A Survey of Symptom Experience, Symptom Management and Quality of Life of Indonesian Patients with Advanced Cancer

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ABSTRACT

This study aims to describe the symptom experience, symptom management and quality of life of Indonesian patients with advanced cancer. The study was conducted at two tertiary hospitals in Central Java Province, Indonesia, and involved two hundreds and one (201) subjects. They were all patients with stage III and IV of cancer and were selected from surgical and gynecological wards and radiotherapy units of the studied hospitals. The data were obtained using self-report questionnaires consisting of the Edmonton Symptom Assessment Scale-revised (ESAS-r), the Symptom Management Questionnaire, the Functional Assessment of Cancer Therapy-General (FACT-G) Scale and the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp) Scale. The internal consistency reliability coefficients of the Indonesian version of the FACT-G scale and the FACIT-Sp scale yielded values of .84 and .92, respectively.

The majority of the subjects participating in this study were female with age ranging from 19 to 60 years (*Med* = 49 years). Most of them were diagnosed with the female specific cancers. Nearly half of them were currently receiving one cancer treatment and most of the subjects had ever received at least one type of cancer treatment.

Over the past 24 hours, the subjects experienced, on average, four symptoms (*M* = 3.78, *SD* = 1.93) and over the past one month the subjects experienced five symptoms (*M* = 4.63, *SD* = 1.99). Over the past 24 hours and the past one month, pain, fatigue, lack of appetite, depression and nausea were the most common symptoms experienced by the subjects. Modern medicine was the most commonly used strategy to reduce cancer-related symptoms. The second in the list was herbal medicine, for example the extract of sour-sop leaves, sour-sop fruit and the extract of curcuma. Traditional healing modalities and praying were also generally used strategies to ease their symptoms.

Overall, level of quality of life of the subjects was at the slightly high level (*M* = 2.71, *SD* = .59). The spiritual well-being subscale had the highest score (*M* = 2.95, *SD* = .66) compared to other subscales. The mean scores of the physical well-being and the functional well-being subscales were at the moderate level.

Pain management and programs enhancing physical functioning should be applied. The nurses also need to encourage and offer spiritual supporting activities, such as reciting the Quran, listening to the preaching from an imam and inviting an imam to the ward if needed.

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CHAPTER 1

INTRODUCTION

Background and Significance of the Problem

Cancer is a leading cause of death worldwide. The number of new cases of cancer would increase significantly to become 15 million in the year 2020 (World Health Organization [WHO], 2003). For patients with cancer, this disease has given many significant effects to their lives. In fact, in the last decade cancer disease has become a major concern in the healthcare services. There have been many studies to explore the cancer symptoms experience, symptom management and quality of life (QoL) of patients with cancer, particularly those in the advanced stage. The findings from the previous studies showed that symptoms occurred throughout the cancer trajectory and influenced the patients' QoL (Dodd, Cooper, & Miaskowski, 2010; Motl & McAuley, 2010; Ryu et al., 2010).

There are many symptoms experienced by patients with advanced stage of cancer. This group of patients experiences many symptoms because of the natural development of cancer and the number of treatments that they received (Karabalu, Erci, Ozer, & Ozdemir, 2009). The most common symptoms suffered by patients with advanced cancer are pain, fatigue, sleepless, lack of energy and depression (Dodd et al., 2010; Karabalu et al., 2009; Ryu et al., 2010). Cancer medications and treatments also bring their side effects along with their benefits and those side effects add the suffering to the patients. Nausea, vomiting, hair loss, fatigue, loss of appetite, and bone marrow suppression are the example of symptoms which are often experienced by patients with cancer after cancer treatments such as chemotherapy (Lemieux, Maunsell, & Provencher, 2008). For patients with cancer, both physical and psychological symptoms caused significant impacts in almost every aspect of their lives especially in their QoL (Lagman, Davis, LeGrand, & Walsh, 2005; Mcmillan, Tofthagen, & Morgan, 2008; Ryu et al., 2010). Recent studies on cancer symptoms confirmed that patients with advanced cancer who had high QoL experienced only least symptoms in quantity and its intensity (Dodd et al., 2010; Motl & McAuley, 2010). On the contrary, patients who experienced severe symptoms and had many symptoms had worst QoL (Dodd et al., 2010; Motl & McAuley, 2010).

However, these symptoms related to cancer still can be managed. The strategies on managing symptoms have been conceptualized as the significant influencing factor in the Symptom Management Model by Dodd et al. (2001). The intervention strategy is considered as a dynamic process because it depends on the symptoms which occurred, the difference in acceptance of each individual, and also the need of being evaluated over time (Dodd et al., 2001). The most common symptoms experienced by patients with advanced cancer such as pain and fatigue are likely to have more evidences to support the management and those studies' findings revealed the various levels of effectiveness. For instance, until now pain medication has been considered as the gold standard to treat moderate to severe pain, yet pain self-control program, behavioral intervention and massage are also proven as effective therapies (Grealish, Lomasney, & Whiteman, 2000; Miaskowski et al., 2004; Sherwood et al., 2005). Moreover, the supervised aerobic exercise was reported to have a moderate significance to decrease cancer-related fatigue (CRF) (Courneya et al., 2007; Velthuis, Agasi-Idenburg, Aufdemkampe, & Wittink, 2010). In relation to the QoL, the studies on patients with advanced cancer showed that the decrease of symptom severity score even in a small number of changed scores (e.g., pain score reduced from 5 to 3 out of 10) had made a significant difference in the functional status and QoL of the patients (Miaskowski et al., 2006; Ryu et al., 2010). It means that the effectiveness of symptom management interventions will lead to the improvement of QoL of the patients with advanced cancer. This was later also proved by the study of Chan, A. Richardson and Richardson (2011). The functional status of patients with lung cancer increased when the severity of breathlessness, fatigue, and anxiety decreased after following the psycho-educational intervention and physical exercise (Chan, A. Richardson, & Richardson, 2011).

In the cancer field, symptom experience, symptom management and the QoL have been well established in the conceptualization and the application. Dodd et al. (2001) has depicted these phenomena in the Symptom Management Model (SMM). Further studies related to these cancer phenomena have been well conducted and the findings reported that the patients with advanced cancer experienced many symptoms either caused by the disease or the side effects of the cancer treatments (Karabulu et al., 2009; Miaskowski, Dodd, & Lee, 2004). They also confirmed that managing the cancer symptoms effectively would improve the QoL of the patients. Then studies on managing each particular cancer symptom for example fatigue, nausea, vomiting and depression are being developed continuously. The effectiveness of each intervention strategy is various from least significant to significantly effective. One example is in pain control program. The Self-Care Intervention (PRO-SELF$^{©}$) was reported to be a significant effective management for cancer patients with mild, moderate or severe pain, while music intervention is still considered to have a little effect in relieving the pain (Miaskowski et al., 2004).

Many evidences on symptom experience, symptom management and QoL in patients with advanced cancer have been well established in western countries. Following other studies also have been conducted in Asian counties such as Korea and Thailand (Fan, Filipczak, & Chow, 2007; Nilmanat, Petpichetchian, & Wiroonpanitch, 2008; Ryu et al., 2010). These studies reported that patients with advanced cancer perceived many symptoms at the same time in which they disrupted patients' functional status and worsen their QoL. The studies' findings also showed the importance and significance of symptom experience and symptom management on the patients' daily living. The aspects of QoL including functioning, mental status and spirituality are affected by the symptom experience and symptom management strategies they have used.

Although the studies on symptom experience, symptom management and the QoL have been far conducted in other countries, in Indonesia there were only two studies that were related to patients with cancer's QoL. The studies only covered the QoL assessment and one attribute of QoL (psychological well-being) (Karyono, Dewi, & Lela, 2008; Witjaksono, 2007). There is no study which covers symptoms, symptom management and the QoL of Indonesian patients with cancer, in particular patients with advanced stage of cancer. The reason of conducting this preliminary study also led by the fact that there are some differences in terms of socioeconomic status, culture, accessibility to health care services, advancement of health care services and the medical equipments between Indonesia and other countries. These facts may greatly distinguish the symptom experience, symptom management and the QoL of patients with advanced cancer in Indonesia comparing with other countries. According to the symptom management model of Dodd et al. (2001), the occurrence of symptom, its management, and the QoL are unique process and are influenced by many factors, especially the patients' demographics, health illness status and environment. In addition, the QoL in its conceptualization is also affected by social, environmental and cultural factors (Dodd et al., 2001; Ferrell, Smith, Cullinane & Melancon, 2003). Therefore, conducting the survey study which covers symptom experience, symptom management and QoL of patients with advanced cancer in Indonesia was considered very important.

Objectives

The objectives of the study were to:

1. Identify the common symptoms experienced by patients with advanced cancer.
2. Explore the symptom management strategies used by patients with advanced cancer.
3. Determine the level of QoL of patients with advanced cancer.

Research Questions

The research questions of the study were:

1. What are the common symptoms experienced by patients with advanced cancer?
2. What are the symptom management strategies used by patients with advanced cancer?
3. What is the level of QoL of patients with advanced cancer?

Conceptual Framework

This survey used two main frameworks to guide its study. The first framework is the Symptom Management Model (Dodd et al., 2001). It is composed of three dimensions; (1) symptom experience, (2) symptom management strategies and (3) symptom outcomes. In addition, this model also has three domains. The domains are person, environment, and health and illness. They are conceptualized as the factors contributing to three symptom dimensions. However, this part would only review the dimensions related to the study, while the complete review of the Symptom Management Model will be explained in the second chapter or the literature review. The second framework is the Quality of Life Conceptual Model by Ferrell et al. (2003) which comprises four attributes of QoL. They are physical well-being, psychological well-being, social well-being and spiritual well-being.

Dimensions of the Symptom Management Model

As conceptualized, the Symptom Management Model has three dimensions, symptom experience, symptom management strategies and symptom outcomes. Symptom experience consists of three concepts; perception, evaluation and response to symptom (Dodd et al., 2001; Jablonski & Wyatt, 2005).

Symptom perception. The perception of symptom can be interpreted as the ability of an individual in noticing the changes of his or her body’s normal function or the occurrence of the symptoms. This assessment requires the subjectivity of each individual in reporting the symptoms that he/she experiences. In this study the perception of symptom is used to guide in understanding the occurrence of cancer symptoms which are experienced by patients with advanced cancer.

Symptom evaluation. The evaluation of symptom requires the individual’s judgment towards the severity, value or meaning to the symptom on their lives. The evaluation of symptom in this model is used in understanding the severity of cancer symptoms which are experienced by patients with advanced cancer. In summary, variables from the symptom experience that were measured in this study were only the symptom perception and the symptom evaluation.

Symptom management strategies. The second dimension is symptom management strategies. The symptom management strategies include any interventions used to manage symptoms, the person who performs, where he/she performs the strategy, the time to perform the strategy, the duration, the certain purpose of performing an intervention and its effectiveness. In this study, the symptom management strategies were explored to guide in understanding the practices or interventions the patients used to manage cancer symptoms. Those interventions can be performed by the patients themselves, the family members, health care providers, or the patients with any help from the health care providers.

The symptom experience and the symptom management strategies domains would eventually affect the symptom outcomes. In the component of symptom outcomes, functional status, emotional status, self-care and symptom status of the patient are included in this model, the QoL is also one of them. This domain is the result as well as the antecedent of the other two domains (Dodd et al., 2001). In other words, all three domains are interrelated and dynamic. Symptom experienced last month might lead to their management decision and utilization of symptom management strategies, which in turn resulting changes in current symptom experience with this conceptualization, symptom experience was measured twice in this study, over 24 hours and over the past one month.

The quality of life. Dodd et al.'s model (2001) did not explain the attributes of QoL in great details. Therefore, the second framework by Ferrell, Smith, Cullinane, and Melancon (2003) was used because it was developed specifically from the experience of patients with cancer. They conceptualized the four attributes of QoL experienced with cancers: physical, psychological, social and spiritual well-being. Physical well-being depicts the patients' strength/fatigue, sleep and rest, pain, appetite and nausea/constipation. The psychological well-being of the patients with cancer can be measured by examining their self-control, anxiety, and level of depression, happiness and the fear towards the recurrence or metastasis of the cancer. Furthermore, distress from the cancer diagnosis or treatment, patients' coping, self-concept and patients' cognition of the disease are included in psychological well-being as well. Meanwhile, the attributes of social well-being of patients with cancer include the patient's perception of family distress and their roles and relationship with family members and their social networks. It depicts their roles and relationship with regard to sexuality, finance, work and support. In this study, roles and relationship with family members and other social networks were primarily focused. The last attribute of QoL is spiritual well-being. It explains about patients with advanced cancer give meaning of their illness, religiosity, their spiritual life, hope, and their purposes in life. These four attributes were used to guide the study on QoL of patients with advanced cancer.

Definition of Terms

Symptom Experience

Symptoms experience refers to the perception and the evaluation of patients with advanced cancer about their symptoms and it was reported by the patients with regards to the occurrence and the severity. These symptoms occurrence were measured using the Edmonton Symptom Assessment System-revised (ESAS-r) developed by Watanabe et al. (2011). It is a measurement tool to measure symptoms which are experienced by patients with cancer. It also measures the severity of the symptoms with an 11-numeric scale, ranging from 0 (not at all) to 10 (worst). This symptom experience was measured twice (over 24 hours and over the past one month).

Symptom Management

The symptom management of the patients with advanced cancer refers to any kinds of strategies, activities or actions which were used by the patients to manage, to decrease the severity of symptoms over the past one month. It included the person who performed the strategy (the patient him/herself or with the aids of others), when it was performed, the frequency of performing and it effectiveness. The questionnaire was developed by the researcher with the guidance from the conceptual framework of the Symptom Management Model (Dodd et al., 2001).

Quality of Life

The quality of life refers to the perception of how important each attribute of well-being to the patients with advanced cancer. The four attributes of the QoL consisted of physical, psychological, social, and spiritual well-beings. The Quality of Life of patients with cancer was measured by the Functional Assessment of Cancer Therapy – General Version 4 (FACT-G version 4). This measurement tool consists of four subscales regarding the patients' well-being. They are physical, social/family, emotional, and functional well-beings. As the spiritual well-being is not included by the FACT-G version 4, the researcher added the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Subscale (FACIT-Sp) to measure the spiritual domain.

Scope of the Study

This study focused on examining the symptom occurrence, symptom management and the QoL of patients with advanced cancer. The subjects who were involved in this study were any patients with cancer in advanced stage (stage III and IV). Only the patients with advanced cancer who attended at the study hospitals between December 2012 and February 2013 for the cancer or cancer symptom treatments were recruited.

Significance of the Study

The finding of this study was expected to provide the baseline data for further research related to symptoms and the QoL of patients with advanced cancer. Furthermore, the finding of this study would be beneficial for the nursing practice in knowing the kinds of cancer symptoms and giving knowledge of the symptom management which had been performed by the patients. Therefore, if the nurses are going to conduct the symptom management, they can adjust it with the patients' preference and the healthcare setting.

This study would be significant for further development of care providing for patients with advanced cancer. It also provides evidences for knowledge development in cancer care, particularly for Muslim countries.

CHAPTER 2

LITERATURE REVIEW

This chapter is to give a further insight on patients with advanced cancer, particularly their symptom experience, symptom management and QoL. This study was guided by reviewing literatures regarding (1) cancer and cancer treatments, (2) symptom management model, (3) symptoms of patients with advanced cancer, (4) symptom management strategies, and (5) quality of life of patients with advanced cancer.

Overview of Cancer

This part gives a brief overview of cancer disease and cancer treatments. In its review, the Symptom Management Model includes cancer treatment in the health and illness domain. For patients with advanced cancer, cancer treatments and its side effects give significant consequences on their lives. Therefore, this part will also review the side effects of cancer treatments.

Cancer

Cancer is a genetic disease in its origin. The word cancer is derived from the Latin word meaning “crablike” because cancer grows and spreads into the normal surrounding tissues (Black & Hawks, 2009). The progression from normal tissue to invasive cancer is considered to take place over years or only months and is influenced by many factors. Cancer progression is a multistep process and may begin from the molecular level (Black & Hawks, 2009; DeVita, Hellman, & Rosenberg, 2005). Clinical manifestations such as the appearance of symptoms are only the final stages in the natural history of a cancer.

The characteristics of cancer are different from normal cells. Cancer cells are characterized by two main features: (1) abnormal and rapid proliferation and (2) loss of differentiation. The cancer cells do not exhibit normal features and properties of differentiated cells and hence are more similar to embryonic cells (DeVita et al., 2005). Cancer spreads by direct invasion and extension. The cancer cells seed in the body cavities (Black & Hawks, 2009). Metastatic cancer cells spread through the blood or lymph pathways. The seeding of cancer cells into body cavities occurs when tumor sheds into these spaces (Black & Hawks, 2009).

There are some factors which initiate cancer. They are called carcinogens, which may be from radiation, chemicals, viruses or other physical agents (Black & Hawks, 2009). Although still under investigation, genetics and hormones are considered to play a significant role in the development of many cancers. Cancer cells have the ability to spread from the original site of the tumor to distant organs. This phenomenon is called metastasis (from the Greek *meta*, beyond, and *stasis,* standing) (Black & Hawks, 2009). There are many examples of malignant neoplasm (cancer). The examples of common cancer types are breast cancer, lung cancer, colorectal cancer, prostate cancer, head and neck cancer (HNC).

Staging of Cancer

After a physician determines the diagnosis of cancer, the staging of the tumor needs to be identified. The generally used classifications and staging system of cancer is the TNM system. Some organ systems may have specific classification such as classification from the International Federation of Gynecology and Obstetrics (FIGO) system developed specifically for the female reproductive system. In general, the staging according to TNM classification involves a systematic search for the characteristics of the primary tumor (T), involvement of lymph nodes (N) and the evidence of metastasis (M) on the basic knowledge of the natural history of the disease (American Joint Committee on Cancer, 2010; Singletary et al., 2002). The classification of the breast cancer (Table 1) and the staging of breast cancer (Table 2) are given as the examples here.

Table 1

Staging of the Breast Cancer Based on the TNM Classification

Primary Tumor (T)	Regional Lymph Nodes (N)	Distant Metastasis (M)
Primary tumor cannot be assessed (TX)	Regional lymph nodes cannot be assessed (NX) (for example, previously removed)	Distant metastasis cannot be evaluated (MX)
No evidence of primary tumor (T0)	No regional lymph node involvement (N0)	No clinical or radiographic evidence of distant metastases, but deposits of molecularly or microscopically detected tumor cells in circulating blood, bone marrow, or other non-regional nodal tissue that are no larger than 0.2 mm in a patient

Table 1 (continued)

Primary Tumor (T)	Regional Lymph Nodes (N)	Distant Metastasis (M)
		without symptoms or signs of metastases (M0)
Ductal carcinoma in situ (DCIS/Tis)	Metastases to movable ipsilateral level I, II axilary lymph node(s) (N1)	Distant detectable metastases as determined by classic clinical and radiographic means and/or histologically proven larger than 0.2 mm (M1)
Lobular carcinoma in situ (LCIS/Tis)	Metastases in ipsilateral level I, II axillary lymph nodes that are clinically fixed or matted; or in clinically detected ipsilateral internal mammary nodes in the absence of clinically evident axillary lymph node metastases (N2) Metastases in ipsilateral level I, II axillary lymph nodes fixed to one another (matted) or to other structures (N2a)	
Paget's disease of the nipple not associated with invasive carcinoma and/or carcinoma in situ (DCIS and/or LCIS) in the underlying breast parenchyma. Carcinomas in the breast parenchyma associated based on the size and characteristics of the parenchymal disease, although the presence of Paget's disease should still be noted	Metastases only in clinically detected ipsilateral internal mammary nodes and in the absence of clinically evident level I, II axillary lymph node metastases (N2b)	

Table 1 (continued)

Primary Tumor (T)	Regional Lymph Nodes (N)	Distant Metastasis (M)
Tumor ≤ 20mm in greatest dimension (T1)	Metastases in ipsilateral infraclavicular (level II axillary) lymph node(s) with without level I, II axillary lymph node involvement; or in clinically evident level I, II axillary lymph node metastases; or metastases in ipsilateral supraclavicular lymph node(s) with or without axillary or internal mammary lymph node involvement (N3)	
Tumor ≤ 1mm in greatest dimension (T1mi)	Metastases in ipsilateral infraclavicular lymph node(s) (N3a)	
Tumor > 1mm but ≤ 5mm in greatest dimension (T1a)	Metastases in ipsilateral internal mammary lymph node(s) and axillary lymph node(s) (N3b)	
Tumor > 1mm but ≤ 10mm in greatest dimension (T1b)	Metastases in ipsilateral supraclavicular lymph node(s)	
Tumor > 10mm but ≤ 20mm in greatest dimension (T1c)		
Tumor > 20mm but ≤ 50mm in greatest dimension (T2)		
Tumor > 50mm in greatest dimension (T3)		

Table 1 (continued)

Primary Tumor (T)	Regional Lymph Nodes (N)	Distant Metastasis (M)
Tumor of any size with direct extension to the chest wall and/or to the skin (T4) (ulceration or skin nodule) Note: invasion of the dermis alone does not qualify as T4. Extension to the chest wall, not including only pectoralis muscle adherence/invasion (T4a) Ulceration and/or ipisilateral satellite nodules and/or edema (including peau d'orange) of the skin, which do not meet the criteria for inflammatory carcinoma (T4b) Both T4a and T4b (T4c) Inflammatory carcinoma (T4d)		

Note. Adopted from *Cancer Staging Handbook: From the AJCC Cancer Staging Manual.* (7th ed.) by American Joint Committee on Cancer, 2010, Springer, p.439.

Table 2

Breast Cancer Staging Based on the American Joint Committee on Cancer

Stage	TNM			
0	TisN0M0			
IA	T1*N0M0			
IB	T0N1mi	T1*miM0		
IIA	T0N1**M0	T1*N1**M0	T2N0M0	
IIB	T2N1M0	T3N0M0		
IIIA	T0N2M0	T1*N2M0	T2N2M0	T3N1M0, T3N2M0

Table 2 (continued)

Stage	TNM
IIIB	T4N0M0
	T4N1M0
	T4N2M0
IIIC	anyTN3M0
IV	anyTanyNM1

NOTE: * T1 includes T1mi
**T0 and T1 tumors with nodal metastases only are excluded from stage IIA and are classified stage IIB. Adopted from *Cancer Staging Handbook: From the AJCC Cancer Staging Manual.* (7th ed.) by American Joint Committee on Cancer, 2010, Springer, p.421.

The advanced stage of cancer disease in this study refers to stage III and stage IV of cancer. As one of the most prevalent cancer diseases among women, breast cancer staging is given as an example. According to the TNM classification, stage III of breast cancer has only local metastases, whereas stage IV has metastases to distant organs such as the lungs, the brain, the bones and so on. Therefore in general, this study included both the locally advanced stage (stage IIIA, IIIB, IIIC) and advanced stage (stage IV) of cancer disease.

