psychological (12–85%), spiritual (14–51%), information (6–93%), and psychosocial (1–89%) (Harrison et al., 2009). When comparison to these previous studies, the needs in palliative care for HCC patients in Vietnamese patients were in high level in many aspects from the physical to the psychological.

For the needs of physical symptoms and psychological symptoms, the study revealed that multidisciplinary health care team for treating HCC should include doctors, nurses, pharmacists, social workers, and a chaplain (Van Cleave et al., 1999). The specific symptoms might be controlling such as abdominal distention and ascites, hepatic encephalopathy, and pruritus with all supportive therapies. Besides, Opioids were used reduce abdominal pain. The patients with poor prognosis and family were supported for mental and the result showed high satisfaction with their care. This meant that the HCC patients really needed in palliative care because of the 105,000 people who died yearly and 700,000 persons needed palliative care (Kalvach, 2004). While, cancer patients at least 20% needed specific palliative care in the last year of life (Gesundheit et al., 2005).

The results in this study and other studies supported that HCC patients have a high problems and needs in palliative care. Palliative care is not only useful for patients but also for their families too. The good symptom managements and palliative care could increase the patient quality of life and improve the satisfaction of their families.

5.3. The relationship between physical symptoms, anxiety and depression, social support and needs in palliative care among HCC patients.

The HCC patients are experiencing a number of burdens for example physical, psychological, social, spiritual, existential, medical, financial and social difficulties (Sun & Sarna, 2008). Consequently, symptom management is particularly important to support the functional status and quality of life (QOL) in HCC patients.

The objective of the study was to investigate the relationships between physical symptoms, anxiety and depression, social support and needs in palliative care among HCC patients. This evidence is useful for nurse who can apply this knowledge for developing palliative care and improving effective clinical practice guideline program to HCC patients. Otherwhile, this knowledge can be used for the other researches in areas of HCC study.

Results of this study were fulfilled the hypothesis that physical symptoms, anxiety and depression were positive correlate with problems and needs in palliative care. Social support had negative correlation with problems and needs in palliative care. These findings would partly contribute to the planning to promote palliative care for HCC patients.

5.3.1. Physical symptoms

In this study, the physical symptoms for HCC patients were measured using the Cohen-Hoberman Inventory of physical symptoms (CHIPS). It includes 33 common physical symptoms. Each item is rated for how much that problem bothered or distressed the individual during the past two weeks (Cohen. S & Hoberman. H, 1983). Result this research showed the proportion of patients affected by the physical symptoms was high. The ratio of participants having a little bothered was 39.1% and quite a bit was 40.9 %. The mean scores of physical symptoms were 64.11 ± 2.544 . The participants who were extremely bothered with physical symptoms were low (6.1%). The participants who had not suffered from physical symptoms were 13.9%. In a research amongst HCC patients in Taiwan, dull abdominal pain is considered as the most common symptom at about 75%. Furthermore, there are also other

considerable symptoms for example fatigue, anorexia, cachexia, vomiting, peripheral edema, ascites, and dyspnea (Lin, Wu, Tsai, Lin, Chen, & Hwang, 2004). Additionally, all of these symptoms create a syndrome that appears in HCC patients of 80-90% of (Ramsey, Kernagis, Soulen, & Geschwind, 2002).

The previous research had shown that HCC patients are often detected at later stages, and limited the effective treatments like transplantation or curative ablation. Meanwhile, they usually suffer from a lot of physical symptoms. In this study, physical symptoms were positively correlated with problems and needs in palliative care at $r = .808$, $p = .000$. It means that physical symptoms increased which leads to the higher need for palliative care. According symptom management theory, in order to improve the quality of palliative care, it's necessary to manage symptoms perfectly well. Supportive care professionals are one of the most significant parts that combined with the skills of health care personal to deliver a quality symptom management. (Sun & Sarna, 2008). It is necessary for nurses to understand and conduct the clinical assessment and cope with cancer-related symptoms to provide patients a good outcome. (Sun & Sarna, 2008). Therefore, better physical symptoms management will help reduce the need in palliative care.

5.3.2. Anxiety and depression

In this study the percentage of samples that suffered from anxiety was 56.5% with mean score of anxiety being 2.15 ± 0.89 . Consequently, advanced cancer patients with stage 3 (17.4%) and stage 4 (80.9%) could cause anxiety and depression in common. Besides, the results also showed that the proportion of patients had depression symptoms were quite high with 60.9% with mean scores of depression were 2.29 ± 0.89 . Overall, the result showed that the percentage of patients who had anxiety and depression (56.5%) were higher than the non-symptomatic patients (43.5%). With the mean scores of anxiety and depression were 2.24 ± 0.88 . Because these HCC patients were in life-threatening stages, the result of these psychological problems were close to many studies reported up to 72.1% of patients as having anxiety (Tsai et al, 2006), 58% - 68.42% depressive symptoms and up to 38% as having major depression (Massie, 2004; Hong, & Tian, 2014) As a result, anxiety and depression were associated with poorer quality of life (Williams & Dale, 2006).

Anxiety and depression had high positive correlation with problems and needs in palliative care ($r = .886$, $p = .000$). It means that anxiety and depression increased lead to needs in palliative care needs increase. Thus, care for the patient needed in the psychological problems like anxiety and depression were one important part of palliative care. For advance cancer, the patients with psychological problems should be guided by a palliative care approach focused on symptom reduction and pharmacotherapy, irrespective of whether the patient meets diagnostic criteria for major depression (Rosenstein, 2011).

5.3.3 Social support

The result was mentioned in three subscales and showed that patients who received support from family was the highest (26.17 ± 3.10), the second was from friends (23.07 ± 5.84) and from significant other was the lowest (10.03 ± 4.50). The mean of total items in MSPSS were 59.28 ± 10.08 . HCC patients who were treated in oncology received social support at a good level. This study result was close to the study of Ege and Pamukkale University Hospitals and Denizli State Hospital reported that the total score in social support was higher with mean score 70.94 ± 16.01 . While, the support from a special person subgroup score was 25 ± 4.96 , a family subgroup score was 24 ± 5.43 , and a friend subgroup score was 21 ± 8.37 (Ogce, Ozkan, & Baltalarli, 2007).

In this study, social support had low negative correlation with problems and needs in palliative care ($r = -.219$, $p = .00$). This means that an increase in level of social support lead to an reduce needs in palliative care. According to the study of Harrison et al. (2009), HCC patients needed so many support to deal with physical symptoms (86.1%) and psychological symptoms (67.8%). However, the prevalence of unmet need was still high (57%). Incident of unmet need covered all aspects and at all time points. The patients needed more help in the domain of activities of daily living (1–73%), physical (7–89%), psychological (12–85%), spiritual (14–51%), information (6–93%), and psychosocial (1–89%) (Harrison et al., 2009). When comparison to these previous studies, the needs for social support in palliative care for HCC patients in Vietnamese patients were in high level in many aspects from the physical to the psychological.

5.4 Conclusion

In conclusion, it can be state that he results of this study complied with the concept of Symptom Management Theory. It means that when HCC patients were controlled symptoms and perceived good social support it leads to reduce problems and needs in palliative care so the unmet needs will decrease. Many factors that affect needs in palliative care were physical symptoms ($r = .775, p < .01$), anxiety and depression ($r = .828, p < .01$), and social support ($r = -.307, p < .01$). Accordingly, to full support needs of the HCC patients in palliative care and improve palliative practice among HCC patients, nursing should take measures to control symptoms effectively and emotional support for patients and their families. Other factors that should be managed and control to decrease need in palliative care patients are physical symptoms, anxiety and depression. These measures would assist HCC patients have good palliative care.

