Navigating Shared Decision-Making in the Palliative Journey of Cancer Patients

A Systematic Literature Review

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Abstract

Cancer patients in palliative care often encounter complex decisions and challenges throughout their journey. Shared decision-making (SDM) is an element of patient-centred care where decisions concerning patients' care are made by collaborating with the patient, the healthcare team and the patient's family to align with patients' values, preferences, and goals. This study aimed to explore and promote the facilitation of SDM in palliative care for cancer patients.

A qualitative systematic literature review methodology with a comprehensive literature search of scientific electronic databases which included EBSCO, CINAHL, PubMed, Springer Link and DOAJ was employed in this study. The theoretical framework employed in this study is Brendan McCormack's Person-Centred Nursing (PCN) framework.

Six (6) key themes and fifteen (15) sub-themes emerged in total from the twenty (20) articles analysed. The main findings showed that cancer patients prefer collaborative decision-making and wish to discuss issues that extend beyond their illness. Education of patients and training of health care professionals (HCPs) also proved to be vital strategies for promoting SDM.

In conclusion, a clear understanding of experiences, values, and preferences of cancer patients helps in the development of tailored strategies to facilitate the shared decision-making process, ultimately enhancing a more holistic and patient-centred approach to palliative care.

Language: English

Key words: Cancer Patients, Communication, Shared decision-making, Palliative care, Patient-centred care, Patient participation, Patient perspectives

List of Abbreviations

Abbreviation	Definition
ACP	Advance Care Planning
BCV	Breast Cancer Video
DAs	Decision Aids
DCPs	Decisional Control Preferences
EAPC	The European Association for Palliative Care
HCPs	Health Care Professionals
NSCLC	Non- Small Cell Lung Cancer
PCC	Patient Centred Care
PCN	Patient Centred Nursing
RN	Registered Nurses
SDM	Shared Decision Making
WHO	World Health Organization

Table of contents

1 Introduction

Palliative care entails active and comprehensive care provided to a patient with an illness expected to significantly limit their lifespan. A wide array of diseases such as cardiovascular diseases, cancer, chronic respiratory diseases, and diabetes necessitates the provision of palliative care (WHO, 2021) however, this study focuses on cancer because of its uniqueness to other illnesses, including the many forms it takes and the distinctiveness of its journey for every patient (OSF Healthcare, 2022). Palliative care often involves helping patients and their families in navigating challenging decisions (Sullivan et al., 2021).

In 2020, cancer was responsible for almost ten million deaths worldwide, making it a leading cause of mortality (WHO, 2023). Palliative care is a pressing humanitarian need for people suffering from cancer and other chronic, life-threatening diseases worldwide, however, only 14% of those requiring palliative care have access to it. Cancer emerges as the second most prevalent disease accounting for 34% of adults requiring palliative care (WHO, 2020). Palliative care is a human right specified under the human right to health and is needed in places with a high proportion of advanced-stage cancer patients with little chance of cure (WHO, 2010).

Shared decision-making (SDM) is an element of patient-centred care (PCC) and an essential aspect of palliative care where the decisions concerning patients' care are made by collaborating with the patient, the healthcare team and the patient's family about treatment options that align with patients' values, preferences, and goals. In accordance with the guidelines set by the European Association for Palliative Care (EAPC) patients receiving palliative care have the right to participate in the decisions-making processes concerning their care (Kousmanen et al., 2021).

This research is motivated by the recognition that advanced cancer patients in palliative care are often faced with complex decisions especially in the progression stages of the disease where there may be treatment failure and subsequent deterioration in the patient's condition. This awareness propels the exploration of SDM in the context of palliative care emphasizing a broader focus that extends beyond the disease itself.

The enhancement of patient-centred shared decisions improves the quality of care, and patient satisfaction and reduces the overall cost of care. The desire for patients' comprehensive involvement in shared decision-making is however rarely met by healthcare professionals (Kousmanen et al., 2021). Therefore, in exploring how SDM can be promoted in palliative care for cancer patients, it is crucial to examine patients' perceptions, preferences, and experiences regarding the decision-making process (Shamieh, 2023). This study offers insights into facilitating decisions that enhance the overall well-being of cancer patients with a focus on their values and needs and encourages healthcare providers including nurses, and organisations to prioritise PCC and empower patients to participate in decision-making, which will result in better patient outcomes, increased patient satisfaction and an improvement in the quality of palliative care.