Another example of cancer staging is in female reproductive system. The first rules for the classification and staging of female genital cancers were firstly adapted from the FIGO and the work was conducted by the Radiological Sub-Commission of the Cancer Commission of the Health Organization of the League of Nations (Pecorelli, 2009). The revision towards the staging system for carcinoma of the vulva, cervix, and endometrium has been through several processes. The staging of carcinoma of the cervix uteri is given as the example in this review (Table 3).

Table 3

Carcinoma of the Cervix Uteri Staging

Stage	Definition
Stage I	The carcinoma is strictly confined to the cervix (extension to the corpus would be disregarded)
IA	Invasive carcinoma which can be diagnosed only by microscopy, with deepest invasion ≤5 mm and largest extension ≥7 mm
IA1	Measured stromal invasion of ≤3 mm in depth and extension of ≤7 mm
IA2	Measured stromal invasion ≥3 mm and not >5 mm with an extension of not >7 mm
IB	Clinically visible lesions limited to the cervix uteri or pre-clinical cancers greater than stage IA*
IB1	Clinically visible lesion ≤4 cm in greatest dimension
IB2	Clinically visible lesion >4 cm in greatest dimension
Stage II	Cervical carcinoma invades beyond the uterus, but not to the pelvic wall or to the lower third of the vagina
IIA	Without parametrial invasion
IIA1	Clinically visible lesion ≤4 cm in greatest dimension
IIA2	Clinically visible lesion >4 cm in greatest dimension
IIB	With obvious parametrial invasion
Stage III	The tumor extends to the pelvic wall and/or involves lower third of the vagina and/or causes hydronephrosis or non-functioning kidney**
IIIA	Tumor involves lower third of the vagina, with no extension to the pelvic wall
IIIB	Extension to the pelvic wall and/or hydronephrosis or non-functioning kidney
Stage IV	The carcinoma has extended beyond the true pelvis or has involved (biopsy proven) the mucosa of the bladder or rectum. A bullous edema, as such, does not permit a case to be allotted to stage IV
IVA	Spread to adjacent organs
IVB	Spread to distant organs

NOTE. *All microscopically visible lesions, even with superficial invasion, are allotted to stage IB carcinomas. Invasion is limited to a measured stromal invasion with a maximal depth of 5.0 mm and a horizontal extension of not >7 mm. Depth of invasion should not be >5 mm taken from the base of the epithelium of the original tissue-superficial or glandular. The depth of invasion should always be reported in mm, even in those cases with “early (minimal) stromal invasion” (1 mm). The involvement of vascular/lymphatic spaces should not change the stage allotment.
**On rectal examination, there is no cancer-free space between the tumor and the pelvic wall. All cases with hydronephrosis or non-functioning kidney are included, unless they are known to be due to another cause. Adopted from “Revised FIGO Staging for Carcinoma of The Vulva, Cervix, and Endometrium” by S. Pecorelli, 2009, *International Journal of Gynecology and Obstetrics, 105,* p.104.

Cancer Treatments and Their Side Effects

The most common methods of treating patients with cancer are surgery, radiation therapy and chemotherapy. In giving the cancer treatments, physicians would make a decision based on weighing up the advantages and disadvantage. However, such side effects from the treatments are mostly difficult to be avoided. In fact many patients with an advanced stage of cancer receive more than one treatment. Thus, despite the appearance of symptoms from the nature of the disease, patients with advanced cancer are more likely to experience the side effects from cancer treatments.

The effects can be physical and/or physiological. As an example chemotherapy drugs (adjuvant chemotherapy) are given in order to eradicate or lessen the cancer cells of breast, on the contrary it also causes hair loss and nausea (Billhult, Bergbom, & Stener-Victorin, 2007; Grealish et al., 2000). Similarly, other cancer treatments (radiotherapy and surgery) are actually expected to have more benefits rather than harms to the patients. Most patients with advanced cancer would eventually experience predicted or unpredicted symptoms as the side effects of these cancer treatments. The side effects from these treatments given to patients with advanced cancer will be reviewed further.

Surgery. Surgery has the major role in the treatment of the cancer. It is also an integral part of the rehabilitation and palliation for patients with cancer. Surgery as a treatment is performed mostly for patients with localized cancer, from the original organ until the regional lymph node (Black & Hawks, 2009). Although the surgery has been performed, it might be that the cancer cells have spread to other sites through the blood circulation. Therefore, local therapies (surgery or radiation) generally must be accompanied by systemic therapies (chemotherapy) to improve the patients' survival. Surgery is not always performed as the first phase of cancer treatment because many treatment protocols begin with chemotherapy or radiation therapy to shrink the tumor mass and decrease the micro metastasis (Black & Hawks, 2009). Besides having the benefits, this treatment has side effects which contribute to the symptoms experience of patients with advanced cancer.

Anxiety and depression were found in women with breast cancer in Hong Kong after a mastectomy and then undergoing the adjuvant therapy (chemotherapy/radiation) (So et al., 2010). Previous study conducted by Kenefick (2006) reported that fatigue, pain, changing of body image and insomnia were the symptoms which mostly occurred with severe level in patients with breast cancer after underwent breast surgery. Younger, better educated and married women were later found to experience greater symptom distress after the surgery (Kenefick, 2006). This is because losing a very essential part of the body such as breast, among this group of women, would greatly impact on their body image.

Radiotherapy. Radiation therapy or radiotherapy is one common treatment being used to treat cancer disease. This therapy may be used as a primary, an adjuvant or a palliative treatment. When it is used as a primary treatment, it is the only treatment used and is aimed to achieve a cure for a localized cancer, whereas as an adjuvant treatment, radiation is used either preoperatively to diminish cancer cells or postoperatively to destroy the cancer cells remaining in the body. In some situations, where chemotherapy is used as a radio-sensitizer, radiotherapy is administered after the chemotherapy. This regiment combination is performed to enhance the effects of radiotherapy (Bharatha, Yu, Symons, & Bartlet, 2012). Radiotherapy may be used to treat localized tumors such as tumor of head and neck.

Radiotherapy uses high energy, penetrating waves or particles such as X-rays, gamma rays, proton rays or proton rays to destroy cancer cells or keep them from reproducing (Mallick & Waldron, 2009). There are two kinds of radiation therapy; external beam radiotherapy and internal radiotherapy. External beam radiation is the therapy which uses high-energy X-ray or gamma-ray from some distance of the target site. Whereas the external radiation therapy is carried out by placing radioisotopes (radioactive isotope) directly near the cancer sites. Especially for head and neck cancer (HNC), radiation is the crucial management of regiment (Mallick & Waldron, 2009). However like other cancer treatments, radiotherapy has some adverse effects for the patients.

The adverse effects of radiation therapy have been found in many studies. The common side effects of this therapy are tissue oedema especially in the region of the head and neck, mucositis, a disturbance/complication of salivary glands which leads to xerostomia, radiation injury to the lungs in particular the apex areas, and damage to the bones and cartilages (Baratha et al., 2012). The damage of mucosal lining of the upper aerodigestive tract and the epidermal layer of skin usually appear during a course of treatment and within 12 weeks of the completion of treatment

(Mallick & Waldron, 2009). Radiation induced mucositis (RIM), stomatitis/pharyngitis are very common acute toxicity to head and neck cancer (HNC) patients after receiving radiotherapy (Giro et al., 2009; Mallick & Waldron, 2009). The occurrence of this side effect would increase because of the use of more intensive altered radiation fractionation and concurrent chemotherapy regimens. The extent of the injury is directly related to the mucosal volume irradiated, anatomic sub site exposed, treatment intensity, and individual patient predisposition (Mallick & Waldron, 2009). The following consequences of mucositis are pain, dysphagia including feeding tube dependency, dehydration, micronutrient deficiencies, weight loss, and potentially life-threatening aspiration (Mallick & Waldron, 2009; Rosentral & Trotti, 2009).

Furthermore, the most dangerous side effects of radiation are the damage to the nervous system and small and large vessel vasculopathy (Baratha et al., 2012). Psychosocial distress such as depression was also found in patients with cancer who had undergone radiotherapy (Chen et al., 2009; Neilson et al., 2010). The findings showed the patients with cancer started to feel depression even before the beginning of the treatment and the number of depression case increased significantly during radiation therapy (Chen et al., 2009; Neilson et al., 2010).

Other possible side effects such as dermatitis or skin reaction in the radiation areas were also found (Giro et al., 2009). They studied 125 HNC patients from 28 cancer institutions in 11 countries. Grade III/IV of dermatitis reaction was found in 49% of HNC patients who underwent radiotherapy and received Cetuximab (Giro et al., 2009). They reported that there were skin reactions in the radiation field and outside the radiation portals are conditions such as erythema, acne, nail changes and allergic reactions. It was also reported that the higher the dose of the radiotherapy, the more severe radiation dermatitis. These side effects of radiotherapy must be managed or, if possible, be prevented.

Chemotherapy. Chemotherapy is a systemic intervention and is appropriate in the situation which the cancer is widespread, the risk of undetectable cancer is high and the tumor cannot be taken by surgery and resistant to radiotherapy (Black & Hawks, 2009). The objective of chemotherapy is to destroy malignant tumor cells without too much destruction of normal cells. Chemotherapy works on the cycle cells life. Normally the cells of the human body will grow, repair or regenerate in an orderly manner. If the need of the body is sufficient, the normal cells will enter into the resting phase or slowing the growth. Cancer cells reproduce in the same manner as normal cells. However cancer cells do not have a resting phase or they grow continuously. Chemotherapy works on the dividing phase of the cancer cells which is considered sensitive to chemotherapy drugs. Chemotherapy drugs directly or indirectly disturb the reproduction of the cancer cells (Black & Hawks, 2009).

In the clinical practice, the combination of chemotherapy drugs is considered more effective than single agent therapy. The principle is that each drug attacks the cancer cells in different points of the cancer cell cycle (Black & Hawks, 2009; DeVit et al., 2005). But they mostly target the dividing phase of the cells. Therefore, it is expected that each drug must be effective against the cancer cell which is being treated. The regimens are complex, cyclic and individualized for the patient and the type of cancer (Black & Hawks, 2009; DeVita et al., 2005). Above all the benefits of cancer treatments there are side effects for the patients as well.

Any patients with cancer can be prescribed to receive chemotherapy as the treatment. Some of the chemotherapy drugs are given through the blood stream. The drugs will go thoroughly all over the body and reach both the cancer cells and normal cells. As cancer drugs target in the dividing phase of the cells, the cells like hair follicles, digestive cell lining, and bone marrow which are often dividing themselves, are vulnerable to be also destroyed by chemotherapy drugs. Therefore, the side effects which might appear are nausea, hair loss, fatigue, decreased immunity and anemia (Akin, Can, Aydiner, Ozdili, & Durna, 2010; Trueb, 2009).

The most common side effect of chemotherapy is hair loss or alopecia. It is the unavoidable and transient side effect of adjuvant and metastatic chemotherapy (Lemieux et al., 2008). According to this literature review study, patients with breast cancer who underwent chemotherapy later on got alopecia or hair loss especially because of the high dose of chemotherapy drugs. Lemieux et al. (2008) found that alopecia ranked as the first three most distressed symptom perceived by patients with breast cancer. Only few patients accepted positively that alopecia was the sign of effective chemotherapy regimen whereas many studies informed that alopecia could lead to refusal of chemotherapy because it was very distressing and traumatizing for the patients (Lemieux et al., 2008).

Furthermore, chemotherapy toxicity then results in secondary side effects to patients’ emotional, physical and social well being. One study about the effect of chemotherapy reported that the common physical side effects of chemotherapy were lack of energy, coughing, pain, lack of appetite, and nausea (Akin et al., 2010). There was an interesting finding in Akin et al.’s research (2010). They found that the physical symptoms from chemotherapy although caused little distress, patients reported significantly decreased QoL. It is obvious that patients who undergo chemotherapy would present with some limitations whether in physical or psychological conditions. It would not be easy for them to perform their normal function as they used to before they got sick. Thus, to make them have control of their functional status, they need to be assessed and supported regularly.

In summary, either from the natural development of the disease, the occurrence of symptoms of patients with advanced cancer may possibly come from the side effects of the cancer treatments. When the quantity of these symptoms is numerous and the severity is worst, they can be very disturbing physically, psychologically, socially and spiritually. Therefore, patients with advanced cancer need the strategies to manage their symptoms.

Symptom Management Model

This part presents the definition of symptom and the symptom management model. The concept of symptom experience will be explained using a concept analysis by Armstrong (2003). While the Symptom Management Model by Dodd et al. (2001) which comprises of three dimensions and three domains will be discussed to explain further about the symptom experience and symptom management phenomena.

Definition of Symptom

Symptom is a common word used by lay people and health professionals. It refers to a change in the body or mind which shows an unhealthy condition. For health professionals, this term is used to indicate what an individual feels requiring medical attention. For examples, headache, stomachache, tiredness or breathlessness are symptoms that bring people to seek medical help. It is a “subjective experience”, and can be complicated when it lasts for a period of time or causes suffering, particularly in some chronic and devastating health conditions, including advanced cancer.

Armstrong (2003) conducted a concept analysis of symptoms experience. Based on her review, symptom is a subjective phenomenon experienced by individuals when there is something not normal. This is congruent with the one defined by Lenz et al. as the perception of changes in normal functioning in oneself (as cited in Armstrong, 2003). Leventhal and Johnson (as cited in Armstrong, 2003) added that it is not only the occurrence of the symptom but also includes the emotional response of such occurrence. As such Armstrong delineated that symptom is subjective in nature, its occurrence indicates a departure from a normal frame time, and it has multi-dimensions, including an emotional response to the symptom and meaning of such symptoms. She concluded that symptoms experience is defined as “perception of the frequency, intensity, distress and meaning occurring as symptoms are produced and expressed” (p.602). In addition, Armstrong (2003) highlighted that symptoms often occur in clusters. In other words, several symptoms can be experienced at the same time.

The above definition of symptoms experience is well defined and constructed to help us understand better how symptoms are perceived by patients, particularly those with advanced cancer. There are multi variables influencing symptoms experience such as age, role, education (demographic characteristics), type and stage, type of treatment (disease characteristics), values and past experience (individual characteristics). As a result, the expression of symptoms occurrence in QoL, mood or functional status will vary from one patient to another. Therefore, symptom of patients with advanced cancer is the subjective phenomenon or individual perception towards the changes of their body which is not normal because of cancer disease.

Symptom Management Model

The Symptom Management Model is a systematic approach developed by a group of researchers from the School of Nursing, University of California, San Francisco to understand symptoms, at first especially, of patients with cancer (Dodd et al., 2001). This model provides direction for selecting clinical intervention, informing research and bridging an array of symptoms related to a variety of diseases and conditions as well. The main factor in this model is symptom, consisting of symptom experience, symptom management strategies and symptom outcomes. Moreover, there are three main domains of nursing influencing the symptoms, person, health/illness and environmental domains. Figure 1 shows the three domains and three dimensions of the Symptom Management Model and their relationships. This model can be used to explain the symptom-related condition of chronic diseases including cancer.

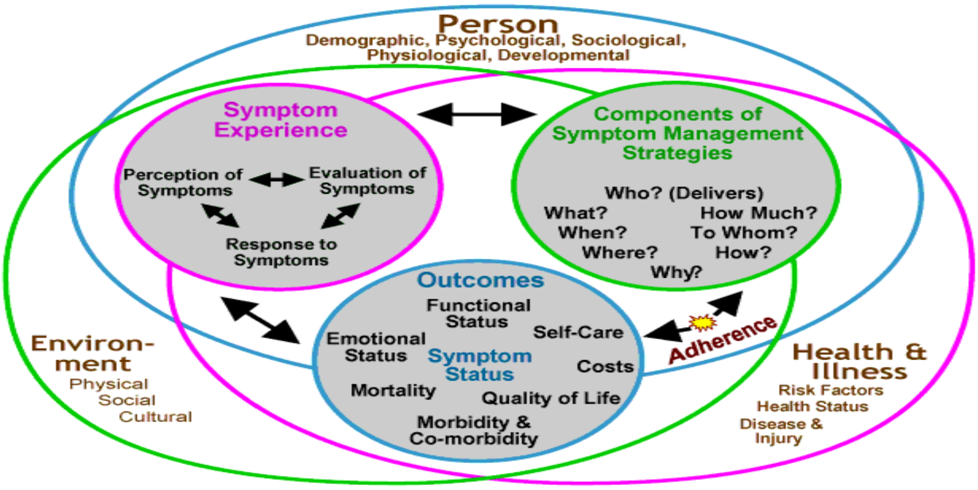

Figure 1. The symptom management model. Adopted from “Advancing the Science of Symptom Management” by M. Dodd et al., 2001, *Journal of Advanced Nursing, 33,* p.670.

Dimensions of the Symptom Management Model. As conceptualized, the Symptom Management Model has three dimensions, symptom experience, symptom management strategies and symptom outcomes. In this study the concept of Symptom Management Model will be related to patients with advanced cancer. These are the main variables of the Symptom Management Model.

Symptom experience. Symptom Experience consists of three subsets. They are the perception of symptoms, the evaluation of symptoms, and the response to symptoms (Figure 1.). The perception of symptoms means an individual perception of symptoms, the evaluation of symptoms is the meaning given to symptoms, while the response to symptoms is the physiological, cognitive, emotional and behavioral response to symptoms (Dodd et al., 2001; Jablonski & Wyatt, 2005). Their relationships are shown by two-way arrows. It means that there is a reciprocal relationship; one can cause the other and vice-versa. The meaning of these three variables of symptoms experience will be reviewed further.

First is the perception of symptoms. It can be interpreted as the ability of the individual in noticing the changes of his or her body’s normal function or the recognizing or feeling of such symptoms. This assessment requires the subjectivity of the patients in reporting the symptoms that they experience (self-report). Sometimes, this self-report cannot be objectively observed by other people such as nurses and physicians. If the symptom, such as fatigue, occurs, the patient reports that he/she feels fatigue, no energy or lack of energy to do anything. Healthcare providers might think that the patients are resting on the bed, not experiencing fatigue. Second is the evaluation of symptom that requires the individual’s judgment towards the severity, value or meaning of the symptom on their life. This value can be measured numerically, by a face or visual scale of the symptom. The commonly used measure is an 11-Point Numerical Rating Scale for pain. It has the interpretation that the higher the score the more severe the symptom is. When the patient reports zero (0), she/he does not feel pain. Whereas when the patient reports ten (10), it means he/she feels very much or severe pain. Third is the response to a symptom. It could be the distress or mental behavior when an individual is experiencing symptom. This response can be different from one patient to another, although the patients report the same severity level of the symptom. Given an example of two female patients with advanced breast cancer experiencing fatigue at the same score, but both of them are able to function differently. One patient is still able to walk, take a bath by herself and prepare her family’s food, while the other patient only lies on the bed and asks for help from her family members to do her daily needs. Symptom experience, its meaning and concept will be reviewed further in the following sub topic as analyzed by Armstrong (2003).

Symptom management strategies. The second dimension is the symptom management strategies. Referring to Figure 1, there are many components of symptom management strategies; who (delivers), what, when, where, why, how much, to whom and how. The intervention or program can be performed by the patient his/herself and/or with the assistance from the caregivers or healthcare providers such as nurses or physicians. Symptom management strategy is a vital aspect of cancer care for the entire trajectory of the disease and treatment. The intervention or program to manage the symptom must be from the evidence-based practice or research studies. One intervention can be effective only to manage one symptom or on the other hand one intervention is effective to treat more than one symptom. The time (the frequency and the duration) considered to deliver the symptom management also depends on the symptom and the evidence supporting it.

Furthermore, although we have determined to perform the symptom management strategy according to the evidence based-practice, we still need to have a critical thinking to consider the feasibility of the intervention in our own setting. The components such as the place of conducting the intervention; whether it is in the hospital or at the patient’s house, the availability of sources/equipment, caregivers and the patients’ preference are very crucial to be considered. The component “to whom” the symptom management strategies are delivered means that the interventions can be implemented/given to the patient only, to his/her caregivers or both of them at the same time. For example, in the PRO-SELF$^{©}$ pain control program, besides encouraging and couching the patients with cancer to take their pain medication at the clock time, the nurses also included the caregivers or the family members to remind and help the patients to take the pain medication as at the time prescribed

(Miaskowski et al., 2004). In terms of “how and how much” we do the intervention, we have to refer to the evidence-based practice or research studies related to it.

Symptom management is expected to be subjective, intentional and experimental phenomena of the patients which cover universal and particular experience. The universal experience provides a framework for the healthcare providers to individualize the intervention or cares to fit with each patient’s unique characteristics (Fu, LeMone, & McDaniel, 2004). Therefore, in conducting the symptom management strategies, we are expected to see the patient as a whole individual system consisting of physical, psychological, social and spiritual aspects. We have to take a look at carefully each patient’s condition, needs and preference regarding the intervention to manage their symptoms. The example of research studies on symptom management strategies interventions will be reviewed in the following part.

Symptom outcomes. As shown in the model, the symptom experience and the symptom management strategies dimensions would eventually affect the symptom outcomes. In the component of symptom outcomes, functional status, emotional status, self-care and symptom status of the patient are included in this model, the QoL is also one of them. This domain is the result as well as the antecedent of the other two domains (Dodd et al., 2001). The experience of a symptom of a patient with advanced cancer could affect on the quality and quantity of the patient’s daily functioning. After performing an effective symptom management program, the occurrence of symptom as well as its severity is expected to be diminished. Therefore, later on, the patient can be able to perform his/her daily functions better than before being treated. Not only to treat the symptom after the symptom occurs, the symptom management strategies are expected to prevent the occurrence of the symptom. Thus, the patient does not need to experience the same symptom with the same severity as before. Moreover, the implementation and the effectiveness of the strategies need to be evaluated regularly.

Outcomes of the Symptom Management Model can be changed or modified by modifying the other two dimensions. The major indicators of the outcomes dimension are the symptom status, the QoL and the functional status. Symptom status is a direct outcome of the symptom management strategies. Effective symptom management strategies should lead to relieving and decreasing the symptom or preventing the occurrence of the symptom. The QoL is also one of the outcomes of the symptom management strategies. This variable is related to the symptom status in which many studies reported that the decrease in the number of cancer symptoms is associated with a better QoL (Dodd et al., 2001; Motl & McAuley, 2010). In other words, having poor QoL might cause the patient unable to perform the symptom management, thus she/he keeps experiencing the symptom with the same severity level or even worse. It means that QoL remains as the result as well as the antecedent of the other two domains.