CHAPTER VI

CONCLUSION

6.1 Conclusion of the study

This was descriptive correlation research which aimed to study the relationship between physical symptoms, anxiety and depression, social support with needs in palliative care among HCC patients. The patients had ages ranging from 22 to 80 in The Nuclear Medicine and Oncology Center from August to October, 2016. Symptom Management Theory was utilized as a framework in this study. The sample size in this study was calculated by using G*power version 3.1.9.2 program to determine the minimum number of participants needed for co-relational design. The sample calculation yielded 115 samples. The research setting was conducted in Oncology Center, Bach Mai Hospital.

After study obtained approval from Institutional Review Board of Nursing faculty, Mahidol University and Institutional of Review Board of SMP, Vietnam National University, Hanoi, Vietnam. The researcher used 5 instruments: 1) The demographic data questionnaire, 2) Cohen-Hoberman Inventory of Physical Symptoms (CHIPS); 3) Hopkins Symptom Checklist 25 (HSCL- 25), 4) The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv), 5) The Multidimensional Scale Perceived Social Support (MSPSS) to collected data.

All instruments were tested for their validity and reliability as clearly explained in chapter 3. Cronbach's alpha coefficient of Scale Perceived Social Support (MSPSS) was 0.88; Cohen-Hoberman Inventory of Physical Symptoms (CHIPS) was 0.94; Hopkins Symptom Checklist 25 (HSCL- 25) was 0.98, The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv) was 0.94. The 115 samples were selected according to the inclusion criteria. The researcher collected data by herself from 11.00 am to 5.00 pm from Mondays to Fridays until the sample reached the target of the studied sample size. For each sample, the researcher spent 30 to 40 minutes on interviewing and collected some data from their patients' records. During

the time of data collection, there was no adverse event among the samples. All samples recruited in the study remained throughout the study process with no attrition.

Data analysis was conducted by using computer program. The statistics were used to describe general information and study variables, including physical symptoms, anxiety and depression, social support, and needs in palliative care. The assumption of Pearson's Product Moment Correlation was tested and it was found that all variables were not in normal distribution. Accordingly, Spearman's rho was used to examine correlation physical symptom, anxiety and depression, social support, and needs in palliative care among HCC patients.

The findings are summarized as follows:

1. As regards demographic characteristics of 115 HCC patients with the majority of patients were male (74.8 %). The average age was 57.3 (SD = 11.29) and age range from 22 to 80 years. The education level was mainly in secondary school (34.8%) and high school (30.4%). Most of the patients were retired (38.3%) and farmers (21.7%). They mostly lived in cities (42.6%) and rural areas (53.0%). The average monthly income of patient was 147.7 USD (SD = 95.26) and family was 304.2 USD (SD= 190.70). All of patients had government insurance (100%). The amount of the patient who were living with less than 3 people were 74.8% while living with more than 4 people were 25.2%.

2. All patients were diagnosed as hepatocellular carcinoma and had advanced stage of disease (stage 4: 80.9%, stage 3: 17.4%). There are three main treatment methods for all participants: Chemotherapy (23.5%), Palliative treatment (33.9%) and Combination (28.7%). Of the patients enrolled, there were two main level weights which underweight were 33.9%, normal weight was 52.2%. The ratio of participants in hospital less than one week was highest (35.7%). The proportion of patients who stayed from one to two weeks was a little less about 28.7% and those who stayed from two to four weeks were least (23.5%).

3. The patients who were suffered physical symptoms with extremely bothered were low (6.1%), a little bothered were 39.1% and quite a bit was 40.9%. The mean scores of physical symptoms were 64.11 ± 2.544 . The participants who had not suffered from physical symptoms were 13.9%.

4. The result mentioned in three subscales were perceived support from family, from friends, and from a significant other. The mean scores that was represented for family were 26.17 ± 3.10 ; friends 23.07 ± 5.84 ; significant other 10.03 ± 4.50 . And the mean of total items in MSPSS were 59.28 ± 10.08 .

5. The percentage of samples that suffered from anxiety with considered symptomatic was 56.5%. The mean scores of anxieties were 2.15 ± 0.89 . Besides, the results also showed that the proportion of patients had depression symptoms were quite high with 60.9%. The mean scores of depressions were 2.29 ± 0.89 . Overall, the result showed that the percentage of patients who had anxiety and depression (56.5%) were higher than the non-symptomatic patients (43.5%). With the mean scores of anxiety and depression were 2.24 ± 0.88 .

6. The prevalence of problems in carrying out daily activities was 36.5%, physical symptoms 83.5%, self-reliance 18.3%, social issues 33.0%, psychological issues 65.2%, spiritual issues 18.3%, financial issues 20.0%, and information needs 33.0%. With these problems of patients, the proportion of being needed in carrying out daily activities was 47.8%, physical symptoms 86.1%, self-reliance 21.7%, social issues 39.1%, psychological issues 67.8%, spiritual issues 17.4%, financial issues 16.5%, and information needs 32.2%.

7. Physical symptoms were positive high correlate with problems and needs in palliative care at $r = .808$, $p = .000$; anxiety and depression had high positive correlation with problems and needs in palliative care ($r = .886$, $p = .000$). Social support had low negative correlation with problems and needs in palliative care ($r = -.219$, $p = .000$).

6.2 Recommendations

6.2.1 Implications for nursing practice

1. Routine assessment should include CHIPS and HSCL-25 because this information could be used to predict the need of palliative care. If the symptoms can be managed properly, the needs will be reduced. Patient's whose scores show that they

experience those symptoms or diseases have to be referred to the specialist nurses and health team for proper managements.

2. The common symptoms like fatigue, nausea, vomiting, ascites, edema, jaundice, dyspnea, loss appetite, abdominal pain and weight loss must be meticulous managed to reduce symptom problems Moreover, nurses and health care team must response to the needs of HCC patients.

3. Develop guidelines to symptom managements and palliative care by using support from social network of patients.

4. Training program using those instruments should be developed and uses for training to improve nurses' competencies and health care team for symptom managements and palliative care.

6.2.2 Implications for further study

1. Multi settings research should be conducted to add more samples and more variety of settings in Vietnam. The results from the multisettings research can be used to test psychometric property of CHIPS, HSCL-25 and MSPSS.

2. Quasi experimental research should be conducted to test effectiveness of the training program to improve nurses' competencies related to using those instruments to manage HCC patients.

3. The effectiveness of clinical practice guidelines can be evaluated by one group pre- test and post-test observational research.

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APPENDICES

APPENDIX A

LIST OF THE EXPERTS

1. Prof Dr. Mai Trong Khoa , MD, PhD

Vice Director Bach Mai hospital.

Director of the Medical nuclear and Oncology center in Bach Mai hospital

2. Prof Dr. Truong Viet Dung, MD, PhD.

Chairman of Independent Ethic Committee, Ministry of Health, Vietnam

Dean of School of Medicine and Pharmacy, Vietnam National University, Vietnam.

3. Assoc. Prof Dr Tran Dinh Ha, MD, PhD.

Vice director of the Medical nuclear and Oncology center in Bach Mai hospital.

4. PhD Pham Cam Phuong, MD, PhD.

Vice director of the Medical nuclear and Oncology center in Bach Mai hospital.

5. BA. Phan Thi Thu Hue

Head nursing of the Medical nuclear and Oncology center in Bach Mai hospital.

