

“I Feel Like a Baby”: A Cancer-Related Fatigue Experience Based on a Male Perspective

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ABSTRACT

Cancer-Related Fatigue (CRF) is one of the symptoms of cancer as a result of illness or treatment that is usually experienced with subjective feelings by male and female cancer patients. However, male patients tend to ignore it resulting in that these symptoms receive less attention. This study aimed to explore the experience of fatigue in male cancer patients. This study used a qualitative design with a phenomenological approach. This study involved 15 male cancer patients who were selected using a purposive sampling technique. Data collection was carried out using semi-structured interviews. Data were analyzed using the Van Mannen approach with the help of NVivo 12 software. There are four themes identified in this study, namely 1) powerlessness, 2) fulfillment of roles and responsibilities, 3) adjustment, and 4) social support. According to most male informants, fatigue is powerlessness in

living life. Fatigue can reduce the predicate of men as a strong and masculine individual which results in a decrease in roles and responsibilities. Adjustment and social support are needed to overcome these problems. Fatigue in participants leads to disturbances in their masculinity roles and has an impact on their daily lives. Nursing management is expected to enable patients to secure specific interventions that are oriented toward patient welfare.

Keywords: cancer, fatigue, life experience, male perspective

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INTRODUCTION

Cancer can cause several health problems that affect the patient's life. One such disorder is cancer-related fatigue (CRF).¹ CRF can be experienced in all phases of the disease, but is often not reported by patients (especially men), resulting in this disorder receiving less attention.²⁻⁴ Seen from a gender health perspective, men generally consider themselves to be fine, as having no health complaints, and tend to avoid medical examinations.^{5,6} Qualitative research is needed on fatigue in male cancer patients. The prevalence of CRF ranges from 70% -100% during active treatment and around 30% in post-treatment.^{2,7}

Fatigue can affect daily life.⁸ CRF affects patient life, functional status, and activities.⁹ Prolonged fatigue accompanied by disruption of social and spiritual wellbeing can cause individuals to become isolated and lead to uncertainty, despair, and worries about death.¹⁰ Fatigue symptoms can also increase the prevalence of depression in cancer patients, which can, in turn, affect the components of the immune function against tumors, which has an impact on decreasing the activity of cytotoxic T cells and NK cells.¹¹ Fatigue does not only affect the sufferer, but also the people around them.¹² Fatigue can result in the decreased independence of cancer patients, which can increase nurses' stress.¹³

Attention to the health of men and women is very important in tackling the global epidemic of non-communicable diseases such as cancer.¹⁴ Men receive less health attention than women.¹⁵ Research is needed on CRF in men with cancer to perceive fatigue, impact, and how to adapt to these conditions.

METHODS

Design

This is a qualitative research with a phenomenological approach that aims to reveal the experience of men with cancer who experience fatigue. Interpretative phenomenology uses interpretive and descriptive elements to gain a deeper understanding of the essential nature of everyday experience.¹⁶ Van Mannen (1990) stated that reflection describes phenomena through the art of authoring strong relationships and is oriented toward events and the environment as a whole.¹⁶

Participants and setting

Participants in this study were cancer patients at the Indonesian Cancer Foundation in East Java. The foundation is a haven for cancer patients who will undergo treatment. Determination of participants was carried out using a purposive sampling method whereby participants are selected based on the objectives or research problems through several considerations to obtain accurate and adequate information in accordance with the objectives or issues being studied.¹⁷ The participants had to be over 18 years old, have been diagnosed with cancer for at least 6 months, and experienced mild to severe fatigue. Fatigue assessment was carried out using a brief fatigue inventory.¹⁸ In addition, patients also had to be able to communicate in Indonesian.

Data collection

Data collection was carried out using semi-structured individual interviews for three months (February - May 2019). Interviews were recorded, transcribed, and validated by listening to the recording. The questions used in the interview led to describing the experiences of fatigue encountered during cancer.

Data analysis

Thematic analysis of interview transcripts was carried out in detail, highlighted, and was holistic.¹⁶ First, the interview transcript was read carefully and repeatedly. In a holistic approach, the researchers must read the text carefully in order to understand its overall meaning. The researcher then highlights or chooses sentences and statements that seem important for this study. Second, the researcher develops keywords and concepts through dialogue with the text. The researchers work to gain understanding and involvement with the phenomenon and, finally, each sentence is analyzed, and, through this process, important themes are found. These themes are then reconstructed into a description of the participants' life experiences.¹⁹ The data analysis process was carried out with the help of the NVivo 12 software.