2 Background

The background of this study began with a look into previous studies that have been carried out in shared decision-making (SDM). This enabled the researcher to identify gaps that need to be tackled also serving as the foundation for this research. The interest in SDM has significantly risen in recent years, however, there are still significant gaps that need to be addressed to ensure that palliative care aligns with patients' values and preferences within various healthcare systems (Belanger, 2017). Palliative care teams encounter several barriers to actively involving patients and families in decision-making, limiting the chances to explore the fundamental values, preferences and goals that ideally shape the provision of care for individuals facing serious illness (Washington et al., 2022).

Brom et al., 2015, conducted a study to explore whether and in what ways SDM can be realised regarding second and third-line chemotherapy. The results of this study showed that despite patients' satisfaction with the decision-making process, the implementation of the steps involved in SDM was not noticed in daily practice. Patients were not adequately informed about all the treatment options available, and therefore their desires and concerns were not adequately addressed, which led to varied expectations about the effectiveness of subsequent lines of chemotherapy for improved survival.

Rocque et al., 2019 also recognized the presence of dissimilarities in the perspectives of patients and oncologists concerning treatment and care objectives, resulting in a participation deficit. The insufficiency of precise guidelines for patients and doctors to facilitate effective participation in the decision-making process has also played a role in this deficit (Rocque et al., 2019).

Additionally, Arends et al., 2022 have revealed nurses' desire to participate more in SDM than their actual role allows them and prefer to be actively involved in the support of patients' treatment decisions. Nevertheless, studies in this field have not shed much light on the involvement of everyday nursing care decisions which is also important in the provision of more holistic and patient-centred palliative care (Kousmanen et al., 2021).

2.1 Overview of palliative care

The term "palliation" originates from the Latin word *'pilliare'* which means to conceal or shield. We can view palliation as protection against the adverse effects of illness. Palliative care is interpreted differently among individuals. According to the World Health Organization (WHO), palliative care upholds life and considers dying as a natural phenomenon of life with no intention of speeding up or delaying death. The emphasis is on the management of symptoms (Hallenbeck, 2022, p.9). Enhancing the well-being of individuals in palliative care is not limited to only timely identification and treatment of pain, but also relief of suffering from other problems which include physical, psychosocial, and spiritual (MacLeod & Block, 2019, p.4).

In summary, the physical forms of palliative care include pain relief, symptom management and alleviation of discomfort. The psychosocial aspect involves emotional and mental support as well as the fulfilment of goals and desires whereas the spiritual form encompasses empowerment, finding purpose and closure (Oasis, 2023).

Following the WHO definition of palliative care, some principles of care have been outlined (see Box 2.1) serving as the basis for attaining the primary objectives of palliative care which includes improving the quality of life and alleviating the suffering of patients from a life-threatening illness (Faull & Blankey 2015, p.4) regardless of whether they are close to dying or not (Hallenbeck, 2022, p.9). These care principles indicate a multidisciplinary approach to palliative care. The palliative care team comprises patient carers, nursing care, medical care, social care, spiritual care, therapists, and volunteer workers (Bryan et al., 2015, p.35). It is unrealistic to expect a single profession or person to possess the expertise for the needed assessment, implementation of interventions and continuous monitoring (O'Neill & Fallon

1997). The principles can be seen as those of good clinical practice; a holistic approach encompassing all aspects of care such as medical, nursing, psychological, social, cultural, and spiritual (Doyle, 2023).

Box 2.1 The principles of palliative care (adapted from WHO definition)

- Affirmation of life and viewing dying as a normal process.
- No intention to hasten or postpone death.
- Alleviation of pain and other distressing symptoms.
- Holistic care approach (physical, psychological, social, and spiritual care needs of the patient)
- Support of patients to live actively as much as possible until death.
- Support of family throughout the duration of the patient's illness and when they are bereaved.
- The use of a team approach to facilitate patient and family needs.
- Applicability in the early stage of illness, in combination with other therapies aimed at prolonging life.

Adapted from Faull, C., & Blankley, K. (2015). Palliative care (Second edition.). Oxford University Press.