APPENDIX B



MAHIDOL UNIVERSITY

Since 1888

The Institutional Review Board
Faculty of Nursing, Mahidol University
Tel 0-2441-5333 Ext 2531-32


Document No. 0517.0510/IRB-NS 457
Date May 3, 2016
Subject Result of research project considerations after the revision
Dear Chair, Master of Nursing Science Program in Adult Nursing (for Vietnamese Nurses)

According to the student named Mrs. Le thi Hien has submitted the research project entitled Factors related to needs in palliative care among patients with Hepatocellular carcinoma protocol no. IRB-NS2016/25.0703 at the Institutional Review Board, Faculty of Nursing, Mahidol University on the (date) May 2, 2016 the IRB committee have examined and found the research protocol and all the research documents are revised according to the suggestions of the IRB. The IRB committee have made the decision and the results are as follows:

- Approve.
On the date May 2, 2016
Please look at the guideline for the research conduct post approval.
The document is attached together with the COA

Fongcum Tilokskulchai
(Associate Professor Dr. Fongcum Tilokskulchai)
Chair, Institutional Review Board

Copy to Assistant Professor Dr. Wallada Chanruangvanich
Mrs. Le thi Hien



CERTIFICATE OF APPROVAL
From
Institutional Review Board Faculty of Nursing Mahidol University

COA No. IRB-NS2016/25.0703

Title of Project: **FACTORS RELATED TO NEEDS IN PALLIATIVE CARE AMONG PATIENTS WITH HEPATOCELLULAR CARCINOMA**

Project Number: **IRB-NS2016/25.0703**

Principal Investigator: **Mrs. Le Thi Hien**

Name of Institution: **Faculty of Nursing Mahidol University**

Approval includes: 1) IRB-NS Subprotocol form version received date 2 May 2016
 2) Participant Information sheet version date 2 May 2016
 3) Consent form version date 2 May 2016
 4) Questionnaire version received date 2 May 2016

Institutional Review Board Faculty of Nursing Mahidol University is in full compliance with International Guidelines for Human Research Protection such as Declaration of Helsinki, The Belmont Report, CIOMS Guidelines and the International Conference on Harmonization in Good Clinical Practice (ICH-GCP)

Date of Approval: **02 May 2016**

Date of Expiration: **01 May 2017**

Signature of Chair: *Fongwan Tikhakulcha*
 (Associate Professor Dr. Fongwan Tikhakulcha)
 Chair

Signature of Dean, Faculty of Nursing: *Yajai Sittipol*
 (Associate Professor Dr. Yajai Sittipol)
 Dean, Faculty of Nursing

Office of Institutional Review Board Faculty of Nursing Mahidol University Room 503 Faculty of Nursing, Mahidol University
 999 Phrasarathwong Road, Sakon Nakhon Pathom 31170, THAILAND Tel: (662)-441-5133 Ext. 2531, 2532

KHOA Y DƯỢC
HỘI ĐỒNG ĐẠO ĐỨC
TRONG NGHIÊN CỨU Y SINH HỌC

CỘNG HÒA XÃ HỘI CHỦ NGHĨA VIỆT NAM
Độc lập - Tự do - Hạnh phúc

Số: KYD-HDDD

Hà Nội, ngày 16 tháng 08 năm 2016

GIẤY CHỨNG NHẬN
Chấp thuận của Hội đồng đạo đức trong nghiên cứu y sinh học

Căn cứ Quyết định số 89/QĐ-KYD ngày 22/10/2013 của Khoa Y Dược về việc thành lập Hội đồng đạo đức trong nghiên cứu y sinh học Khoa Y Dược nhiệm kỳ 2013-2018;

Căn cứ Quyết định số 235/QĐ-KYD ngày 23/10/2015 của Khoa Y Dược về việc điều chỉnh, bổ sung thành viên Hội đồng đạo đức trong nghiên cứu y sinh học Khoa Y Dược nhiệm kỳ 2013-2018;

Căn cứ Biên bản họp ngày 02/08/2015 của Hội đồng đạo đức trong nghiên cứu y sinh học Khoa Y Dược nhiệm kỳ 2013-2018;

Hội đồng đạo đức trong nghiên cứu y sinh học Khoa Y Dược chấp thuận về các khía cạnh đạo đức trong nghiên cứu đối với đề tài sau:

1. Tên đề tài: Các yếu tố liên quan đến nhu cầu chăm sóc giảm nhẹ của bệnh nhân Carcinoma tế bào gan
2. Người thực hiện nghiên cứu: Lê Thị Hiền (Học viên cao học điều dưỡng DH Mahidol)
3. Địa điểm nghiên cứu lâm sàng: Bệnh viện Bạch Mai
4. Thời gian nghiên cứu: Từ tháng 08/2016 đến tháng 12/2016

Các tài liệu được chấp thuận bao gồm:

1. Đề cương nghiên cứu (tiếng Anh) phiên bản số 01 ngày 08/08/2016
2. Thông tin dành cho đối tượng nghiên cứu (tiếng Việt) phiên bản số 02 ngày 08/08/2016
3. Bản chấp thuận tham gia nghiên cứu (tiếng Việt) phiên bản số 02 ngày 08/08/2016
4. Bộ câu hỏi nghiên cứu (tiếng Việt)

Ngày chấp thuận: Ngày 16 tháng 08 năm 2016

Nghiên cứu viên chính phải tuân thủ việc báo cáo cho Hội đồng đạo đức trong nghiên cứu y sinh học Khoa Y Dược về các trường hợp có biến cố bất lợi, báo cáo tiến độ theo đúng các hướng dẫn và quy định hiện hành.

Nơi nhận:

- Bệnh viện Bạch Mai
- Nghiên cứu viên
- Lưu HDDD

CHỦ TỊCH



PGS.TS. Lê Thị Luyên

IRB-NS Form No. 3.1

- 2 MAY 2016
25.0703

Participant Information Sheet

In this document, there may be some statements that you do not understand. Please ask the principal investigator or his/her representative to give you explanations until they are well understood. To help your decision making in participating the research, you may bring this document home to read and consult your relatives, intimates, personal doctor or other doctor.

Title of Research Project: Factors related to needs in palliative care among patients with Hepatocellular carcinoma.

Name of Researcher: Le Thi Hien

Research Site-Office and its telephone number available for contact both in and out of the office hours:

Bach Mai hospital, 78 Giai Phong street, Dong Da District, Hanoi City, Vietnam. Code: 100.000, Phone number: (+84) 912513284 (contact Mrs. Bui Minh Thu), Fax: (+84) 438691607.

Source of Fund: No research funding

This research project aims to examine the correlation between physical symptom, anxiety and depression, social support and needs in palliative care among patients with HCC, which expects the following benefits: 1) Providing basic data about factors related needs in palliative care in HCC patients. 2) In the future, developing program by using this data to promote palliative care in HCC patients.

However, in this study, the sample does not get any benefit directly but HCC patients will get benefit in future.

You are invited to participate in this research project because you have been diagnosis in HCC patients and being age 18 years old or above.

There will be 115 participants, and the research will last for 30-40 minutes for answer questionnaires.

*To participate in this research is completely VOLUNTARY.

If you decide to participation the research project, you will go through the following procedure.

1. The researcher will organize private room to do questionnaire by themselves. Then, researcher uses five questionnaires for data collection. Questionnaire are 1) Demographic data questionnaire has 18 items, 2) Cohen-Hoberman Inventory of Physical Symptoms (CHIPS) scale has 33 items, 3) Multidimensional Scale of Perceived Social Support has 12 items ,4) Hopkins Symptom Checklist 25 (HSCL- 25) scale has 25 items, 5) The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv) has 33 items. The time used for complete this data collection is about 30-40 minutes.

Participant Information Sheet for version 5 date 10 August 2015

Approved by Institutional Review Board
Faculty of Nursing Mahidol University
Project Number IRB-NS 2016/25.0703
Date of Approval = 2 MAY 2016

APPENDIX C

Thông tin dành cho đối tượng nghiên cứu Phiên bản 02 /ngày 15 tháng 08 năm 2016

THÔNG TIN DÀNH CHO ĐỐI TƯỢNG NGHIÊN CỨU

Tài liệu này sẽ có một số vấn đề Ông/bà có thể không hiểu. Hãy hỏi người nghiên cứu hoặc người đại diện của cô ấy để đưa cho Ông/Bà lời giải thích cho đến khi Ông/Bà hiểu rõ ràng vấn đề. Để giúp cho việc quyết định có tham gia vào chương trình nghiên cứu hay không, Ông/Bà có thể mang tài liệu này về nhà để đọc hoặc hỏi ý kiến người thân và các bác sĩ.

