

# Factors Related to Needs in Palliative Care among Patients with Hepatocellular Carcinoma\*

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## Abstract

**Purpose:** To identify relationships between physical symptoms, anxiety and depression, social support, and needs in palliative care among patients with hepatocellular carcinoma (HCC).

**Design:** Descriptive correlational study.

**Methods:** The study was conducted among 115 patients with HCC at the Nuclear Medicine and Oncology Center in Hanoi, Vietnam. Data were collected from the patients' record and interviewed using demographic questionnaire, the Cohen-Hoberman Inventory of Physical Symptoms scale (CHIPS), the Hopkins Symptoms Checklist-25 scale (HSCL- 25), the Multidimensional Scale Perceived Social Support (MSPSS), and the Problems and Needs in Palliative Care-short version (PNPC-sv). Spearman's Rho was employed to test the relationship among studied variables.

**Main findings:** Physical symptoms, anxiety, and depression were significant positively correlated with needs in palliative care ( $r_s = .775$ ,  $r_s = .828$ ,  $p < .05$ ). Social support had a significant negative correlation with needs in palliative care ( $r_s = -.307$ ,  $p < .05$ ).

**Conclusion and recommendations:** Nurses should assess and manage patients' symptoms, control their psychology and promote their social support. To improve palliative care, standard guidelines for symptom management in palliative care should be developed and implemented.

**Keywords:** palliative care, hepatocellular carcinoma, social support, physical symptoms, anxiety and depression

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# ปัจจัยที่มีความสัมพันธ์กับความต้องการการดูแลแบบประคับประคองของผู้ป่วยมะเร็งตับ\*

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## บทคัดย่อ

**วัตถุประสงค์:** เพื่อศึกษาปัจจัยที่มีความสัมพันธ์ระหว่างอาการทางกาย ความวิตกกังวลและชีมเคร้า และความสนับสนุนทางสังคม กับความต้องการการดูแลแบบประคับประคองของผู้ป่วยมะเร็งตับ

**รูปแบบการวิจัย:** วิจัยเชิงสหสัมพันธ์

**วิธีดำเนินการวิจัย:** กลุ่มตัวอย่างเป็นผู้ป่วยมะเร็งตับ จำนวน 115 คน ที่มารับการรักษาที่ศูนย์มะเร็งและเวชศาสตร์นิวเคลียร์ เมืองขอนอย ประเทศไทย วิเคราะห์โดยใช้แบบประเมินอาการทางกาย (CHIPS) ความวิตกกังวล (HSCL- 25 scale) การสนับสนุนทางสังคม (MSPSS) และความต้องการการดูแลแบบประคับประคอง (PNPC-sv) จากนั้นหาค่าความสัมพันธ์ด้วยสถิติ Spearman's Rho

**ผลการวิจัย:** อาการทางกาย ความวิตกกังวลและภาวะชีมเคร้า มีสัมพันธ์เชิงบวกกับความต้องการการดูแลแบบประคับประคองอย่างมีนัยสำคัญทางสถิติ ( $r_s = .775$ ,  $r_s = .828$ ,  $p < .05$ ) การสนับสนุนทางสังคมมีความสัมพันธ์เชิงลบกับความต้องการการดูแลแบบประคับประคองอย่างมีนัยสำคัญทางสถิติ ( $r_s = -.307$ ,  $p < .05$ ).

**สรุปและข้อเสนอแนะ:** พยาบาลควรประเมินอาการไม่สุขสบายด้านร่างกาย จิตใจ และส่งเสริมการสนับสนุนทางสังคมแก่ผู้ป่วย ตลอดจนพัฒนาแนวปฏิบัติมาตรฐานเพื่อการดูแลแบบประคับประคอง

**คำสำคัญ:** การดูแลแบบประคับประคอง มะเร็งตับ ความวิตกกังวลและภาวะชีมเคร้า การสนับสนุนทางสังคม อาการทางกาย

## Background and Significance

Hepatocellular carcinoma (HCC) is the 5<sup>th</sup> most common type of cancer in the world and the 3<sup>rd</sup> cause of cancer-related death in the Asia-Pacific region.<sup>1,2</sup> More than 70% of all new cases of liver cancer diagnosed worldwide were in Asia. The highest rate of HCC was reported in Eastern and South-Eastern Asia; whereas Middle Eastern countries have a moderate prevalence rate.<sup>3</sup> Thus, HCC is an important health problem in Asia and the world that caused the deaths of 19,610 males and 9,310 females in 2016.<sup>4</sup> HCC often appears in poor and developing country especially in Asian; due to viral hepatitis infections.<sup>5</sup> In Vietnam, HCC is one of the most common cancers and is the fifth cause of death.<sup>6</sup>

