

**Original article:**

**Symptom Experiences and Symptom Management among Persons with Lung Cancer in Bangladesh**

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**Abstract:**

**Objective:** Lung cancer is one of the most common cancers. Previous studies findings are not suitable to explain symptom experience and symptom management of Bangladeshi persons with lung cancer. This study was aimed to identify the symptom experiences and determines the management strategies among persons with lung cancer. **Methods:** A descriptive study design, using combined both quantitative and qualitative research methods, was chosen for this study. Convenient sampling was used to recruit 382 persons with lung cancer from two public and two private tertiary hospitals and 16 participants were invited for an in-depth interview in the qualitative part. Data collection was conducted from October 2015 to July 2016, using the MD Anderson Symptom Inventory Lung Cancer (MDASI-LC) questionnaire and using a semi-structured interview guide to explore their symptom management strategies. The quantitative data were analyzed using descriptive and inferential statistics and qualitative data by content analysis. **Results:** Pain was the most frequently reported physical symptom and the most severe one, followed by sleep disturbance and fatigue. Psychological symptoms such as sadness and distress were also frequent. Participants also reported other symptoms that interfered with daily living in terms of mood, general activity, work, enjoyment of life, walking and relationships with others. The symptom management consisted of three categories, which were taking modern medicine, adopting complementary therapies, and cultivating mind and body balance. Most of the participants addressed uses of more than one strategy. **Conclusions:** Participants experienced several physical and psychological symptoms that interfered with their lives. This finding will be beneficial for health care personnel regarding clinical practice to manage symptoms and further research may be conducted to obtain proper interventions to alleviate symptoms, and improve quality of life.

**Keywords:** Lung cancer; Symptom experience; Symptom management; Bangladesh.

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**Introduction**

Lung cancer is the leading cause of death globally<sup>1</sup>. It is a major public health problem in both developed and developing countries. Lung cancer incidence and prevalence in developed countries has been estimated at 15.2% and 6.9% respectively. In developing countries, the incidence and prevalence were estimated to be 18% and 10%<sup>2</sup>. In Bangladesh, a developing country in South Asia, the incidence and prevalence were reported to be 14.4% and

7.2% with a mortality rate of 12.3%<sup>2</sup>. Mortality due to lung cancer was found more frequently among Bangladeshi males than females for tobacco use<sup>3</sup>.

Empirically, persons with cancers experience a variety of symptoms. Symptom is the unpleasant experience of a person. Dodd's Symptom Management Model<sup>4</sup> identified three dimensions of cancer symptoms; symptom experience, symptom management strategies (SMS), and outcomes<sup>4</sup>. This model focuses on symptom perception, evaluation

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and response including the nursing domains of person, health and environment which is directly related to nursing profession and help to reflect the complete picture of symptom experience. Symptom experience refers to the perception, severity, and response to a symptom<sup>5,6</sup>. Perception of symptom indicates the recognition or realization of a symptom as the occurrence of the symptom of an individual. Severity of the symptom focuses on the individual's judgment of a symptom's intensity and response to the symptom describing the physiological, psychological and sociological changes of interferences as realized by the individual. In addition, SMS refers to the activities that are taken to prevent, reduce or delay the symptoms or their consequences. The outcomes refer to level of satisfaction of relief or reduction in the severity of symptom<sup>4</sup>. This study focuses on the symptom experience dimension because they are strongly associated with impaired functional ability, mood disturbances, and negative relationships, all of which lead to poor quality of life<sup>7,8</sup>.

In Bangladesh, participants' socio-economic status, medical facilities, local traditional cultural beliefs and practices, all differ from those in developed countries. There are very few studies that explore the strategies used by persons with lung cancer to manage their symptoms. Some studies from developed countries were found. However, the previous studies supported further endeavor as required with the existing support<sup>5</sup>. This study aimed to determine the symptom experiences that encompasses symptom perception, severity, and response based on modified Dodd's symptom management model and explore symptom management strategies among persons with lung cancer in Bangladesh.

### **Materials and methods**

A combine method of cross-sectional descriptive design was used. Persons with lung cancer were recruited by convenient sampling with the following inclusion criteria: aged 18 and above, any stage of lung cancer, receiving one or more type of conventional treatments, able to understand and communicate in Bengali language, willing to sign informed consent and to join in the study. Participants were excluded if they were suffering from any psychological disorder such as dementia, psychosis, neurosis, schizophrenia.