In summary, all dimensions in the Symptom Management Model would work as the cause and effect to each other (Dodd et al., 2001). As Dodd et al.'s model does not explain in detail about the attributes QoL, this variable will be reviewed further with the QoL conceptualization by Ferrell et al. (2003) which is developed specifically for patients with cancer.

Domains of the Symptom Management Model. As delineated in the Figure 1., the symptom management model has three domains; person, environment and health and illness. These three domains give certain meaning or huge influence to the symptom dimensions.

Person domain. The person domain is characterized by demographic, psychological, developmental, social and physiological variables of an individual. Person variables are the internal factors which influence the ways and responses of the patients to their symptom experience. Each person responds to symptom occurrence and severity differently depending on his/her demographic, psychological, sociological, physiological and developmental factors.

There are gender and age differences in the occurrence of cancer symptoms. Six studies included in a systematic review conducted by Teunissen et al. (2007) found that both dysphagia and insomnia were more prevalent in men, whereas nausea and vomiting were more prevalent in women. The relation between age and symptom prevalence was investigated in four studies and found that pain and dysphagia decreased in occurrence with increasing age. This finding was in coherence with Bacon, Hughes, and Mark's study (2009). The older the patients, the more they were concerned with pain and the better they managed their symptoms compared with that of younger patients with advanced cancer (Bacon et al., 2009). This study indicated that the age has an important correlation to an effective symptom management application. Moreover, in a regression analysis of Karabulu et al.'s study (2009), age, educational level, stage of cancer and cancer sites were indicated as the significant predictors to the symptom experience.

Patient's perception, belief and education also have a certain influence on the symptom experience, the management and its outcomes. For instance, two studies in patients with cancer showed that demographics, a patient's belief, and symptom experience can exist as barriers for patients in following the pain management (Dawson et al., 2005; Jacobsen, Samsanaviciene, Liubarskiene, & Sciupokas, 2010). Jacobsen et al.'s study (2010) reported that the patients who stopped taking pain medication (opioids) were worried of the psychological consequences (addiction) and the drug's side effects. Incorrect beliefs in pain communication (wish to be a good patient by not reporting their pain and unwillingness to distract physicians from treating the cancer) were also detected as the barriers of effective pain management (Jacobsen et al., 2010). Thus, the health care providers must really concern on the patients' psychological status, their beliefs and knowledge related to the treatment. These studies also reported that patients who have higher academic education experienced lower mean scores of anxiety and depression compared to those with low education level (Jacobsen et al., 2010).

Moreover, the previous healthcare treatment gave an important influence in patients to interpret and perform the symptom management in the future. Patients who have good prior experience in symptom treatment would follow better in the next symptom management program than those who did not meet their expectations from the program (Jacobsen et al., 2010). Jacobsen et al. (2010) reported that patients who continue to take pain medication had better pain relief than those who stop taking the medication because of concerning to the medicine side effects. And people who were not satisfied with their prior experience would try to seek other healthcare alternatives that might work for their symptoms.

Health and illness domain. The second domain is health and illness which is related to the risk factors, health status and disease & injury. This domain has direct or indirect effect in symptom experience. Patients with cancer in the early stage are likely to have better QoL than those in the advanced stage. Because generally they experience only few cancer symptoms, and they might only receive one and low dose cancer treatment and their disease prognosis would have a better chance of cure.

The factors related to health and illness status such as treatment, cancer drugs, type and stage of cancer also influence the symptoms and the management of them. The type of cancer affects the choice of treatment, thus certain patients with cancer are predicted to have more specific treatment side effects than others. For example, generally patients with HNC would experience oral mucositis because of the radiation treatment in that area (Dodd et al., 2010). Patients who suffered from a terminal stage of lung cancer would get more drugs for their chemotherapy than those who were at the early stage of cancer. The patients with advanced cancer who received more drugs reported that the symptoms were higher in the number and quality compared to the patients in the early stage. Hence, the side effects of the drugs lowered their functional status (Akin et al., 2010). Furthermore, a study among Turkish patients with advanced cancer reported that loss of appetite, fatigue, sadness, dry mouth and distress were the common symptoms experienced by 48% among 287 patients (Karabulu et al., 2009). Those patients experienced multiple symptoms because of the progression of the cancer, acute psychological changes associated with the cancer treatment, early and late effect of cancer treatments, and long term consequences of the disease (Karabulu et al., 2009). Those patients certainly needed symptom management since multiple symptoms had disturbed their functional status.

Environment domain. The third domain is the environmental domain that is defined as the total condition or context within which a symptom occurs. The influencing variables on this domain are physical, social and cultural variables. How strong the environment affects the patients' symptoms was shown in patients' perception of their surrounding environment (Dodd et al., 2001). In other situations, patients with cancer may perceive that the hospital environment has initiated their nausea and vomiting due to their previous experience of taking chemotherapy. Being in a familiar environment which makes them experience symptoms similar as the previous time would raise anxiety, fear or the same symptoms as well (Dodd et al., 2001). This may have developed by the patients' belief or knowledge that they will again get the symptoms during the treatment (Dodd et al., 2001). The availability of medical services and medical equipment are also factors which influence the patients to treat and manage their health status. Adequate and proper medical services and equipment would serve and facilitate the patients better.

The data of these three domains were collected in this study in order to help explain the differences which might occur in the symptoms experience, symptom management and QoL of the patients with advanced cancer.

Symptoms of Patients with Advanced Cancer

This section is to review further about the symptom experience of patients with advanced cancer. It covers the pathophysiology of cancer symptoms, a review of the symptoms which are mostly experienced by patients with advanced cancer. The symptom measurement tool will also be reviewed.

Pathophysiology of Cancer Symptoms

Beside the influence of cancer treatments, the symptom occurrence will depend on the type of cancer, the size of tumor, the location and the metastases of the cancer. Therefore, the pathophysiology of the most common cancer symptoms for instance pain, fatigue and depression need to be understood. This part defines briefly the pathophysiology of these three symptoms.

According to Puntillo, Miaskowski, and Summer (2003), pain is described as “a complex experience with sensory, affective, behavioral, and cognitive characteristics” (p.235), whereas based on McCaffery, (1968) pain is “whatever the experiencing person says it is, existing whenever the experiencing person says it does” (as cited in Bernhofer, 2011). It means that pain is a subjective experience and influenced by multidimensional factors, for example the nature of cancer disease. As the cancer grows, it can begin to push nearby organs, blood vessels and nerves (American Cancer Society, 2012) which then could initiate pain. According to the time frame, generally the type of pain can be divided into two categories, acute (nociceptive) and chronic pain. These types of cancer pain may occur from tissue injury (such as surgery wound or cancer wound) and nervous system alteration (Puntillo et al., 2003). Patients with cancer may have one type of this pain (tissue pain or nervous pain) or combination of both. Chronic pain which is experienced by patients with cancer is generally associated with the injury or dysfunction of the pain nervous system. There is another term for cancer pain, the breakthrough pain. This pain exists at irregular intervals, for example during changing position, walking or turning in bed (Puntillo et al., 2003). When the pain is untreated, other symptoms such as fatigue, depression, fear and anxiety may occur (Puntillo et al., 2003).

Lack of energy or cancer-related fatigue (CRF) is also often experienced by patients with advanced cancer. Although the pathophysiology of CRF is not yet completely identified, some theories might help to understand the factors that induce this symptom (Wang, 2008). The initiation of fatigue develops in the brain and spinal cord (central fatigue). Fatigue occurs when the patients with cancer fail to accomplish physical and mental tasks which need self-motivation and internal signs. In this condition the patients do not show any sign of cognitive failure or motor weakness (Wang, 2008). According to National Comprehensive Cancer Network (NCCN) guidelines (2013), the causes of CRF include the cancer itself, chemotherapy, bone marrow transplants, immunotherapy and radiotherapy and anemia. While other factors which are considered as the frequent factors that induce fatigue are pain, emotional distress, sleeping disturbance, anemia, and nutritional deficiency (Wang, 2008). This symptom can be regarded as subjective phenomenon as well as pain, therefore, the patients with cancer actually can rate the severity of their fatigue by themselves (Piper, 2003).

Depression is classified as a psychiatric syndrome which may also be experienced by patients with cancer in the advanced stage (Massie, 2004). The spectrum of depression is broad from sadness to a major affective disorder because mood change fluctuates from time to time, especially when the patients face a life threatening event such as cancer disease (Massie, 2004). This psychological disorder also can occur when the patients are undertreated with cancer treatment, related with or experiencing other symptoms for example anxiety, pain or fatigue (Massie, 2004). It starts from the stress response, the factors related to stress or depression initiate the central nervous system which then cause the release of hormones such as cortisol

(Page & Lindsey, 2003). On the other hand, depression can be initiated or related with other symptoms which are untreated, such as chronic pain (Page & Lindsey, 2003).

Prevalence of Symptoms in Patients with Advanced Cancer

Patients with cancer experience multi symptoms throughout their cancer trajectory. The patients with advanced cancer usually experience more than one symptom at the same time. On average patients with cancer suffered from 10-13 symptoms (Table 4). A systematic review of the common symptom prevalence in patients with advanced cancer by Teunissen et al. (2007) reported that in general these patients experienced five symptoms concurrently. The most common symptoms included pain, lack of energy (fatigue), dry mouth (xerostomia), followed by nausea and loss of appetite. Psychological symptoms include worrying, feeling nervous and feeling irritable. There have been many studies that have reported that patients with cancer experience symptom severity from mild to severe. These three studies, as shown in the Table 4, were conducted in the USA, Switzerland and Canada.

Table 4

Prevalence of Common Symptoms in Patients with Advanced Cancer

Symptom	Chang et al. (2000) (*N* = 240) %	Spichiger et al. (2011a) (*N* = 103) %	Tranmer et al. (2003) (*N* = 66) %
Lack of energy	62	82	83
Pain	59	72	78
Dry mouth	54	65	82
Loss of appetite	29	63	61
Nausea	Not reported	43	61
Difficulty sleeping	45	54	55
Shortness of breath	50	46	38

Table 4 (continued)

Symptom	Chang et al. (2000) (*N* = 240) %	Spichiger et al. (2011a) (*N* = 103) %	Tranmer et al. (2003) (*N* = 66) %
Worrying	40	75	61
Feeling sad	Not reported	51	55
Feeling nervous	37	48	41
Feeling irritable	28	33	29

Patients with advanced cancer experienced multi-organ dysfunction with many physical and psychological symptoms. The study of Tranmer et al. (2003) on 66 patients with metastatic cancer reported that lack of energy, pain, and dry mouth were the top most common symptoms experienced by the patients (Table 4). Around 80% of the patients experienced these three symptoms, followed by nausea and loss of appetite with 61% of the total percentage of patients. Similar to Tranmer et al.'s study (2003), Chang, Hwang, Feuerman, and Kasimis's study (2000) and Spichiger et al.'s study (2011a) also reported that the prevalence of fatigue, pain and dry mouth was high in patients with advanced cancer. Besides physical symptoms, psychological symptoms such as worrying and feeling sad were also found in patients with advanced cancer with the prevalence of 55% and 61% respectively (Tranmer et al., 2003). The other two studies in Table 4 also captured the occurrence of psychological symptoms such as worrying and feeling nervous (Chang, Hwang, Feuerman, & Kasimis, 2000; Spichiger et al., 2011a).

In Spichiger et al.'s study (2011a), over 10 days of hospitalization of Switzerland patients with advanced cancer (Table 4), lack of energy was the most prevalent (82% of patients) and the most frequent, whereas regarding the severity, pain was found to be the most severe and distressing for patients with cancer.

However in a systematic review study for pain prevalence over 40 years, it was found that pain occurred in patients with cancer during the cancer treatments and all stages of cancer (van den Beuken-van Everdingen et al., 2007). Pooled prevalence of pain was rated in studies among patients under anticancer treatment: 59% (CI 44% to 73%); studies which included patients characterized as advanced/metastatic/terminal disease, 64% (CI 58% to 69%) (Teunissen et al., 2007). Pain along with fatigue, lack of energy, weakness and loss of appetite occurred in more than 50% of the patients with advanced cancer (Teunissen et al., 2007). In summary, those symptoms listed above were the most common symptoms occurring in patients with advanced cancer.

Symptom Measurement Tools

As the symptoms of patients with advanced cancer are mostly subjective, the existence of a validated measurement tools is apparently needed. The well-known existing measurement tools for advanced cancer symptoms are the Edmonton Symptom Assessment Scale (ESAS), the Brief Pain Inventory (BPI) and the Memorial Symptom Assessment Scale (MSAS). There have been many studies conducted either by physicians, nurses or other health professionals in examining the validity and reliability of these three measures. The ESAS is considered the most appropriate to measure the symptom occurrence in this study.

The ESAS was initially developed for patients with advanced cancer (Watanabe et al., 2011). Since its first conception by Bruera and colleagues in 1991, this tool has been widely used in the palliative care setting (Watanabe et al., 2011). The ESAS is considered the simplest compared to the other measurement tools. The original ESAS is a visual analog measurement tool (VAS) which was first developed by the Regional Palliative Care Program, Capital Health in Edmonton, Alberta, Canada in 2003. It measures the severity of the eight most common symptoms in patients with cancer, one well-being and an open-ended question related to other cancer symptom experience. The severity of the symptom is measured using an 11-point scale ranging from 0 (not at all) to 10 (the worst). The symptoms listed in this questionnaire are pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, and shortness of breath. The higher the score indicates the more severe the intensity of the symptom experienced by the patient.

In a systematic search of Richardson and Jones (2009), the ESAS has a good reliability but it has restricted validity. The most common physical symptoms of cancer are included in this tool but the psychological symptoms are poorly captured (Richardson & Jones, 2009). The ESAS had been validated in different kinds of cancer populations. It also has been cross-validated with other measurement tools (Chang, Hwang & Feurman, 2000). Chang et al.’s study (2000) reported that each individual item has good internal consistency and especially the item distress in the ESAS significantly related with physical subscale of the Functional Assessment of Chronic Therapy-General (FACT-G) and the MSAS. They measured the stability reliability twice, one day test re-test and one week test re-test yielding the coefficients of .86 and .45, respectively. The internal consistency reliability reported with the Cronbach’s alpha coefficient of the ESAS was .79 (Chang, Hwang, & Feuerman, 2000). Furthermore, they measured its concurrent validity with correlation to other measurement tools, the FACT-G and the MSAS pain. The results were .85 the ESAS correlated with the FACT-G and .83 with the MSAS pain. The last validity test was construct validity where they found that the ESAS overall distress was significantly greater for in-patients than for out-patients (Chang, Hwang, & Feuerman, 2000; Webber & Davis, 2011).

The original ESAS has now been revised. The latest version of the ESAS is the Edmonton Symptom Assessment Scale-revised (ESAS-r). It has some modifications compared to the original form, in terms of symptom assessment time frame, terminology, item order and format and also regarding the sequence and cluster of the related symptoms (Watanabe et al., 2011). However, it has a similar scoring scale as the original ESAS. There is a shaded gray line of score in every second scale to make it easier for the patients to read the symptoms listed. Brief definitions have been added to explain the most possibly confusing symptoms such as tiredness was used to explain fatigue (lack of energy) and "feeling sad" was added to explain the symptom of depression. The last question of the ESAS-r is an open-ended question measuring other symptoms or problems which are confirmed by the patients with cancer a given example; constipation. The time frame for symptom rating is specified as "now" (Watanabe et al., 2011). For interpretation, the higher the scale indicates the more severe the symptom which is perceived by the patient.

Both the ESAS and the ESAS-r were validated among 160 patients with lung and gastrointestinal cancer (Watanabe et al., 2011). It aimed to compare the consistency of patients' symptoms ratings and to get the patient's point of view regarding the ease of understanding and the completion between these two measures. It was reported that the substantive differences in symptom intensity ratings between the ESAS and the ESAS-r were observed for three of the defined symptoms, drowsiness, appetite, and well-being, with the interclass correlations (ICCs) below .80 for these three symptoms. These response differences may have been because of differences in interpretations, as a result brief clear definitions were added. The study reported that the ESAS-r was significantly easier to be understood than the ESAS ($p = .008$). Significantly, more patients preferred the ESAS-r (39%) than the ESAS (14%, $p < .001$) because of its definitions, clarity, and format (Watanabe et al., 2011).

Symptom Management Strategies

Symptom management strategy is one of the domains conceptualized in the Symptom Management Model (Dodd et al., 2001). It has the purpose to prevent or delay a negative outcome through biomedical, professional and self-strategies. Management begins with the assessment of the symptom experience from the individual's perspective. Assessment is followed by identifying the focus for the intervention strategies. The intervention strategies maybe targeted at one or more components of the individual's symptom experience to achieve one or more desired outcomes. Symptom management is a dynamic process, often requiring changes in strategies over time or in response to acceptance or lack of acceptance of the strategies device (Dodd et al., 2001). A conceptual analysis of symptom management presented that this strategy is a subjective, experimental phenomenon which encompasses the universal and particular experience of the patient. This universal experience guides the healthcare providers to develop an individual intervention or care to fit with the unique characteristics of the patients (Fu, LeMone, & McDaniel, 2004). It also suggested that the evaluation of symptom management needs to be done continuously.

The symptoms which are commonly experienced by patients with advanced cancer are pain, nausea vomiting, fatigue (lack of energy), loss of appetite, mucositis, hair loss, depression (feeling sad) and many psychological distresses (Nilmanat et al., 2008; Spichiger et al., 2011). The studies regarding strategies in managing these symptoms were various. In managing the symptoms effectively, the interdisciplinary teamwork is crucial. Healthcare providers, the patients and their families need to work together to achieve the desired goal, relieving symptoms. A strategy could be targeted to reduce one symptom, nevertheless the strategy could also help to reduce other symptoms. The management can be divided into two parts, conducted by the patients with the supervision from the healthcare providers and conducted with the aids from the health care providers and/or from the family members. Patients with advanced cancer can perform the strategies to manage their symptom experience, for example by performing aerobic exercise (Courneya et al., 2007), PRO-SELF© pain control program (Miaskowski et al., 2004), and religious activities (Ferrell at al., 2003). These strategies however will give better outcomes with the aids from others such as the family members. The contribution of healthcare providers is needed as well in some of the strategies. There are some management strategies in which its application needs the aid particularly from the healthcare providers. They are massage therapy, behavioral cognitive intervention and modern medications therapy such as pain medicine and anti-emetic medicine.

Interventions Conducted by the Patients

In 2004 the PRO-SELF© Pain Control Program was developed through a randomized control trial study (Miaskowski et al., 2004). This program was effective to decrease the pain in patients with advanced cancer. In this pain control program, the patients with advanced cancer need to be able to take their pain medicine on a regular basis or “around the clock”, document their pain score in a pain diary and convey to their physician if the medicine does not give enough efficacy to reduce their pain. In the beginning of this intervention, the nurse has to assist the patients to use their pill box (to have the pain medication on schedule), teach them to fill in the pain diary daily, teach them how to communicate with the physician if their symptom gets worst. To ensure that this strategy is going well, the nurse needs to do a regular home visit and encourage the patients to keep improving their cancer pain management (Miaskowski et al., 2004). It was reported that the pain scores in the three level groups of pain decreased, 28.4% for mild pain, 32.5% for moderate and 27% for severe pain. In contrast, the pain score in the control group increased (Miaskowski et al., 2004).

The physical exercise program is a strategy to reduce CRF. A meta-analysis study evaluated the effect of exercise programs to CRF from 18 RCT studies (Velthuis et al., 2010).There were 14 RCT studies about exercise to reduce fatigue among patients with breast cancer and four studies in patients with prostate cancer. During breast cancer treatment, home based exercise lead to a small, non-significant reduction (standardized mean difference .10, 95% confidence interval (CI) is .25 to .45), whereas supervised aerobic exercise showed a medium significant reduction in CRF (standardized mean difference .30, 95% confidence interval is .09 to 0.51) compared with no exercise. Courneya et al. (2007) conducted a multicenter randomized control trial of aerobic and resistant exercise in patients with breast cancer to alleviate the CRF. Their study revealed that fatigue and depression of the patients who followed either aerobic or resistance exercise for three times a week (45 minutes duration per session) during their chemotherapy process had decreased and later their QoL improved (Courneya et al., 2007).

Furthermore, the psycho educational intervention (PEI) and progressive muscle relaxation in patients with advanced lung cancer also had a significant effect in decreasing the severity of some symptoms (Chan et al., 2011). Patients with advanced cancer were given the PEI and performed a progressive muscle relaxation program a week before radiotherapy. The symptoms of breathlessness, fatigue and anxiety of these patients decreased (p = .002, p = .011 and p = .001, respectively) and later on, their functional status increased (p = .000). The intervention of using nature sounds, symptom imagery and nature imagery were found to be feasible for patients with advanced cancer who experienced fatigue and sleeping difficulty (Kwekkeboom, Abbott-Anderson, & Wanta, 2010). These strategies had a positive effect to reduce fatigue and sleep difficulty.

The spiritual intervention produced certain effects for patients with cancer in managing their symptoms, according to Ferrell et al. (2003). Patients who decided to get involved in many spiritual activities such as praying, having a strong faith in God and having spiritual faith were more likely be able to manage their symptoms and have good QoL. They tried to compromise and accept their disease as a part of their lives (Ferrell et al., 2003). This strategy can be delivered by the patients themselves.

Interventions Conducted by Healthcare Providers

The intervention which need help from the healthcare providers are modern medicine, massage and cognitive behavioral practices. Pain medicines such as opioids have been well known for their efficacy to manage acute and chronic pain. The World Health Organization (WHO) ladder conceptualized the guidelines to direct the use of drugs in the management of cancer pain (WHO, 2009). It is now widely used by medical professionals for the management of all types of pain. The prescription is started from the first step drugs, and then climbed the ladder if the pain is still present. Firstly, the ladder begins with non-opioids (e.g. aspirin, Paracetamol or nonsteroidal anti-inflammatory drugs (NSAIDs) for mild pain, then increases to weak opioids like codeine and its derivatives as the second step for the intermediate level of pain, and finally escalating to strong opioids like morphine, methadone and even fentanyl as the third step for the highest level of pain. The analgesic should be given at “around the clock” or at regular intervals rather than on demand (Leung, 2012).

Besides the pain medications, there are other strategies to manage cancer pain. Giving a foot massage or massage therapy from 5 to 15 minutes a day using eastern or western techniques gave certain effects to reduce pain and nausea related cancer (Billhult, Bergbom, & Stener-Victorin, 2007; Grealish et al., 2000). This technique can reduce the pain severity from moderate to mild. A behavioral educational program is one of the symptom management strategies to alleviate pain severity (Chan et al., 2011). It was conducted as the implementation that cancer pain is influenced by many factors such as behavior and patients’ attitudes towards pain. The patients with advanced cancer who experience chronic pain need to be aware of their pain. They need to be taught to be honest with their pain severity when it is measured by the healthcare providers. The knowledge and attitude of the patients towards the pain medication such as opioids also must be correct. In both quasi and randomized controlled trials, behavioral education was also found to be effective to manage fatigue and nausea. Pain, fatigue, anxiety and sleep disturbance were managed by using cognitive (education), psychological and behavioral interventions (self-care strategies and training/practice) (Chan et al., 2011; M. E. Kurtz, Kurtz, C. W. Given, & Given, 2007; Kwekkeboom et al., 2010).