Available evidence indicated that palliative care has not been appropriately provided for patients with HCC. Those patients still have unmet needs including information, education, support groups, nutrition, physical, and psychological issues.<sup>7</sup> Especially in Vietnam, at least 90% of Vietnamese patients died at home without receiving palliative care.<sup>8</sup> Therefore, patients with HCC must cope with several symptoms, treatment decisions, and insufficient information, and unmet demands for palliative care.<sup>9</sup> The needs in palliative care for patients with HCC mostly focus on patients with end-stage or terminal HCC including management of pain, nutrition, and psychological support.<sup>10</sup>

The World Health Organization (WHO) has shown that palliative care helps provide a better quality of life for HCC patients and their families. The concept of palliative care consists of avoidance and reduction of suffering by early diagnosis, assessment, and alleviation of pain and other physical, psychosocial and spiritual problems.<sup>11</sup> The end-stage patients with terminal illness often suffer from physical distress. Appropriate symptom management helps patients and their families maintain hope, connections with society, and optimism.<sup>10</sup>

Patients with HCC often suffered from a number of physical symptoms such as fatigue,

weight loss, pain, ascites, and jaundice.<sup>5</sup> Patients with HCC were incapable of caring for themselves; they need special care from medical institutions or hospital. The pain of HCC was a common symptom. It should be assessed and needs to be re-assessed frequently.<sup>10</sup> The most frequently encountered physical symptoms included tiredness (100%), anorexia (89%), pain (82%), drowsiness (53%), shortness of breath (34%) and nausea (26%).<sup>12</sup> Patients with HCC need to have better control of symptoms and to receive good social support.

After patients were diagnosed with HCC, there was often a negative effect on their psychology and that of their family. It was not only from poor physical status but also mental health from anxiety and depression.<sup>11</sup> The psychological problems were varying with 68.42% of liver cancer patients being affected by depression.<sup>13</sup> Many of these patients have psychological problems that need assessment and treatment.<sup>14</sup>

Social support is an important aspect of modern cancer care which includes financial and spiritual support that an individual receives from their close environment.<sup>15,16</sup> This will help patients with HCC reduce burden from disease and treatment in order to meet the palliative care needs.<sup>16</sup> The social relationship between patients and health professionals is a more realistic approach to decrease the burden of hospitalizations for patients.<sup>16</sup> Furthermore, it is proved that the establishment of support groups plays an important part in psychosocial service which helps cancer patients lessen stress and be more active.<sup>17</sup> It is also a common type of social support.<sup>17</sup> Thus, social support is very important for patients with HCC during the treatment process and improves palliative care and unmet needs of the patients.

There was little previous research on the needs for palliative care among patients with HCC in Vietnam. Thus, this study aimed to explore the needs for palliative care by identifying the relationships between physical symptoms, anxiety and depression, social support and

needs for palliative care among hospitalized patients with HCC. This findings could be used to improve quality of nursing care and palliative care programs for patients with HCC.

## Objective

To identify relationships between physical symptoms, anxiety and depression, and social support with needs in palliative care among patients with HCC.

## Hypothesis

1. Physical symptoms, anxiety and depression were positively correlated with needs in palliative care among patients with HCC.

2. Social support was negatively correlated with needs in palliative care among patients with HCC.

## Methodology

### Population and Sample

The population of this study included patients who were diagnosed with HCC and received treatment in The Nuclear Medicine and Oncology Center in Bach Mai Hospital. The samples were selected according to the inclusion criteria as follows: 1) age 18 years and older both males and females, 2) able to communicate in Vietnamese language. Patients with HCC who were in end-stage with unstable vital signs were excluded.

The sample size was calculated using G\*power program.<sup>18</sup> The researchers selected a medium correlation for this study ( $r = .3$ )<sup>19</sup> based on the level of significance of  $\alpha = .05$ , power  $1-\beta = .80$  with the effect size  $f^2 = .099$ . Therefore, sample size was 115 patients with HCC.

### Research Instruments

The instruments used for data collection were as follows:

1. Demographic and medical information included age, weight, height, gender, occupation, level of education, marital status, payment method, income, disease diagnosis, date of treatment, duration of illness, stage of disease,

and treatment method.

2. The Cohen-Hoberman Inventory of Physical Symptoms scale (CHIPS) developed by Cohen and Hoberman.<sup>20</sup> CHIPS composed of 33 items; each item was rated for how much that problem bothered or distressed the individual during the past two weeks. Items were rated on a five-point Likert scale from "not at all" to "extremely". Total scores were from 0 to 132 and high scores indicated multiple physical symptoms.<sup>20</sup> The Cronbach's alpha was tested among 30 and 115 patients. It was equal to .89 and .94, respectively.