The sample size was estimated by using a proportional estimation formula for the number of the population. The latest cancer statistics, as reported by the NICRH

in 2013, stated that the total number of individuals with lung cancer in Bangladesh was 1,647. The sample size was yielded 322. To account for a 20% possible attrition rate, the number of subjects was increased to 382. The 16 participants in the qualitative part are the persons that provides better response, active, and eagerness to consider their time freely. In case of agreement, participants were invited for an in-depth interview.

An informed consent process was carried out before signing the consent form.

The data were collected from inpatient and out-patient departments of four teaching-based medical college (tertiary level) hospitals in Bangladesh October 2015 to July 2016 through interviewer-administered questionnaire and face to face interview through qualitative guide. The researcher and four trained research assistants were engaged to collect data. They conducted one to one direct interview with the selected participants.

**Data Analysis:** Descriptive statistics were used to analyze the data. The frequency, percentage, means, median and inter-quartile rank was used to describe symptom experiences including occurrence, severity, and interference. In this study, the researcher used median and interquartile-range, since the study data were not normally distributed (Table 2 and Table 3). The inferential statistic was conducted to find out relationship between top five symptom and age variation (Table 3). Qualitative data used content analysis. After the in-depth interview was conducted, the researcher transcribed it verbatim in Bengali language, using the digital recorder and filed notes. Then coding was done and the codes put in the right place in predetermined categories.

### **Research Instrument**

The authors obtained permission to use the research instruments from the instrument developer through email. The research instrument was a questionnaire with two parts: demographic data and the MD Anderson Symptom Inventory Lung Cancer (MDASI-LC) data. The MDASI-LC was translated into Bengali language using the back-translation method (Brislin, 1970). In this process, the researcher used three bilingual translators. The result showed that the translated version and original English version were congruent<sup>9</sup>.

Reliability of the MDASI-LC Bengali version was tested using the test-retest method with 20 conveniently picked up participants having similar

inclusion criteria as the study participants. The correlation range was 0.74 to 0.99. The internal consistency, using Cronbach’s alpha coefficient, was 0.90. For Determination by dimension, the good internal consistency of symptom severity items was 0.80, and the interference item was 0.82.

The qualitative data collection used a semi-structured interview and continued until data saturation. A guide for open question interview was used in accordance with subcategories predetermined.

**Ethical clearance:** Ethical approval was obtained from the Research Ethics Review Committee of the Faculty of Nursing, Chiang Mai University (Ref: 116/2015, ID: 551255801, Study Code: EXP-091-2558), and from the four selected hospitals in Bangladesh.

**Results**

The participants’ mean age was 48.2 years (SD=10.8). The majority of them (88.5%) were under 60 years old. Most were males (86.9%), married (98.7%) and Muslim (81.4%). More than half (53.6) had an educational level below high school. More than half (51.0%) were employed. Most of them (86.1%) had monthly incomes within 20,000 BDT [Bangladesh Taka; 80 Taka = 1\$]. Over half (57.1%) had stage II lung cancer. Most of them (97.6%) had been diagnosed in the last 12 months. Majority (85.3%) had no family history of cancer. More than half of them (64.4%) received chemotherapy.

**Symptom Experience:** Participants reported between 4–16 symptoms with a median score of severity between 2 and 7 (possible scores were 0 to 10). The first top-five symptom experiences were pain, which was the most frequently reported and severe symptom, followed by sleep disturbance, sadness, fatigue, and distress (Table 1). **Table 1.** Symptoms Perception and Severity (n=382)

Symptoms	Occurrence		Severity	
	(%)	n	Median	IQR
Pain	366 (95.8)		7.0	4.0
Sleep disturbance	363 (95.0)		6.0	4.0
Sadness	330 (86.4)		6.0	5.0
Fatigue	353 (92.4)		5.0	4.0
Distress	354 (92.7)		5.0	4.0
Drowsiness	346 (90.6)		5.0	4.0
Nausea	340 (89.0)		5.0	4.0
Shortness of breath	361 (94.5)		4.0	4.0

Symptoms	Occurrence		Severity	
	(%)	n	Median	IQR
Lack of appetite	361 (94.5)		4.0	3.0
Cough	347 (90.8)		4.0	4.0
Dry mouth	347 (90.8)		4.0	4.0
Constipation	340 (89.0)		4.0	4.0
Vomiting	322 (84.3)		4.0	4.0
Numbness / tingling	282 (73.8)		4.0	5.0
Sore throat	285 (74.6)		3.0	4.0
Memory problems (difficulties in or less ability to remember)	111 (29.1)		2.0	1.0

\* **Note.** None of the participants experienced all of the symptoms. IQR = Inter-quartile range.

