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The Experience of Symptom Cluster and Symptom Alleviation Self-Care in Patients with Head and Neck Cancer: A Qualitative Study

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Abstract

Patients with head and neck cancer usually experience physical and psychological changes and adjustments related to the disease and management of therapy. The patients will experience symptom cluster and will use effective symptom alleviation self-care to relieve the symptoms. The proper identification of symptom cluster and the effectiveness of using symptom alleviation self-care will be the basis for the success of disease management. This study aimed to investigate the symptom cluster and symptom alleviation self-care in patients with head and neck cancer, and which has an impact on the quality of life. This research was a pilot study using a qualitative design and involved five patients at the public hospital in Semarang, Indonesia. The qualitative design has been chosen to explore the varied of symptom experienced by the patients about the nature, number, location, duration and intensity of experiences, which may different experiences of symptom cluster and symptom alleviation self-care for each patient with Head and Neck Cancer. Data were collected through semi-structured interviews and analyzed used the qualitative content analysis process. Three themes were identified in this study, including: the patients' experience of symptom cluster, the patients' experience of symptom alleviation self-care, and the impaired quality of life domain. The results of this study showed that the patients' experience sickness and gastrointestinal symptom cluster during illness and undergoing therapy, as well as variations in the symptom alleviation self-care, including: diet/ nutrition/ lifestyle changes, mind/ body/ spiritual control, biological treatment, herbal treatment, and prescribed medicine. The symptom cluster and symptom alleviation self-care has an impact on the patients' outcome that is the quality of life. This study showed that the experience of symptom cluster and symptom alleviation self-care varied and highly individualized, which has an impact on the quality of life. The importance of proper identification about symptom cluster and the effectiveness of using symptom alleviation self-care by the nurses will be the basis for the success of disease management to improve the patients' quality of life. Therefore, optimizing the nurses' role is needed as the basis for the development of symptom management nursing programs.

Keywords: Head and neck cancer, symptom alleviation self-care, symptom cluster, quality of life.

Introduction

Head and neck cancer included in the top six incidences of cancer in the world (Jemal et al., 2011). This disease can cause death and suffering caused by experiences of physical and psychological changes and adjustments related to the disease and management of therapy (Cheng & Lee, 2011; Caldeira, Carvalho, & Vieira, 2014). During this time, patients experience many individual symptoms associated with physical and psychological changes. The physical changes experienced by head and neck cancer patients include pain, fatigue, drowsiness, nausea, vomiting, sleep disturbance, lack of appetite, and other symptoms (Cheng & Lee, 2011). Psychological changes due to depression, anxiety, and distress can also occur (Haisfield-Wolfe, McGuire, & Krumm, 2012). Sometimes, multiple symptoms will appear simultaneously.

The phenomenon associated with the emergence of symptom cluster needs to be investigated because cancer patients have multiple symptoms that can cause suffering (Marylin J. Dodd, Miaskowski, & Lee, 2004). Some studies support this statement (Barsevick, 2016; Kirkova, Aktas, Walsh, & Davis, 2011). Symptom cluster will affect outcomes, which will subsequently affect survival, ultimately decrease functional status over time, and decrease adherence to therapy, even death (M. Dodd & Faan, 2001; Kurniawati, Kuhuwael, & Punagi, 2013). Furthermore, symptoms in symptom cluster experienced by patients are subjective phenomena that must be assessed by patients who report or experience them. An example is research on nausea which states that the nature, number, location, duration and intensity of experiences described as nausea varied. Some patients identified symptoms as part of the experience of nausea, and others described symptoms associated with nausea but separate from it (Olver & Eliott & Koczwara, 2014). Therefore, a qualitative study is needed when they report nausea or other symptoms, which are designed to explore the possibility that patients use the term to to describe a cluster of symptoms, rather than just regarding them as separate associated symptoms. Nevertheless, the symptom cluster related investigation deals not only with how the symptom cluster is formed, but also the symptom management strategies used.

Self-care management is one of the useful strategies to control and manage symptoms complained by patents. S (M.J. Dodd, Miaskowski, & Paul, 2001; Richard & Shea, 2011; Temtap & Nilmanat, 2011). The use of self care methods to treat symptoms is commonly called symptom alleviation self care. Several studies have suggested that cancer patients perform various symptom alleviation self cares to relieve and manage multiple symptoms (Williams et al., 2010; Williams, Lantican, Bader, & Lerma, 2014). Therefore, an effective self care method is required as a condition in the symptom management. With data of an effective self care strategy, patients' quality of life may increase (M.J. Dodd et al., 2001).