Tên đề tài nghiên cứu: Các yếu tố liên quan đến nhu cầu chăm sóc giảm nhẹ ở bệnh nhân carcinoma tế bào gan.

Người thực hiện nghiên cứu: Lê Thị Hiền

Địa chỉ và điện thoại liên hệ trong và ngoài giờ hành chính (Đại diện của người nghiên cứu): Bệnh viện Bạch Mai: 78 đường Giải Phóng, Quận Đống Đa, Hà Nội, Việt Nam. Mã bưu chính: 100000, Số điện thoại: (+84) 438683731 Fax: (+84). 438691607

Nguồn hỗ trợ: Không có.

Mục đích của nghiên cứu: nhằm đánh giá các yếu tố liên quan đến nhu cầu chăm sóc giảm nhẹ ở bệnh nhân carcinoma tế bào gan, với các lợi ích được kì vọng, bao gồm:

- 1) Nghiên cứu cung cấp các dữ liệu cơ bản về các yếu tố cơ bản liên quan đến nhu cầu chăm sóc giảm nhẹ cho bệnh nhân ung thư tế bào gan.
- 2) Trong tương lai, phát triển các chương trình nhằm nâng cao chăm sóc giảm nhẹ cho bệnh nhân ung thư tế bào gan dựa trên các dữ liệu đã thu nhận được từ nghiên cứu này.

Tuy nhiên, trong nghiên cứu này, người tham gia nghiên cứu có thể không thu được các lợi ích trực tiếp, nhưng sẽ mang lại nhiều lợi ích cho những người mắc bệnh carcinoma tế bào gan trong tương lai.

Ông/Bà được mời tham gia chương trình nghiên cứu này bởi vì Ông/Bà đã trên 18 tuổi và được chẩn đoán là carcinoma tế bào gan.

Sẽ có khoảng 115 người tham gia, và cả cuộc phỏng vấn sẽ kéo dài trong khoảng từ 30 đến 40 phút nhằm trả lời các câu hỏi nghiên cứu.

Việc tham gia nghiên cứu này của Ông/Bà là hoàn toàn TỰ NGUYỆN.

Nếu Ông/Bà quyết định tham gia nghiên cứu này, Ông/Bà sẽ trải qua các bước sau:

- 1) Người nghiên cứu sẽ yêu cầu Ông/Bà ký tên vào bản chấp thuận tham gia nghiên cứu
- 2) Người nghiên cứu sẽ thu thập một số thông tin của Ông/Bà từ hồ sơ bệnh án.
- 3) Nghiên cứu viên sẽ chuẩn bị phòng riêng để phỏng vấn Ông/bà hoặc Ông/bà có thể tự trả lời các câu hỏi. Sau đó nghiên cứu viên sẽ sử dụng bộ câu hỏi bao gồm 5 phần: 1) thông tin chung của người bệnh có 18 câu hỏi, 2) bộ câu hỏi đánh giá triệu chứng thể chất của Cohen-Hoberman gồm 25 câu hỏi, 3) Thang đo đa khía cạnh về Nhận thức hỗ trợ xã hội có 12 câu hỏi, 4) Bộ câu hỏi đánh giá triệu chứng Hopkins 25 có 25 câu hỏi, 5) Bộ câu hỏi về những vấn đề và nhu cầu về chăm sóc giảm nhẹ của bệnh nhân (PNPC-sv) có 33 câu hỏi. Tổng số câu hỏi là 113 câu và được hoàn thành trong khoảng 30 – 40 phút. Trong suốt quá trình trả lời câu hỏi, nếu có câu hỏi nào Ông/Bà không hài lòng hoặc khó trả lời Ông/ Bà có thể không trả lời.

APPENDIX D

- 2 MAY 2016
25.0703

IRB-NS Form No. 4

Consent Form for Informed and Voluntary Participation in Research

Date...../...../.....

My name is....., aged.....years old,

Now living at the address: No.....Road/street.....

Sub-district/tambon.....District/amphur.....

Province.....Postal code.....Tel.No.....

I give my consent to participate as a subject in the research project entitled: factors related to needs in palliative care among patients with Hepatocellular carcinoma.

In so doing, I am informed of the background and purpose of research project; its procedural details to carry out or to be carried out; its expected benefits and risks that may occur to the subjects, including methods to prevent and handle harmful consequences; and payment/ incentives, and expense. I thoroughly read the detailed statements in the information sheet given to the research subjects, I was also given explanations and my questions were answered by the head of the research project. I was explained that researcher will collect some demographic data from my medical record form. I was explained that during interview or use questionnaire, if I feel uncomfortable. The researcher will stop the process until I feel comfort to continue or I can stop participation in the study.

I consent to participate as a subject in this research project.

On the condition that I have any questions about the research procedures, or on the condition that I suffer from an undesirable side effect from this research, I can contact Mrs. Le Thi Hien, Mobile phone number (+84)984343188, Email: lehien84bm@yahoo.com.

On the condition that I am not treated as indicated in the information sheet distributed to the subjects, I can contact the Chair, or the representative of the IRB-NS at the office of IRB-NS room 503 5th floor, Faculty of Nursing, Mahidol University, 999 Phuttamonthon 4 Road, Salaya, Nakhon Pathom 73170 Thailand Tel 0066 2 441 5333 ext 2531, 2532 Fax 0066 2 441 5333 ext 2531, Email: nsirbnursing@mahidol.ac.th

Version 5 date 10 August 2015

Approved by Institutional Review Board
Faculty of Nursing Mahidol University
Project Number IRB-NS 2016/25.0703
Date of Approval - 2 MAY 2016

Bản chấp thuận tham gia nghiên cứu Phiên bản 02 /ngày 15 tháng 08 năm 2016



BẢN CHẤP THUẬN THAM GIA NGHIÊN CỨU

Ngày...../...../.....
 Tên tôi là Tuổi:
 Mã ID (Người nghiên cứu ghi):.....
 Địa chỉ:
 Mã vùng: Số điện thoại:

Trước tiên, tôi xin bày tỏ sự đồng ý tham gia vào đề tài nghiên cứu có tên là: ***Các yếu tố liên quan đến nhu cầu chăm sóc giảm nhẹ của bệnh nhân carcinoma tế bào gan.***

Trước khi tham gia nghiên cứu tôi đã được thông báo về mục đích của nghiên cứu này, chi tiết quá trình thực hiện nghiên cứu, các lợi ích và rủi ro có thể xảy ra đối với người tham gia nghiên cứu, các biện pháp ngăn ngừa và giải quyết các tác dụng không mong muốn có thể xảy ra đối với người tham gia nghiên cứu, cả về chi phí tham gia nghiên cứu. Tôi đã đọc kỹ toàn bộ thông tin trong bản thông tin dành cho đối tượng nghiên cứu. Bên cạnh đó, các câu hỏi của tôi cũng được giải đáp bởi người thực hiện nghiên cứu.

Tôi đồng ý tham gia vào nghiên cứu này như một đối tượng nghiên cứu.

Trong trường hợp có bất cứ câu hỏi nào hoặc có vấn đề mới phát sinh trong quá trình nghiên cứu, tôi có thể liên hệ với chị Lê Thị Hiền số điện thoại: +84 984343188 email: lehien84bm@gmail.com (Số điện thoại liên lạc trên được kết nối 24/24 h).

Nếu tôi không được điều trị và chăm sóc như những gì đề cập đến trong bản thông tin dành cho đối tượng nghiên cứu, tôi có thể liên hệ với Hội đồng đạo đức, Khoa Điều Dưỡng, Đại học Mahidol Thái Lan, đặt văn phòng tại tầng 5 phòng 504, Đại học Mahidol, đường Phuttamonthon 4, Salaya, Nakhon Pathom 73170, Thái Lan. Điện thoại: 66 2 441 5333 số máy lẻ 2531, 2532. Fax 0066 2 441 5333 số máy kè 2531, Email: nsirbnursing@mahidol.ac.th, ns.irbnursing@gmail.com

Tôi cũng có thể liên lạc với Hội đồng đạo đức trong nghiên cứu Y sinh học, Khoa Y Dược, Đại học Quốc Gia Hà Nội. Địa chỉ: tòa nhà Y1, số 144 phố Xuân Thủy, quận Cầu Giấy, Hà Nội, Việt Nam; điện thoại: 04-37450188; fax: +84437450146; email: smp@vnu.edu.vn.