For symptom interference, the median severity of interference was rated between 2 and 4 (possible scores were 0 to 10). The majority of participants reported mood as the most disturbing symptom, followed by general activity, working, enjoyment of life, walking, and relationships with others (Table 2). **Table 2.** Severity of Symptom Interference in life (n=382)

Interference of symptom	Occurrence		Severity of Interference	
	n (%)	Median	IQR	
Mood	336 (88.0)	4.0	3.0	
General activity	322 (84.3)	4.0	4.0	
Working	321 (84.0)	4.0	4.0	
Enjoyment of life	294 (77.0)	4.0	5.0	
Walking	327 (85.6)	3.0	4.0	
Relationships with others	185 (48.4)	2.0	2.0	

\***Note.** None of the participants experienced all of the symptoms. IQR = Inter-quartile range

Correlation between the Top-Five Symptom Experiences and Age.

Most of the symptoms were strongly correlated with each other and few of them were at age. Namely the pain was significantly associated with sleep disturbance, followed by sadness, fatigue, and distress (p=.243, =.268, =.347 and =.175). Similarly, the sadness was correlated with sleep disturbance

followed by fatigue, and distress ( $p=.210$ ,  $=.326$ , and  $.537$ ). In addition, the sadness was correlated with fatigue, followed by distress, and age diagnosis ( $p=.187$ ,  $=.146$ ,  $=.137$  and  $=.181$ ). Furthermore, the fatigue was correlated with distress followed by stage since diagnosis ( $p=.334$  and  $=.204$ ) (Table 3).

**Table 3.** Relationship between the Top-Five Symptom Experiences and Age ( $n=382$ )

Variables	1	2	3	4	5
1. Pain	-				
2. Sleep disturbance	.243**	-			
3. Sadness	.268**	.210**	-		
4. Fatigue	.347**	.326**	.187**	-	
5. Distress	.175**	.537**	.146**	.334**	-
6. Age	-.033	.073	.137**	.013	-.027

\*\* . Correlation is significant at the 0.01 level (2-tailed)

**Symptom management strategies:** We classified symptom management strategies under three categories, which were 1) taking modern medicine, 2) adopting complementary therapies, and 3) cultivating mind and body balance (Table 4).

**Table 4.** Categories and Sub Categories of Symptom Management Strategies ( $n=16$ )

Category	Subcategory
1. Taking modern medicine	1.1 Relieving physical symptoms
	1.2 Relieving psychological symptoms
2. Adopting complementary therapy	2.1 Minimizing unpleasant symptoms
	1.2 Preventing anticipated symptoms
3. Cultivating mind and body	1.1 Calming anxious mind
	1.2 Distracting stressful conditions
	1.3 Receiving support from significant others

Most of the participants addressed uses of more than one strategy.

**Category 1: Taking modern medicine.** This category was classified into two subcategories including relieving physical symptoms, relieving psychological symptoms.

**Subcategory 1.1 Relieving physical symptoms:** The participants described that they used pain killer for pain symptom, cough suppressants for cough, antiemetic for nausea vomiting, and vitamins tablet with liquid glycerin for sore throat symptom management. For example

*"I was receiving injection for pain from hospital and felt better."* (P-8)

**Subcategory 1.2 Relieving psychological symptoms:** The participants took medicine to reduce sleeping disturbance and depression or sadness, distress and pain symptoms. For example

*"To get relief doctor gave me anti-depressant tablet. I take every night"* (P 2)

**Category 2: Adopting complementary therapy:** This category included two subcategories minimizing unpleasant symptom and preventing anticipated symptoms.

**Subcategory 2.1: Minimizing unpleasant symptom.** The participants used black cumin, massage, and homeopathy for pain; basil leaves (tulsi) honey, for cough; sleeping oil for sleep disturbance; lemon juice and sariboddhi salsa for lack of appetite. These were added-on to minimize the specific unpleasant symptoms rather than the main disease treatments. For example

*"I ate black cumin ... whenever I need; to follow our religious leader's suggestion for minimizing pain. It was best effective."* (P-13)

**Sub Category 2.2: Preventing anticipated symptom.** The participant preventing anticipated symptom by drinking lemon juice or lemon pieces chewing for nausea vomiting; eating fresh fruits and vegetables for weakness and fatigue; ginger piece in mouth or drinking ginger tea for coughing. These behavioral approaches of preventing anticipated symptom management were developed based on their knowledge of cultural or traditional practices. For example

*"I had extreme nausea and vomiting after radiotherapy... I had chewed lemon piece with a few salt at any time ...to increase appetite and taste of food"* (P-9)