Based on the research background, the head and neck cancer patients' experiences of symptom cluster and symptom alleviation self care and the impact on the quality of life need to be explored. This research could become a basis for improvement of symptoms and disease management so that the distress can be reduced and the occurrence of the symptoms can be prevented.

Method

The study used qualitative method. The participants consisted of 5 head and neck cancer patients at the public hospital in Semarang, Indonesia. The inclusion criteria are adult patients aged 18–70 years old, able to communicate well and cooperatively, have been diagnosed as having head and neck cancer without metastasis to the brain that proven by diagnostic tests and signs of accompanying symptoms, and not experiencing mental disorders.

Data collection was done using semi-structured interviews. An interview guide with 3 open-ended questions was prepared by the researcher. The question of the interview guide about the patients' experience of symptom cluster, the patients' experience of symptom alleviation self care, and the impaired quality of life domain. The

questions focus on how the patients perceive symptoms and how to manage symptoms called symptom alleviation self care.

Total of 5 cancer patients being semi-structured interviews about symptom cluster. Interview results were analyzed using content analysis. It consists of transcribing (making transcripts of the patients' conversations), determining the meaning unit for searching relationships between words, sentences or paragraphs and finally, abstracting data to form several themes (Elo & Kyngäs, 2008).

Result

Participants who participated in this study were 5 patients with head and neck cancer; 2 patients were male and 3 patients were female. The participants' age ranges from 40 to 60 years. Three themes were identified in the study. The themes indicate the interrelations and describe the symptom cluster and symptom alleviation self care among head and neck cancer patients. The study conducted by Kim mentions that a symptom cluster is a stable group of two or more concurrent symptoms and is related to each other and independent of other symptom clusters (M.J. Dodd et al., 2001; Kim, McGuire, Tulman, & Barsevick, 2005). The explanation of each of the themes is as follows:

Theme 1: The patients' experience of symptom cluster

The patients mentioned that they experienced sickness and gastrointestinal symptom cluster. They exprienced multiple symptoms simultaneously, which are independent of symptoms or other symptom groups.

Subtheme 1: Sickness symptom cluster

Sickness symptom cluster is a physical disorder caused by disease and therapy management. This symptom consists of a collection of symptoms of pain, fatigue, sleep disturbance and decreased appetite. The following statements describes the occurrence of cluster symptoms because of cancer experienced by the participants:

"When I feel tired or too much activity, the cancer will be painful. When the pain appears, I will not be able to sleep. So, my activities must be reduced and I must take some rest. "(P 1)

"The pain that I feel heavy in the area of cancer. it is so painful, every day I cried. The medicine from the doctor is not very helpful, I cannot sleep. Sometimes I sleep only in a chair and very short "(P 2)

In addition, sickness symptom cluster can also occur due to chemotherapy process. One of the participants stated:

"Ever since I had this chemotherapy, I felt a growing pain in the area of cancer and the whole body. Therefore, I finally decreased my appetite, I just spent ¼ portion than usual, and I substitute with lontong (rice cake). Since I have decreased my appetite, I also feel tired and weak when doing daily activities. That may be due to reduced food intake "(P 3)

Subtheme 2: Gastrointestinal symptom cluster

This cluster symptom consists of a groups of symptoms of nausea and vomiting. It can be caused by chemotherapy. The following statement is related to this:

"After chemotherapy I experienced nausea and wanted to vomit. For 2 weeks, I felt the effects of chemotherapy, every day I feel both. I still feel nauseated even though I have taken medicine from the doctor and sometimes vomited "(P 3)

Theme 2: The patients' experience of symptom alleviation self care

Symptom alleviation self care is done to overcome the patients' symptoms. The symptom alleviation self care performed by the 5 participants varied, including 5 complementary therapy, as follows:

Subtheme 1: Diet/ nutrition/ lifestyle changes

A total of 4 participants used diet/ nutrition/ lifestyle changes as a self care method to solve the symptoms. This method was done by avoiding sweet foods, animal protein, and fried foods, eating fruits and vegetables, replacing white rice with brown rice, eating little but often, eating ice cream, avoiding scent/ smell.

"What is my taste or what I want then will eat and I drink, so it can overcome the nausea.