3. The Hopkins Symptom Checklist 25 (HSCL-25) as originally designed by Parloff, Kelman, and Frank at Johns Hopkins University and further developed by Rickels<sup>21</sup>, was used to measure anxiety and depression. HSCL- 25 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 on a Likert scale; "1 = not at all", "2 = a little", "3 = quite a bit", "4 = extremely". The scores of the two parts were calculated, the total score was the average of all 25 items and higher scores indicated a higher level of symptoms. Individuals with average score greater than 1.75 were considered symptomatic.<sup>21</sup> The Cronbach's alpha was tested among 30 and 115 patients. It was equal to .90 and .98, respectively.

4. The Multidimensional Scale Perceived Social Support (MSPSS) as developed by Zimet et al.<sup>22</sup> MSPSS was used to measure the perception of social support as it was offered from special persons (4 items), family (4 items), and friends (4 items)<sup>22</sup> scored on a seven-point Likert scale ranged from very strongly disagree to very strongly agree. Total scores ranged from 12 to 84 with higher scores indicated better social support. The Cronbach's alpha was tested among 30 and 115 patients. It was equal to .75 and .88, respectively.

5. The Problems and Needs in Palliative Care questionnaire-short version (PNPC-sv) as developed by Osse et al.<sup>23</sup>, it has 33 items

including 8 topics. For these 33 items, 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 the need for more help.<sup>23</sup> The Cronbach's alpha was tested among 30 and 115 patients. It was equal to .91 and .97, respectively.

In this study, all instruments were translated into Vietnamese using back translation technique which was then verified by 3 experts including an oncology doctor, oncology nurse, and oncology nursing instructors. The content validity index (CVI) of CHIPS, the HSCL-25, the MSPSS, and the PNPC-sv were .90.

#### **Protection Right of Human Subjects**

This project was approved by the Institutional Review Board (IRB) of Faculty of Nursing, Mahidol University, Thailand (COA No.IRB-NS 2016/350.0205) and IRB of Vietnam National University, Vietnam. The researcher recruited subjects as standard process specified by the IRB. The issues of independently to make decision to consent, anonymity, and confidentiality were warranted.

#### **Data Collection Process**

1. After getting permission to collect data, the researcher met the director of The Nuclear Medicine and Oncology Center and the head nurse of the Center in order to explain the purpose of this study.

2. On the data collecting date, the head nurse provided information regarding the research project to the patients with HCC. If the patient was interested in participating in this project, the head nurse introduced to the researcher.

3. The researcher self-introduced, made a relationship with the patients, then informed them about the objectives of study and invited them to join the study. They were then invited to sign the consent form. After the consent forms

were signed, patients were asked to complete the questionnaires. Some demographic data was collected from the patient's medical records. The time used for completing this data collection was about 30-40 minutes.

#### **Data Analysis**

Data were analyzed using the computer statistical package with the significant level of .05 as follows:

1. Descriptive statistics: frequency, percentage, mean, and standard deviation and range.

2. None of the studied variables showed normal distribution, thus Spearman's Rho was employed to test correlation among the variables.

#### **Findings**

The majority of 115 subjects were male (74.8%) with average age of 57.3 (SD = 11.29), age ranged from 22 to 80 years, 34.8% finished secondary school and 30.40% finished high school, 21.7% were farmers, 38.3% were retired, 42.6% lived in cities and 53% lived in rural areas. The average monthly income of the subjects was 147.7 USD (SD = 95.26) and for their families' was 304.2 USD (SD = 190.7). All of patients had government insurance.

Most of subjects had stage 4 of cancer (80.9%), 33.9% were underweight, 23.5% received chemotherapy, 33.9% received palliative treatment, and 28.7% received combination of palliative and chemotherapy.

#### ***Correlation between physical symptoms, anxiety and depression, social support and problems and needs for palliative care among HCC patients***

The results supported the proposed hypotheses that physical symptoms, anxiety and depression were significant positively correlated with needs in palliative care ( $r_s = .775$ ,  $r_s = .828$ ,  $p < .05$ ). Social support had a significant negative correlation with needs in palliative care ( $r_s = -.307$ ,  $p < .05$ ). (Table 1)

**Table 1:** Correlation between physical symptom, anxiety and depression, social support 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 < .05, Spearman's Rho Correlation

## Discussion

The majority of cases of HCC in this study group were detected at advanced stages: stage 3 (17.4%) and stage 4 (80.9%). Unfortunately, most patients were found in late stage without the opportunity for operation.<sup>9,10</sup> This result was higher than reported from Kumar and Panda with 15-20% presenting with end-stage or terminal stage HCC.<sup>10</sup>

### *Needs for palliative care among patients with HCC*

This study showed the high prevalence of problems in carrying out daily activities and physical symptoms because the HCC was usually detected in an advanced stage. The needs of patients with HCC were highest in physical symptoms (86.1%) followed by psychological symptoms (67.8%). Several domains showed quite more problems such as carrying out daily activities. The finding was lower than the results of the research of Buzgova et al.<sup>24</sup> Within each overall domain of needs at least one need was identified as important by more than 95% of patients.<sup>24</sup> In addition, it was similar to study in North Carolina reporting that 40% to 60% indicated a need for some assistance with most activities of daily living and 40% of patients reflecting severe debilitation and a need for considerable assistance.<sup>25</sup> The results in this study and other studies supported that patients with HCC have many problems and needs in palliative care.