2.1.1 Palliative care in the context of cancer

The oncological meaning of palliative care basically implies noncurative, life prolonging care (Hallenbeck, 2003). According to WHO, cancer stands as one of the most common causes of mortality (WHO, 2020). Cancer cases in Europe will increase by 24 per cent by the year 2035 if rapid measures are not taken. As the number of persons affected by cancer increases, public health is faced with significant challenges both on a national and global level which will impact the lives of many (Sulosaari, 2022). Simultaneously, there has been improvement in the results of treatment and a decrease in death rates. However, research and developmental efforts have particularly centred on medicine, even though providing cancer care demands multi-professional and multidisciplinary research and cooperation (Sulosaari, 2022).

Palliative care has been developed as a specialized medical care that is not particularly centred on disease control but also addresses the physical and psychological needs of the patient. It may also be provided together with cancer treatments with chances to decrease the tumour burden and depressive symptom alleviation. This information must however be communicated effectively to the patient by healthcare professionals and emphasis laid on securing effective palliative care and helping to preserve patient dignity. There is a smooth transition to palliative care when the status of the illness and prognosis are communicated. The emotions of the family are also addressed which makes the palliative care conversation possible. The patient-physician relationship is improved when the values and wishes of terminally ill patients and their relatives are assessed (Kaur & Mohanti, 2011).

Howie & Peppercorn, (2013) have highlighted in their study that when palliative care in cancer is initiated in the preliminary stages of the disease, it can lead to improved management of symptoms, and less stress during therapy and care delivery that aligns with the patient's goals.

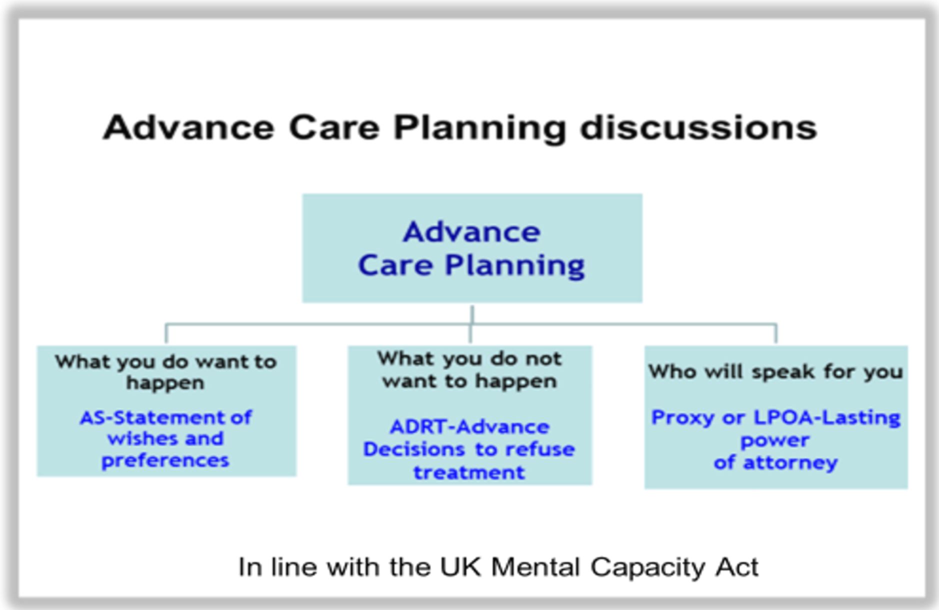
A major approach to improving the quality of life among cancer patients in palliative care is the use of radiation therapy and chemotherapy to alleviate symptoms and relieve pain (Ghandourh, 2016). Advanced cancer patients often misconceive the purpose of treatment and their overall prognosis (Robinson, et al., 2008) and hold unrealistic expectations of their cancer being cured (Ghandourh, 2016). When patients do not have a full understanding of their prognosis and treatment restrictions, they are unable to make informed decisions about choices of treatment and end-of-life care (Ghandourh, 2016).

The effects of cancer and its treatment vary from one person to the other. Palliative care addresses a wide range of issues taking into consideration the unique needs of each patient which include physical, emotional, and coping needs, spiritual, caregiver needs and other practical needs (National Cancer Institute, 2021).

