The lived experience of colorectal cancer patients with undernutrition in meeting their nutritional needs

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KEYWORDS
Colorectal cancer patients; Experience; Nutritional needs; Undernutrition

Abstract
Objective: This study aimed to explore the lived experience of colorectal cancer patients with undernutrition in meeting their nutritional needs.
Method: We employed a phenomenological approach involving seven colorectal patients with undernutrition selected using purposive sampling method. We employed in-depth interviews to collect data and Colaizzi’s content analysis to analyze data.
Results: We identified the following six themes: (1) cancer is the cause of weight loss, (2) preferred foods have potential to cause cancers; (3) concerns regarding digestive issues; (4) pathological response toward foods; (5) delayed meal times; and (6) suicidal thoughts outside the context of the disease.
Conclusions: It is important for nurses to provide patient education and design teaching instructions for patients in meeting their nutritional needs by considering barriers experienced by patients. Nurses along with dietitians and physicians may also develop guidelines to address undernutrition for colorectal cancer patients.
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Introduction
Undernutrition is a condition with a decline in nutritional status of energy, protein, and nutrients or other necessary substances that cause adverse effects on body functions or clinical outcomes. Undernutrition patients are those who have less food intake, body mass index (BMI) of <18.5 kg/m² and serum albumin level of <3.0 g/dL. Various factors may cause undernutrition in cancer patients, such as tumors, (directly or indirectly), surgery, radiation therapy, chemotherapy, and psychological factors.

Some studies demonstrated that undernutrition in cancer patients is influenced by the type, location, stage of the cancer, anti-cancer therapy, and patient characteristics include age, gender, and the susceptibility of patients to undernutrition. A factor that greatly impacts the condition of undernutrition is the ability of cancer patients to

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meet nutritional needs. A study conducted by Bapuji and Sawatzky found that undernutrition is resulted from a mixture of patient’s physiological, pathophysiological, behaviors responses and perspectives to the cancer.

Healthy individuals are able to recognize foods from their smells and taste and consume them with appetite. On contrary, cancer patients are difficult to have a healthy appetite due to smell and taste distortions. These distortions include smelling foods as carrions, persistent bitter taste, hypersensitivity to the food’s smell and taste, and reluctance to eat due to nausea and vomiting. Patients, consequently, tend to restrict their food intake despite their nutritional needs increase along with the disease and cancer processes, hypermetabolic conditions, and nitrogen imbalances. Thus, nutritional imbalances may presence and therefore support to meet nutritional needs becomes crucial for cancer patients.

In general, adequate nutritional support is the major treatment for patients with undernutrition. Nonetheless, it is not enough to prevent undernutrition. MacDonald described that patients’ compliance to meet their nutritional needs may be attained by implementing therapy management, such as identifying their hope to deal with anorexia, addressing nutritional deficiencies and/or hypermetabolic conditions.

Therapy management is not only beneficial to address physical problems among cancer patients, but also to provide psychological support to help them cope with their conditions. A study conducted that the stress level may increase along with the presence of undernutrition. Patients’ inability to manage stress will worsens their cancer since it will lead to the disturbance on immune system integrity, changes on eating behaviors and nutritional status. Thus, patient and family supports from healthcare professional play an essential role to help patients cope with their stress. Personal conflicts may arise when patients cannot deal with physical and psychological changes due to cancer. Loss of appetite is one of the most common problems occurs among cancer patients with undernutrition. Thus, nurses play an essential role in educating and providing advocacy for them.

A qualitative research conducted by Reid found that cancer patients with undernutrition have limited food intake although they still have desire to eat. This conflict may aggravate patients more when family members continuously enforce them to eating. Based on the above phenomenon, researchers were interested to have a deeper understanding of the lived experience of colorectal cancer patients with undernutrition in meeting their nutritional needs.

Method

A phenomenological qualitative approach was employed to better understand the lived experience of patient with colorectal cancer. In-depth interviews were carried out from April to May 2013 to delve into the perceptions of the participants who experienced colorectal cancer-associated undernutrition in fulfilling their nutritional requirements.

Eligible participants were colorectal cancer patients aged between 18 and 64 years old, living with colorectal cancer stage I/II/III/IV, responding to cancer therapy and treatments, with BMI of <19/m², experiencing hypoalbumin with albumin level of <3.2 g/dL, having no chronic diseases that may increase the risk of undernutrition such as diabetes mellitus, kidney failure, and heart failure, having no cognitive impairments, and being able to communicate verbally in Bahasa Indonesia.