Lincoln and Guba's Framework shows that qualitative research must have a component of validity, a test of credibility (internal validity), transferability (external validity), dependability (reliability), and conformability

(objectivity).²⁰ The credibility test is done through member checking. Participants are asked to reconfirm the results of the interviews that have been conducted. After that, they agree that the results of the study are in accordance with the interviews that have been conducted. The dependability test is carried out during the consultation activity, which is from the initial determination of the research problem, how to conduct data analysis, compilation of research activity reports, and sharing of interview transcripts. A follow-up

interview is aimed at clarifying understanding of their experiences to increase trust.

Ethical approval

The ethical license was approved by the Health Ethics Committee, Airlangga University, Surabaya, under a decree of 1280-KEPK. Respondents were informed and agreed that this research was voluntary. The researchers guaranteed the confidentiality and anonymity of respondents' data.

Table 1. Participants' Characteristics

Age	Marital status	Caregiver	Occupation (before/during the sickness)	Diagnosis	Stadium	Duration	Types of treatment	Level of Fatigue
P1 (61 y/o)	Married. 3 children	Family (wife)	Retired	Intra-abdominal tumor	III	1 year	Chemotherapy. radiotherapy	Moderate fatigue
P2 (59 y/o)	Married. 2 children	Family (children)	Farmer/ does not work	Rectosigmoid carcinoma	II	7 months	Surgery	Moderate fatigue
P3 (44 y/o)	Married. 2 children	Family (wife)	Civil servant/paid leave	Paranasal sinus carcinoma	III	1.5 years	Surgery. radiotherapy	Moderate fatigue
P4 (19 y/o)	Single	Family (parents)	does not work	Brain tumor	II	1 year	Chemotherapy. radiotherapy	Moderate fatigue
P5 (69 y/o)	Married. 3 children	Family (wife)	Retired	Breast cancer	III	2.5 years	Chemotherapy. radiotherapy	Moderate fatigue
P6 (40 y/o)	Married. 1 child	Family (wife)	Private/ does not work	Nasopharyngeal carcinoma	II	1 year	Chemotherapy. radiotherapy	Moderate fatigue
P7 (50 y/o)	Married. 2 children	Family (children)	Private/ does not work	Lung cancer	III	8 months	Chemotherapy	Moderate fatigue
P8 (38 y/o)	Divorced. 1 child	Family (mother)	Farmer/ does not work	Osteosarcoma	III	3 years	Chemotherapy	Severe fatigue
P9 (36 y/o)	Married. 1 child	Family (wife)	Laborer/ does not work	Intra-abdominal tumor	II	7 months	Chemotherapy	Moderate fatigue
P10 (56 y/o)	Married. 2 children	Family (wife)	Civil Servant/ paid leave	Nasopharyngeal carcinoma	III	1.5 years	Chemotherapy	Moderate fatigue
P11 (58 y/o)	Married. 2 children	Family (wife)	Farm worker/ does not work	Oral squamous cell carcinoma	II	1 year	Chemotherapy. radiotherapy	Moderate fatigue
P12 (62 y/o)	Married. 2 children	Family (wife)	Tailor/does not work	Thyroid cancer	IV	6 years	Chemotherapy. Radiotherapy. Nuclear therapy	Severe fatigue
P13 (48 y/o)	Married. 3 children	Family (wife)	Civil Servant/ paid leave	Nasopharyngeal carcinoma	III	1 year	Chemotherapy. radiotherapy	Severe fatigue
P14 (50 y/o)	Married. 3 children	Family (wife)	Farm worker/ does not work	Colorectal cancer	III	1 year	Chemotherapy	Moderate fatigue
P15 (40 y/o)	Married. 2 children	Family (wife)	Laborer/ does not work	Thyroid cancer	II	1 year	Chemotherapy	Moderate fatigue

RESULTS

Table 1 shows the profiles of 15 participants who were involved in this study. All interviewees were men aged 19 - 69 years (mean age: 49 years). The majority of participants were married (13/15), one participant was not married, and one participant was divorced. The caregiver of all participants was family (wife or children). The participants were civil servants, worked in the private sector, laborers, farmers and tailors. Three of them were on leave, nine others did not work, and the rest were still working. Each participant had different cancers, such as intra-abdominal tumor, rectosigmoid carcinoma, paranasal sinus carcinoma, brain tumor, breast cancer, nasopharyngeal carcinoma, lung cancer, osetosarcoma, oral squamous cell carcinoma, thyroid cancer, and colorectal cancer. The majority of participants were in stage III and had been diagnosed from between seven months to six years. Most participants underwent chemotherapy and radiotherapy. Three participants experienced mild fatigue, nine participants had moderate fatigue, and three participants severe fatigue.