Tôi nhận thức được quyền thông tin liên quan tới lợi ích và rủi ro của người tham gia trong dự án nghiên cứu và quyền được rút khỏi dự án bất cứ lúc nào mà không gặp vấn đề gì về dịch vụ cũng như việc chăm sóc sức khỏe mà tôi sẽ nhận được trong tương lai. Tôi đồng ý cho bên nghiên cứu sử dụng thông tin cá nhân trong việc nghiên cứu, nhưng không đồng ý việc tiết lộ thông tin cá nhân. Các thông tin phải được trình bày như là một phần của kết quả nghiên cứu.

Tôi hoàn toàn hiểu được tuyên bố trong bản thông tin dành cho đối tượng nghiên cứu và trong phiếu chấp thuận tham gia nghiên cứu này. Sau đây là chữ ký của tôi.

Chủ nhiệm đề tài
(Ký và ghi rõ họ tên)

Người tham gia nghiên cứu
(Ký và ghi rõ họ tên)

APPENDIX E

- 2 MAY 2016
25.0103

Fac. of Grad. Studies, Mahidol Univ.

M.N.S (Adult Nursing)/1

INSTRUMENT

Code.....

Part 1: Patients' general information

Patients' general information includes personal information and illness information of the patients (Researcher collects data from medication recorded). The following questions are related to patient's personal information and illness information. Please tick (✓) or fill in the blanks to complete:

1. Gender: Male Female
 2. Age:years old (current age in Western calendar)
 3. Weight (Kg).....Height (m).....BMI (kg/m²).....
 4. Marital status:
 - Married Single
 - Separated Divorced Widowed
 5. What is your highest education level?
 - Primary school (level 1 to 5) Secondary School (level 6 to 9)
 - High school (level 10 to 12) Two years certificate
 - College (3 years) Bachelor (University)
 - Others (please specify)
 6. What is your occupation?
 - Professional Farmer
 - Industrial worker Salesperson
 - Home worker Retired
 - Other jobs (please specify).....
 7. Location of residence:
 - City Rural Mountain
 8. How much of your income and your family income per month?
 - Your income per month:USD
 - Your family income per month:USD
 9. Do you have your health insurance?
 - Yes No
- If yes, please indicate how much it covers for your treatment? (Percent)

Part 2: Clinical information

1. Name of hospital before to Bach Mai Hospital:
2. Admitted date:
3. Diagnosis:
4. History of illness:
5. Date of collection data:
6. Length of stay in the hospital (From admitted time):
7. State of disease: Stage 1 Stage 2 Stage 3 Stage 4
8. Treatment method
 - Liver transplant Biological therapy
 - Liver resection Chemotherapy
 - Radio frequency ablation (RFA) Radiotherapy
 - Microwave ablation Palliative treatments
 - Injecting alcohol into the tumour Combination
 - Chemoembolisation (TACE or TOCE)

Approved by Institutional Review Board

Faculty of Nursing Mahidol University

Project Number IRB-NS 2016/25,0103

- 2 MAY 2016

Date of Approval:

Le Thi Hien

Appendix/ 2

Part 3: Cohen-Hoberman Inventory of Physical Symptoms (CHIPS)

Instructions:All of these items will be asked about how much that problem has bothered or distressed you for the past two weeks. Read each statement carefully. Mark only one number for each item. Number 0 means that you are completely not bothered by the problem. On the other hand, number 4 means that the problem has extremely bothered you.

HOW MUCH WERE YOU BOTHERED BY:

1. Sleep problems (can't fall asleep, wake up in middle of night or early in morning)	0	1	2	3	4
2. Weight change (gain or loss of 5 lbs. or more)	0	1	2	3	4
3. Back pain	0	1	2	3	4
4. Constipation	0	1	2	3	4
5. Dizziness	0	1	2	3	4
6. Diarrhea	0	1	2	3	4
7. Faintness	0	1	2	3	4
8. Constant fatigue	0	1	2	3	4
9. Headache	0	1	2	3	4
10. Migraine headache	0	1	2	3	4
11. Nausea and/ or vomiting	0	1	2	3	4
12. Acid stomach or indigestion	0	1	2	3	4
13. Stomach pain (e.g., cramps)	0	1	2	3	4
14. Hot or cold spells	0	1	2	3	4
15. Hands trembling	0	1	2	3	4
16. Heart pounding or racing	0	1	2	3	4
17. Poor appetite	0	1	2	3	4
18. Shortness of breath when not exercising or working hard	0	1	2	3	4
19. Numbness or tingling in parts of your body	0	1	2	3	4
20. Felt weak all over	0	1	2	3	4
21. Pains in heart or chest	0	1	2	3	4
22. Feeling low in energy	0	1	2	3	4
23. Stuffy head or nose	0	1	2	3	4
24. Blurred vision	0	1	2	3	4
25. Muscle tension or soreness	0	1	2	3	4
26. Muscle cramps	0	1	2	3	4
27. Severe aches and pains	0	1	2	3	4
28. Acne	0	1	2	3	4
29. Bruises	0	1	2	3	4
30. Nosebleed	0	1	2	3	4
31. Pulled (strained) muscles	0	1	2	3	4
32. Pulled (strained) ligaments	0	1	2	3	4
33. Cold or cough	0	1	2	3	4

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Fac. of Grad. Studies, Mahidol Univ.

M.N.S (Adult Nursing)/3

Part 4: Hopkins Symptom Checklist 25 (HSCL- 25)

Instructions:Listed items below are symptoms or problems that people sometimes have. Please read each one carefully and describe how much the symptoms bothered you or distressed you in the last week until today. Place a check “√”in the appropriate column.

For the responses to each item, assign the following numbers:
1 = Not at all; 2 = A little; 3 = Quite a bite; 4 = Extremely

Code:		Date:			
Date of birth:		Sex:			
Marital status:		Clinician:			
Psychiatric diagnosis:					
No	PART I: ANXIETY SYMPTOMS	Not at all	A little	Quite a bit	Extremely
1	Suddenly scared for no reason				
2	Feeling fearful				
3	Faintness, dizziness or weakness				
4	Nervousness or shakiness inside				
5	Heart pounding or racing				
6	Trembling				
7	Feeling tense or Keyed up				
8	Headache				
9	Spell of terror or panic				
10	Feeling restless or can't sit still				
	PART II: DEPRESSION SYMPTOMS	Not at all	A little	Quite a bit	Extremely
11	Feeling low in energy, slowed down				
12	Blaming yourself for things				
13	Crying easily				
14	Loss of sexual interest or pleasure				
15	Poor appetite				
16	Difficulty falling asleep, staying asleep				
17	Feeling hopeless about future				
18	Feeling blue				
19	Feeling blue				
20	Thought of ending your life				
21	Feeling of being trapped or caught				
22	Worry too much about things				
23	Feeling no interest in things				
24	Feeling everything is an effort				
25	Feeling of worthlessness				

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Le Thi Hien

Appendix/ 4

Part 5: Multidimensional Scale of Perceived Social Support

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

- Circle the "1" if you Very Strongly Disagree
- Circle the "2" if you Strongly Disagree
- Circle the "3" if you Mildly Disagree
- Circle the "4" if you are Neutral
- Circle the "5" if you Mildly Agree
- Circle the "6" if you Strongly Agree
- Circle the "7" if you Very Strongly Agree

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO)

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Fac. of Grad. Studies, Mahidol Univ.

