

CHAPTER I

INTRODUCTION

A. Background

Cancer is a great concern due to the global increasing number of new cases and death Wang et al. (2016). The International Agency for Research on Cancer (IARC) in 2018 stated a global increased of new cases of cancer which up to 18,1 million and 9,6 million deaths during that year. The overall number of individuals living within 5 years of cancer diagnosis, considered 5-year prevalence, is estimated at 43.8 million worldwide (WHO., 2018).

People who have been diagnosed with cancer experiences devastating changes in their lives as it threatens their bodies and their existence (Madsen et al., 2018). A study by Morgan et al. (2017) found that patients with advanced cancer experience a decreased body functionality that lead to vulnerable, unfamiliar, and unpredictable body. Regarding patient emotional reactions, Erol et al. (2018) found that advanced cancer patients who had pain experienced anxiety, helplessness, and hopelessness. They also have an inability to cope with pain and have many limitations in daily life. Furthermore, a study by Stanze et al. (2019) revealed that patients with cancer feel powerless due to high psychological and social tensions and the side effects of treatment that lead to a desire to die, this leads to suffering.

In 1982, Cassel published an important article describing the difference between suffering and physical distress. This article has been a foundation of literature on suffering since then. Casel (1982) state suffering as complex entity that threaten patient's integrity including nature, causes and impact in patients receiving medical treatment. The majority of patients experiences physical suffering, that is manifested in existential pain and movement limitations (Ellis et al., 2015; Erol et al., 2018). Suffering becomes an individual, subjective, meaningful, and complex experience that is multi-dimensional, holistic and all negative things become one, characterized with helplessness, alienation, hopelessness, and powerlessness (Best et al., 2015). Patients tend to experience suffering during the illness trajectory (Chan et al., 2019).

Patients with cancer experience three phases of the illness trajectory, including becoming ill, living with advanced illness, and end-of-life. In the first phase, some patients clearly remember their initial identification of their disease and when being diagnosed. The

shocking news triggered fear for them, because the possibility of die soon arises (Kendall et al., 2015). Besides death, fear occurred when they were concerned about further development of the disease and side-effects of the illness and treatment. Fear can also lead to heightened alienation from society. In contrast, not knowing details of diagnosis and prognosis of the disease, creates excruciating uncertainty (Hartogh, 2017).

In the phase of living with advanced cancer, patients generally move rapidly into a cancer world dominated by physical or psychological complaints, hospital care regimens, and medical appointments (Kendall et al., 2015; van Roij et al., 2019). Uncertainty and low mood often occur as a result of managing treatments and difficulty adjusting to life as a patient with cancer. Any symptoms that appear are sometimes interpreted as implying relapse (Kendall et al., 2015). Symptoms of advanced cancer include pain, weakened physical strength, and paralysis. This make patients lose the ability to move freely and become dependent and being unable actively contribute to society as well (Hartogh, 2017; Madsen et al., 2018). Patients are treated differently from social life since they are diagnosed, cancer becomes the center of their social identity (van Roij et al., 2019). Patients more concerned about how others perceive them that they feel isolated and excluded from social life, especially when being asked questions that focus on cancer and its treatment (Abdollahzadeh et al., 2017; Madsen et al., 2018; van Roij et al., 2019). In this situation, feelings of losing control of their own lives and feelings of alienation make the suffering even more real. The desire to hasten death arises in patients who avoid continuing suffering, leading to the possibility of suicide (Granek et al., 2017).

Suffering increases when death is imminent and inevitable, especially when patients who will die of cancer continue to be treated for their disease (Best et al., 2015; Hartogh, 2017; Kendall et al., 2015). Death becomes clear with relapse and increasing symptoms at end of life (Kendall et al., 2015). The negative emotions that arise in patients who do not accept death are depression and anxiety (Kyota & Kanda, 2019). Not only that, the desire to hasten death is increasing at the end of life in patients who have given up on their lives (Granek et al., 2017).