Purposive sampling was used to offer as much insight as possible into the phenomenon of the nutritional fulfillment amongst colorectal cancer patients with undernutrition. Recruitment of the participants were conducted after obtaining approval from the Ethical committee of Dharmais Cancer Hospital. Nurse managers from different inpatient units in the hospital facilitated the selection of participants who met the study criteria.

In this study, 7 participants who met the criteria received both oral and written information regarding the study. They agreed to participate in the study and gave written informed consent. Semi-structured interviews with open-ended questions were performed until saturation. The interviews were taped, and the recordings were transcribed and analyzed using Colaizzi content analysis. Data were coded and grouped to generate themes. The accuracy of data was examined by considering the principles of credibility, dependability, confirmability, and transferability.

Results

Seven interviews were conducted with 3 men and 4 women aged 50.5 years on average, ranging from 21 to 65 years old. Most participants described themselves as Muslims (n = 6). Nearly half attended elementary school (n = 3), and only one participant attended university at diploma level. Of all female participants, 3 were housewives. Whilst, all male participants were unskilled labors. Four participants were Betawinese and the remaining participants were Javanese, Batakene, and Sundanese.

The mean BMI score of the participants was 17.49 g/dL, ranging from 15.6 g/dL to 18.9 g/dL, whereas the mean albumin value was 2.7 g/dL. The histology examination showed that all participants have gastric adenocarcinoma cell types.

There were differences in cancer type and stage at diagnosis among participants. Four participants were diagnosed with rectal cancer, 2 participants were diagnosed with sigmoid adenocarcinoma, and 1 participant was diagnosed with transverse colon carcinoma. In addition, 5 participants were at stage 2, and 2 participants were at stage 4 of cancer. All participants had undergone abdominal or rectal resection surgery as a therapy to address the disease. Two participants (participants 3 and 4) had undergone surgery combined with chemotherapy and radiotherapy.

For the eating patterns, our study found that 6 participants had full meals for breakfast, lunch and dinner that includes rice, side dishes, and vegetables within the last one month. Three participants took food supplements such as vitamins, fujimin, and date palm extracts.

Our study also identified the respondents’ digestive system functions within one last month, including the ability to chew, the ability to swallow, the presence of nausea, diarrhea, dry mouth, or food intolerance. All participants had no difficulties to chew and/or swallow foods. Four participants experienced nausea without vomiting. Six
participants reported that vomiting was absent within the last one month.

Six themes were identified from the in-depth interviews (Table 1). These themes were as follows: (1) cancer is the cause of weight loss; (2) preferred foods have potential to cause cancers; (3) concerns regarding digestive issues; (4) pathological response toward foods; (5) delayed meal times; and (6) suicidal thoughts outside the context of the disease.

### Table 1: Categories and themes of the study.

<table>
<thead>
<tr>
<th>Category (s)</th>
<th>Theme (s)</th>
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<tbody>
<tr>
<td>1</td>
<td>The mass steals nutrients</td>
</tr>
<tr>
<td>2</td>
<td>Regular consumption of instant noodles or fatty foods</td>
</tr>
<tr>
<td>3</td>
<td>Digestive problem that get worse with time</td>
</tr>
<tr>
<td>4</td>
<td>Sensitive stomach Taste and smell alterations</td>
</tr>
<tr>
<td>5</td>
<td>Early satiety Eating fatigue</td>
</tr>
<tr>
<td>6</td>
<td>Suicidal thoughts due to family problems</td>
</tr>
</tbody>
</table>

**Theme 1: Cancer is the cause of weight loss**
Participants described cancerous cells as the abnormal growing mass that consumed nutrients in the body, causing digestive impairments and, eventually, weight loss. This theme was generated from two categories: "the mass steals nutrients" and "the imbalance between nutrient intake and nutrient requirements".

"This mass causes pain in my stomach. I still have a good appetite, but my weight steadily declines. It seems that everything I eat will not help me gaining more weight. Perhaps, it is all because of the disease" (with the emphasis on the words of 'the disease' while pointing finger on the stomach) (P.1)

**Theme 2: Preferred foods have potential to cause cancers**
Participants expressed their concern regarding the quality of foods they preferred to consume everyday. As they reflected on the causes of cancer, foods were regarded as the promoter of cancer. They felt that regular consumption of instant noodles or fatty foods, along with low intake of fruits and vegetables might have contributed to the development of their cancer.