M.N.S (Adult Nursing)/5

Part 6: The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv)

Instructions: there are 33 items in this scale. All of the items will be asked about how you feel about the following statements. Read each statement carefully. Please tick (✓) the appropriate option to complete:

Do you consider any of these to be a problem?			Problems and care requirements	Do you require personnel to help with this problem?		
Yes	Sometimes	No		Need more help than at present	Current level of help sufficient	Not needed

Carrying Out Daily Activities

- | | | | | | | |
|--------------------------|--------------------------|--------------------------|---|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 1. Looking after yourself such as taking a shower, dressing, toileting, etc. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 2. Travelling alone (riding bicycle, driving car, using public transports, etc) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 3. Doing light housework such as et, tidying up | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Physical symptoms

- | | | | | | | |
|--------------------------|--------------------------|--------------------------|---|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 4. Pain | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 5. Fatigue | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 6. Sleep problems | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 7. Breathlessness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 8. Coughing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 9. Itching | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 10. Sexual problems | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 11. Shooting pain like a needle prick or numbness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 12. Night sweating or hot flushes | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Self-Reliance

- | | | | | | | |
|--------------------------|--------------------------|--------------------------|--|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 13. Experience difficulties doing activities you used to do before | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 14. Difficulties in fulfilling responsibilities at work | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 15. Need to depend on others | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | 16. Cannot manage or supervise other people's live | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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 Faculty of Nursing Mahidol University
 Project Number IRB-NS 2016/25-0703
 - 2 MAY 2016
 Date of Approval

Le Thi Hien

Appendix/ 6

Do you consider any of these to be a problem?			Problems and care requirements	Do you require personnel to help with this problem?		
Yes	Sometimes	No		Need more help than at present	Current level of help sufficient	Not needed
<u>Social Issues</u>						
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	17. Relationship problems with spouse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	18. Talking about the disease with spouse is hard	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	19. Find it hard to mention pain because of not wanting to be a burden to others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	20. Find that the people around you are not particularly willing to talk about your disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	21. Difficult to find someone you trust to talk about things to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Psychological Issues</u>						
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	22. Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	23. Fear of severe physical symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	24. Fear of disease spreading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	25. Faced with an uncertain future is difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	26. Hard to express emotions and feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Spiritual Issues</u>						
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	27. Hard to participate in activities that are useful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	28. Hard to find the time to spend with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	29. Difficult to access feelings about death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	30. Acceptance of the disease you are suffering from is difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Financial Issues</u>						
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	31. Expenses have risen due to the illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	32. Income has lowered due to illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<u>Information Needs</u>						
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	33. Insufficient information received such as: disease and treatment data, alternative treatments, sources of assistance and support, etc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Approved by Institutional Review Board
 Faculty of Nursing Mahidol University
 Project Number IRB-NS 2016/25,0703
 Date of Approval - 2 MAY 2016

BỘ CÂU HỎI NGHIÊN CỨU

Phần 1: Thông tin chung của người bệnh

Số thứ tự: Mã bệnh án:

Mã ID:.....

Dưới đây là các câu hỏi bao gồm: các thông tin chung và các thông tin liên quan đến tình trạng bệnh của bệnh nhân (phần người nghiên cứu lấy từ bệnh án). Làm ơn hãy sử dụng để điền vào ô trống cho mỗi câu trả lời phù hợp.

1. Giới tính : Nam; Nữ
2. Tuổi
3. Cân nặng (Kg) Chiều cao (m) BMI (kg/m²).....
4. Tình trạng hôn nhân
 - Đã lập gia đình Độc thân Ly thân
 - Ly hôn Góa (chồng hoặc vợ)
5. Trình độ học vấn
 - Tiểu học Trung học cơ sở Trung học phổ thông
 - Trung cấp Cao đẳng (3 năm) Cử nhân Đại học
 - Khác (ghi cụ thể)
6. Nghề nghiệp
 - Chuyên gia Nông dân Công nhân
 - Buôn bán Nội trợ Nghỉ hưu
 - Công việc khác (ghi cụ thể).....
7. Nơi ở:
 - Thành thị Nông thôn Miền núi
8. Thu nhập
 - Thu nhập của gia đình là bao nhiêu trong một tháng:USD
 - Thu nhập của bản thân bao nhiêu một tháng:USD
9. Bản thân có thể bảo hiểm y tế không? Có; Không..... (%)
10. Có bao nhiêu người sống cùng với bạn?

Phần 2: Thông tin lâm sàng

1. Bệnh viện điều trị trước khi vào bệnh viện Bạch Mai
2. Ngày nhập viện:
3. Chẩn đoán:
4. Lịch sử bệnh:
5. Ngày lấy thông tin.....
6. Thời gian nằm viện (từ lúc nhập viện):.....
7. Giai đoạn bệnh Giai đoạn 1 Giai đoạn 2 Giai đoạn 3 Giai đoạn 4
8. Phương pháp điều trị
 - Ghép gan Liệu pháp sinh học
 - Phẫu thuật cắt gan Hóa chất
 - Đốt sóng cao tần (RFA) Xạ trị
 - Đốt bằng vi sóng Điều trị giảm nhẹ
 - Tiêm cồn vào khối u Điều trị kết hợp
 - Nút mạch (TACE hoặc TOCE)

Phần 3: Đánh giá triệu chứng thực thể của người bệnh theo Cohen-Hoberman

Hướng dẫn: tất cả câu hỏi đề cập đến việc liệu những triệu chứng làm phiền hoặc làm bạn thấy mệt mỏi trong 2 tuần qua cho đến nay. Ở mức 0 có nghĩa rằng bạn không bị làm phiền bởi những vấn đề này. Còn ở mức 4 có nghĩa là vấn đề đã làm bạn cực kỳ bận tâm đến nó. Đánh dấu vào một số cho mỗi mục ở dưới.

Bạn bị làm phiền như thế nào bởi các vấn đề sau:

1. Vấn đề về giấc ngủ (không thể ngủ, thức dậy giữa đêm hoặc dậy sớm mỗi sáng)	0	1	2	3	4
2. Thay đổi về cân nặng (tăng hoặc giảm khoảng 5kg hoặc nhiều hơn)	0	1	2	3	4
3. Đau lưng	0	1	2	3	4
4. Táo bón	0	1	2	3	4
5. Chóng mặt	0	1	2	3	4
6. Tiêu chảy	0	1	2	3	4
7. Uể oải	0	1	2	3	4
8. Mệt mỏi thường xuyên	0	1	2	3	4
9. Đau đầu	0	1	2	3	4
10. Đau nửa đầu	0	1	2	3	4
11. Buồn nôn và/ hoặc nôn	0	1	2	3	4
12. Đầy bụng và khó tiêu	0	1	2	3	4
13. Đau dạ dày (ví dụ có cơn co thắt dạ dày)	0	1	2	3	4
14. Nóng lạnh bất thường	0	1	2	3	4
15. Run tay	0	1	2	3	4
16. Đánh trống ngực hoặc tim đập nhanh	0	1	2	3	4
17. Chán ăn	0	1	2	3	4
18. Khó thở khi tập thể dục hoặc làm việc nặng	0	1	2	3	4
19. Tê bì hoặc đau nhói ở các bộ phận trên cơ thể	0	1	2	3	4
20. Cảm thấy yếu ớt và mệt mỏi	0	1	2	3	4
21. Đau tim hoặc ngực	0	1	2	3	4
22. Cảm thấy không có năng lượng	0	1	2	3	4
23. Đau đầu và nghẹt mũi	0	1	2	3	4
24. Mờ mắt	0	1	2	3	4
25. Căng cơ bắp hoặc đau nhức cơ	0	1	2	3	4
26. Chuột rút	0	1	2	3	4
27. Đau nhức nặng	0	1	2	3	4
28. Nổi mụn	0	1	2	3	4
29. Có các vết thâm	0	1	2	3	4
30. Chảy máu mũi	0	1	2	3	4
31. Căng cơ	0	1	2	3	4
32. Căng dây chằng	0	1	2	3	4
33. Lạnh và ho	0	1	2	3	4