A randomized control trial about cognitive behavioral therapy-intervention (CBT-I) was conducted by Dirksen and Epstein (2007) for insomnia on fatigue, mood and QoL among breast cancer survivors. The subjects of the experimental group in this study were taught to easily fall asleep, have a tight sleeping schedule, and lastly they were taught about sleep education and hygiene (Dirksen & Epstein, 2007). The subjects had a significant improvement in relieving fatigue, anxiety and depression. The research group in this study also tended to have better QoL after the treatment (Dirksen & Epstein, 2007).

Antiemetic drugs just like analgesics or pain killers are generally used to relieve nausea. However, other therapies were also effective to complement to help relieve nausea in patients with cancer. A combined massage between eastern and western methods and also foot massaging for between 5 and 15 minutes is an example of a non pharmacological therapy to ease nausea in patients with cancer (Billhult et al., 2007; Grealish et al., 2000). Relaxation and distraction can also be considered in treating nausea (Kwekkeboom et al., 2010). Furthermore, a meta-analysis study reported that performing mouth care to treat and prevent mucositis for patients who underwent cancer treatments were significantly effective (Worthington et al., 2011).

The symptom management strategies above require the patients, as well as their family members, to actively participate. The healthcare providers give the intervention, coaching, assistance and supervision in conducting the strategy. Some of the strategies such as pain medications, massage and cognitive behavioral therapy can be conducted while the patients with advanced cancer are hospitalized.

And other strategies for instance PROSELF© and aerobic therapy are considered to be effective and applicable especially when the patients have to be discharged from the hospital and still continue their long treatment for their cancer symptoms.

Quality of Life of Patients with Advanced Cancer

Conceptualizing the QoL of patients with advanced cancer is very complex, where there are many aspects of patients' lives and external factors surrounding that may contribute to it. There will be two models to help explain the definition of QoL and one model to explain the factors contributing to QoL. The model by Ferrell et al. (2003) is the main model of QoL in this study. However Ferrans and Powers conceptualization (1992) will also be reviewed in brief to guide defining the QoL. The model of Wilson and Clearly (1995) will be used to explain the factors contributing to QoL.

Concept of Quality of Life

Two studies from Ferrell, Smith, Cullinane, and Melancon (2003) and Ferrans and Powers (1992) have conceptualized clearer on the attributes of QoL. Ferrell et al. (2003) conducted a qualitative study among patients with ovarian cancer throughout their disease trajectory. The study reported about correspondence letters from more than 20,000 of ovarian cancer survivors who shared their feelings, experiences, understanding, distress, coping and their life changes. The four well-beings were proposed as the attributes to delineate the QoL of patients with advanced cancer (Ferrell et al., 2003). They are physical, psychological, social and spiritual well-beings (Figure 2). The patient variables including age, race, level of education, religion, family support, income, stage of disease and treatments, were put as definitive factors. All of the attitudes, behavior, coping mechanisms and results of the patient's QoL would be according to the patient variables (Figure 2).

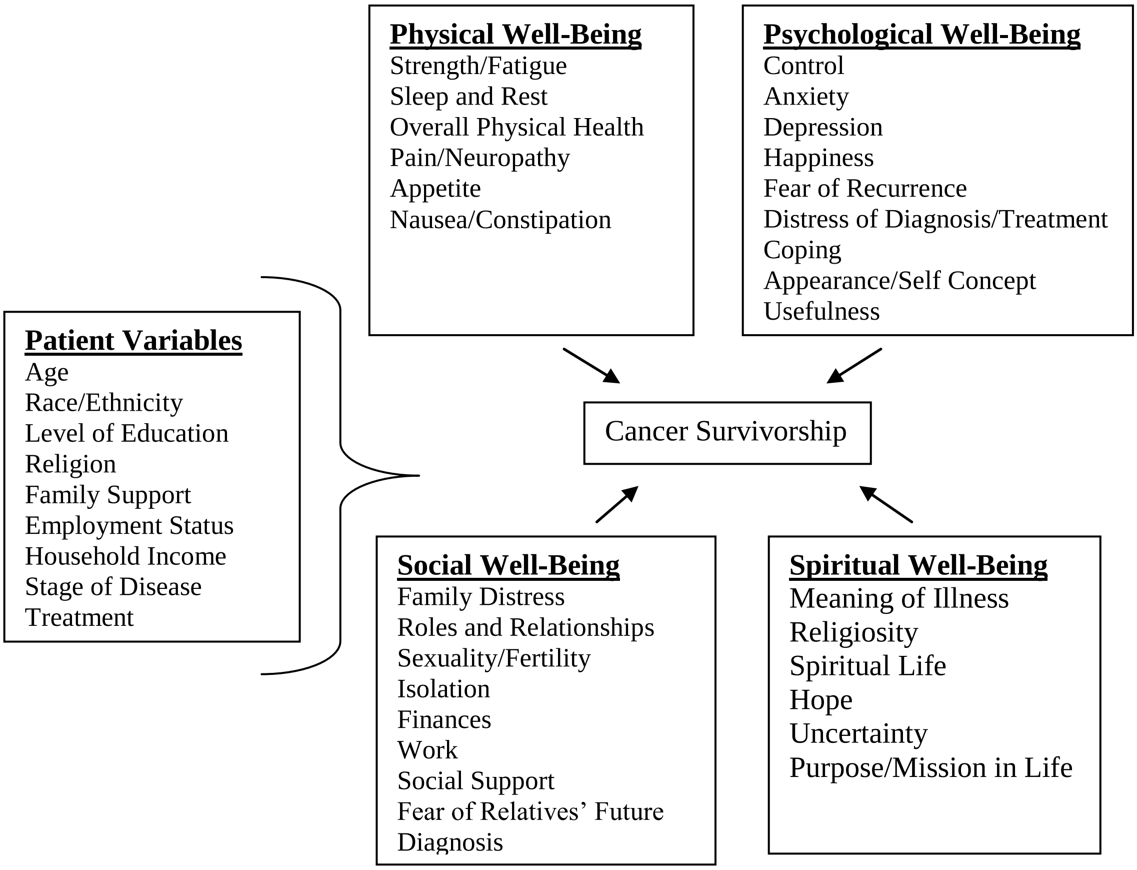

Figure 2. Quality of life conceptual model. Adopted from "Psychological Well-being and QoL in Ovarian Cancer Survivors" by B. R. Ferrell, S. L., Smith, C. A. Cullinane, and C. Melancon, 2003, *American Cancer Society, 98,* p.1063.

For patients with advanced cancer, the QoL is interpreted as patients' well-being, particularly the physical, social, psychological and spiritual well-beings (Ferrell et al., 2003). The four attributes of QoL conceptual from Ferrell et al. (2003) will be explained further in this part.

Physical well-being. Ferrell et al. (2003) conceptualized the physical well-being as the physical condition which is generally affected by the cancer treatments and/or the nature of this disease. The acute or late physical effects can be experienced by the cancer patients or the survivors. Patients with cancer experienced many symptoms such as pain, fatigue, sleeplessness, nausea, loss of appetite, anxiety and depression. The symptoms which these patients experienced sometimes are overwhelming. For instance fatigue which is too excessive or exhausting for them to handle eventually effects their mental and psychological well-being (Ferrell et al., 2003). These symptoms initiate the patients to seek medical help and cancer treatment. When these symptoms are managed to the level which they can bear, their overall physical health would be maintained well. On the contrary, when their symptoms are severe, the patients would feel horrible and suffered. They cannot perform their routine activities, enjoy life and feel relaxed (Ferrell et al., 2003).

Psychological well-being. Ferrell et al. (2003) in their study have seen throughout the disease phase, the psychological impact existed among patients with ovarian cancer. Therefore, psychological well-being is concluded as one of the attributes of the patients’ QoL. The positive attitudes that have been shown by the patients include sense of control, cognition or attention to what happen in their life and the appearance of self-concept. Meanwhile, instead of being sad some patients showed happiness while experiencing the disease and many treatments in the hospital. The difficulties or limitations they experienced because of cancer have made patients develop their own psychological mechanism to lessen their burdened mind. For example, they focused on living rather than the disease; they felt more appreciation in their lives compared to when they did not have the cancer. Moreover, helping and supporting other survivors have made them psychologically stronger (Ferrell et al., 2003).

Social well-being. Not only the patients with cancer, but also the family members must go through the distress as well. The family distress mostly caused by seeing their beloved suffering from and dying from cancer. Even the family members also got stress when they knew that the patients had lost their hope for living. This family distress also influences the patients' condition. Still according to Ferrell et al. (2003) roles and relationships, sexuality and fertility are considered as what would be altered among patients with ovarian cancer. Their roles in the family as a wife and mother cannot be performed fully after they got cancer. These women also thought that ovarian cancer is a kind of cancer which can be genetically endowed to their future generation. Understandably they have fears of having their daughters possibly getting the same type of cancer in the future. The relationship in the family can be either worse or stronger when one of the family members is suffering from a cancer disease. Cancer disease and its long term treatments could make them fight together as a unity or tear them a part. Social relationships, financial matters and professional ability are included as the components of social well-being (Ferrell et al., 2003).

Likewise their distress in the family, in the social relationships ovarian cancer survivors felt isolated from other cancer survivors. This happened because this kind of cancer is counted lesser than other types; for example breast cancer. They felt detached because they had difficulty to access other patients with ovarian cancer, to whom they share feelings and knowledge. That is why family and social support is considered very important for patients with cancer (Ferrans & Power as cited in Kimura & Silva, 2009; Ferrell et al., 2003). Furthermore, other problem which we cannot step aside is finance. The high cost of cancer treatments and other materials lost which cannot be valued by money are the finance problems which usually happen while patients with cancer are fighting against the disease. Meanwhile, women who have jobs or careers mostly have to postpone or lose their full capacity of working. These are the example which Ferrell et al. (2003) included as components of social well-being (Ferrell et al., 2003).

Spiritual well-being. The fourth well-being according to Ferrell et al. (2003) is spiritual well-being. They did a separate analysis for the spiritually among ovarian cancer survivors. It was because spirituality had a deep meaning as “a method of deriving meaning from the ovarian cancer experience” (p.249). Having spirituality helped the patients and their family members go through the disease and have hopefulness. It is not only related to religion but also hope, transcendence and purpose. The components under the spiritual well-being are religious practices and experiences, spiritual activities and experiences, changes in religion for both positive and negative changes (Ferrell et al., 2003). The patients found that being involved in religious practices and regarding having cancer as a spiritual experience made them peaceful and ready to cope with the disease. The patients with cancer held on to the faith of God and the power of God to lead them in their lives. They believed that God gave this disease to them for goodness. Therefore, they tried to get closer to God by doing the religious activities. This finding is suitable with the components of psychological/spiritual aspect from Ferrans and Powers (1992); patients’ faith in God and peaceful mind. For those who do not have religion, they used spiritual activities and experiences as the means to get meaning from the disease. The patients held on to positive minds in seeing the disease and to guide them through it. Whereas, there were also negative changes in their religious belief, when patients with cancer felt overwhelmed, exhausted and a lost hope. They lost their belief in God and felt depressed. Although they knew their family members were suffering in seeing them like this but they seemed to have no power to change it (Ferrell et al., 2003). As for them who had strong faith, they took the disease as the most gracious moment from God. The patients believed that having cancer made them appreciate deeply every small thing they could have in their lives.

Furthermore, their changes in the spiritually aspect were having new purpose of life, hopefulness and awareness of death (Ferrell et al., 2003). Ferrans and Power (1992) added other components of the spiritual aspect which they found from patients with cancer. The patients with cancer would reach their well-being in spirituality when they have an achievement of personal goals, happiness and life satisfaction in general as well as good personal appearance (as cited in Kimura & Silva, 2009).

Ferrans and Powers (1992) proposed four attributes of QoL as well; health and functioning, social and economic, psychological/spiritual and family. They emphasized the QoL in satisfaction, thus only the patient with cancer who can judge or value it. Their definition as cited in Kimura and Silva is “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (p.1098). As well as Ferrell et al.’s model (2003), Ferrans and Powers’s model (1992) has the family aspect as one of the four aspects to value the QoL of patients with cancer (as cited in Kimura & Silva, 2009). Family is regarded as a very essential aspect of patients’ lives. Therefore, Ferrans and Power (1992) were concerned on the family health and happiness, including the children, spouses, lovers and partners. This model has been widely applied to evaluate many kinds of patients, such as cancer, pulmonary disorders, diabetes, multiple sclerosis, stroke, patients in homecare and patients on dialysis. The total items that they measure for each component are 33 items. Thirteen items in health and functioning, eight items in social and economic aspects, seven items in psychological/spiritual aspect and five items in the family aspect.

As it has been reviewed, the attributes of QoL of patients with cancer consists of physical, psychological, social and spiritual well-being. These four satisfactions or well-being were derived from the experiences of patients with breast cancer who were experiencing the disease stages or the cancer survivors. This conceptualization of QoL, later on, is applied to other types of patients with cancer and chronically ill patients.

Factors Contributing to Quality of Life

The study of Wilson and Clearly in 1995 composed a model which explained about the factors contributing to QoL (Figure 3). Their model of health-related QoL contains five main variables; biological and physiological variables, symptom status, functional health, general health perception and overall QoL (Wilson & Clearly, 1995). Wilson and Clearly (1995) conceptualized that biological and physiological factors, symptom status, patient variables, environment characteristic and patients functioning status are the determinants of patients' overall well-being. As shown in the Figure 3., they portrayed in their model that the first four variables are the factors contributing or the antecedent of overall QoL. These five main variables are connected by straight arrows in sequence level. However, Wilson and Clearly (1995) stated plainly, although these variables are in a causal relationship, yet they ought to be considered to have bidirectional or adverse relationships.

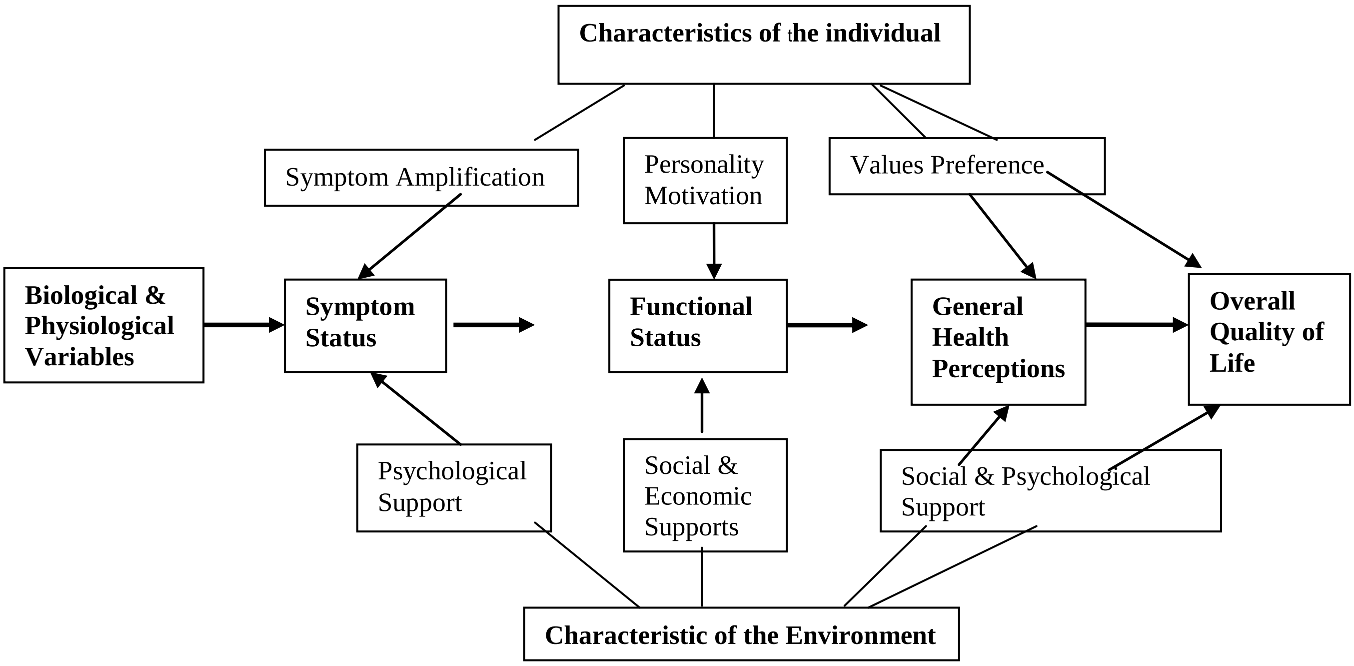

Figure 3. Factors contributing to quality of life. Adapted from “Linking clinical variables with health-related QoL: A conceptual model of patient outcomes” by I. B. Wilson and P. D. Clearly, 1995, *The Journal of the American Medical Association, 273,* p.60.

Biological and physiological factors. The first most fundamental determinants of this model are biological and physiological factors. They are referred to the clinical data from the physical and psychological assessment. The alterations of cells, organ or organ systems in our body are assumed to influence the occurrence or appearance of symptoms status. There are mainly two symptoms that appear; physical and psychological symptoms. But there is another kind of symptom which Wilson and Clearly (1995) defined as psychophysical symptom. It is referred to as “primarily associated with mental health” or symptoms not clearly physical or psychological in origin (p.61). Therefore, to cover all these three symptom concepts, they finally defined symptom as the patients’ perception of abnormal physical, emotional or cognitive states (Wilson & Clearly, 1995). In a point of fact, as they continued, biological or physical factors were no an automatically profound analog with symptoms reported by patients. For example, patients with ovarian cancer might not experience any specific physical symptom until the cancer develops to the advanced stage (stage III or IV). Moreover, depression in patients with cancer could not be identified clinically from the abnormality biologically or physiologically but many symptoms bound to depression have presented. That is why the relationship between the symptoms reported and physiological/biological factors are considered as complex (Wilson & Clearly, 1995). Similar to the model of Ferrell et al. (2003) which also included symptoms such as fatigue and nausea in patients with cancer and overall physical health as determining factors of physical well-being in QoL. Patients with cancer who were taking chemotherapy or radiotherapy or who had undergone surgery might possibly experience many symptoms which influence their functioning and their QoL (Ferrell et al., 2003).

Symptom status. The next levels which come after symptom status are functional status and patients' perception on their health. Four domains of functioning usually assessed are physical function, social function, role function and psychological function. Yet even though they have one-straight arrow, it does not mean that they do not have reciprocal association. The term of interchangeably is used in this model to draw attention in that these related factors can be modified or substituted at any time depending on the individual and environment characteristics. It means that the occurrence of symptoms in each individual could differently affect their functions of which patients eventually will build their perception of health unequally (Wilson & Clearly, 1995). A patient with breast cancer who experienced moderate pain might not find much difficulty in performing her function as a wife because she gets supports and aid from her family and, if any, a house maid (Wilson

& Clearly, 1995). The symptom status would be lighter when the cancer patient receives psychological support from his or her environment. It could be from the family, friends, neighbors or other cancer sufferers, whereas the severity of symptom status would also depend on the personal characteristics of the patient.

Functional status. The functional status is an individual's ability to perform normal daily activities required to meet basic needs, fulfill usual roles, and maintain health and well-being (National Palliative Care, 2013). The personal characteristics such as personality and motivation have a significant contribution in the variation of functioning among individuals. Furthermore, the functional status would be affected from the personality motivation of the individual and the social and economic support of the environment. The reference value of an individual and the social and psychological support from the environment would influence the general health perception and eventually the QoL (Wilson and Clearly, 1995).

As being conceptualized in quality of life conceptualization by Ferrell et al. (2003), patients’ variables are also included as an interfering factor. Wilson and Clearly (1995) excerpted the meaning of QoL as a wide range of experiences and feeling related to health related QoL and important life circumstances which people might have (Wilson & Clearly, 1995). Even so, they did not conceptualize further the attributes of QoL.

These factors affecting QoL in fact resemble the symptom management model by Dodd et al. (2001). The domains of the symptom management model such as person, environment and patients health related problems are conceptualized as the factors affecting the QoL (Dodd et al., 2001). To support the definition of QoL itself, the component of physical condition or functioning was reported as the major cause if the patients have lower QoL. Whereas the demographic data like gender and age were certainly affecting the patients' functional status. For example, older patients were likely to have better physical function, thus they could perform better QoL, compared to the younger patients (Bacon et al., 2009). Those patients were able to spend time on their leisure activities as well as other activities despite having or experiencing cancer symptoms.

All of the models from Dodd et al. (2001), Ferrell et al. (2003), and Wilson and Clearly (2003) have proposed that each factor contributes to QoL. The Ferrell et al.'s model (2003) implied that if deterioration among those attributes occurs, the QoL would be impaired. Whereas according to Wilson and Clearly (1995), the factors which will contribute to the changes of QoL are biological and physiological variables, symptom status, functional health, and general health perception. Out of these factors, there are also two variables which will affect each of these factors. They are the characteristics of the individual and the characteristics of the environment. These two variables have their amplification on each of the factor of QoL.

Quality of Life of Patients with Advanced Cancer

The occurrence of symptoms in patients with advanced cancer correlates significantly with their QoL. The higher the quantity and severity of the symptoms experienced by patients with advanced cancer, the worst QoL and functional status they will have (Dodd et al., 2010). In fact patients with advanced stage cancer have high possibility to experience more than one symptom at the same time. Dodd et al. (2010) investigated 112 women with breast cancer who underwent chemotherapy and grouped those patients according to the amount of symptoms they experienced. They found that the patients with high severity levels of all symptoms had poorer functional status and QoL compared to those who had lesser symptom in quantity and severity (Dodd et al., 2010). Similar result with Dodd et al.'s study (2010) was found in Korean patients with hepatocellular carcinoma (HCC) conducted by Ryu et al. (2010). The patients who received active treatments for HCC were identified based on the severity of the cancer symptoms they experienced. The symptoms were pain, loss of appetite, fatigue, gastrointestinal symptoms (nausea vomiting), itching and constipation (Ryu et al., 2010). They found that patients in the high-symptom group had significant poorer functional status and poorer QoL in all the domains except for social well-being. Those patients also tended to experience anxiety and depression. While, among women with breast cancer who underwent chemotherapy, the QoL was better when they succeeded to manage their fatigue, anxiety and depression (Fu et al., 2007).