For example I want to eat ice cream then I will eat it, sometimes I also avoid the smell that can make me nauseous. "(P 1)

"When I feel nauseated, I will stop eating and when I do not feel vomit, then I start to eat again, spend a portion of it long. Then, for example I am not appetizing rice then I will replace with other foods, such as eating fruit or before eating I drink juice first, eat other foods so my stomach is not empty. "(P 2)

"I eat brown rice and vegetables to reduce nausea and vomiting. I keep my food for example, avoiding sweet foods, animal protein, and fried foods. I replace it by drinking fruit juice every day, but using fruit that is not sweet too. "(P 5)

Subtheme 2: Mind/ body/ spiritual control
Symptom alleviation self care was done by praying, distraction, activity. Two participants performed this method to treat nausea, pain, and other symptoms that appeared. This was expressed by the participants, as follows:
"Our minds are also transferred to others to cope with nausea. We also created activities to reduce the pain. "(P 1)

"In addition, I read the istiqfar to relieve the pain, read the prayer I do every time when the pain appears, so I do not feel it" (P 2)

Subtheme 3: Biological treatment (vitamin)
This method was done by taking vitamins. Symptom alleviation self care was done by 2 participants, as indicated by the following statement:
"I consumed vitamins, wine extract which is a sackly product to accelerate the growth of dead cells." (P 5)

Subtheme 4: Herbal treatment
A total of 4 participants used herbal treatment to solve the symptoms that appear. This method was done by consuming mangosteen peel, garlic, and Chinese herbs. This is supported by the following statement:
"I just take herbal medicine to overcome the nausea, mangosteen skin consumption that has been sold in the form of packing and biocipres, and the consumption of onion (bawang lanang) to boost immunity." (P 1)

"I bought Chinese herbs at Pharmacies to relieve my pain. Because I have taken medicine from a doctor but it cannot overcome it. "(P 2)

"I have a habit of chemotherapy, I bring dates, every time I feel nauseated I take one, so I do not vomit." (P 3)

"At first, I was told my friend to consume malikus leaves or his name is African leaf. When consuming it, the pain as sliced can disappear and stop, so the pain is not the terrace. "(P 5)

Subtheme 5: Treatment prescribed
Consuming oral medicine and using pacth from doctors were done by two participants to relieve pain. This is expressed in the following statement:
"I was given medicine by a doctor in the form of plastic outboard. The medicine was only used for 3 days only. Although the drug can not reduce pain too much but I can still sleep about 5 minutes compared to previous types of drugs given by doctors. "(Ps 2)

"I take pain medication from a doctor to reduce pain in the area of cancer." (P 5)

Theme 3: The impaired quality of life domain
All participants expressed that there was life quality decrease during illness. All patients experienced disturbance in the domain of functional scale, scale of symptoms (fatigue, pain), global QOL, and single item (financial difficulties). This is reflected by the following statements as follows:
"I have not been able to work to make a living, even just for my daily activities I still can not be maximized. This is because I still have to undergo routine checks to the hospital "(P 1)

"When I get sick and feel severe pain, my family forbids me to do daily activities. Food and drink had been prepared by my family and placed on the table above my bed. I feel the pain every day and it does not decrease. So, I can only cry even I cannot sleep and do other activities. "(P 2)

"I feel fear and anxiety, when the verdict suffered from cancer. I feel this life will end, until I do not want to do anything and just cry in my room. "(P 3)

"Now, when walking can not run quickly, should slowly because if the road is too fast I easily tired, tired and the body feels pain. I realize it is not as strong as it used to be. "(P 5)

Disccusion

In this study, the patient experienced many individual symptoms that form the symptom cluster, namely: the experience of sickness and gastrointestinal symptom cluster. The patients experienced two or more symptoms that occur together; they are interconnected and independent of other symptoms or groups of symptoms (M.J. Dodd et al., 2001; Kim, McGuire, Tulman, & Barsevick, 2005). Several studies have shown a correlation between two or more symptoms that make up the sickness of the cluster. These results are supported by two studies, indicating that head and neck cancer patients can experience sickness symptom cluster, consisting of a group of symptoms of pain, fatigue, sleep disturbance and decreased appetite (Chen & Lin, 2007; Kirkova et al., 2011). In addition to the sickness symptom of the cluster, the patients also experience nausea and vomiting, forming a gastrointestinal symptom cluster. Several studies have shown that these two symptoms are consistently present in the same clusters (Barsevick, 2016; Chen & Lin, 2007; Jiménez et al., 2011; Kirkova et al., 2011). It can be concluded that the experience of nausea included unique symptoms that occurred among cancer patients. It was identified that there were concurrent symptoms, which were considered separate but related to nausea, such as vomiting. And they called symptom cluster because they are a stable group of two or more concurrent symptoms and is related to each other and independent of other symptom clusters.

In addition, this study also explore the self care methods used by the patients. The patients used several variations of symptom alleviation self care to treat symptoms, such as: pain, fatigue, sleep disturbance, decreased appetite, nausea and vomiting. They can be classified into 5 categorical complementary therapies, including: diet/ nutrition/ lifestyle changes, mind/ body/ spiritual control, prescribed treatment, herbal treatment, and biological treatment (vitamins). Self care is a method that benefits cancer patients (Williams et al., 2010). Self care interventions will reduce the side effects of treatment and may affect adherence to treatment regimens, thereby enhancing quality of life (Williams et al., 2014).