**Category 3: Cultivating mind and body balance.** This category was classified into three subcategories as follows:

**Subcategory 3.1: Calming anxious mind.** Most of the participants perform calming anxious mind activities comprise of meditation, chanting, pray and surrender to God, listening to religious scriptures, and reading religious scriptures. They thought these practices led them to be calm in mind and keep

inner quiet. The participants manage their symptom of pain, distress, anxiety, sleep disturbance and depression with the activity of calming anxious mind. For example

*"...I tried to practice meditation... took a deep breath in, and out, closed eyes, and went on with the imagination. It was helpful to be calm, quiet and realized eternal peace to get good sleep"*(P-1)

### **Subcategory 3.2: Distracting stressful conditions.**

Participants expressed that they applied distracting stressful conditions, including listening to music and watching television (TV) in order to forget or keep away from suffering of discomfort and symptom, and decrease distress and sleep disturbance. For example

*"...I used to listen religious song such as Gajol and surrender up on God. I felt calmness and cheers as well as blow away the anxiety"*(P-6)

### **Subcategory 3.3: Receiving supports from significant others.**

Living with lung cancer leads to feel sadness, anxiety, anger, and hopelessness in both patients and family members. Receiving support from significant others such as spouse and religious leaders helped them to manage with their disease and cope with sufferings. Participants expressed that they received mental support from spouse, traditional healer, and religious leader or Imam.

### **Discussion:**

Symptom experience included three dimensions: perception of symptom, severity of the symptom, and response to the symptom, which is indicated by symptom occurrence, severity, and interference as realized by persons with lung cancer. In this study, based on severity the participants perceived five major symptoms namely: pain, sleep disturbance, sadness, fatigue and distress. These symptoms were reported to affect their mood, general activity, work, enjoyment of life, walking and relationships with other persons. Some possible explanations are given.

*Symptom Experience:Pain.* the participants evaluated their pain symptom experiences as of high frequency and severity (96%, median 7.0). Previous study supported pain experiences trigger from disease pathophysiology and treatment regimen<sup>5,10,11</sup>. The disease pathophysiology describes that the invasion of cancerous growth into soft tissue, nerves or bone, either at the primary site or metastatic focus leads to pain<sup>25</sup>. In addition, the treatment regimen

such as chemotherapy cause peripheral neuropathy through inflammatory mechanism<sup>5</sup>; radiotherapy cause brachial plexopathy<sup>15</sup>; and surgery cause nerve damage<sup>11</sup>. Similarly, participants of this study received all types of treatment, nearly two thirds (64.4%) received chemotherapy; radiotherapy (18.8%); combination of chemotherapy and radiotherapy (12.8%), and surgery (3.93%), thus all activate pain.

*Sleep disturbance.* Sleep disturbance was found to have the second highest degree of frequency and severity (95%, median 6.0). Lou and associates braced that chemotherapy causes excessive nausea and vomiting, and lung cancer pathology causes waking them up from sleep resulting in sleep disturbance. In the present study, more than half of the participants were receiving chemotherapy and reported symptoms such as dyspnea, coughing, nausea, and vomiting. These explicably led to sleep disturbance<sup>12</sup>.

*Sadness:* Sadness is the third-top symptom (86.4%, median-6.0). The large burden of symptoms increases distress when they are diagnosed with lung cancer; they feel shame, social stigma, and anxiety. They do not want to make contact with people in the community. Moreover, they do not want to talk with people via telephone<sup>13</sup> as a result of their sadness. Simialr to this, the present study participants experienced a higher degree of frequency and severity of pain, sleep disturbance, fatigue and distress. These symptoms are intensify the development of sadness for them.

*Fatigue:* Fatigue is the fourth top symptom (92.4%, median-5.0). Previous study explained that the large tumor growth cause disruption in basal ganglia and frontal lobe function, hypothalamic–pituitary–adrenal axis dysfunction, and enhanced pro-inflammatory cytokine release affecting neuronal metabolism<sup>14</sup>. In addition, peripheral impaired muscle contraction, nerve conduction, and other neuromuscular abnormalities are responsible for influencing fatigue or cancer related fatigue (CRF)<sup>15</sup>. Likewise, previous study supported that the symptom burden exacerbates fatigue, which could be explained by the pain interfering with sleep patterns. The sleep disturbance elevates distress and stimulates fatigue<sup>16</sup>. In addition, the fatigue causes clusters of symptom that stimulate pain, and pain elevates depression.

*Distress:* The findings revealed that distress is one

of the top-five symptoms (Table 2). It might be that participants had negative perceptions after suffering a long time with the disease and during its progression. These burdened them and thus led to becoming distressed. Furthermore, unemployment status of the participants' may have contributed to depression, which leads distress<sup>17</sup>.