Thus, these studies proved that the level of QoL of patients with cancer have an adverse relationship with symptom status. When the amount of symptoms and the severity are high, the level of QoL is low or worst. In particular, those patients who are in an advanced stage of cancer experience many severe symptoms, because of the nature of the disease and many cancer treatments they received. These patients with advanced cancer possibly develop low level of QoL.

Quality of Life Measurement Tools

Many QoL measures studies have been published related to their validity and reliability. The QoL measures for patients with cancer are usually being tested with other validated QoL measures. The existing QoL measures are sensitive and have been tested with patients with cancer. However, some considerations are needed to decide which tool is mostly suitable with this study.

There are around 16 widely used questionnaires to measure health related QoL (Granda-Cameron, Viola, Lynch, & Polomano, 2008). The Functional Status Karnofsky Performance Scale (KPS), the Palliative Performance Scale (PPS version 2) and the 36-item Short-Form Health Survey (SF-36 version 2) are used to measure the functional status in general, while the other thirteen measurement tools are for QoL of patients with cancer. Furthermore, QoL tools for patients with cancer are divided into two categories, for general and for specific groups of patients with cancer. The examples of QoL tools for general patients with cancer are the European Organization for Research and Treatment of Cancer QoL-Core 30 (EORTC QLQ-C30), the Functional Assessment of Cancer Therapy-General (FACT-G version 4), the McGill QoL Questionnaires (MQoL), the Cancer Rehabilitation Evaluation System-Short Form (CARES-SF), the Spitzer QoL Index (SQLI) and the Functional Living Index-Cancer (FLIC). Meanwhile the QoL tools for specific group of patients with cancer are the Functional Assessment of Cancer Therapy-Bone Marrow Transplant (FACT-BMT version 3), the FACT-Fatigue (FACT-F), the FACT-Anemia (FACT-An), the EORTC QLQ for Head and Neck 35 (EORTC QLQ-H&N35), and the EORTC QLQ-BM22 for patients with cancer with bone marrow metastasis (Granda-Cameron et al., 2008). In this part, only QoL measures for general cancer will be reviewed for their validity and reliability. They are the EORTC QLQ C-30, the FACT-G version 4 and the CARES SF.

The European organization for research and treatment of cancer QoL-core 30 (EORTC QLQ-C 30). The EORTC QLQ-C30 is one of the cancer measures. This measure has 30 items of questions which measures five functional status subscales (physical, role, social, emotional and cognitive dimensions), three symptom scales (fatigue, pain and nausea vomiting), six-single item symptom measures and a global health and QoL scales. In the EORTC QLQ-C30 there are 28 items with a four-point Likert scale (0 = not at all to 4 = very much) and two items with a 7-point Likert scale (1= very poor to 7 = excellent). This measurement tool measures the QoL of patients with cancer during the past one week (seven days). The EORTC QLQ-C30 has been validated and compared with other QoL measures for patients with cancer.

It was tested for the discriminant and convergent validity in 2001 with the Medical Outcome Study QoL Questionnaire Short Form 36 (SF-36) and the Functional Living Index Cancer questionnaire (FLIC) (Kuenstner et al., 2001). The study reported that using the multitrait-multimethod analysis, the score of convergent validity for physical functioning, emotion, pain, fatigue/vitality and nausea/vomiting exceeded the discriminant validity score. The result of the social functioning subscale and overall health subscale were less clear. However, the overall health subscales of these three questionnaires could not be equated (Kuenstner et al., 2001). The EORTC QLQ C-30 does not only measures patients with cancer in general, but also measures other specific group of patients with cancer.

As well as the FACT-G version 4, the EORTC QLQ-C30 also has particular forms which are used to measure QoL of certain group of patients with cancer such as the EORTC QLQ-H&N35 for patients with head and neck cancer. This measure also has been validated with the original EORTC QLQ-C 30. The EORTC QLQ-C 30 has been translated into many languages including Indonesia. Its validation was conducted in 2011 on Indonesian patients with cancer who received chemotherapy, together with SF-36 (Perwitasari et al., 2011). The researchers did translation and back translation for EORTC QLQ-C30 and SF-36. The results showed that the translation into Indonesian language was satisfactory, and only some words in EORTC QLQ-C30 needed to be changed to adjust with the Indonesian culture (Perwitasari et al., 2011). In fact in the pilot study, patients with cancer took a longer time to complete the questionnaires than healthy persons because of the severity of their condition. Their study reported the internal consistency using Cronbach’s alpha coefficient was greater than .70 and the convergent validity with SF-36 was ≥ .40 for all item, except item no.5 with the value of .38 (Perwitasari et al., 2011). This study reported that the correlation of these two translated-questionnaires were moderate between .18 and .48 for the physical, emotional, social, fatigue and pain domains (Perwitasari et al., 2011). Although this measurement tool has been translated and validated in Indonesian patients with cancer, the researcher did not use this measure because the contents or items of this tool do not best fit with the conceptual framework of the study.

The cancer rehabilitation evaluation system-short form (CARES-SF). The second QoL measure is the Cancer Rehabilitation Evaluation System-Short Form (CARES-SF). It is meant to measure the rehabilitation status of patients with cancer. This questionnaire has five domains; physical, psychosocial, medical interaction, marital and sexual (Schag, Ganz, & Heinrich, 1991). It gathers specific information about day-to-day problems and rehabilitation needs of patients with

cancer. The CARES-SF was derived from the original CARES in which all the questions in the short form are also presented in the long form (original form) (Schag et al., 1991). The original CARES has 139 items while the short form consists of 59 items. It has a 5-point scale ranging from 0 (not at all/no problem) to 4 (very much/severe problem). The CARES-SF also has one global or total score. Those items can be put mainly into these details (1) Physical: the physical changes and disruption of daily activity caused by the disease or treatment;
(2) Psychosocial: psychosocial issues, communication, and relationship problems (other than partner's problems); (3) Medical interaction: problems interacting and communicating with the medical team; (4) Marital: problems associated with a significant, marital-type relationship and (5) Sexual: problems related to interest and performance of sexual activity (Schag et al., 1991).

The CARES-SF has been considered as a validated measurement tool of QoL for patients with cancer. From the study of Schag et al. (1991), the finding revealed that the CARES-SF has a high relationship with CARES (r = .98). It also has an excellent test-retest reliability (86% agreement), concurrent validity with related measures and acceptable internal consistency of summary scales (alpha = .85 to .61). When it was tested with patients with breast cancer, the study showed that the CARES-SF was sensitive to changes. It was tested within three points of time (one month, seven months and 13 months after diagnosis). Moreover the CARES-SF has a high correlation with the FLIC (Schag et al., 1991). However this tool was not used to measure the QoL because it does not represent the QoL framework of this study.

The functional assessment cancer therapy-general (FACT-G version 4). The Functional Assessment Cancer Therapy-General version 4 (FACT-G version 4) was first developed by David Cella in 1987 as a generic core questionnaire for health-related QoL (Webster, Cella, & Yost, 2003). It is an appropriate questionnaire used for any form of cancer (Webster et al., 2003). The second version (FACT-G version 2) was developed and validated in 1993. The tool was still in the form of a 33-item cancer QoL questionnaire which was divided into five QoL domains; physical well-being, social/family well-being, relationship with doctor, emotional well-being, and functional well-being (Cella et al., 1993). From then on the third version of FACT-G (FACT-G version 3) was developed and then translated into different languages. Until then the French translation of FACT-G version 3 was validated by Conroy et al. in 2004, comparing with other cancer specific measures.

Conroy et al. (2004) tested the validation of the French version of FACT-G (version 3) comparing it to the other two tools, the EORTC QLQ-C30 and the FLIC. They compared the important features among these three measurement tools as well. The EORTC QLQ-C30 and the FACT-G version 3 have more items compared to the FLIC, 30 and 34 items respectively. Only the EORTC QLQ-C30 does not measure the global or total score, whereas the others do. The syntax structure and item's order between the EORTC QLQ-C30 and the FLIC are mainly the same. The FACT-G version 3 uses statements to measure patients' QoL while the others use questions. The EORTC QLQ-C30 and the FLIC have a mixed item order and they also have cancer symptoms as their questionnaire content. The EORTC QLQ-C30 and the FACT-G version 3 evaluated the cancer patients' QoL over the past 7 days, as the time frame. In addition, only the FACT-G version 3 specifically measured the patients' well-being. In their study, Conroy et al. (2004) examined test-retest reliability and internal consistency reliability. The test-retest reliability was within a

21-day interval and yielded a value of .79 to .88. Whereas the internal consistency of the FACT-G version 3 with Conbach’s alpha coefficient were from .66 to .88 (Conroy et al., 2004). The study concluded that the French translation of the FACT-G version 3 was internally consistent and its reproducibility was excellent. The study recommended that the domain of relationship with doctor needed to be omitted because it had a very high ceiling effect in its factor analysis (Conroy et al., 2004).

The latest version of the FACT-G now is the version 4 (FACT-G version 4). It is a 27-item compilation of general questions which has four main QoL domains; physical, social/family, emotional, and functional well-being (Conroy et al., 2004; King et al., 2010; Webster et al., 2003). There are some changes in the FACT-G version 4 to adjust with the patients. Two items (no.13 and no. 14) were changed from a negative expression sentence into positive sentence (“I am satisfied with family communication about my illness”) and item no.21 became “I am satisfied with how I am coping with my illness”. The subscale ‘Relationship with Doctor’ was deleted because it showed a very high ceiling effect (30.75) (Conroy et al., 2004).

This questionnaire uses a 5- Likert scale varying from 0 to 4, where 0 = not at all, 1 = a little bit, 2 = somewhat, 3 = quite a bit and 4 = very much. The numbers of the item in each subscale are physical well-being (PWB, seven items), emotional well-being (EWB, six items), social/family well-being (SWB, seven items) and functional well-being (FWB, seven items). The FACT-G version 4 mainly consists of positive statement items but it has several items of negative statements. All of the items in the physical well-being are in negative form. All items, except item no.2 of the emotional well-being are in the negative form.

The validity of the FACT-G version 4 has been tested in many studies. A meta-analysis study conducted by King et al. in 2010 specifically tested about the evidence-based effect size of the FACT-G version 4. From each domain yielded a range of effect size from small to large mean effect size. It also reported that the FACT-G version 4 has a clinical significance (King et al., 2010). Furthermore, Lee et al. (2004) measured the validity and reliability of the FACT-G version 4 especially in the cultural sensitivity among Korean patients with breast cancer. In their study the FACT-G version 4 was validated using two steps: pretest and test of reliability and validity to patients with breast cancer who underwent chemotherapy. It revealed that some items (Physical Well-being no.2 and no.7) were needed to be adapted to the Korean patients' situation regarding their culture and language. Furthermore, the Kaiser-Meyer-Olkin (KMO) test and Barlett's test of spericity were performed to justify the suitability of the data for a factor analysis and the value of KMO's measure of sampling adequacy was .87. It means that the FACT-G version 4 was constructively valid, particularly for Korean patients with breast cancer (Lee et al., 2004). The internal consistency reliability of the FACT-G version 4 according to Lee et al. (2004) for the total scale was .89, whereas the Cronbach's alpha coefficient for the sub-scales ranged from .78 to .90 (Lee, et al., 2004).

This FACT-G version 4 was used in this survey study. The FACT-G version 4 is considered to be the best available measurement tool to measure the QoL of patients with advanced cancer. First of all, it has been proven for its validity and reliability in many studies and it is suitable for the clinical setting and research (Conroy et al., 2004; King et al., 2010; Lee et al., 2010). Secondly, the FACT-G version 4 has a large size effect for a cross-sectional and longitudinal setting study

(Cheung et al., 2005). Thirdly, it has been validated in the Asian population (Lau et al., 2002; Lee et al., 2004). Furthermore, since the FACT-G version 4 measures the satisfaction or well-being, it is suitable to measure the attributes of QoL based on the framework QoL Conceptual model by Ferrell et al. (2003). The spiritual well-being was measured using the Functional Assessment for Chronic Illness Therapy-Spiritual Well-being subscale (FACIT-Sp).Other reasons are about the number of items of the FACT-G version 4 (27 items) and the ease to fill in the questionnaire (circle the number) are reasonable for patients who are in the advanced stage of cancer. The FACT-G version 4 Indonesian version was used and this was permitted and given by one of the developers (D. Cella, personal communication, August, 25, 2012).

The functional assessment for chronic illness therapy-spiritual well-being subscale (FACIT-Sp). The FACIT-Spiritual Well-being subscale (FACIT-Sp) is a part of FACIT measurement system to complement the FACT-G version 4 as the core instrument (Peterman et al., 2002). This questionnaire has 12 items with similar scoring to the FACT-G version 4. It measures the spiritual or religious aspect which comprises of 3 factors; meaning, peace and faith (Canada, Murphy, Fitchett, Peterman, & Schover, 2008). The meaning factor includes four items which measure the meaning and purpose in life and four items of the peace factor which measure the peacefulness in life. The third factor (Faith) in FACIT-Sp measures the relationship between illness and one's faith and spiritual belief (Canada et al., 2008). This questionnaire has two items with negative statement, they are item no.4 and item no.8. The Canada et al.'s study (2008) reported the total reliability using Cronbach's alpha coefficient of the FACIT-Sp to be .87. These measurement tools, since their first development by Cella et al. in 1987, have been tested in all various types of cancer patients as well as other chronic illness patients.

Summary

There are three main points in regards to patients with advanced cancer which will be studied; symptom, symptom management and QoL. The symptom experience symptom management strategies and QoL are delineated in the Symptom Management Model by Dodd et al. (2001). Both symptom experience and symptom management strategies are conceptualized clearly as the appraisal of the individual of his or her symptoms, the meaning given to symptoms and the physiological, cognitive, emotional and behavioral response to symptoms and the interventions which are conducted to manage the cancer symptoms. While the QoL attributes are conceptualized in the model of QoL Conceptual from Ferrell et al. (2003). They are physical well-being, psychological well-being, emotional well-being and spiritual well-being. These three dimensions are influenced by many factors which make the dimensions are unique for each patient. The domains that can influence the symptom, symptom management and QoL are person variables, environment and health and illness.

In many studies conducted in western and some Asian countries, the symptoms commonly experienced by patients with advanced cancer have been detected. They are pain, fatigue, nausea, vomiting, feeling sad/depression, lack of appetite and shortness of breath. Because of their significance, the most common symptoms such as pain, fatigue and nausea are likely to have more studies on their management. Even so, other symptoms are also being continuously studied in regards to symptom management. The ESAS-r developed by Watanabe et al. (2011) is one of the best existing tools to measure the occurrence and severity of symptoms-related cancer.

There are four attributes of QoL of patients with advanced cancer which was conceptualized by Ferrell et al. (2003). These attributes are the physical, psychological, social and spiritual well-beings. The level of QoL of patients with cancer is influenced significantly by the number and severity of the symptoms they experienced as well as other variables such as personal factor, environment and health and illness status. To measure the QoL of patients with advanced cancer, this survey study used the FACT-G version 4 and FACIT-Sp.

CHAPTER 3

RESEARCH METHODOLOGY

This chapter describes the research methodology of this descriptive survey study. The following topics are included: population and setting, sample and sampling, instruments for measuring the study variables, data collection, ethical considerations and data analysis.

Population and Setting

Java Island was the location to conduct this survey because two-thirds of the Indonesian population live in this island. There are six provinces in Java Island; Jakarta, Banten, West Java, Central Java, East java and Yogyakarta provinces. Each of these provinces has at least one general referral hospital with the details as follow:

Jakarta Province has one National General Hospital (Rumah Sakit Cipto Mangunkusomo/RSCM Hospital) and one National Cancer Referral Hospital (Dharmais Hospital). West Java Province has one general referral hospital (Hasan Sadikin Hospital). Central Java Province has one general referral hospital (Dr. Kariadi Hospital). East Java Province has one general referral hospital (Dr. Soetomo Hospital). Yogyakarta Province has one general hospital (Dr. Sardjito Hospital). Banten Province which is considered as a new province in Java Island has not had a general hospital yet.

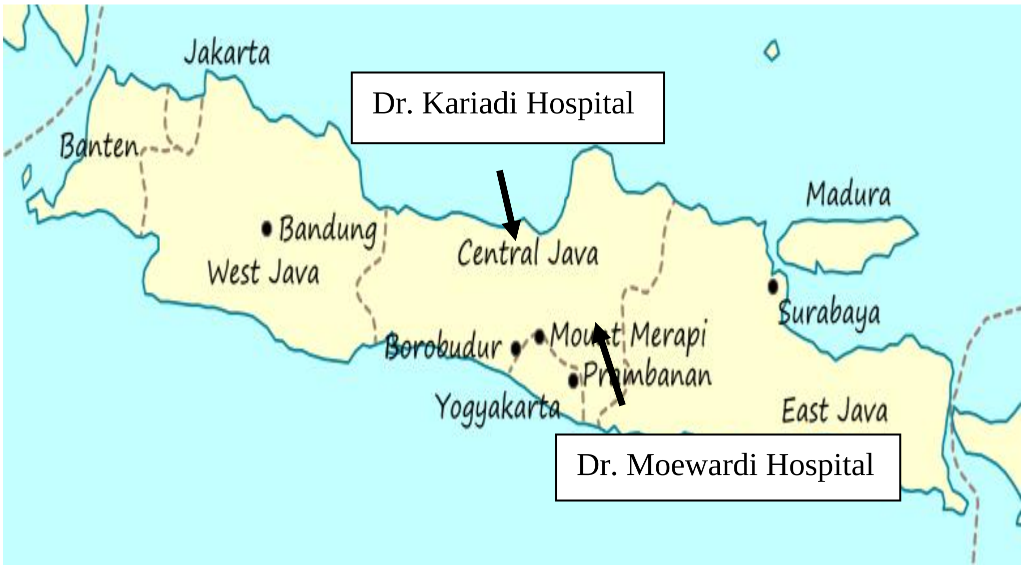

Figure 4. Java island map

Based on the regulation from Ministry of Health Indonesia number 439/Menkes/Per/VI/2009, General hospital is defined the hospital which provides health care services for any diseases. Whereas a specific hospital is the hospital which provides the main health care services on a specific illness based on the science basis, age level, organ or one kind of disease (such as children hospital and cancer hospital). There are four levels of hospitals; level A, level B, level C and level D. The criteria of general hospital with level A are having facility and capability to provide at least four basic specialist medical services (Obstetrics and Gynecology, Medical, Pediatric, and Surgical services), 5 specialist supporting medical services, 12 other specialist medical services and 12 sub specialist medical services. Only level A hospitals were selected because they are the top level hospitals and have cancer care services for the target population of this study.

Two general level A hospitals; Dr. Kariadi and Dr. Moewardi hospitals in Central Java province, and one specific level A hospital; Dharmais Cancer Center Hospital in Jakarta province were initially approached to be the target settings.

Unfortunately, Dharmais Cancer Center Hospital, the only cancer center in Indonesia was inaccessible due to the hospital regulation mandated that researchers whose studies can be conducted must come from formal agreed institutions. As a result, only two general level A hospitals were included. Both Dr. Kariadi and Dr. Moewardi hospitals have cancer specialists and all facilities needed for cancer treatments. The survey in the first hospital took place in the IPD (male and female surgical ward, gynecology ward, eyes and ear nose throat wards) and the OPD (radiotherapy unit). The study in the second hospital was conducted in the male and female surgical wards (IPD) chemotherapy unit (OPD) and radiotherapy unit (OPD).

The data collection took place between November 2012 and February 2013. The target populations were adult patients with cancer both locally advanced (stage III) and systemic (distant) advanced metastasis (stage IV) and had been hospitalized at the hospitals or temporarily attended for cancer treatments (surgery, chemotherapy or radiotherapy).

Sample and Sampling

In this study, the subjects were recruited using these following inclusion criteria:

1) Cancer patients diagnosed with newly or recurrence advanced stage including locally advanced stage (stage III) and advanced stage (stage IV) of cancers.
2) Being admitted (IPD) or attended (OPD/radiotherapy or chemotherapy units).
3) Age ranging from 18 to 60 years old and be able to understand Indonesian and local language.

The sample size needed for this study if estimated using Krejcie and Morgan’s table (Jones, Lee, Phillips, Zhang, & Jaceldo, 2001; Krejcie & Morgan, 1970) would require a total number of 248 based on the approximate population of cancer patients in 2010 of 700 cases from these two hospitals. This number included all cancer stages, the actual cases of stage III and IV were unknown. During the study period, 201 subjects who met the inclusion criteria were recruited and this size of the sample was considered adequate for a survey study (“Sampling:introduction,” 2011).

There were two patients refused to participate. The first patient (at the OPD) refused because his soar-throat was too severe which made him could not speak and the second patient (at the IPD) told us that she needed more rest after getting radiotherapy every day.

Instrumentation

The instruments for this study consisted of four parts to measure subjects’ characteristics and study variables (Appendix B - E) symptom experience, symptom management and QoL.

Part A: Demographics and Health-related Data Form

The demographics and health-related data form was developed by the researcher. It composed of three main parts. Part one was used to assess the patients’ demographic characteristics including gender, age, marital status, education level, occupation, monthly income, and ethnicity. Part two was used to assess the environmental variables contributing to symptoms occurrence. The details of environmental domain were hospital/ward environment that could initiate the symptoms, family caregivers, and patients' health insurance. The third part assed the health and illness status, including functional status, type of cancer, cancer diagnosis, time since being diagnosed, family history of cancer, comorbid disease, and type of cancer treatments.

Part B: Edmonton Symptom Assessment System-revised

The Edmonton Symptom Assessment-revised (ESAS-r) (Watanabe et al., 2003) was used to measure the symptom experience of the patients with advanced stage of cancer. It measures the severity of eight most common symptoms of patients with advanced cancer, one well-being and an open-ended question related to other symptom experience. The severity of the symptom was measured using an 11-point scale ranging from 0 (not at all) to 10 (the worst). The well-being scale (item no.9) was skipped to prevent the redundancy with the FACT-G version 4 and the FACIT-Sp. There was an open-ended question in the ESAS-r used to measure other symptoms or problems which might be experienced by patients with advanced cancer. In this study, the subjects were asked about the symptoms in two periods of time, over the past 24 hours and over the past one month. The reason was to capture the dynamicity of symptom experience during this course of illness. Part B (1) was the ESAS-r over the past 24 hours (p.139), Part B (2) was the ESAS-r over the past one month (p.140). Each of the numerical score of the symptom was calculated independently. For interpretation, the higher the score indicated the more severe the severity of the symptom.

Part C: The Symptom Management Questionnaire

The symptom management questionnaire asked the subjects any kinds of strategies that they used over the past one month with regard to the type (what), the time they did (when), duration and/or frequency, person who performed or delivered the intervention (who), place it was done/given (where), and its effectiveness. It was developed based on the description of the Symptom Management Model (Dodd et al., 2001) which was used by patients with advanced stage cancer to manage or decrease their symptoms. The patients were asked about the symptom management strategies which had been done over the past one month. The symptom management was explored by interviewing the patients about the strategies they had done and who delivered it (the patient him/herself or with the aids of others), the time of conducting the strategy, the duration and the effectiveness of the strategy. This questionnaire was developed by the researcher. The effectiveness of the strategy was rated form 0 (not effective) to 3 (effective).