The consequences of suffering are complex and significant and this must be realized by health professionals such as nurses and doctors, as well as others involved with the patient (Hartogh, 2017). Meanwhile, if an individual's suffering is neglected by health care providers, the patient's distress and feelings of isolation become worse, excessive symptoms of pain and deprivation may arise, requiring more treatments, involving more forms and higher doses of pharmaceuticals, and extending the duration of stay in the

hospital (Deleemans et al., 2020; Sacks, 2013). Due to the lack of understanding of suffering among health care providers, they can unknowingly exacerbate and prolong the patient's suffering experience (Sacks, 2013).

Patients with cancer who experience suffering during illness trajectory need healing (Stuart et al., 2019). Rather than complete recovery from cancer, intended healing is re-establishment of a sense of integrity and wholeness even though pain or other symptoms may continue. The healing process is not simple, but is a complex journey involving relationships with other people and other resources to transcend suffering. Patient suffering can be reduced when appropriate resources such as health professionals, family, friends and other people who are close to the patient accompany the patient in dealing with their illnesses (Scott et al., 2017).

Janice Morse's Theory of Suffering, the experience of illness is used to explain the concepts of suffering and patience. Suffering in this theory is defined as an emotional response to what has been experienced, to current changes, or to anticipate future changes. Individuals move from enduring to suffering when they are able to acknowledge what is being endured, and when they are emotionally strong enough to experience emotional attacks from suffering (Morse & Carter, 1996). Morse developed a practical theory of suffering in which she identified two broad and divergent behavioral conditions of suffering. Morse refers to these conditions as emotional suppression or enduring, and emotional suffering (Foss & Nåden, 2009; Morse, 2001).

Suffering is very important to be understood holistically, because it involves pain and other physical symptoms, and also psychological, existential, and social dimensions (Hartogh, 2017). Health care professionals need to know more about the experience of suffering to be able to assist patients to achieve healing. This illustrates our need to explore suffering in a holistic way. A review conducted by Sacks in 2013 examining patient's experience of suffering but focused on the end of life section of adults with various illness. It is therefore important to carry out a comprehensive systematic review of all phases of the illness trajectory. In an area of limited research, it is important to review all available research that investigated suffering during the cancer trajectory to provide more understanding of the phenomenon. We uses a systematic approach to understanding suffering in patients with cancer during the illness trajectory. This review is intended to contribute to the development and implementation of comprehensive evidence-based care for the experiences of patients suffering particularly from cancer across all phases of the illness trajectory.

B. Review Question

What is the experience of suffering from adult patients with cancer (P) across the cancer trajectory (I) in hospital settings, hospice care and other health care settings (Co)?

C. Objective

The main purpose of this review is to identify, appraise, and synthesize the available qualitative evidence exploring the suffering of patients with cancer across their illness trajectories in hospital settings, hospice care, and other health care settings.

This review will particularly seek to:

1. Knowing the characteristics (eg, design of study & patient characteristics) in the available studies related to suffering in cancer patients across their illness trajectory in hospital settings, hospice care, and other health care settings.
2. Knowing the results of the synthesis and analysis in the form of themes from the evidence included in the available research exploring the suffering of patients with cancer across their illness trajectories in hospital settings, hospice care, and other health care settings.

D. Advantages**1. Nursing practice**

The synthesized findings will highlight experiences of suffering in patients with cancer that are individual, holistic and multidimensional. It is recommended that nurses in hospitals, hospice care, and other primary care places maintain awareness to be able to help patients not give up and accompany patients during cancer trajectories. In addition, after understanding the context of suffering in cancer patients, nurses are expected to be able to help patients to achieve a healing process earlier, not to mean complete recovery from the disease, but rather to re-establish a sense of integrity and wholeness even though pain or other symptoms appear continuously.

2. Education

Providing education by increasing the ability of palliative care services, nurses who are still in education can be taught to understand the context of suffering in patients with life-limiting illnesses, one of which is cancer. Education can guide students to help, assist, and overcome suffering in patients. The context of suffering a cancer patient is given when education starts with orientation and continues throughout the nurse's career.

3. Future research

The results of this review may be used as a basis for further research. Future studies of the form of qualitative study may be carried out by exploring the context of suffering in patients with life-limiting illnesses, one of which is cancer, not only of the patient but also of the family and health professionals. Through quantitative research, the findings of the review may be used as a basis for identifying effective treatments as interventions to minimize suffering in patients with life-limiting illnesses, one of which is cancer.