

CHAPTER I

INTRODUCTION

This chapter explains the background, formulation of the problem, and the purpose of the study which aims to show how parents are involved in decision-making related to cancer treatment in children.

1.1 Background

Cancer was once considered a relatively straightforward disease, advancements in our understanding of its genetics, pathology, and treatment options have made it more challenging to manage. Conventional cancer therapies often require a trial-and-error approach to find the most effective patient-specific treatment combinations (Sebastian & Peter., 2022). Cancer patients usually face a dilemma when choosing treatments, as each option carries different risks and impacts on both survival rates and quality of life (Rietjens et al., 2024). To assist patients in making these complex decisions, a collaborative approach known as shared decision-making (SDM) is a suitable solution (Shickh et al., 2023). This SDM was mentioned to empower patients, promote informed choices, align care with patient preferences, foster patient-centered care, challenge medical paternalism, and promote high-value care (Stiggelbout et al., 2012).

Preferences for patient-centered, family-led, doctor-led, or paternalistic decision-making are influenced by their beliefs and views on patients' rights, the responsibilities they experience, or the patient's inability to undergo treatment independently (Martina et al., 2022). According to Tan et al. (2022), the decision-making process among Asian Americans is heavily influenced by the role of family and community, who provide emotional, social, and functional support. Patients often make the final decision with close family members or delegate it entirely to them. According to the study by Ozdemir et al. (2021), the most reported perceived and preferred role in decision-making across all countries was one with no patient

involvement. This is likely due to the collectivistic nature of the countries involved in the study, where the family plays a key role in decisions and a more paternalistic view of physicians is prevalent. A passive role in decision-making may still be commonly experienced and preferred by advanced cancer patients in low- and middle-income countries in Asia. As preferences in decision-making continue to evolve, paternalistic practices have been increasingly criticized, giving way to shared decision-making as the preferred approach (Fleisje, 2024). In fact, effective SDM should require the involvement of at least two participants, not only the healthcare provider but also the patient or family caregiver, with both parties establishing communication in sharing information about decision-making and taking the necessary steps to reach a consensus on the preferred treatment (Faiman & Tariman, 2019). However, a study in Indonesia points out that physicians frequently exhibit reluctance to engage in meaningful conversations with their patients. Factors such as excessive workloads and the perception that medical professionals possess superior knowledge often contribute to this issue. Consequently, patients often feel disrespected and excluded from the decision-making process regarding their care (Khairunnisa et al., 2023).

Many global healthcare systems recognize the benefits of shared decision-making between patients and healthcare providers and the importance of focusing on patient needs in healthcare (Colligan et al., 2017). Instead of doctors making all the decisions, patients are now more involved in their treatment decisions. SDM is now popular in several Western countries moving away from the old "doctor knows best" approach (Rostoft et al., 2021). Given that parents may be legitimately concerned about their children's healthcare. As an example, in a study in Guatemala, some parents were offered with the option to select treatment and to make decisions for future treatment. While some parents were not given any options. A certain group of parents prefer that the doctor make the most or the best decision rather than being offered additional possibilities. Additionally, certain patients' parents were granted the opportunity to make a decision; however, they were only provided with the choice between the finest possibilities, while others were not (Graetz et al., 2022). In contrast, a study in Norway stated that some

parents feel a lack of influence and control over their child's healthcare (Aarthun et al., 2019).

Shared decision-making (SDM) in pediatric care is complex due to the involvement of various caregivers and the dynamic nature of children's decision-making skills (Lipstein et al., 2016). These collaborative relationships must extend beyond the patient to include the family, particularly parents, who are integral in making decisions on behalf of their child (Shickh et al., 2023). It's considered as part of the cultural aspect which plays a key role in making the decision (Pun et al., 2018). He further explained that in many Asian cultures, healthcare decision-making is deeply rooted in communal values, particularly within families. This cultural context often leads to lower patient involvement in decision-making, regardless of educational level. A previous study in Yogyakarta explained that there are parents who decide on life-sustaining treatment of critically ill children in Indonesia (Nurnaningsih et al., 2021). In line with this study, a health survey study done by Prasetyo et al. (2022) showed that parental decision-making regarding the treatment for children under five years old is decided by their parents, especially the father. The father, who serves as the chief of the family in Indonesia's patriarchal and authoritarian culture, has a highly predominant position within the family. This also influences the decision-making process in the family based on the Father's Decision (Mustika et al., 2013). Across various systems worldwide, this might be due to the differences in healthcare systems, for example, access to treatments is inconsistent, making it challenging and uncertain for parents to navigate treatment decisions (Pearson et al., 2022).

Based on the background above, the researchers investigated parental involvement in pediatric cancer patients' treatment decision-making. This research has provided more specific and relevant insights to support optimal decision-making processes for pediatric cancer patients.

1.2 Problem Statement

Based on the study conducted in Norway, parental involvement in children with cancer treatment decision-making is important. However, implementing shared decision-making (SDM) is still lacking in several countries. Some parents feel they are not fully involved in their child's treatment decisions. Various forms of involvement, such as emotional support and advocacy, as well as participation in clinical decisions, play an important role in decision-making. In addition, the impact of parental involvement on the parents specifically for pediatric cancer treatment decisions remains unclear. This study aims to identify preferences, various forms of parental involvement in decision-making and the impact of parental involvement on the parents globally.

1.3 Aim of the Study

1.3.1 General objectives

The objective of this study was to explore and explain on the parental involvement in pediatric cancer treatment decision-making.

1.3.2 Specific objectives

- 1) This study investigated the parents' preferences in pediatric cancer treatment decision-making.
- 2) This study identified the types of parental participation in pediatric cancer treatment decision-making.
- 3) This study examined the impact of parental participation on the parents themselves.

1.4 Research Question

- 1) What are parents' preferences for involvement in decision-making for pediatric cancer treatment?
- 2) What kinds of parental involvement in the decision-making process regarding the treatment of pediatric cancer patients?

- 3) What are the impact of parental participation on the parents' themselves?

1.5 Research Benefits

1.5.1 Theoretical Benefits

The findings of this review are expected to contribute significantly to nursing knowledge, specifically in facilitating decision-making in pediatric cancer care. It is expected that this study's outcome will be presented at the international nursing conference and be published in the International Nursing Journal.

1.5.2 Practical Benefits

- 1) This study could help to understand the types of parental involvement in decision-making and their impact. By this understanding, healthcare providers can develop strategies to optimize parental involvement in decision-making, potentially leading to better treatment outcomes and improved quality of life for pediatric cancer patients.
- 2) This study could help to improve the overall experience of children with cancer and their families by providing them with greater opportunities for involvement in decision-making.
- 3) The findings of this study could inform the development of policies and guidelines related to parental involvement in decision-making pediatric cancer care.