Part D: Quality of Life

The QoL data were measured by using two sets of questionnaires. They are the Functional Assessment of Cancer Therapy-General (FACT-G) version 4 and the Functional Assessment for Chronic Illness Therapy-Spiritual Well-being subscale (FACIT-Sp).

Functional Assessment of Cancer Therapy-General (FACT-G) version 4. The FACT-G version 4 is a 27-item compilation of general statements with four QoL domains; physical well-being (seven items), social/family well-being (seven items), emotional well-being (six items), and functional well-being (seven items). It uses a 5-point Likert scale varying from 0 (not at all) to 4 (very much). The FACT-G Indonesian version was used and this was permitted and given by one of the developers (D. Cella, personal communication, August, 25, 2012).

The FACIT-Spiritual Well-being subscale (FACIT-Sp). The FACIT-Spiritual Well-being subscale (FACIT-Sp) is a part of FACIT measurement system to complement the FACT-G as the core instrument (Peterman et al., 2002). This questionnaire has 12 items with similar scoring to the FACT-G. It measures the spiritual or religious aspect which comprises of three factors; meaning, peace and faith (Canada et al., 2008). The meaning factor includes four items which measure the meaning and purpose in life, and four items of the peace factor which measure peaceful in life. The third factor (faith) in the FACIT-Sp measures the relationship between illness and one's faith and spiritual belief (Canada et al., 2008).

The subscale scores were calculated by averaging all items in each subscale and the total score were computed in the same fashion. The higher the FACT-G version 4 scores indicate the better QoL (Webster2003). The FACT-G version 4 scoring guide identifies the negative items must be reversed before being added to obtain the subscale total scores. Negatively stated items were reversed. After reversing proper items, all subscale items are summed to a total, which is the subscale score. For all the subscales of the FACT G version 4 indicate the higher the score the better the QOL.

The FACT-G version 4 scale is considered to be an acceptable indicator of the patients' QoL as long as overall item response rate is greater than 80% (e.g., at least 22 of 27 FACT-G version 4 items completed). In this study, all responses were greater than 80%. In addition, a total score should only be calculated if all of the components of the subscales have valid scores (Webster et al., 2003). For interpretation, the means of both subscale scores and total score were categorized into three levels as follows: low (0 - 1.33), moderate (1.34 – 2.66) and high (2.67 – 4.00).

Translation and Validity

The ESAS-r and the QoL measures were developed originally in English language. Since the study was conducted in Indonesia and the sample was Indonesian, the tools were translated into Indonesian language. The tools must be translated by back translation process to make sure the content of the original instrument and the translated one is equivalent (Brislin, 1970; Jones, Lee, Phillips, Zhang, & Jaceldo, 2001). The first bilingual translator translated the instruments from English version into the Indonesian version. The second bilingual translator translated back the instruments from Indonesian version into the English version without seeing the original version. Both translators were the bachelor graduates of English science from the Semarang University and had at least 3 years of teaching English subjects in a university or a college. The third translator clarified and identified the discrepancies in several items between the two versions. There were no major differences in the translation. Since this study was a cross cultural study, therefore the Indonesian version must be reviewed by a cancer specialist to check its cultural relevance to be applied in the study settings.

The FACT-G version 4 Indonesian version was used and this was permitted and given by one of the developers (D. Cella, personal communication, August, 26, 2012). The ESAS-r and the FACIT-Spiritual well-being scale were back translated into the Indonesian language. The ESAS, the FACT-G version 4 and the

FACIT-Sp were then reviewed by a cancer specialist at the target setting to check its cultural relevance with the local context.

There were two items of the FACT-G version 4 Indonesian version being revised. The 6th item of physical well-being subscale (GP6) “I feel ill” was revised to be similarly to “I feel unhealthy” because the Indonesian translation of the original version could be interpreted to be “I feel pain”. The last item of social/family well-being (GS7) was adjusted specifically to be “I am satisfied with my marriage sexual life”, because it is not applicable in Indonesia (socially and religion norms) to refer the sexual life out of marriage relationship. The third revision was done to the FACIT-Sp subscale towards the word “spiritual” in the item SP 9 (“find comfort in my faith or spiritual beliefs”), SP 10 (“I find strength in my faith or spiritual beliefs”), SP 11 (“My illness has strengthened my faith or spiritual beliefs”). This word was changed to be specifically “my belief to God or other important things in life”. The first reason is because the un-familiarity of word “spiritual” for lay people or community. The second reason is because the spirituality for Muslim people in Indonesia is related to God (Allah the Most Merciful and the Most Gracious).

The internal consistency reliability of FACT-G version 4 and FACIT-Sp tested with 20 subjects yielded the Cronbach’s Alpha coefficients of .84 and .92, respectively. The internal consistency of both questionnaires from the total subjects of this study were .89 and .88, respectively.

Data Collection Procedure

The processes of data collection were as follow:

Data were collected after obtaining the approval from the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University, Thailand. The further approval was also acquired from the Review Teams and the Directors of Dr. Kariadi Hospital and Dr. Moewardi Hospital, Central Java Province, Indonesia.

In this study two research assistants (RAs) were responsible to collect the data (questionnaire and interview). They were nursing students who have passed the medical surgical course (adult nursing course) and clinical practice program. Before collecting the data, they received a detail explanation from the researcher about the objectives of the study and the data collection procedures.

The researcher or the RAs reviewed the medical records of the patients in each of the targeted ward. Patients who met the inclusion criteria were approached. The researcher introduced herself and gave the explanation regarding the study's purpose. After receiving the explanation, the subjects were asked to sign an informed consent form. In addition, the subjects were informed that they had full right to withdraw at any time without any penalty or consequence.

The researcher or the RAs explained how to fill in their responses to each of questionnaire to ensure that they had understood and were able to complete the questionnaires by themselves. The researcher allowed the subjects to have time to answer all the questions. For the subjects who were illiterate, the researcher or the RAs read the questionnaires to them verbatim and fill the responses exactly as they indicated. For the Symptom Management questionnaire (Part C), the researcher interviewed the subjects. The data collection time was approximately last from 30 minutes to an hour.

There were sometimes in the middle of the data collection that the subjects' symptom(s) appeared, such as pain, felt the cancer symptoms, the researcher stopped the data collection and then asked the nurses in the ward to help the subjects. The data collection was continued again when the subjects were ready and willing to participate.

The researcher checked the completeness of the questionnaires. If they were not, the researcher asked the subject to check again. The researcher gave coding (number) to the questionnaires to ensure the anonymity of the subjects. Finally the researcher gave score to the responses, transcribed and compiled them for the data analysis.

Ethical Considerations

The research approval of the study was obtained from the university and the study hospitals. The subjects were informed about the protection of their human rights. The researcher clearly provided and explained the information about the study, such as the objectives, the outcomes and the publication of the study. The subjects acted voluntarily and they could withdraw at anytime without giving any reason. This study did not affect to any care that they receive from any health care setting. Even though this study does not intend to harm the subjects, it might be initiate their negative feelings or emotions such as sadness, anxiety and worry about their illness. When those feeling happened, the researcher stopped the data collection and gave the subjects some times to feel relax again. When during the data collection the subjects felt exhausted or tiredness, the researcher stopped the data collection process for a while, then asked the subjects to continue again when they were ready or still willing to continue to fill in the questionnaire. Moreover, when the cancer symptom occurred during the data collection, the researcher asked the nurses in ward to help the subjects. All of the information was kept confidentially and the researcher will destroy it after finishing the research process.

Data Analysis

A preliminary data analysis was conducted in order to screen and clean the dataset. Subsequently, descriptive statistics were used to describe subjects' characteristics and study variables. Frequency and percentage were used to describe categorical variables. Median and interquartile range were used to describe non-normally distributed continuous variables (i.e. age and monthly income) and ordinal variable (single symptom). Mean and standard deviation were used to describe normally distributed continuous variables.

CHAPTER 4

RESULTS AND DISCUSSION

This descriptive study was conducted to identify the symptom experience, symptom management and quality of life of Indonesian patients with advanced cancer. The results are presented as follows: subjects' characteristics, symptom occurrence, symptom management and quality of life of patients with advanced cancer.

Results

Subjects' Characteristics

A total of 201 patients with advanced cancer consented and completed the study. Table 5 shows the characteristics of the subjects in this study. They had ages ranging from 19 to 60 years (*Med* = 49 years). The majority of them were women (86.6%) and married (78.6%). More than half of the subjects (64.7%) had low education level. Approximately two-thirds of the subjects (67.3%) were unemployed and labor workers. More than 95% of the subjects were Muslim. Approximately two-fifths of the subjects (41.2%) needed help from others to perform their daily activities (Table 5).

Three-fourths of the subjects (75.1%) were diagnosed with the female-specific cancers. The majority reported to have no family history of cancer (86.1%). More than three-fourths of subjects (77.1%) were newly diagnosed with advanced stage cancer. The majority of them (83.65%) were recently receiving one cancer treatment, and two-fifths of the subjects (40.3%) reported to have an environment initiating their symptoms, for example the ward environment and hearing other patients vomiting (Table 5).

Table 5

Demographics and Health-related Data (N = 201)

Variable	*n*	%
Gender		
Male	27	13.4
Female	174	86.6
Age (years)		
18 – 30	15	7.5
31 – 45	59	29.3
46 – 60	127	63.2
Med (*IQR*) : 49.0 (13)		
Min – max : 19 – 60		
Religion		
Islam	194	96.5
Christian	7	3.5
Ethnicity		
Javanese	200	99.5
Chinese	1	0.5
Marital status		
Single	11	5.5
Married	158	78.6
Divorced/widow	32	15.9
Level of Education		
No education	47	23.4
Elementary school	83	41.3
Junior high school	34	16.9
Senior high school	29	14.4
University/Graduate	8	4.0
Employment		
Unemployed	85	42.3
Government employee	4	2.0
Private employee	14	7.0
Business/seller	27	13.4
Farmer	23	11.4
Laborer	48	23.9
Family income (*n* = 97)		
Med (*IQR*) = 750,000* (1,050,000)		
Min - max = 100,000 – 10,000,000*		

Table 5 (continued)

Variable	*n*	%
Health insurance		
Yes	189	94.0
No	12	6.0
Types of health insurance (*n* = 189)		
National	126	66.7
Others	63	33.3
Functional status		
Independent	118	58.7
Partial	59	29.4
Dependent	24	11.9
Types of cancer		
Female reproductive system	88	43.8
Cervix	62	70.4
Ovary	17	19.3
Vulva	5	5.7
Endometrium	4	4.6
Breast	63	31.3
Head and Neck	24	11.9
Gastro-intestine	7	3.5
Connective tissue	4	2.0
Bone	4	2.0
Bladder & Prostate	3	1.5
Lung	2	1.0
Not defined	6	3.0
Stage		
III	144	71.6
IV	57	28.4
New case/recurrence		
New case	155	77.1
Recurrence	46	22.9
Time since being firstly diagnosed (months) (*n* = 155)		
1	12	7.7
2 – 3	19	12.3
4 – 6	29	18.7
7 – 12	58	37.4
>12	37	23.9
Cancer family history		
Yes	28	13.9
No	173	86.1
Cancer treatment received		
No (never received)	33	16.4
Yes	168	83.6

Note. *1USD = Rp 9,690,-

Table 5 (continued)

Variable	*n*	%
Cancer treatment		
Surgery n=26		
Previous	23	11.5
Recently	3	88.5
Radiotherapy (days) (*n* = 46)		
1 – 5	6	13.0
6 – 10	6	13.0
11 – 15	13	28.3
16 – 20	7	15.2
21 – 25	3	6.5
26 – 30	8	17.5
>30	3	6.5
Chemotherapy (cycle) (*n* = 96)		
1	16	16.7
2	18	18.7
3	26	27.2
4	13	13.5
5	10	10.4
6	13	13.5
Comorbid disease		
Yes	56	27.9
No	145	72.1
Caregivers		
Yes	190	94.5
No	11	5.5
Caregivers at hospital (*n* = 190)		
Spouse	84	44.2
Family	74	39.0
Others	4	2.1
Spouse and family	26	13.7
Spouse, family and others	2	1.0
Environment initiating symptoms		
Yes	81	40.3
No	120	59.7

Symptoms Experience

Table 6 shows the occurrence of symptoms in patients with advanced cancer over 24 hours and over the past one month. Pain was first on the list of the most commonly found symptoms for both time periods (66.2% and 73.6%), followed by fatigue, depression, lack of appetite and anxiety. Table 7 shows the average number of symptoms experienced by the subjects over 24 hours and over the past one month. Over the past 24 hours the subjects experienced on average four symptoms (*M* = 3.78, *SD* = 1.93) while over the past one month the subjects experienced five symptoms (*M* = 4.63, *SD* = 1.99).

Table 6

The Occurrence of Symptoms in Patients with Advanced Cancer (N = 201)

Symptom	Over 24 hours	Over the past 1 month
	n (%)	*n* (%)
Pain	133 (66.2)	148 (73.6)
Fatigue (tiredness)	109 (54.2)	136 (67.7)
Depression	91 (45.3)	104 (51.7)
Lack of appetite	87 (43.3)	109 (54.2)
Anxiety	83 (41.3)	109 (54.2)
Drowsiness	64 (31.8)	66 (32.8)
Nausea	54 (26.9)	101 (50.2)
Shortness of breath	30 (14.9)	39 (19.4)
Sleeping problem	20 (10.0)	29 (14.4)
Alopecia	16 (8.0)	19 (9.5)
Vomiting	3 (1.5)	6 (3.0)
Mucositis	3 (1.5)	4 (2.0)
Others (cough, constipation, itchiness, oedema)	31 (15.4)	33 (16.4)

Table 7

The Number of Symptoms in Patients with Advanced Cancer (N = 201)

Number of symptoms	*M (SD)*	Min – Max	Skewness/SE	Kurtosis/SE
Over 24 hours	3.78 (1.93)	1 – 8	.392/.175	-.751/.349
Over the past 1 month	4.63 (1.99)	1 – 9	-.015/.174	-.691/.346

Concerning the severity of each symptom, Table 8 shows that within 24 hours pain was third on the list after alopecia and sleeping problems. Severe pain was reported by 33.1% of the subjects. Severe fatigue was experienced by approximately a quarter of the subjects. Over the past one month, the severity of alopecia and sleeping problems were still ranked first and the second respectively, while pain was third (Table 9). Approximately three-fourths of the subjects reported to have moderate to severe lack of appetite and sleeping problems.

Table 8

The Number of Subject (%) Classified by the Level of Symptom Severity Over 24 Hours (N = 201)

Symptoms	*Med (IQR)*	Severity Level (%)		
		1 – 3	4 – 6	7 - 10
Alopecia	10.0 (1.0)	12.5	6.3	81.3
Sleeping problem	7.0 (10.0)	0.0	20.0	80.0
Pain	5.0 (4.0)	29.3	37.5	33.1
Lack of appetite	5.0 (5.0)	29.9	37.9	32.1
Mucositis	4.0 (0.0)	33.3	66.7	0.0
Fatigue	5.0 (4.0)	35.8	37.7	26.5
Nausea	5.0 (5.0)	42.6	22.3	35.3
Depression	5.0 (5.0)	43.5	26.1	30.3
Anxiety	4.0 (5.0)	45.8	27.7	26.4
Shortness of breath	4.0 (4.0)	46.7	40.0	13.3
Drowsiness	3.0 (3.0)	64.1	26.6	14.1
Vomiting	2.0 (0.0)	66.7	33.3	0.0

Note. 1-3 = mild level, 4-6 = moderate level, 7 – 10 = severe level.

Table 9

The Number of Subject (%) Classified by Level of Symptom Severity over the Past One Month (N = 201)

Symptoms	*Med (IQR)*	Severity level (%)		
		1 – 3	4 – 6	7 - 10
Alopecia	10.0 (1.0)	10.5	10.6	78.9
Sleeping problem	9.0 (5.0)	13.8	27.6	58.6
Pain	5.0 (5.0)	25.7	34.5	39.9
Lack of appetite	5.0 (4.0)	33.9	37.7	28.4
Depression	5.0 (5.0)	36.5	27.9	35.6
Nausea	5.0 (5.0)	37.6	31.7	30.7
Shortness of breath	5.0 (6.0)	41.0	25.7	7.6
Fatigue	4.0 (4.0)	42.6	28.0	29.4
Anxiety	4.0 (4.0)	46.8	28.4	24.8
Drowsiness	3.0 (2.0)	63.6	27.3	9.1
Mucositis	3.0 (1.0)	75.0	25.0	0.0
Vomiting	4.5 (8.0)	100.0	0.0	0.0

Note. 1-3 = mild level, 4-6 = moderate level, 7 – 10 = severe level.

Symptom Management

Table 10 presents the types of symptom management strategies commonly used by the subjects. There were 25 subjects (10.0%) who did not perform any management strategies to alleviate their symptoms. Modern medicine such as Paracetamol and antiemetic was first on the list of commonly used symptom management strategies. It was followed by herbal medicine for instance the extract of sour-sop leaves (Graviola tree leaves) and sour-sop fruit (Graviola tree fruit), tea, the extract of curcuma and warm water. The third in the sequence was traditional healing modalities and then the praying strategy.

Table 10

Symptom Management Strategies (N = 201)

Variable	*n*	%
Managing the symptoms		
Yes	176	90.0
No	25	10.0
Who deliver the management*		
The patients	161	89.1
Their family	92	46.8
Health care providers	31	14.4
Strategies*		
Modern medicine	66	32.8
Herbal medicine	56	27.9
Traditional modalities	53	26.4
Praying	48	23.9
Sharing	34	16.9
Resting	33	16.4
Massage	29	14.4
Family support	28	13.9
Touching	16	8.0
Smelling scent from ointment	11	5.5
Hobby	10	5.0
Sport/exercise	5	2.5

Note. *Percentage is greater than 100 because each subject can answer more than one option.

The symptom management strategies for pain, fatigue, and depression were listed among those who experienced the symptoms (Table 11). Herbs or herbal medicine ranked as the most commonly-used strategy to relieve pain, followed by modern medicine such as Mefenamic acid and Paracetamol. Only very few subjects performed symptom management strategies to reduce fatigue. Sharing with their family members and healthcare providers especially a doctor, was used by the subjects to alleviate feelings of sadness (depression), it then was followed by praying and doing their hobby as a distraction strategy from their sadness.

Table 11

Symptom Management Strategies for the Three Most Common Symptoms (N = 201)

Symptom	Strategy	*n*	%
Pain	Herbs	50	24.9
	Modern medicine	42	20.9
	Massage	17	8.5
	Praying	15	7.5
	Others (traditional modalities, resting, and listening to music/hobby)	12	6.0
	Touching	6	3.0
Fatigue	Resting	5	2.5
	Massage	2	1.0
	Exercise	1	0.5
Depression	Sharing	14	7.0
	Praying	6	3.0
	Hobby	2	1.0

The effectiveness of four generally-used strategies and other strategies are presented (Table 12). Among those who conducted the symptom management strategies, on average, modern medicine, praying and traditional healing modalities were reported to be effective enough to decrease some symptoms while according to the subjects herbal medicine was less effective to relieve the symptoms.

Table 12

The Effectiveness of the Symptom Management Strategies

Strategies	Min – max	*Med (IQR)*	*M (SD)*	Skewness/SE	Kurtosis/SE
Modern medicine	0 – 3	2.0 (1.0)	2.29 (0.78)	-1.285/.322	1.952/.634
Herbal medicine	0 – 3	2.0 (2.0)	1.43 (1.06)	-.406/.374	-1.331/.733
Praying	2 – 3	2.0 (1.0)	2.36 (0.49)	.609/.491	-1.802/.953
Traditional modalities	0 – 3	2.0 (0.0)	2.00 (0.79)	-.852/.350	.987/.688
Others	0 – 3	2.0 (1.0)	2.22 (0.84)	-1.131/.274	1.072/.541

Note. 0 = not at all, 1 = little/least, 2 = somewhat, 3 = effective.

Quality of Life of Patients with Advanced Cancer

The mean scores of the QoL subscales are shown in Table 13. The mean score of the total FACIT was 2.7 (*SD* = 0.59). The results showed that the mean scores of the Physical Well-being (PWB) and the Functional Well-being (FWB) subscales were at a moderate level.

Table 13

The Quality of Life of Patients with Advanced Cancer (N = 201)

Variable	Min - Max	*M (SD)*	Skewness/SE	Kurtosis/SE	Level
PWB	0.29 – 4.00	2.49 (0.94)	-.258/.172	-.741/.341	Moderate
SWB	0.00 – 4.00	2.79 (0.68)	-.710/.172	1.204/.341	High
EWB	0.50 – 4.00	2.87 (0.85)	-.749/.172	-.196/.341	High
FWB	0.14 – 4.00	2.32 (0.87)	-.327/.172	-.346/.341	Moderate
FACIT-Sp	0.67 – 4.00	2.95 (0.66)	-.596/.172	.160/.341	High
Total	1.18 – 3.90	2.71 (0.59)	-.442/.172	-.146/.341	High

Note. PWB = Physical Well-being; SWB = Social Well-being; EWB = Emotional Well-being; FWB = Functional Well-being; FACIT-Sp = Spiritual Well-being.

Table 14 presents the items with the lowest scores in each subscale of the FACT-G version 4 and the FACIT-Sp. Inability to fulfill family needs, pain and feeling unhealthy were items in the physical well-being subscale which were rated very low. In the social/family well-being subscale, the scores of the social relationship with friends, satisfaction of communication with their family about their illness and satisfaction towards their married sexual life were also rated very low. Moreover, Table 14 shows three items in the functional well-being and spiritual subscales which were rated very low by the subjects.