There are four main themes, namely 1) powerlessness, 2) fulfillment of roles and responsibilities, 3) adjustment, and 4) social support. The themes are based on the results of the interview and are illustrated with quotes from participants. This research reveals that fatigue is a complex phenomenon for men which affects physical, psychological, and social aspects.

Theme 1: Powerlessness

Participants interpreted fatigue as powerlessness and individual experiences that can affect daily life. Participants described fatigue as a decrease in strength and limited physical ability to carry out daily activities as a consequence of cancer. This theme was identified through sub-themes: 1) fatigue characteristics; 2) physical fatigue; 3) non-physical fatigue; and 4) causes of fatigue.

Fatigue characteristics

Participants described fatigue as extraordinary, non-stop, and not relieved by rest.

"Men usually look strong, but it (cancer) makes me weak and I cannot do anything" (P9).

"When I am healthy, I can get rid of fatigue with just a short rest. But now I always feel tired, even after resting or taking medication though" (P7).

Physical fatigue

Participants described physical fatigue as unpleasant experiences that hinder daily activities.

"Because of this (cancer), bathing, praying, or other activities I often do sitting or even lying down" (P7).

"I feel troublesome for others. I don't want to bother others, but this condition forces me to be in that situation (dependent on others)" (P6).

Non-physical fatigue

Cancer patients also feel non-physical fatigue (psychological and financial distress).

"I'm experiencing psychological fatigue; something that I think is human. It's like, emotional. I become more irritable. Little things I exaggerate" (P7).

"Both of us (the patient and his wife) are not working, meaning there is no income, we only have medical expenses" (P9).

Causes of fatigue

Participants revealed several factors that can cause and exacerbate fatigue. The participants revealed that fatigue was caused by the course of treatment, uncertainty of health conditions, cancer and symptoms, as well as inadequate nutrition and rest.

"Waiting is something tiring. We seek treatment to recover, but we don't know when. We feel that this treatment actually reduces our health condition, and it is tiring" (P3).

"The treatment queue is making us tired. I had to go back and forth to the hospital and wait for my name to be called. Sometimes the queue is quite long because there is only one doctor there" (P12).

"Cancer is eating away at my body and nutrition. I think that's what makes me tired" (P10).

"In the past, when I first received nuclear treatment, my condition was very weak; might be called a baby. I even had to practice sitting and standing. At that time, I had to struggle just to sit" (P12).

Theme 2: Fulfillment of roles and responsibilities

The second theme is fulfillment of roles and responsibilities in living everyday life. Cancer affects the roles and responsibilities of a person at the individual, family, community, and occupation levels. The participants can no longer be leaders and breadwinners for families. This second theme is divided into three sub-themes, namely family, community, and occupation.

Family

In a family, men play roles and adopt responsibilities as the head of the family, husband, and parents. Fatigue interferes with them in carrying out their roles and responsibilities.

"I can't work at all. At present, my wife and child must work to meet our needs. I regret that very much. This cancer ruins everything, I surrender, I surrender to God" (P2)

"I have been able to carry out my roles and responsibilities. I pray that my family will be fine, especially my children" (P10).

Community

Humans are social creatures who need to interact with others. Participants revealed that their current conditions disrupted the fulfillment of roles and responsibilities in social life.

"Now I rarely get together with friends because I am too tired. I could not meet with them during the day, because I was tired. While they do not have time at night (where physical conditions are not too tired)" (P4).

"I can't. I have been unable to participate in activities in the community because of my limited physical abilities" (P9).

Occupation

Occupation is one of the determinants of male identity. It can become one of the most important things in a man's life. Those with cancer cannot fulfill their roles and responsibilities in terms of work.

"Physically, we cannot work optimally. I used to work from 07.00 to 03.30, but now I am only able to work until 12 because I am too tired" (P6).

"I'm a tailor. Now I started working again by making pants. If in the past I could make one pair in three hours, now I need about two days to do it" (P12).