"I usually eat rice or instant noodles at each meal, and I have three to four meals everyday. When I get hungry, instant noodles is all that I have in hand." (P.6)

**Theme 3: Concerns regarding digestive issues**
Participants reported abdominal discomforts as a result of colorectal cancer. They said that they were aware and concerned about the disease process that gets worse over time.

"I was feeling so sick and having pains because of the lump in my stomach, and I went to the surgeon right away..." (P.4)

**Theme 4: Pathological response toward foods**
This theme falls into three categories: sensitive stomach, taste and smell alterations, and food aversion.

"everything that goes in my mouth seems wrong. I eat vegetables as they said would help me beat the cancer. But my stomach becomes upset. I eat fish, I eat this, and that, and get diarrhea. Everything I eat will turn my stomach. My stomach is now way much more sensitive..." (P.1)

Along with sensitive stomach, participants had to cope with an unpleasant smell and a bitter taste of particular foods. They reported that digestive problems, hospitalization, surgery, radiation, and chemotherapy changed their senses of smell and taste. These changes can affect appetite and food aversion may develop.

**Theme 5: Delayed meal times**
This theme was obtained from the following two categories: early satiety and eating fatigue.

"whenever I see foods, I always feel queasy and it makes me lose my appetite. When i am really hungry, i will just drink a glass of milk or juice to help me feel more satiated.." (P.2)

**Theme 6: Suicidal thoughts outside the context of the disease**
Participants stated that family problems, and other circumstances outside the illnesses limited their abilities to meet their nutritional needs.

"I barely get to sleep, thinking about my son who would never want to listen. It somehow makes my appetite diminish. I feel so stressful and become suicidal... thinking about my son is kind of a stressor to me. Only if committing suicide is allowed, I would do it for sure... I lose my appetite whenever I remember my son..." (P.1)
Discussion

Theme 1: Cancer is the cause of weight loss

Perception is the ability to comprehend the information, influenced by knowledge, experience, and habits that may be similar or different between one individual to another.\(^{18,19}\) A study conducted by Koo\(^{18}\) in Australia indicated that Australian-born participants had a better perception regarding the importance of colorectal cancer screening compared to that of overseas-born participants. The study furthermore showed that knowledge level, educational background, the availability of information, and acquaintance with other colorectal cancer patients have a significant influence on how patient perceive the necessity of cancer screening.

Cancer refers to a type of malignant neoplasm in which abnormal growth of cells occurs. These cells invade the nearby healthy tissues and may metastasize to other parts of the body through blood or lymphatic circulation systems.\(^ {20,21}\) This process is initiated by carcinogenesis, or the transformation of normal cells into cancerous cells. Cancer is closely associated with weight loss. Nonetheless weight loss in cancer patients is distinct from that in healthy individuals. Weight loss in cancer patients occurs because metabolic demands of cancer cells exceed the food intake.\(^3\)

Characteristics of participants in this study may affect their perception regarding the causes of weight loss. Higher age (50.5 years old), lower educational level (elementary school or primary level education), type of occupation (housewives and unskilled labor), and culture (Betawinese) may have an impact on how they perceive the underlying causes of weight loss that they experienced. Perception may also be influenced by patient’s experience with healthcare services and information provided by healthcare providers. Hawkins\(^ {22}\) stated that information provided by healthcare professionals concerning the effectiveness and side effects of therapies and treatment of cancer can help patients and family cope with stress that comes after a cancer diagnosis.

Theme 2: Preferred foods have potential to cause cancers

Food selection highly depends on the individual preference. The high intake of fatty foods induces the secretion of secondary bile acids and neutral steroids.\(^ {23}\) Furthermore, it also alters the activities of decomposing bacteria, which in turn promotes colony formations of cancer cells.\(^ {24}\) In this study, the participants voiced similar views, that low-fiber and high-fat diet, like instant noodles, might put them in higher risks of cancer.

Theme 3: Concerns regarding digestive issues

Colorectal cancer is often difficult to diagnose since it has no clear-cut symptoms at the earliest process of the disease.\(^ {25}\) In our study, participants started to notice the problems in their digestive system after experiencing unexplained weight loss, accompanied by other physical symptoms, such as rectal bleeding, blood in the stools, small-caliber (narrow) or ribbon-like stools, lump in the stomach, and constipation. With these symptoms, participants felt alarmed of a need to seek medical advice.