Diet/ nutrition/ lifestyle changes and herbal treatments are mostly used by the participants in this study than other self care methods. Similar results were also obtained among cancer patients in the southwestern United States where diet/ nutrition/ lifestyle change had high numbers of self-care responses. Self-care methods used are reported over 90% can be helpful (Williams et al., 2014). The intervensions in this method, such as changing eating habits or food modifications, consuming vegetables and fruits, and using nutritional supplements. Another method of self care mostly used is herbal plants. This method has been used as a medicine since ancient times by all cultures. Herbal medicine is made from leaves, branches/ branches, roots, seeds, or even flowers. This medicine may consist of a single herb or combination of herbs, such as traditional Chinese herbs and Ayurvedic from India (Wesa, Gubili, & Cassileth, 2008). Several studies have revealed that herbal treatments are obtained from local herbs. Both methods of self care are used to overcome the pain, fatigue, sleep disorders, lack of appetite, depression, sadness, nausea, vomiting, and anxiety (Temtap & Nilmanat, 2011; Williams et al., 2010, 2014). The used of herbal plant can give the advantages to relieve the symptoms.

Two participants chose to use mind/ body/ spiritual control, biological treatments (vitamins), and prescribed medications. This method was chosen to relieve symptoms of pain, fatigue, sleep disturbances, lack of appetite, nausea, vomiting, and mood disorders (Temtap & Nilmanat, 2011; Williams et al., 2010, 2014). Body/ mind/ spiritual control methods are increasing in popularity and available as part of major medical care (Wesa

et al., 2008). The mind, body, and spiritual modality focus on the interaction between brain, mind, body, spiritual and behavior with the aim of reducing symptoms and improving health. Similar to this study, several other studies have indicated that praying, distraction, and other activities are effective (Temtap & Nilmanat, 2011; Williams et al., 2010, 2014). Mind-body-spiritual therapies are generally safe (Deng & Cassileth, 2013; Mujar et al., 2017; Pinzon-Perez & Pérez, 2016). Biological treatment is an option that patients also use as a self-care method. In this method, the biological treatment that patients often use is the use of vitamins (Christanti & Prasetyo, 2012). Some vitamins and minerals are essential for life and health. In just a few milligrams, the amount of each vitamin is needed by the human body. However, a small amount is very important for all body's biochemical processes. It is used to convert food into energy and to help the body produce hormones, blood cells, and nervous system chemicals (Cassileth, 2011). In addition, prescribed medicines by doctors are still used by patients. Medically determined treatment measures are incorporated into self care to help patients control the symptoms of pain, nausea/ vomiting, sleep disorders and anxiety in cancer patients (Temtap & Nilmanat, 2011; Williams et al., 2010, 2014).so what? In discussion you as author need to explain your opinion for future implication

This study also shows that head and neck cancer patients experience various life quality disorders in the form of weaknesses both physical, psychological, and social. This is supported by a study reporting that patients with nasopharyngeal cancer experienced all the disturbances on the 15 scale of quality of life, including: 5 functional scale, 3 symptoms scale, global QoL and six single items (Kurniawati et al., 2013). Other studies on head and neck cancer patients also showed results similar to previous studies (Leung et al., 2011).

The effects of disease and therapy on the patients' quality of life are illustrated in this study. Proper quality of life assessment will affect the patients' overall sustainability, adherence to therapy and even death (M. Dodd & Faan, 2001; Kurniawati et al., 2013). The assessment of quality of life also needs to pay attention to the use of symptom management strategies embodied with the symptom alleviation self care and the emergence of symptom experience (M. Dodd & Faan, 2001). Therefore, symptom management for head and neck cancer patients should focus on these three things. This can be an indicator of the successful action of health care providers and the patients' satisfaction to the achievement of their health.

Conclusion

The experiences of symptom cluster and symptom alleviation self care vary and are highly individualized, depending on how individuals respond to the disease and management therapy. The existence of the impact caused by the disease and the management therapy will affect the condition of the patients, that is the disruption of quality of life. The importance of proper identification of symptom cluster and the effectiveness of using symptom alleviation self-care by nurses will be the basis for the success of disease management to improve the patients' quality of life. Therefore, optimizing the role of nurses in the case of symptom cluster assessment, symptom alleviation self care, and quality of life monitoring is needed as a basis for the development of symptom management nursing programs.

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