Theme 3: Adjustment

The third theme is related to adjustment. The participants had to adjust to the decline in their health conditions, leading to changes in the form of masculinity that involves a new awareness of vulnerability to fatigue. This study found that adjustments (such as changing habits or lifestyles) can effectively deal with stress due to fatigue. This theme was identified through physical, psychological, and spiritual approaches.

Physical approach

One of the efforts made by participants to reduce and adapt to their conditions was to take a variety of physical approaches.

"I control my activities. I try to reduce strenuous activities because I get tired easily" (P6).

"Because of this (cancer), bathing, praying, or other activities I often do sitting or even lying down" (P7).

Psychological approach

Participants faced physical and mental problems. Although anger and frustration are accepted as normative aspects of the experience of cancer fatigue, many participants tried to distance themselves from things that can cause stress and to always think positively.

"I don't want to fight or think about things that make me depressed; I have to adjust my mindset. We know that stress will worsen our health condition" (P6).

"One thing for sure that I will recover. I'm sure that every disease can be cured. God will cure me. We must be patient, sincere, and huznuzon (think positive)" (P1).

Spiritual approach

One of the efforts made by participants to adapt to their conditions was through spiritual approaches, such as praying, surrendering to God, and participating in religious activities.

"I have to accept this situation; this is God's plan. I have to accept it sincerely. I only hope that Allah will heal me" (P11).

"I do dhikr, tahajjud, join recitation, or visit an orphanage to calm down. Calmness can reduce my fatigue" (P12).

Theme 4: Social support

The fourth theme in this study is social support. Social support was an important aspect needed by participants in living life. This theme was identified through source of social support and type of social support.

Source of social support

Social support comes from the people closest to the participant. This sub-theme was identified from the family, community, and health worker categories.

"I have the full support of my family. They always take care of me so that I avoid fatigue. They require me to take a nap" (P5).

"This support kept me going. My children, family, friends and neighbors support me" (P7).

Type of social support

Social support plays an important role for patients in dealing with their health problems and includes information,

emotional support, and instrumental support. Instrumental support is related to participants' daily needs.

"For now, I ask for their support. The biggest support comes from the family. They do many things; they even get food for me" (P6).

"With the current conditions, obviously I need family support and assistance. They always ask me to keep fighting and not give up. You know, my wife helps me to do various things. She is amazing" (P9).

DISCUSSION

This study produced four themes that reflect the experiences of men with cancer in dealing with fatigue due to their illness. The first theme is powerlessness. Participants interpreted fatigue as powerlessness and individual experiences that can affect daily life. The fatigue has unique characteristics and is totally different from the fatigue that is felt in a healthy condition. Men with cancer reveal that the body feels tired more easily. They feel physical fatigue where the body feels weak and results in limited ability to perform daily activities. They also feel non-physical fatigue, such as uncontrolled emotions, jealousy toward healthy people, hopelessness, and not being interested in activities. Some participants revealed factors that cause fatigue, such as treatment pathways, health uncertainty, cancer and the symptoms, treatment, and inadequate nutrition and rest. Fatigue is a multidimensional symptom, which includes physical, mental, and emotional aspects.²¹ Men with chronic pain often hide their health condition to maintain their 'image'.²² In fact, they can normalize their cancer experience by promoting responsibility for one's health. By 'becoming aware of his condition', men can emphasize normality as a condition that can affect anyone.²³ Physical and emotional strength is the narrative of all men.²⁴ Chronic diseases, especially diseases that arouse feelings of helplessness, are most likely to generate gender role conflicts in men.²⁵ Negative emotions (vulnerability, fear, or uncertainty related to cancer) are the opposite of the image of men as individuals who are strong, independent, and unemotional. Aspects of cancer experience, including decreased physical function and vitality, are considered a threat to masculinity.²⁶ The predicate of men as strong individuals, as a paradigm of traffic, does not appear in cases of fatigue. Therefore, it is important for patients to be aware of the form of fatigue that is felt through the help of health workers.