Phần 4: Bộ câu hỏi đánh giá triệu chứng Hopkins 25 (HSCL- 25)

Hướng dẫn: Các câu hỏi dưới đây mô tả về những vấn đề hoặc triệu chứng mà mọi người gặp phải. Vui lòng đọc mỗi triệu chứng một cách cẩn thận và mô tả mức độ triệu chứng làm bạn khó chịu trong tuần qua cho đến hôm nay. Đánh dấu tích vào cột thích hợp. Đối với các câu trả lời cho từng hạng mục, có các điểm sau đây: 1 = Không khó chịu; 2 = Khó chịu một ít; 3 = Khó chịu nhiều; 4 = Rất khó chịu

Tên:	Ngày :
Ngày sinh:	Giới tính :
Tình trạng hôn nhân :	Bác sĩ điều trị :
Chẩn đoán tâm thần :	

Số thứ tự	PHẦN I: NHỮNG TRIỆU CHỨNG LO ÂU	Không khó chịu	Khó chịu một ít	Khó chịu nhiều	Rất khó chịu
1	Đột nhiên sợ mà không có lý do				
2	Cảm giác sợ hãi				
3	Ngất, chóng mặt hoặc yếu				
4	Căng thẳng hoặc run rẩy bên trong				
5	Hồi hộp và đánh trống ngực				
6	Run sợ				
7	Cảm thấy căng thẳng				
8	Đau đầu				
9	Tình trạng khiếp sợ, hoảng loạn				
10	Cảm thấy bồn chồn hoặc không thể ngồi yên				
	PHẦN II: CÁC TRIỆU CHỨNG TRẦM CẢM	Không khó chịu	Khó chịu một ít	Khó chịu nhiều	Rất khó chịu
11	Cảm thấy ít năng lượng, chậm chạp				
12	Đổ lỗi cho bản thân về mọi thứ				
13	Dễ rơi nước mắt				
14	Mất ham muốn tình dục hoặc cảm giác vui vẻ				
15	Chán ăn/ kém ăn				
16	Khó ngủ, trằn trọc				
17	Cảm thấy vô vọng về tương lai				
18	Cảm thấy buồn bã				
19	Cảm thấy buồn bã				
20	Có tư tưởng kết thúc cuộc sống				
21	Cảm giác bị mắc kẹt hoặc bị bắt				
22	Lo lắng quá nhiều về mọi thứ				
23	Cảm thấy không quan tâm đến mọi thứ xung quanh				
24	Cảm thấy tất cả mọi thứ đều phải ráng sức				
25	Cảm giác mình vô dụng				

Phần 5: Thang đo đa khía cạnh về Nhận thức hỗ trợ xã hội (MSPSS)

Hướng dẫn: chúng tôi quan tâm đến việc bạn cảm nhận như thế nào về các câu sau. Đọc các câu sau cẩn thận và đưa ra nhận định về suy nghĩ của bạn với mỗi câu sau:

- Khoanh tròn “1” nếu bạn hoàn toàn không đồng ý
- Khoanh tròn “2” nếu bạn rất không đồng ý
- Khoanh tròn “3” nếu bạn không đồng ý
- Khoanh tròn “4” nếu bạn không có ý kiến
- Khoanh tròn “5” nếu bạn đồng ý
- Khoanh tròn “6” nếu bạn rất đồng ý
- Khoanh tròn “7” nếu bạn hoàn toàn đồng ý

1. Luôn có một người đặc biệt ở bên cạnh tôi mỗi khi tôi cần.	1	2	3	4	5	6	7	Xã hội
2. Luôn có một người đặc biệt ở bên cạnh tôi, người tôi có thể chia sẻ buồn vui.	1	2	3	4	5	6	7	Xã hội
3. Gia đình tôi luôn cố gắng giúp tôi	1	2	3	4	5	6	7	Gia đình
4. Tôi nhận được sự giúp đỡ và hỗ trợ về mặt tinh cảm từ gia đình tôi mỗi khi tôi cần.	1	2	3	4	5	6	7	Gia đình
5. Luôn có một người đặc biệt làm cho tôi thấy thoải mái.	1	2	3	4	5	6	7	Xã hội
6. Những người bạn của tôi luôn cố gắng giúp tôi.	1	2	3	4	5	6	7	Bạn bè
7. Tôi có thể tin tưởng vào những người bạn của tôi khi tôi có những hướng đi sai lầm	1	2	3	4	5	6	7	Bạn bè
8. Tôi có thể nói chuyện với gia đình về các vấn đề của tôi.	1	2	3	4	5	6	7	Gia đình
9. Luôn có những người bạn ở bên cạnh tôi, người tôi có thể chia sẻ buồn vui.	1	2	3	4	5	6	7	Bạn bè
10. Luôn có một người đặc biệt trong cuộc đời tôi, luôn quan tâm đến cảm xúc của tôi.	1	2	3	4	5	6	7	Xã hội
11. Gia đình tôi luôn sẵn sàng giúp tôi đưa ra quyết định.	1	2	3	4	5	6	7	Gia đình
12. Tôi có thể nói chuyện với những người bạn về các vấn đề của tôi.	1	2	3	4	5	6	7	Bạn bè

Các câu hỏi có xu hướng chia thành các nhóm yếu tố có liên quan đến nguồn gốc của sự hỗ trợ xã hội bao gồm gia đình (Fra), bạn bè (Fri) và xã hội (So).


Phần 6: Bộ câu hỏi về những vấn đề và nhu cầu về chăm sóc giảm nhẹ của bệnh nhân (PNPC-sv)

Hướng dẫn: Có 33 mệnh đề trong thang đo này. Tất cả các mệnh đề đều đề cập đến việc bạn cảm thấy thế nào về các phát biểu dưới đây. Hãy đọc các phát biểu cẩn thận và tích vào lựa chọn phù hợp:

Bạn có để ý và coi đó là một vấn đề không?			Các vấn đề và yêu cầu chăm sóc	Bạn có yêu cầu ai đó giúp bạn với những vấn đề này?		
Có	Thỉnh thoảng	Không		Cần sự giúp đỡ hơn hiện tại	Có chiều hướng không cần sự giúp đỡ	Không cần sự giúp đỡ
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Thực hiện hoạt động hàng ngày	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			Triệu chứng thực thể			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1. Tự chăm sóc bản thân như tắm mặc quần áo, đi vệ sinh.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2. Di chuyển một mình (đi xe đạp, lái xe, sử dụng phương tiện công cộng...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3. Làm các việc nhà nhẹ nhàng như dọn dẹp nhà cửa	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4. Đau	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5. Mệt mỏi	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	6. Vấn đề về giấc ngủ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	7. Khó thở	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8. Ho	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9. Mẩn ngứa	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10. Các vấn đề tình dục	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11. Đau nhói như kim châm hoặc tê bì	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	12. Ra mồ hôi đêm hoặc bốc hỏa	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			Sự tự tin vào bản thân			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	13. Khó khăn khi thực hiện các công việc trước đây	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	14. Khó khăn khi đảm nhiệm công việc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	15. Phụ thuộc vào người khác	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	16. Không thể quản lý hoặc kiểm soát cuộc sống của người khác	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Bạn có cho những phát biểu dưới đây là vấn đề không?			Các vấn đề và yêu cầu chăm sóc	Bạn có yêu cầu ai đó giúp giải quyết những vấn đề này?		
Có	Thỉnh thoảng	Không		Cần sự giúp đỡ hơn hiện tại	Có chiều hướng không cần sự giúp đỡ	Không cần sự giúp đỡ
			Vấn đề xã hội			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	17. Có vấn đề về mối quan hệ vợ chồng	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	18. Khó nói với vợ hoặc chồng về bệnh	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	19. Nhận thấy khó khăn khi đề cập đến sự đau đớn bởi vì không muốn là gánh nặng cho người khác.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	20. Nhận thấy mọi người xung quanh không sẵn sàng để nói về bệnh của bạn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	21. Khó tìm ra một người bạn đáng tin cậy để nói về mọi thứ.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			Vấn đề tâm lý			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	22. Trầm cảm	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	23. Sự lo sợ về các triệu chứng nặng của bệnh	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	24. Lo sợ về sự tiến triển của bệnh	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	25. Khó khăn khi đối mặt với tương lai không chắc chắn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	26. Khó khăn khi biểu lộ tâm trạng và cảm xúc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			Vấn đề tinh thần			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	27. Khó khăn khi tham gia các hoạt động trí óc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	28. Khó khăn khi dành thời gian cho người khác	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	29. Khó khăn khi nghĩ về cái chết	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	30. Thật khó để chấp nhận bệnh bạn mắc phải	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			Vấn đề tài chính			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	31. Chi phí quá nhiều cho bệnh tật	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	32. Thu nhập thấp hơn vì bị bệnh	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			Thông tin cần thiết			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	33. Thiếu hụt về thông tin nhận được như bệnh và quá trình điều trị, sự lựa chọn điều trị, nguồn lực hỗ trợ và chăm sóc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX F
PERMISSION FOR USING INSTRUMENTS