*Symptom interference:* Participants experienced frequent and severe physical and psychological interference, expressed as change in mood, general activity, work, enjoyment of life, walking and relationship with others. Pain results in limited physical function. Chemo-radiotherapy side effects such as anemia and lack of appetite may cause weakness and loss of eagerness to do any work, including personal or general activity and walking<sup>10</sup>. This present study finding was slightly higher than a similar Korean study<sup>18</sup>. This might be because the present study's participants were receiving chemotherapy, radiotherapy, and combined chemo-radiotherapy, whereas the Korean study's patients were receiving only chemotherapy.

*Correlation between the Top-Five Symptom Experiences and Age:* The symptoms were meaningfully correlated each other. Symptoms influence each other and make cluster of symptoms. Previous study supported that pain influence other symptom<sup>19</sup>. This could be explained that the pain stimulus increases the ventilatory drive and in turn increase the sense of dyspnea<sup>20</sup>. Similarly, shortness of breathing, coughing and chest tightness causes sleep disturbance. These symptoms because waking from sleep and interruption of sleep as a result sleep disturbance<sup>12</sup>.

In addition, the sleep disturbance elevates distress as well as stimulating fatigue<sup>16</sup>. More, the fatigue causes clusters of symptoms that stimulate pain, and pain elevates depression. Lastly the depression impaired sleep patterns as well as causing sleep disturbance or insomnia<sup>21</sup>. Furthermore, a later study supported that lung cancer patients' distress symptom influence on pain experience which was made cluster of symptoms such as pain, fatigue, disturb sleep and distress which influenced each other<sup>16</sup>. In regarding age, previous study revealed that the younger patients experience more symptom than older aged. This might be explained that the younger people have less patience than the older. The younger are more sensible to

tolerate symptom than older<sup>22</sup>.

*Symptom management strategies:* Researcher classified the symptom management strategies used among persons with lung cancer in Bangladesh in to three main themes taking prescribed medications, adopting complementary therapy, and cultivating mind body. The finding highlighted that the participant addressed uses of more than one strategy. The participant used symptom management strategies for reducing unpleasant symptom by taking modern medicine for relieving physical and psychological symptom such as pain, sleeping disturbance and depression or sadness. They adopting complementary therapy for minimizing unpleasant symptom and preventing anticipated symptom of post-chemotherapy based on their knowledge of cultural or traditional practices. It was consistent with explanation of cancer in reference to Greco-Arabic literature that used the local herbs to relieve pain<sup>23</sup>. They used black cumin, massage, and homeopathy for pain; basil leaves (tulsi) honey, for cough; sleeping oil for sleep disturbance; lemon juice and sariboddhi salsa for lack of appetite or lemon pieces to chew for nausea vomiting; eating fresh fruits and vegetables for weakness and fatigue; ginger piece in mouth or drinking ginger tea for coughing. The participant cultivating mind and body balance. The participants manage their symptom of pain, distress, anxiety, sleep disturbance and depression with the activity of calming anxious mind. They applied distracting stressful conditions, including listening to music and watching television (TV) in order to forget or keep away from suffering of discomfort and symptom, and decrease distress and sleep disturbance. Receiving support from significant others such as spouse and religious leaders helped them to manage with their disease and cope with sufferings. Participants expressed that they received mental support from spouse, traditional healer, and religious leader or Imam.

This study is different and significant from other previous studies as the participants described their ways and preparation of uses of strategies. This was not found in published previous studies<sup>5,24,6</sup>. This could be helpful and a guide for the next users of these strategies for managing the symptoms with non-pharmacological strategies as being safe and not harmful.

The limitations of this study were convenient sampling, and not including all stages of lung cancer equally. Moreover, symptom management, and outcome dimension of symptom management model may limit the generalizability of the results.

### **Conclusion**

In this study, the symptoms with the highest frequency and severity were pain, sleep disturbance, fatigue, distress, and sadness. These symptoms greatly interfered with their entire lives-mostly with mood, general activity, work, enjoyment of life, walking, and relationship with others. This finding will be beneficial for health care personnel regarding clinical practice to manage symptoms and improve quality

of life. Thus, effective symptom and interference management would enhance the betterment of quality of life.

### **Authors's contribution:**

Data gathering and idea owner of this study: Biplab Halder,AK,PP,PS.

Study design: BH, AK,PP,PS.

Data gathering: BH

Writing and submitting manuscript: BH,AK

Editing and approval of final draft: BH, AK,PP,PS.

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