The second theme is the fulfillment of roles and responsibilities. Participants revealed a decrease in ability related to fulfillment of roles and responsibilities in family, community, and work. In the family, the patient has a decreased ability to fulfill his responsibilities as head of the family and parents. In addition, the participants also experienced difficulties in their social lives. The participants also reported about work. Most of them were no longer working or on leave. Cancer had significantly affected their lives and those around them.²⁷ Hegemony of masculinity defines the ideal masculine attributes, as well as the broader aspects of patriarchal society.²⁸ Men are expected to be able to be independent and meet the needs of their families. Their ability to make a living shows their masculinity.²⁹ In the context of chronic diseases, women are better able to ignore their healthcare needs for the sake of the family, while men tend to reduce work and be taken care of by their wives/families.³⁰ Female patients can continue to carry out their responsibilities and rule out their illness.³¹ Women usually have more responsibilities than men. When a woman has to struggle with healthcare, then their resources may become fatigue, which leads to adjustment problems and difficulties.³² The ability to work is closely related to masculine values to protect and fulfill the needs of families

where work is one of the benchmarks of their masculinity.²⁴ Failure to carry out roles and responsibilities creates pressure, which can cause feelings of failure, stress, and related health symptoms.³³ Fatigue limits one's ability to work. It makes men feel weak and not independent. Such conditions can affect the patient's health so that other family members have to take over the task.

The third theme is adjustment. Fatigue is a complaint that can occur in all cycles of cancer. Adjustment by changing the shape of masculinity involves a new awareness of vulnerability to fatigue. The patients must be aware of their weaknesses. The patient must be able to balance and control emotions (avoid stress), taking into account aspects of strength and control related to lifestyle changes and in obtaining social support. Although cancer can interfere with gender identity, patients (especially men) must be able to express their masculinity through social values, courage, survival ability, and commitment to recover.³⁴ A man's life is not only related to his personal life, but implicitly also to their family.²³ Men tend to endure the disease, especially when dealing with chronic post-treatment difficulties such as economic difficulties and family support. It is possible to reconcile their masculine values through perseverance and positive thinking so that they can fulfill their roles and responsibilities in the family.³⁵ A spiritual approach might reduce the level of vulnerability, overcome disease, and affect the quality of social relationships.³⁶ Religion or spirituality plays a role in attenuating negative coping, reducing stress, or increasing relaxation.³⁷ Self-acceptance of disease through religious and spiritual power can improve psychological wellbeing.³⁸ There are various approaches to adjust to fatigue. An important aspect that needs attention is the suitability of the approach and the ability of the patient. This suitability determines the development of the patient's health condition (improving or worsening).

The final theme that reflects the experience of men in dealing with cancer-related fatigue is social support. Social support is needed by cancer patients who experience fatigue and can come from family, health workers, and the environment. It can also come from other cancer sufferers. Family has a role to meet the needs and provide attention to increase patient motivation. Health workers can provide their support by providing information related to complaints of fatigue experienced by cancer patients. Cancer patients need information about strategies to minimize symptoms of fatigue. The form of social support from the environment is in the form of motivation. The patients can also share experiences about fatigue. Social support can help patients cope with stress and fatigue.³⁹ Social support has a direct impact on quality of life and can help patients manage symptoms experienced.⁴⁰ Inadequate support is also one of the causes of fatigue in cancer patients.⁴¹ Although social support is considered beneficial for health, not all individuals have the same support due to structural factors and the ability of individuals to fulfill their roles and responsibilities.⁴² Individuals who receive family support generally have better mental and physical health.⁴³ Indonesian society, with a large family structure, can provide support (in various forms) to patients and their families because of strong family ties.⁴⁴ Spouse / children can reduce loneliness and depression, which can reduce the possibility of the patient to experience fatigue. Social support (family, community, and health workers) can increase patient motivation to deal with their fatigue.

CONCLUSION

Fatigue is interpreted by patients as powerlessness (physical and psychological) that cannot be avoided and predicted. It results in a decrease in the ability of male cancer patients to fulfill their roles and responsibilities as head of the family.

Responsibility in meeting family needs, as well as the role in decision-making, is associated with the inability of patients to work for a living due to physical conditions. Adjustments in men with cancer are carried out by physical, psychological, and spiritual approaches. Adjustment by changing habits or lifestyles can effectively overcome the stresses caused by fatigue. Social support is very helpful for cancer patients in dealing with and adapting to their fatigue conditions. In addition, the family plays an important role in maintaining and meeting the needs of patients by providing instruments, information, and emotional support. Therefore, educational interventions on CRF issues can address biopsychosocial aspects, and nursing management is expected to enable patients to secure specific interventions that are oriented toward patient welfare.

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