 Gmail hien le <lehien84bm@gmail.com>

ตอบกลับ: **Asking permission to use PNPC-SV**

2 thu

Wallada Chanruangvanich <wallada.cha@mahidol.ac.th>

08:13 28 tháng
1, 2016

Tới: "Myrra.Vernooij-Dassen@radboudumc.nl" <Myrra.Vernooij-Dassen@radboudumc.nl>

Cc: "lehien84bm@gmail.com" <lehien84bm@gmail.com>

Dear Prof. Dr. M. Vernooij-Dassen,

Thank you very much for your kindness and information. Your questionnaires will be used worldwide especially in ASIAN.

Sincerely yours,

Dr. Wallada Canaruangvanich.

Faculty of Nursing , Mahidol University.

Thailand

จาก: Myrra.Vernooij-Dassen@radboudumc.nl [Myrra.Vernooij-Dassen@radboudumc.nl]

ส่ง: 27 มกราคม 2016 20:06

ถึง: Wallada Chanruangvanich

สำเนาถึง: osse.arentz@gmail.com

เรื่อง: Re: Asking permission to use PNPC-SV

Dear professor Chanruangvanich,

Thank you for your interest in our questionnaire. You have permission to use the questionnaire and we would very much like to be informed about the results. You might be interested in the Indonesian results of Dr. Christantie Effendy. You can find her publications on internet (Pubmed).

Best wishes,

Myrra Vernooij

Prof. Dr. M. Vernooij-Dassen

Radboud University Nijmegen Medical Centre

Scientific Institute for Quality of Healthcare

PO Box 9101; 114 IQ healthcare

6500 HB NIJMEGEN

Visiting address: Geert Grooteplein 21, Nijmegen

Honorary visiting professor Gadjah Mada University Yogyakarta, Indonesia

T +3124-3616643 / +316-11079653

E Myrra.Vernooij-Dassen@radboudumc.nl

Van: Wallada Chanruangvanich <wallada.cha@mahidol.ac.th>

Datum: Monday 25 January 2016 04:07

Aan: Myrra Vernooij-Dassen <myrra.vernooij-dassen@radboudumc.nl>

Onderwerp: Asking permission to use PNPC-SV

Dear Prof. Dr. Myrra Vernooij Dassen,

My name is Wallada Chanruangvanich. I am an instructor at the Faculty of Nursing, Mahidol university, Thailand. I am interested in the research of Problems experienced by the Informal caregivers of Cancer patients and Their Needs for support and a practical instrument to explore patients' needs in palliative care: the Problem and Need Care questionnaire- short version developed by Dr. Bart H.P Osse.

I would like to ask permission to use "The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv) in my graduate student research. She is a Vietnamese nurse studying at Faculty of Nursing, Mahidol University. She will use PNPC-sv in the topic of "Factors related to needs in palliative care among Vietnamese patients with hepatocellular carcinoma". We would like to know if hepatocellular carcinoma patients in Vietnam have problems like the others or not.

So, I would like to use your PNPC-sv questionnaire in Vietnamese patients as the results would be useful for her cancer patients and health care professionals in Vietnam.

However your questionnaire would be translated in to Vietnamese language using back transition technique before using them and will be a new knowledge for the health care profession in the future. After we have a Conbrach Alfa of the PNPC-sv questionnaire and the research result, I will send it to you later.

I would greatly appreciate your assistance and look forward to hearing from you.

Sincerely yours,

Assist Prof. Dr. Wallada Chanruangvanich
Faculty of Nursing , Mahidol University.
Thailand

Het Radboudumc staat geregistreerd bij de Kamer van Koophandel in het handelsregister onder nummer 41055629.

The Radboud university medical center is listed in the Commercial Register of the Chamber of Commerce under file number 41055629.

hien le <lehien84bm@gmail.com>

08:30 28 tháng 1, 2016

Tới: Wallada Chanruangvanich <wallada.cha@mahidol.ac.th>

Thank you so much!

Vào Thứ Năm, ngày 28 tháng 1 năm 2016, Wallada Chanruangvanich <wallada.cha@mahidol.ac.th> đã viết:

[Ân văn bản trích dẫn]



Gmail

hien le <lehien84bm@gmail.com>

Permission2 thu

hien le <lehien84bm@gmail.com>

17:15 19 tháng 12, 2015

Tới: KRICKELS@mail.med.upenn.edu

Dear Professor Karl Rickels!

My name is Le Thi Hien. I am master student in Adult nursing in Mahidol University, Thailand. I will conduct thesis about “Factors related to need in palliative care among patients with hepatocellular carcinoma”. I has done thesis under guiding my supervision Assistant profesor Dr. Wallada Chanruangvanich. After read your article I feel that your questionnaires are very suitable for my thesis. So, I am interested to use your questionnaires in my thesis regarding “Hopkins Symptom Checklist 25 (HSCL- 25)”. So, I want to use your questionnaires in my thesis. I would like to ask you that:

- Would you please agree to accept me to use your questionnaires in my thesis?
- Would you please agree to accept me to translate your questionnaires from English to Vietnamese and contrary?

Thank you very much. I am looking forward to your answer

Karl Rickels <krickels@mail.med.upenn.edu>

01:00 22 tháng 12, 2015

Tới: hien le <lehien84bm@gmail.com>

Approved

for

both

Karl Rickels

APPENDIX G

ADDITIONAL STATISTIC ANALYSIS

Tests of Normality

	Kolmogorov-Smirnov ^a			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
SumPS	.120	115	.000	.953	115	.000
SumAD	.176	115	.000	.874	115	.000
SumSS	.193	115	.000	.909	115	.000
SumPC	.148	115	.000	.900	115	.000

a. Lilliefors Significance Correction

BIOGRAPHY

NAME	Le Thi Hien
DATE OF BIRTH	10/10/1984
PLACE OF BIRTH	Nghe An
INSTITUTIONS ATTENDED	Hanoi Medical University, 2003 –2007 Bachelor of Nursing Mahidol University, 2015-2016 Master of Nursing Science (Adult Nursing)
POSITION AND OFFICE	Nursing of The Nuclear medicine and Oncology Center, Bach Mai Hospital, Ha noi, Viet Nam
EMPLOYMENT ADDRESS	No 78 .Giai Phong Street, Dong Da district, Hanoi, Vietnam Workplace telephone number) :84 (04.8693731 Website : www.gov.bachmai.vn
HOME ADDRESS	No97 . , Khuong Trung street Thanh Xuan district, Hanoi Mobile telephone) :84.(984343188. Email :Lehien84bm@gmail.com