Table 14

Items with the Lowest Scores of Each Subscales of the FACT-G and FACIT-Sp

Subscale Item	Min - max	*M (SD)*	Skewness/SE	Kurtosis/SE
Physical				
Inability to fulfill the family needs	0 – 4	2.14 (1.61)	-.191/.175	-1.552/.349
Pain	0 – 4	2.24 (1.45)	-.166/.175	-1.333/.349
Feeling unhealthy	0 – 4	2.26 (1.18)	-.123/.175	-.991/.349
Social				
Feeling close to friends	0 – 4	2.84 (1.07)	-1.706/.241	3.324/.478
Satisfaction with family communication about the illness	0 – 4	3.08 (1.00)	-1.147/.241	1.126/.478
Satisfaction about married sexual life	0 – 4	1.70 (1.55)	.186/.241	-1.488/.478
Emotional				
Feeling sad	0 – 4	2.40 (1.39)	-.406/.174	-1.075/.346
Satisfaction toward their coping ability	0 – 4	2.56 (1.03)	-.566/.174	.036/.346
Feeling nervous/anxiety	0 – 4	2.26 (1.28)	-.618/.174	-.709/.346
Functional				
Ability to work	0 – 4	1.74 (1.44)	.160/.176	-1.376/.350
Satisfaction toward their work	0 – 4	1.74 (1.42)	.149/.176	-1.318/.350
Sleeping quality	0 – 4	2.27 (1.28)	-.921/.176	.232/.350
Spiritual				
Feeling peaceful	0 – 4	2.68 (1.04)	-.671/.184	.066/.366
Productivity of life	0 – 4	2.57 (1.22)	-.633/.184	-.582/.366
Ability to feel comfort by themselves	0 – 4	2.70 (0.99)	-.564/.184	-.306/.366

Note. 0 = not at all, 1 = a little, 2 = somewhat, 3 = quite a bit, 4 = very much.

Table 15 shows the items of QoL with the highest scores regardless of the subscales in the FACT-G and the FACIT-Sp. There were two items from the FACIT-Sp well-being subscale (having purpose in life and having reasons to live). Having emotional support from their family and having a hope to fight their illness were the items from the emotional well-being subscale and being close to their partner in the social/family well-being subscale.

Table 15

Items with the Highest Scores Regardless the Subscales of the FACT-G and FACIT-Sp

Subscale	Item	Min - max	*M (SD)*	Skewness/SE	Kurtosis/SE
Spiritual	Containing the purpose and meaning of life	0 – 4	3.61 (0.92)	-2.514/.184	5.631/.366
	Having reasons to live	0 – 4	3.43 (0.67)	-1.330/.184	3.379/.366
Emotional	Having emotional support from family	0 – 4	3.45 (0.81)	-1.706/.241	3.324/.478
	Having hope to fight the illness	0 – 4	3.39 (1.03)	-1.926/.174	2.549/.346
Social	Feeling close to partner	0 – 4	3.31 (1.10)	-1.860/.241	2.896/.478

Note. 0 = not at all, 1 = a little, 2 = somewhat, 3 = quite a bit, 4 = very much.

Discussion

Subjects' Characteristics

The majority of the study subjects participating in this study were women. During the period of data collection there were more female patients who met the inclusion criteria being found in both the OPDs and IPDs. In addition, there were more wards available for females than for males. For instance, in the first target hospital there are females and males surgical wards with the bed capacity of 40 to 50 for each. In addition, there is a gynecology ward with the capacity of 60 beds. Therefore, this proportion might not be able to represent the actual statistics of cancer cases in Indonesia because the statistics in the last five years showed that there was only a slight difference in the proportion of male and female patients (136,172 and 156,457, respectively) (GLOBOCAN, 2008).

By having more female subjects in this study, unsurprisingly there were more numbers of subjects being diagnosed with cancers of the breast and the female reproductive system. To date, breast cancer has been ranked the first and has been a cause of female deaths globally (GLOBOCAN, 2008). The percentage of breast cancer cases accounted for 23% (1.38 million) of the total cancer cases and it shared 14% (458,400) of the total cause of cancer deaths (Jemal et al., 2011). It was then followed by the cervical cancer and ovarian cancer (Jemal et al., 2011). The finding of this study supported that cervical cancer accounted for 62 cases out of 88 female reproductive system cancer cases. Moreover, the mortality rate in the developing countries was higher than in the developed countries (GLOBOCAN, 2008). It is most likely because of the combination of a late stage diagnosis and limited access to timely and standard treatment (Jemal et al., 2011).

This study finding also showed that more than three-fourths of the subjects were newly diagnosed at the late or advanced stage of the cancer disease. There were some reasons that caused this situation. The Haririchi et al.'s study (2005) reported that poverty was one of the factors which made patients not immediately access medical treatment (Haririchi, Ghaemmaghamic, Karbakhshd, Moghimic, & Mazaheriec, 2005). This reason may be applied to the finding in this study that the majority of subjects (66.2%) were unemployed or had inconsistent work (labor workers). In fact, since their homes were far from the urban areas, many subjects said that they had to rent a car to reach the hospital which was considered very costly. Although healthcare costs had been covered by health insurance, other expenses such as accommodation and transportation were reported as being a very heavy burdensome for them. Three to four hours or even half day were the approximate times that most of them needed to access the hospitals. The subjects reported that they usually tried herbal or alternative medicine before coming to the hospitals. Then, when the herbal medicine did not work to relieve the symptoms or cure the cancer, they eventually came for medical services.

These conditions demonstrated that the socioeconomic level and the accessibility to healthcare services apparently influence the way people manage their health. As a matter of fact, there are only one or two tertiary hospitals in some provinces with cancer services in Indonesia. Dodd et al. (2001) depicted in the Symptom Management Model that the availability of medical services and medical equipments are also factors which contribute to how the patients treat and manage their symptoms. Wealthy people would have more financial support to help them access healthcare services compared to poor people. There was a finding in India which stated that the lack of adequate healthcare services and illiteracy caused the patients with advanced breast cancer from the rural areas to not immediately access healthcare services (Chintamani et al., 2011). Therefore, when healthcare services are easily accessible, including the total coverage from health insurance, people would not hesitate to make use of them.

Furthermore, the low education level is another factor that can confine people from modern healthcare services. Alhurisi et al. (2011) reviewed that the delay of breast cancer presentation was caused by low education levels as well as older age. It was shown in this study finding that more than half of the subjects (64.7%) had low education level and they were above 45 years old. Later studies conducted in Asian countries (India and Iran) supported the previous finding. They showed that illiterate or low educated women were at higher risk to be firstly diagnosed with late stages of breast cancer (Ali, Mathew, & Rajan, 2008; Chintamani et al., 2011; Sharma, Costas, Shulman, & Meara, 2012).

Despite the low education level, the lack of campaigning in the community about specific types of cancers may contribute to inadequacy of cancer knowledge and self-awareness towards cancer. As presented in the study among patients with breast cancer, the delays towards health assessment were because of inadequate knowledge regarding the necessity of such a visit, fear, negligence, lack of access to physician and poverty (Harirchi et al., 2005). In general, the information regarding cancer disease was given to the patients when they have been admitted at the study hospital. However, the health education related to the prevention as well as early detection and its screening are rarely given to the community. With this regard, people may possibly neglect their symptoms-related cancer. In Canada, one of developed countries with advanced healthcare system, this kind of negligence was found in patients with head and neck cancer. These patients delayed to perform the medical assessment and diagnosis, because they thought their symptoms were not serious (Tomlinson, Wong, Au, & Schiller, 2012). Furthermore, Alhurisi et al. (2011) reported that having no family cancer history had a moderate influence to the late breast care presentation. The subjects in this present study might not be aware of the disease because majority of them did not have any family member who had suffered from cancer. Therefore the low level of education, having no family history of cancer plus the limitation of health education made the people unknowledgeable and unaware of their health problem.

Nowadays, a fact of cancer incidence in relation with age in Asian countries is that breast cancer occurs at a relatively young age (G. Agarwal, Pradeep, Agarwal, Yip, & Cheung, 2007; Bhikoo, Sriniva, Yu, Moss, & Hill, 2011) and its incidence increased as age increased (Siegel, Ward, Brawley, & Jemal, 2011). In this study, nearly one-third of the subjects had breast cancer and an additional subgroup analysis (Appendix F) revealed that more than three-fourths of the breast cancer group (48 out of 63 subjects) were older than 45 years old. This picture is actually more congruent with the worldwide statistics which reported that the incidence of breast cancer increased with age (Siegel et al., 2011).

Symptoms Experience

The majority of the subjects were currently receiving or had just received chemotherapy, radiotherapy, or surgery. The subjects experienced symptoms over 24 hours which could be induced by these cancer treatments (Bottomley & Terrasae, 2002). In fact, cancer therapies had not only benefits to eradicate cancer but also had side-effects and negative consequence (So et al., 2009). These antitumor treatments induced both physical and psychological symptoms. Physical symptoms include pain (Viholm, Cold, Rasmussen, & Sindrup, 2008), lack of energy, coughing, lack of appetite, nausea (Akin et al., 2010), alopecia (Yeager & Olsen, 2011; Trueb, 2009) and mucositis (Kumar, Balan, Sankar, & Bose, 2009). These physical symptoms could appear as the acute side effects of the cancer treatments. Whereas psychological symptoms for example anxiety, depression (Chen et al., 2009; So et al., 2009), nervousness, sleeping problem, sadness and worrying (Akin et al., 2010) could be associated as the acute and late psychological disturbances caused by the cancer treatments.

Regarding the prevalence of symptoms, patients with advanced cancer often experienced multiple symptoms throughout their cancer trajectory. On average five symptoms were reported to be experienced concurrently by the subjects over the past one month. This happened because the majority of them had a history of receiving more than one type of cancer treatment over the past one month or more. The progression of the cancer disease, early and late side effects of cancer treatments, and long term consequences of the disease could be the reasons for their symptoms occurrence over the past one month (Husain, Myers, Shelby, Thomson, & Chow, 2011; Karabulu et al., 2009; Spichiger et al., 2011b).

Patients with advanced cancer received more drugs and their symptoms were more prevalent compared to patients in the early stage of cancer disease (Akin et al., 2010) which is the same as the subjects in this study who received more than one type of chemotherapy drug. The type of chemotherapy drugs also may contribute to the occurrence and the severity of cancer symptoms. Giving an example from the study by Wu, Dodd, and Cho (2008) which reported that during the first three days after chemotherapy, particularly for those who received Doxorubicin and Cyclophosphamide (AC), fatigue was detected more severe than those who received non-AC as their regimen. However, because of the limitation of the documentation in the hospitals, for example breaking paper binding, misplacing paper documentation and transferring of paper documentation from one health professional to another, the data about chemo drugs could not be completely retrieved.

Actually the previous studies reported that there were more numbers of symptoms experienced by patients with advanced cancer compared to the finding of this present study. In a systematic review study about the prevalence of symptom in patients with advanced cancer, including 44 studies, 37 cancer-related symptoms were reported in at least 5 studies. Fatigue, pain, lack of energy, weakness and loss of appetite occurred in more than 50% of these patients (Teunissen et al., 2007). While more recent studies indicated that patients with advanced cancer experienced 10 symptoms (Liu et al., 2011), 10 to 13 symptoms in the first admission and 10 days of hospitalization (Spichiger et al., 2011a) and 10 to 14 symptoms during 3 cycles of chemotherapy (Spichiger et al., 2011b).

Some reasons may contribute to the difference in the number of symptoms between the finding of this study and other studies. Firstly, the use of the Memorial Symptom Assessment Scale (MSAS) and M. D Anderson Symptom Inventory (MDASI) in other studies which list more than 20 cancer-related symptoms may help the patients to easily explore their symptoms. This study used the Edmonton Symptom Assessment Scale-revised (ESAS-r) which listed eight common symptoms of cancer. Having an open-ended question aimed at allowing the subjects to indicate other symptoms, but in reality because of its practicability, the majority of the subjects added a maximum of one symptom. Secondly, having enough time to fill in the questionnaire allowed the patients to feel free to report the presence of their symptoms rather than being interviewed by the doctors or nurses about only some common symptoms (Teunissen et al., 2007). In the studies reviewed by Teunissen et al. (2007), doctors or nurses who did a standardized interview only asked about some particular or common symptoms and might not be aware of other symptoms that the patients experienced. They could refer only to some symptoms such as pain, fatigue, nausea and anxiety.

Pain in this study, was continuously the number one symptom on the list of symptoms experienced by the subjects. When the cancer is growing, it begins to push the nearby organs, blood vessels and nerves which later on make the patients experience pain (American Cancer Society, 2012). It is very possible that the size of a tumor in the advanced stage of cancer is big, or in many cases, the tumor has invaded and metastasized to other organs. Because of the cancer development, both types of cancer pain (nociceptive and chronic pain) could be experienced by these subjects (Carrieri-Kohlman et al., 1993). Furthermore, the type of cancer also influences the location of the pain, for instance many patients with breast cancer reported to have pain in their breast wounds while patients with gynecological cancers usually said that their pain was located around their hips or their genital areas.

Over 24 hours and over the past one month pain was experienced by more than half and nearly two-thirds of the subjects, respectively. Many literatures have reported that pain was commonly experienced by patients with advanced stage of cancer (Weingart et al., 2012). A systematic review study on the pain prevalence over 40 years reported that pain occurred in patients with cancer during treatments and in all stages of cancer disease (Chang et al., 2007; van den Beuken-van Everdingen et al., 2007). These previous studies’ findings help to support the reason why pain was ranked first on the list of the symptoms experienced in this present study.

Fatigue on the other hand was identified to be the second symptom most experienced by the subjects. Cancer related fatigue (CRF) could be induced by chemotherapy, and radiotherapy and anemia and also other factors such as untreated pain, emotional distress, sleeping disturbance, and nutritional deficiency (Wang, 2008). Among patients with breast cancer, the worst level of fatigue occurred immediately after receiving chemotherapy regimen but in nature it decreased gradually over time (Wu et al., 2008). The study by Spichiger at al. (2011a),which found that during the ten days of hospitalization, fatigue was found to be the most prevalent symptom (82%, $N = 103$), followed by pain (72%) (Spichiger et al., 2011a). Still according to Spichiger et al. (2011b) fatigue occurred among patients with cancer before and after three cycles of their chemotherapy (Spichiger et al., 2011b). In a study in China among hospitalized patients with far advanced cancer, fatigue was also ranked first on the list, while pain was listed as the common symptom only after lack of appetite and sleep disturbance (Liu et al., 2011).

Meanwhile, depression or feeling sad was reported by approximately half of the subjects in both periods of time. This psychological disturbance could be related with other symptoms for example anxiety, pain or fatigue (Massie, 2004). Long term treatment of cancer could make the subjects feel sad and anxious about their condition. Pain, which is not appropriately managed, for instance could induce the subjects to be sad or depressed (Carrieri-Kohlman et al., 1993).

These three symptoms (pain, fatigue, and depression) are commonly found in the patients with advanced cancer. An additional subgroup analysis (Appendix F) revealed that pain in the periods of time was continuously becoming the first on the list experienced by patients with advanced breast cancer. The difference in terms of these symptoms occurrence was detected among male and female patients. There were more females patients experience these three symptoms compared to male patients. However, the un-equivalent numbers in these groups of patients was very wide. Therefore, we might not be able to decide whether this occurrence happened is because of the gender characteristic.

However, the limitation over the recall bias in the symptom experience should be considered. Subjects might miss their symptom experience over the past one month. It was also possible that the subjects failed to recall how they managed their symptoms over that period. Therefore, having the patient caregivers to confirm the information was very helpful.

There was an interesting finding in this study which informed us that the rating of the severity of cancer symptoms, in the majority, which was at a moderate level. There could be some causes behind this phenomenon. The majority of this study’s subjects were females above 45 years old. These personal characteristics may contribute to the perception of symptoms. It was indicated in the study by Bacon, Hughes, and Mark (2009) that the older the patients, the better they were in managing the symptom than of younger patients with advanced cancer. A study among patients with breast cancer undergoing surgery, reported that the younger, more educated and married women experienced more distress of fatigue, pain, outlook and insomnia after their surgery (Kenefick, 2006). The findings of the previous studies and this present study correlated with Dodd et al.’s model which explained that personal characteristics would influence the experience of symptoms.

In addition, culture in this regards might also influence towards the symptom experience and perception. This could be that the teaching, philosophy and the gender nature in a culture were the influencing factors toward symptom experience particularly in this present study. Women in the Javanese culture tend to accept whatever it is (*nrimo ing pandum*: Javanese term). People who live in the Javanese society do not easily complain about physical and psychological matters. Pain or other symptoms might be kept inside and rated moderately. In the study among Javanese and Batak patients about pain experience 24 – 48 hours after major surgery, the Javanese patients rated their pain as moderate while Batak patients rated their pain at a severe level. Javanese patients tended to demonstrate stoic responses in contrast to Batak patients who were more expressive (Dewi, Petpichetchian, & Songwathana, 2007). In this present study, there were some subjects who were observed feeling so much painful but pretending not to in front of other people. They reported to the researcher that they found it very difficult to let anyone else know exactly what they were feeling. However, this attitude had a negative effect that could cause them to be in their own depression or sadness for feeling the cancer symptoms alone.

Furthermore, other factors which might be related with the moderate rated level of symptoms in this study are the activity engagement and the willingness to accept pain. These two factors had a negative relationship with pain suffering (Gauthier et al., 2009). Patients who had many physical activities might be focusing less on their pain severity. Deep acceptance also helps them to adapt and accept pain as a part of their lives. The acceptance of pain was studied by Gautier et al. (2009). They reported that among patients with cancer, chronic pain was accepted as a part of their lives. In addition, parents who lived with their children tend to have lower pain than those who lived alone (Gauthier et al., 2009). Those characteristics were all found in the majority of the subjects who were mostly involved in farming work, lived in the extended family and had acceptance as part of their culture.

Symptoms Management

Unsurprisingly herbal medicine and praying were found to be the most commonly used strategies by the subjects besides modern medicine. People tend to turn to the most available sources to alleviate their symptoms. The extract of sour-sop leaves, sour-sop fruits, warm water and tea were the examples of ingredients easily found near the house. Some of the subjects believed that consuming herbs could help them to reduce the symptoms as well as curing the cancer cell itself. This strategy in fact was reported to have little effectiveness.

Praying and bekam (traditional healing modalities) were conducted based on the Islamic teaching. The prophet Muhammad PBUH had given example of doing bekam to help cure some diseases and release some symptoms. Although this method is still under investigation or research, many people in some parts of Indonesia still keep performing it. In Islamic teaching, God has instructed Muslim people to pray and ask anything from God, their prayers have been promised to be granted (Al Qur’an, Al Mu’min: 60). With this belief, Muslim people like to do this strategy when they are feeling physically and/or mentally suffered. Praying and reciting Al-Quran have been used to seek the soul comfort, forgiveness from God and the cure from God. In this regards, these spirituality practices based on religious teachings have been used as a symptom management strategy and therefore, would give positive influence to physical and emotional conditions (Brady, Peterman, Fitchet, Mo, & Cella, 1999). On the other hand, some subjects from rural area said that they went to the people with supernatural power. They believed that the spiritual power could help them to heal the cancer. However, according to the subjects who have tried this strategy, they did not find this effective to relieve their symptoms or cure the disease. Eventually they tried to access the medical services.

Modern medicine such as mefenamic acid and Paracetamol prevailed to be general medicine prescribed for pain symptom. Paracetamol, Non-Steroidal Anti Inflammatory Drug (NSAID) or a combination of these were used to treat acute pain in some studies (Hyllested, Jones, Pedersen, & Kehlet, 2002; Moll, Derry, Moore, & McQuay, 2011). In Moll et al.'s study (2011), with limited data, oral mefenamic acid was effective to treat moderate to severe acute pain. The opioid medicine such as ketorolac was commonly prescribed to treat chronic cancer pain in the study hospitals. However, there were some limitations over this treatment regarding the availability of the medicine and the lack of regular pain assessment by the nurses. It was sometimes found by the researcher that the medications were prescribed but were not available. Although there were some subjects who experienced severe pain, the availability of other kinds of opioids such as morphine in the wards was not available.

A study in India revealed that some the major barriers to access opioids were mainly from complicated policies and problems related to attitude and knowledge regarding pain relief and opioids among health professionals and the society (Rajagopal & Joranson, 2007). These situations are also happening in Indonesia. The regulations, the attitude and knowledge of health care providers towards opioids still not supportive. According to the WHO ladder guidelines, NSAID and Paracetamol must be liable and accompanied with opioid analgesia (weak or strong) for patients with moderate to severe chronic pain (WHO, 2009). But the liabilities of these medications were scarce for the patients in the wards. Strong opioids were only prescribed for patients after surgery. Therefore, learning from other countries such as India, Romania and Italy, the government regulations, knowledge and attitude toward pain management have to be enhanced for a better intervention outcome (Joranson & Ryan, 2007).

Moreover, the over load responsibility (one nurse had to take care of eight to twelve patients) in the ward made the nurses not give adequate priority to the pain matter. This is also one of the causes that made the involvement of healthcare providers in symptom management very low. There were only 31 subjects who reported getting adequate help from the healthcare providers in managing their symptoms such as preparing the medicine, being educated about the possible symptoms which the patients might get and how to manage them. It needs to be conveyed again that the healthcare system and healthcare professionals, influence the healthcare management (Dodd et al., 2001).

Beside modern medicine and herbs, other strategies such as touching, massaging and praying were used by the subjects for their pain. An RCT study to compare the effect of massage and simple touch found that both strategies gave positive effects in alleviating pain and performing a massage had an immediate influence on pain and mood in patients with advanced cancer (Kuestner et al., 2008). This study advised to not over estimate these complementary therapies and based on the finding of this present study, these strategies are only slightly effective. However, nowadays many people were still performing these strategies. The reasons could be because these strategies were less costly and also easy to be administered.

Quality of Life of Patients with Advanced Cancer

The QoL level of Indonesian patients with advanced cancer in this study was at the moderate to high level. The items of social support from family and feeling close to their partners or significant others were the items with the highest scores. For social well-being, it was rated high may be because of the subjects social relationship with their family members and friends that may play a significant role in Indonesian people. The family is regarded as a very essential aspect of patients' lives. The support from the family members in particular gave them strength to cope and endure the illness. Even the family is mostly reported as the significant reason to live longer. Members of the family usually stay in the hospital to accompany the patient and it was proven that the majority of the subjects in this study had their spouse, their family members or both accompanied them during their hospitalization. For those who had to attend the OPD, they had also had their family members who took them to the hospitals every day. Majority of the subjects have either spouse, their family or both of them who were at the hospitals to accompany and support them. This could be one of the reasons which makes the overall QoL level of the subjects in this present study was high.

The friendship and neighborhood culture in Indonesia are obviously seen when someone is hospitalized. The neighbors or friends would visit the patient together or in a group and give him/her support physically and emotionally. In fact this kind of support is very important for the patients with advanced cancer, and social support was found to significantly affect the mood status (Shell, Carolan, Zhang, & Meneses, 2008).