### *The relationship between physical symptoms, anxiety and depression, social support and needs for palliative care among patients with HCC*

The results of this study confirmed the hypothesis that physical symptoms, anxiety and depression were positively correlated with problems and needs for palliative care ( $r_s = .775$ ,  $r_s = .828$ ,  $p < .05$ ). Social support had a negative correlation with problems and needs for palliative care ( $r_s = -.307$ ,  $p < .05$ ). These findings would partly contribute to the planning to promote palliative care for patients with HCC.

### *Physical symptoms and needs in palliative care*

This research showed the proportion of patients affected by the physical symptoms was high (47%). A review of cancer patient needs demonstrated that a substantial proportion of patients were not receiving treatment aimed at addressing their symptom concerns.<sup>25</sup> The finding was lower than of Kamal et al., who reported hypochondriac pain was the most common complaint symptom (74%).<sup>25</sup> On the other hand, research of Sun and Sarna<sup>5</sup> showed that fatigue was a very common and distressing symptom in patients with HCC. They reported that fatigue due to terminal illness was the same as our patients with stage 4 (80.9%). In fact, this study found that underweight patients (33.9%) needed more care (47.8%) for the daily activities. Furthermore, jaundice and ascites presented in nearly half of patients at the time of diagnosis with later stages in many studies.<sup>5,26</sup> In accordance with our study, unmet needs due to physical symptoms was found in 86.1%, similar to the need for physical support in other studies.<sup>7,27</sup> Other patients were found to need to consult a nutritionist<sup>27</sup> about their diet. Therefore, the patients with such diagnosis

presented with symptoms that would require early engagement with a specialized palliative care program to address those symptoms<sup>13</sup> and unmet needs.<sup>7,27</sup> It is necessary for nurses to understand and conduct the clinical assessment and cope with cancer-related symptoms to provide patients a good outcome.<sup>5</sup>

#### *Anxiety and depression and needs for palliative care*

In this study, the percentage of patients that suffered from anxiety and depression symptoms was quite high (56.5%). However, our finding was lower than in China cancer patients by Hong and Tian<sup>28</sup> with 68.42% depression and higher than in the research of Khalil et al.<sup>29</sup>, with 48.7%. Anxiety and depression had high positive correlation with needs for palliative care while a majority of our patients felt unmet needs in psychological issues (67.8%). According to the unmet needs in chronic liver disease, many patients felt fear, anxiety, sadness, and need to consult a health care provider for psychological problems.<sup>7</sup> Thus, HCC patients should be guided by a palliative care approach focused on symptom reduction and pharmacotherapy.

#### *Social support and needs for palliative care*

Patients with HCC received quite good social support, with the support from family as the highest (100%; Mean = 26.17, SD = 3.10); the second was from friends (85.2%; Mean = 23.07, SD = 5.84) while that from significant others was the lowest (6.1%; Mean = 10.03, SD = 4.50). The scores in this study were lower than the research at Cumhuriyet University Hospital where the mean social support score was 67.03 (SD = 15.57).<sup>16</sup> In this study, social support had low negative correlation with needs for palliative care. According to the study of Harrison et al., patients with HCC needed much support to deal with physical symptoms (86.1%) and psychological symptoms (67.8%).<sup>27</sup> In our study, the patients with HCC had good family and friend support because of gratitude, attachment, and social tie characteristic in

Vietnamese culture. However, the unmet needs from health care personal were also reported about the disease information, treatment, and symptom control.<sup>7</sup> Thus, the unmet needs were still high in many aspects from the physical to the psychological; some related to overcrowding in the study hospital.

#### **Conclusion and Implications**

In summary, this study revealed that patients with HCC had their symptoms controlled and perceived good social support this led to reduced problems allowing unmet needs to decrease. Factors that affected needs for palliative care were physical symptoms, anxiety and depression, and social support. Accordingly, to fully support the needs of the patients with HCC in palliative care and improve palliative practice, nurses should control physical symptoms, anxiety and depression effectively in order to decrease needs for palliative care. Nurses and other health care team members must respond to the particular needs of patients with HCC and develop guidelines for palliative care using support from the social network of the patients. Multi-settings research should be conducted in Vietnam. The results from the multi-settings research could be used to test psychometric property of CHIPS, HSCL-25, MSPSS, and PNPC-sv in their Vietnamese version.

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