Depending on its location, colorectal cancer patients may have distinct signs and symptoms. Colorectal cancer diagnosis accompanied by its clinical manifestations are debilitating for most patients. Accordingly, patients are more apt to suffer from psychological distress, including anxiety. Participants in this study felt anxious about the illnesses and symptoms that get worse with time.

Theme 4: Pathological response toward foods

Food aversion experienced by participants is a learned response. This aversion presummably occurred through conditioning processes, resulting from repeated unpleasant or distressing experience associated with foods and eating. Participants perceived that their digestive problems were caused by particular foods. If these problems are not resolved, they may lead to anorexia and unintentional weight loss.

Anorexia, weight loss and undernutrition are closely linked. Anorexia can substantially cause weight loss, then subsequently lead to undernutrition. According to Loh,\(^ {26}\) unintentional weight loss is a critical predictor of malnutrition risks. Failures in providing appropriate nutritional management may result in unfavorable prognosis of undernutrition, and may exacerbate the course and severity of anorexia.\(^ {12,27,28}\)

Theme 5: Delayed meal times

This finding showed that delaying meal times occurred as a response to nausea or queasy. Nausea and or vomiting are the two most common symptoms experienced by cancer patients. These symptoms were amongst the most difficult physical effects of colorectal cancer itself and the side effects of cancer therapies, such as radiotherapy and chemotherapy. Nausea furthermore can cause early satiety. In our study, participants indicated that they easily get full after eating a small quantity of food.

Early satiety in colorectal cancer patients occurs due to the presence of solid mass that partially or completely obstructs the bowel, preventing foods and liquid pass through the gastrointestinal (GI) tract. The symptoms of early satiety, along with nausea and or vomiting, and bloating, may be diminished by the administration of gastrointestinal prokinetic agents such as metoclopramide that increase the movement of ingested materials through the digestive system.\(^ {29}\) Low intake of fibers, such as seaweed would help to minimize the development of bezoars which may result in bowel blockages. In addition, patients should eat small and frequent meals to improve digestion and calories intake without overfilling the stomach.

Cancer-related fatigue occurs due to hypermetabolism, and may be elevated during the treatment. This type of fatigue can give negative consequences to everyday activities,\(^ {30}\) including eating patterns. In our study, participants said that they feel too tired to eat. Thus, physical therapy is suggested for cancer patients even during bed rest.
to help maintaining muscle strength and range of motion as well as reducing fatigue and depression.\textsuperscript{31}

**Theme 6: Suicidal thoughts outside the context of the disease**

Individuals will experience psychological alterations, thereby requiring both physical and psychological attention as an adaptive response to restore their optimal functions.\textsuperscript{32} Stress is a normal process of life cycle, however, excessive stress may cause weight loss.\textsuperscript{10} Human body will respond to the stress by releasing catecholamine, and cortisol substances. During the period of stress, catecholamine are released to activate lipolysis and inhibit glucose uptake from peripheral tissues. Catecholamine also acts to reduce protein synthesis in the gastrointestinal tract. Cortisol, similarly, inhibits glucose uptake and reduce protein synthesis in the muscles and other tissues.\textsuperscript{33} Accordingly, stress that leads to suicidal idea outside the context of cancer may greatly affect gastrointestinal system and nutritional needs fulfillment.

**Nursing implications and conflict of interest**

These findings can provide a context for nurses providing patient education and designing teaching instructions for patients in meeting their nutritional needs. Because psychological factors, such as food aversion, early satiety, eating fatigue, and suicidal thoughts due to family problems has been identified as barriers for eating, it is important to consider how these barriers influencing their ability to meet their nutritional needs. Nurses along with dietitians and physicians should develop guidelines to address these psychological factors that had been faced by undernutrition in colorectal cancer patients. This study has no conflict of interest.

**Conclusion**

Our findings suggested that colorectal cancer patients felt barriers for eating both physical (cancer is the cause of weight loss, preferred foods have potential to cause cancers, concerns regarding digesting issues) and psychological (pathological response toward foods, delayed meal times, suicidal thoughts outside the context of the disease). The above themes are relevant with the Human responses to Illness Model in which colorectal cancer patients dealt with conflicts in meeting their nutritional requirements. Nurses play their key roles as an advocate and an educator to address undernutrition and prevent the life threatening problem such as cachexia. Identification of factors that may contribute to undernutrition will help nurses to determine the needs of patient education and develop teaching instruction pertinent to the appropriate nutritional needs fulfillment for colorectal cancer patients.

**Conflict of interests**

The authors declare no conflict of interest.

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**References**

The undernutrition experience of colorectal cancer patients