Furthermore, the emotional and spiritual well-being was also at a high level. This could be because meaning and faith in the spiritual well-being scale have a unique influence on emotional well-being (Canada et al., 2008). The patients' faith and meaning in life which possibly are supported by the Islamic teaching could make them emotionally settle when they are facing a bad condition such as cancer. It has been stated in the holy Quran that Muslim people have to be patient in either good or bad condition. It is mentioned "And why should we not rely upon Allah while He has guided us to our [good] ways. And we will surely be patient against whatever harm you should cause us. And upon Allah let those who would rely [indeed] rely." (Al-Quran, Ibrahim: 12). These conditions are given by Allah as the test for Muslim people and the practice to be always thankful to Allah as stated that "And those who are patient, seeking the countenance of their Lord, and establish prayer and spend from what We have provided for them secretly and publicly and prevent evil with good - those will have the good consequence of [this] home" (Al-Quran, Ar-Ra'd:22). These beliefs, particularly for the strong believers of Islam, gave a huge strength for their emotion and spirituality.

As the patients with advanced cancer experienced many symptoms (Mcmillan, Tofthagen, & Morgan, 2008), it is no wonder that the physical condition or well-being among Indonesian patients in this study was lower than emotional and social well-beings. Even though, in the Gauthier et al.'s study (2009), pain severity had independent relation with physical functioning, the limitation over the physical condition may reduce their physical functioning. In addition, the result from a study conducted among patients receiving palliative care showed that there was only a weak positive relation between physical functioning and QoL scores (Chui et al., 2009).

They further reported that patients who were older, female, or had been married tended to have better QoL. These subjects' characteristics as founded in the Chui et al.'s study (2009) were likely the same with this present study. However according to these age group analysis, there was no significant difference of QoL (*F* = 1.997, *p* = .138).

The occurrence of the physical symptoms particularly prevented the patients' ability to fulfill their family needs. About two-fifths of the subjects were not able to fulfill their family needs at all, and in some case could only on a small level. Specifically, on the items which asked about the functional condition/well-being, 52.7% of the subjects reported that they were unable to do their work including household chores. They also did not feel satisfied because the quantity and quality of their works had decreased since they had suffered from cancer. For example, their roles in the family as a wife and mother cannot be performed fully after they got cancer.

Other subgroups analysis showed more detailed information regarding the QoL level. There were again no significant differences of QoL among cancer type groups (*F* = 0.575, *p* = .790) and among the groups of cancer treatments (*F* = 0.718, *p* = .490). There was only a significant different in the groups of IPD and OPD patients. Those who attended OPD had higher QoL level than those who were admitted at the IPD (*p* = .039). Unlike a study by Pearman (2003) which revealed that while completing cancer treatments, patients with gynecological cancer had poorer QoL levels in several QoL domains compared to breast cancer patients. However after completion of treatment, overall QOL is similar between groups (Pearman, 2003). Pearman's review (2003) also showed that those with low religious belief, those who had received surgical treatment, and those with low educational level had high risk to be maladjustment which later on would influence their QoL.

There were 18.4% patients who were recruited from the OPD (radiotherapy and chemotherapy units). There were many patients who were undergoing radiotherapy and only some who had chemotherapy in the OPD. They had a better QoL level ($p = .039$) than those from the IPD. A study by Awadalla et al. (2007) reported that patients on radiotherapy had better QoL. This also supported this study finding on the subgroup analysis on patients with radiotherapy who had on average the highest QoL among other subgroups of patients with surgery and chemotherapy.

Furthermore, the item with the lowest score among all was the satisfaction towards their married sex life. This item in the social/family well-being subscale was the item which many subjects left blank, they refused to answer or felt reluctant to answer. Many of the subjects also reported feeling unsatisfied or had not thought about sexual matters recently. In the study among patients with lung cancer, sexual function was reported to be worse over time as patients undergo cancer treatment (radiotherapy and chemotherapy) (Shell et al., 2008). Age was included as a factor affecting sexual function (Shell et al., 2008) and in fact the majority of subjects in this present study were in the late adult age group.

The spiritual well-being subscale was rated high by the subjects. Spirituality was delineated in the study by Ferrell et al. (2003) as “a method of deriving meaning from the ovarian cancer experience” (p.1061). The subjects tend to turn to their spiritual beliefs and practices to help them cope with the illness. The patients’ faith and meaning in life which possibly are supported by the Islamic teaching could make them emotionally settled when they are facing a bad condition such as cancer. The patients who have a higher level of spiritual well-being might be able to tolerate severe symptoms (for example, pain or fatigue) (Brady et al., 1999).

The acceptance towards life is close to the teaching of the Islamic religion. The sickness is regarded as the test from God which needs to be accepted. Acceptance, having positive thinking and leaving everything to God are also the philosophy of Muslim (Al-Quran Al-Baqarah: 216; Asy-Syarh: 5-6). It was also shown in Dewi et al.'s study (2007) in that Javanese patients described the pain experience as a spiritual test. One of the teachings in Islam for its people is to be sabr or patient. Sabr literally means enduring, bearing, and resisting pain; suffering and difficulty; and dealing calmly with problems. In more general terms it means patience, which is one of the most important actions of the heart mentioned in the Qur'an. Because of its importance, patience is regarded as half of one's religious life (the other half is thankfulness). Having and living with this belief could make them tolerate the disease that they experienced.

Symptom experience, symptom management and QoL are the variables which are dynamic over the time (Dodd et al, 2001). The occurrence and the severity of symptoms might change in a short period of time, depending on the effectiveness of the strategies used to manage the symptoms. Being able to control their symptom experience and performing an effective symptom management strategy make the patients feel confident and had the sense of feeling of controlling their health problem. This situation would eventually increase the patients' QoL level. In other words, all three domains are interrelated. This situation does not only require the patients’ willingness and ability but the support from their environment such the help from health professionals and the patients’ family and social support.

CHAPTER 5

CONCLUSION AND RECOMMENDATION

Conclusion

A descriptive survey study was designed to identify the symptom experience, symptom management and the level of quality of life of patients with advanced cancer. This study was conducted at two tertiary hospitals in Central Java Province, Indonesia. The subjects were purposely recruited from IPD and OPD of Dr. Moewardi Hospital, Solo and Dr. Kariadi Hospital, Semarang. Two hundred and one patients with advanced cancer consented and completed this study. Data were collected from November 2012 to February 2013. Subjects were asked to respond to the questionnaires which included the Demographic And Health-related Data Form, the Edmonton Symptom Assessment Scale-revised (ESAS-r), the Symptom Management Strategy Questionnaire, the Functional Assessment for Cancer Therapy-General (FACT-G) version 4 Questionnaire and the Functional Assessment for Chronic Illness Therapy-Spiritual (FACIT-Sp) well-being subscale. The FACT-G version 4 has been translated into Indonesian language, the other questionnaires were back translated and an expert of cancer in Indonesia examined the questionnaires for their cultural relevance to the Indonesian context. The FACT-G version 4 and FACIT-Sp were tested with 20 subjects for its reliability and yielded Cronbach’s alpha coefficients of .84 and .92, respectively.

Summary of the Study Findings

The age of the subjects ranged from 19 to 60 years old (*Med* = 49 years). The majority of them were women and married. More than a half of the subjects had low education levels. Approximately two-thirds of the subjects were unemployed and labor workers. Three-fourths of the subjects were diagnosed with the female-specific-type of cancers. The majority reported having no family history of cancer. More than three-fourths of the subjects were newly diagnosed with advanced stage cancer. More than half of them were receiving one cancer treatment or had recently received one cancer treatment.

Pain was first on the list of the most commonly experienced symptom over the past 24 hours and over the past one month. It was followed by fatigue, depression, lack of appetite and anxiety. Over the past 24 hours the subjects experienced on average 4 symptoms and over the past one month the subjects experienced on average 5 symptoms. Pain was the most severe symptom which was experienced by the subjects, they reported moderate to severe pain over 24 hours and over the past one month. Fatigue ranked in the second most severe experienced by the subjects, nearly half of the subjects who had fatigue rated it from moderate to severe level over 24 hours and over the past one month.

There were 20 subjects who did not perform any management strategies to alleviate their symptoms. Modern medicine, such as Paracetamol and antiemetic, was first on the list of commonly used symptom management strategies. It was followed by herbal medicine, for instance the extract of sour-sop leaves (Graviola tree leaves) and sour-sop fruit (Graviola tree fruit), tea and warm water. The third in the sequence was traditional healing modalities and then a praying strategy.

The QoL level of Indonesian patients with advanced cancer in this study was at the moderate to high level. The mean score of the total FACIT was 2.71 (*SD* = 0.59). The results showed that the mean scores of physical well-being and functional well-being were at a moderate level, while other subscales were at high levels. An additional analysis showed that there was a significant different of QoL among patients at the OPD and IPD (*p* = .039).

Strengths and Limitations

The strengths of this study include:

1. This study was the first survey study in Indonesia which included three variables: symptom experience, symptom management and quality of life of Indonesian patients with advanced cancer.
2. This study was conducted at the tertiary hospitals (the level A hospitals), therefore the subjects of this study were representative from many areas.

The limitations of this study include:

1. The self-report particularly in the symptom experience questionnaire over the past one month might present a recall bias. Therefore, the researcher should be aware of this. The information could be cross checked with the patients' caregivers
2. The proportion of the male and female subjects in this study was not equal and this study only had Javanese patients. Therefore, the finding might not be able to be generalized for the Indonesian patients in general or for the other ethnic groups of Indonesian patients.

3. The majority of the subjects of this study had a low education level and needed more time to understand some items of the questionnaires. To solve this situation the researcher helped the subjects by giving some examples. This situation might have an effect on the subjects' responses to the questionnaires.
4. The data of symptom management strategies were not limited to only over the past one month as many subjects also added all the strategies they had performed since they had suffered from the cancer disease.

Implications and Recommendations

The findings of this study provide supporting evidence on the symptom occurrence and symptom severity of patients with advanced cancer in Indonesia. This study also provided the information about the symptom management strategies which had been conducted. The recommendations are as follows:

Clinical Practice

1. Nurses and other health professionals should be aware of the common symptoms such as pain, fatigue and depression which mostly occurred in the patients with advanced cancer. The assessment on these particular symptoms should be conducted on a regular basis and be given a high level of concern towards its management.
2. Nurses should be more proactive in giving education to the patients related to the common symptoms that the patients may get and how to manage them.

3. Nurses should enhance their role as the advocator for patients with advanced cancer particularly when the modern medicine strategy does not give adequate efficacy to relieve cancer symptoms.
4. The documentation system and the completion and nursing and other health professionals' documentation need to be strongly enhanced for better intervention outcomes particularly in the symptom management and quality of life of patients with advanced cancer.
5. The access and availability of modern medicine related to cancer symptoms should be enhanced.
6. Concerning the QoL of patients with advanced cancer, health professionals need to target groups of patients who are admitted at the IPD to get the cancer treatments. In addition, health professionals need to consider more the female patients with advanced breast cancer and general population with gastro-intestine. This group is considered to have lower level of QoL in this study.
7. Nurses and other health professionals can help lessen the patients' sadness toward their cancer diagnosis or cancer disease by providing adequate consultation and being with the patient. Health professionals also should facilitate effective communication between the patients with advanced cancer and their family members particularly on the symptom experience, symptom management and the patients' QoL issues.
8. The items of QoL with high scores should be enhanced and empowered. The nurses should provide spiritual activities among patients, such as reciting the Quran, listening to preaching from an imam and/or inviting an imam to the ward if

needed. Nurses can also help the patients to perform spiritual practices according to their spiritual beliefs.

9. Health education especially for some common cancer types, breast cancer and female reproductive system cancer should be promoted in the community. Health education will enhance peoples' awareness towards this suffering disease. Healthy life style, early detection and screening should be promoted so that the number of, thus newly diagnosed advanced cancer cases for women could be reduced.

Nursing Education

Nursing education is able to benefits from this study finding. The implications of this study are as follows:

1. The finding can support better understanding about symptom experience, symptom management and quality of life of patients with advanced cancer.
2. This study also provided some factors (person, environment and health-related status) which might contribute to these three variables.

Nursing Research

The recommendations related to nursing research were focused more on the instruments of the QoL.

1. For the application in Muslim countries, the majority of items in the FACT-G version 4 are appropriate. Only one item in the social well-being scale about the sexual life needs to be revised to be more appropriate and applicable for the patients with cancer in Muslim countries.
2. During the data collection, the researcher found that there were many subjects who needed more explanations and some examples to help them understand the

items in the FACIT-Sp well-being subscale. Therefore, the adjustment regarding the word choice to be more understandable for lay people is needed.

3. Since there were more female patients available as the subjects in this study, further research needs to adjust the time of data collection in order to get the same number of female and male patients or to stratify the gender groups if needed.

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APPENDIX A

INFORMED CONSENT FORM

Dear Participant,

My name is Susana Widyaningsih. I am a master student in Nursing faculty, Prince of Songkla University, Thailand. I am also a lecturer in Nursing program, Faculty of Medicine, Diponegoro University, Semarang. I am conducting research entitled “A Survey of Symptom, Symptom Management and QoL of Indonesian Patients with Advanced Cancer”. This study has been approved by the Institution Nursing Board of Faculty of Nursing, Prince of Songkla University, Thailand and it is also granted permission by the Ethical Committee of Kariadi Hospital.

You are asked to participate in this research project. However, you have full rights to withdraw at anytime without any penalty or consequence. If you have decided to participate in this study voluntary, I will request you to fill in these four questionnaires:

1. You will be first asked about personal information related to your demographic and health and illness status.
2. You will be asked about the symptoms that you experienced.
3. You will be asked about the symptom management that you have done.
4. And lastly, you will be asked about your QoL as long as you are experiencing the cancer disease. The whole process may take you about 15 minute to 20 minute.

Risks and discomforts:

There is no evidence shown of risk related to finish the. However, there is a possibility that some questions will make you feel physical or psychological uncomfortable, tired or the questionnaires in this study will be a burden to you, during your rest time. When the above situations happened to you, please let me know. I will let you stop answering the questionnaires and let you rest and help you solving the discomfort if you want, or ask the nurses in the ward to help you. Then I will let you continue again answering the questionnaires when you feel better and are willing to continue. There is no compensation to you for your participation in this study.

Benefits:

The findings of this study hopefully will contribute in the education, nursing practice and the future research related to symptoms of cancer patient and the QoL of advanced cancer patients.

Confidentiality:

All information and your responses in this study will remain confidential, only researcher, the advisor and the research committee of this study are eligible to access the data. Neither your name nor any identifying information will be used in the report.

Participation and withdrawal:

Your participation in this study is voluntary. Returning the forms given indicates that you understand what is involved and you agree to participate in this study. You have the full rights to withdraw from the participation at any time without giving any reason.

Lastly, you can contact me by phone +6285225211411 or by email at suzan_que@yahoo.com if you have questions or suggestions or cannot participate. If you agree to participate in this study, please sign your name. If you feel uncomfortable to sign in but you are willing to participate, please let me know. Thank you for your cooperation!

…………………..	…………………	……………….
Name of participant	Signature of participant	Date
Susana Widyaningsih	…………………	……………….
Name of researcher	Signature of researcher	Date

APENDIX B

Please fill in the blank space or give check mark (√)

Part A Demographics and Health-related Data Form **Date:**

No	Code	:
Part 1		**Person Domain**
	Gender	: ☐ Male ☐ Female
	Age	Years
	Marital status	: ☐ Married ☐ Single ☐ Widower ☐ Divorced
	Ethnicity	
	Religion	
	Education	☐ No schooling ☐ Senior high school ☐ Elementary school ☐ University ☐ Junior high school ☐ University/Graduate
	Occupation	☐ Government employee ☐ Private employee ☐ Business ☐ Farmer ☐ Unemployed Other (mention): ………………
	Family Income (per month in Rupiah)	Rp.
	Functional status/ability to perform daily activity	Independent/partial/fully dependent
Part 2		**Environmental domain**
	Environment that initiate symptoms	☐ Hospital (ward) ☐ Work place ☐ Home Others (mention):
	Family caregivers	At hospital: Yes/No if yes, mention: ………………. At home : Yes/No if yes, mention: ………………
	Health insurance	Yes/No if Yes, mention from: National/Local/Workplace

Part 3		**Health and Illness domain**
	Functional status/ability to perform daily activity	Independent/partial/fully dependent
	Type of Cancer	
	Diagnosis	Stage: Newly/recurrence Time since being diagnosed:
	Family cancer history	Yes/No
	Treatments	Surgery Date: Radiation Position/date : / Type of radiation: Chemotherapy Cycle/date : / Type of drug:
	Comorbid disease	

APENDIX C

Part B The Edmonton System Assessment Scale-revised (B1)

Please circle the number that best describes symptoms you have experienced over 24 hours (Adapted from Edmonton System Assessment System-revised/ESAS-r (Watanabe, et al., 2011))

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
No tiredness (Tiredness=lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
………………....												
No nausea	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
…………………………..												
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
No depression (Depression=feeling sad)	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
……………………..												
No __________	0	1	2	3	4	5	6	7	8	9	10	

Other problem (for example, constipation)

___________	0	1	2	3	4	5	6	7	8	9	10

Part B The Edmonton System Assessment Scale-revised (B2)

Please circle the number that best describes symptoms you have experienced over the past one month
(Adapted from Edmonton System Assessment System-revised/ESASr (Watanabe, et al., 2011)

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
No tiredness (Tiredness=lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
No anxiety (Anxiety=feeling nervous)	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety

………………………...

APENDIX D

Part C The Symptom Management Questionnaire

Please answer the symptom management strategies that used/performed over the past one month, including the ones with help from others.

No	Symptom	Symptom Management					
		What	When	Duration/frequency	Who (performers)	Where	Effect
1	Pain (example)	( )Taking medicine Type: ( ) Sleep/rest ( )Sharing to others ( ) Praying Others (mention)					

APENDIX E

Part D The Quality of Life Questionnaire

Adapted from the Functional Assessment for Cancer Therapy – General version 4 (Cella et al., 1993) and the Functional Assessment of Chronic Illness Therapy – Spiritual (FACIT-Sp) (Webster, Cella & Yost, 2003)

FACT-G (Version 4) and FACIT-Sp

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>**

	<u>PHYSICAL WELL-BEING</u>	**Not At all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack energy …………………………………………	0	1	2	3	4
GP2	I have nausea ……………………………………………...	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family …………………………………………..	0	1	2	3	4
GP4	I have pain ………………………………………………...	0	1	2	3	4
	……………..					
	…………….					
	……………					

	<u>SOCIAL/FAMILY WELL-BEING</u>	**Not At all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends …………………………………..	0	1	2	3	4
GS2	I get emotional support from my family …………………...	0	1	2	3	4
GS3	I get support from my friends ……………………………..	0	1	2	3	4
GS4	My family has accepted my illness ………………………..	0	1	2	3	4
	………………					
	………………					
	……………..					
	……………..					

	EMOTIONAL WELL-BEING	**Not At all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad …………………………………………………..	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness ……..	0	1	2	3	4
GE3	I am losing hope in the fight against my illness …………..	0	1	2	3	4
GE4	I feel nervous ……………………………………………	0	1	2	3	4
	…………..					
	…………					

	FUNCTIONAL WELL-BEING	**Not At all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home) ………………...	0	1	2	3	4
GF2	My work (include work at home) is fulfilling ……………..	0	1	2	3	4
GF3	I am able to enjoy life ……………………………………..	0	1	2	3	4
GF4	I have accepted my illness …………………………………	0	1	2	3	4
GF5	I am sleeping well ………………………………………..	0	1	2	3	4
	…………..					
	…………					

	SPIRITUAL WELL-BEING	Not At all	A little bit	Some-what	Quite a bit	Very much
Sp1	I feel peaceful ……………………………………………	0	1	2	3	4
Sp2	I have a reason for living …………………………………..	0	1	2	3	4
Sp3	My life has been productive …………………….………	0	1	2	3	4
Sp4	I have trouble feeling peace of mind ……………..……….	0	1	2	3	4
Sp5	I feel a sense of purpose in my life ……………………….	0	1	2	3	4
	…………….					
	……………					
	……………					
	…………..					

APENDIX F

Additional Analysis

Table 16

Number and Percentage of Patients with Breast Cancer Classified by Age Group (n=63)

Age	*N*	(%)
18 – 30	2	3.2
31 – 45	13	21.0
46 – 60	48	75.8

Table 17

Item Analysis of the FACT-G and FACIT-Sp (N=201)

Subscale	Item	*M(SD)*
Physical	I have a lack energy	2.45 (1.42)
	I have nausea	3.08 (1.28)
	Because of my physical condition, I have trouble meeting the needs of my family	2.24 (1.61)
	I have pain	2.14 (1.45)
	………	
	………	
	……..	
	……….	
Social/Family	I feel close to my friends	2.84 (1.07)
	I get emotional support from my family	3.45 (0.81)
	I get support from my friends	3.19 (0.99)
	My family has accepted my illness	3.21 (0.96)
	……..	
	……..	
	…….	
Emotional	I feel sad	2.40 (1.39)
	I am satisfied with how I am coping with my illness	2.56 (1.03)
	I am losing hope in the fight against my illness	3.39 (1.17)
	……..	
	……..	
	…….	

Table 17 (continued)

Subscale	Item	*M (SD)*
Emotional	I am able to work (include work at home)	1.74 (1.44)
	My work (include work at home) is fulfilling	1.74 (1.42)
	I am able to enjoy life	2.55 (1.14)
	……..	
	……..	
	……..	
Spiritual	I have a reason for living	3.43 (0.67)
	My life has been productive	2.57 (1.22)
	I have trouble feeling peace of mind	2.96 (1.21)
	I know that whatever happens with my illness, things will be okay	3.26 (0.79)
	……..	
	……..	

Table 18

Subgroup Analysis of the QoL Based on the Age, Type of Cancer and the Type of Treatment

Subgroup	*M (SD)*	*F*	*p*
Age (years)		1.997	.138
18 - 30	2.53 (0.56)		
31 - 45	2.63 (0.55)		
46 - 60	2.78 (0.61)		
Type of cancer		0.575	.798
Female reproductive system	2.74 (0.59)		
Breast	2.68 (0.63)		
Head and Neck	2.83 (0.53)		
Gastro-intestine	2.43 (0.68)		
Type of treatment		0.718	.490
Chemotherapy	2.77 (2.56)		
Radiotherapy	2.87 (0.51)		
Surgery	2.53 (0.38)		

Table 19

Subgroup Analysis of the QoL Based on the Type of Ward

Subgroup	*N*	*M (SD)*	*df*	*t*	*p*
Type of ward			197	-2.08	.039
IPD	162	2.67 (0.60)			
OPD	37	2.90 (0.51)			

Table 20

Subgroup Analysis of the Symptom Occurrence in Gender Group

Symptom	Group	
	Male *n* = 27 *n* (%)	Female *n* = 174 *n* (%)
During 24 hours		
Pain	20 (74.1)	113 (64.9)
Fatigue	14 (51.9)	95 (54.6)
Depression	14 (51.9)	78 (44.8)
Over the past one month		
Pain	20 (74.1)	128 (73.6)
Fatigue	15 (55.6)	121 (69.5)
Depression	16 (59.3)	88 (50.6)

VITAE

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