2.1.2 Advance Care Planning for cancer patients in palliative care

Advance care planning (ACP) is a process that involves a conversation about the goals for care providing patients and their family members the chance to consider the type of care and medical interventions that are suitable or not in the future (Tetrault et al., 2022). ACP is highly significant in palliative care due to the several aspects of patients' needs that require careful consideration (Lovell et al., 2012). Discussions of ACP (see Figure 2.1) have resulted in several positive patient outcomes, such as a reduction in hospitalization, decreased levels of anxiety and depression, increased utilization of palliative care services, and improved satisfaction and quality of life (Kubi et al., 2020).

Figure 2.1: Advance Care Planning discussions



Adapted from the gold standards framework.
https://www.goldstandardsframework.org.uk/advance-care-planning

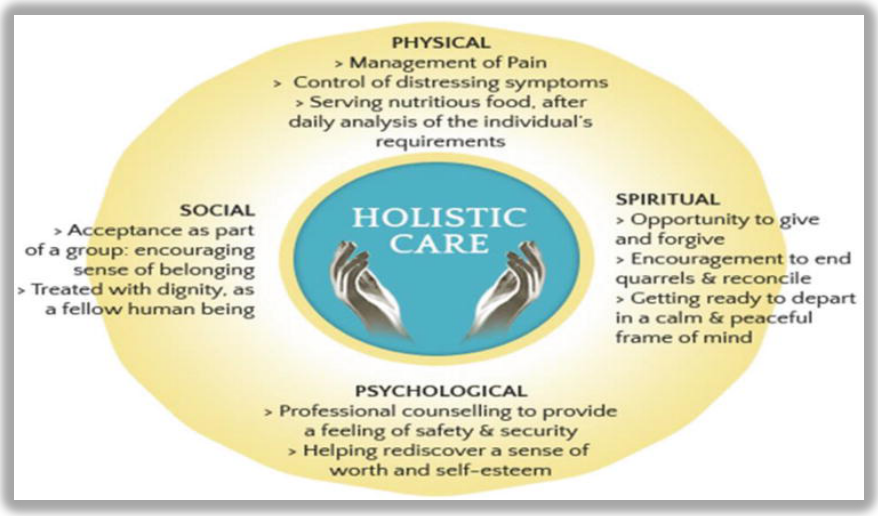
Cancer patients in palliative care represent a population recognized for serious illness and complex management needs for whom conversations about care planning are relevant. ACP plays an important role in comprehensive cancer care. (Berkowitz et al., 2021). Palliative care makes use of ACP which ensures that the care is aligned with the patient's wishes and includes instructions that guide the physicians and nurses in responding to changing situations throughout the duration of care. Making plans well in advance guarantees excellent quality care during the last phase of life. All healthcare professionals involved in the patient's care must have access to the ACP (THL, 2023).

According to a study conducted by Fleuren et al., 2020 the core goals of ACP include respecting individual patient's autonomy, enhancing the quality of care, strengthening patient and healthcare provider relationships, making end-of-life preparations, and reducing unnecessary medical interventions. ACP also includes a reflection on patients' values and preferences for future care in cases of inability to communicate, which may be because of a decline in cognitive capacity or frailty. This could be shared with trusted people like family and friends involved in the patient's care (Vellani et al., 2023). The ACP is written collaboratively by a physician and the patient and/or with the patient's family where necessary. It is a comprehensive plan which includes the wishes of the patient and decisions in advance, medical condition and prognosis, approach to care (care goals), care limitations or procedures that may cause adverse effects, views of family members, place of care, contact persons, guidelines for when the patient's condition worsens which includes pharmaceutical and non-pharmaceutical treatments and prescriptions as well as tools that may assist in alleviating symptoms (THL, 2023).

2.1.3 Palliative care as a holistic approach

Florence Nightingale and other proponents of 'holism' in health care, define holistic care as a reflection of the entirety of a person, physically, psychologically, socially, and spiritually in the provision of care and prevention of illness. For a person to be cared for as a whole, all the above aspects of the person's life must be managed together. A holistic approach is implemented when healthcare providers are well-equipped and understand a patient's whole life situation (Ndiok et al., 2020). The components of holistic care (see Figure 2.2) consider the physical, social, psychological, and spiritual needs of the person (Ndiok et al., 2020) and these have a direct link to the forms of palliative care mentioned in Chapter 2.1 indicating the holistic nature of palliative care. The *'whole person'* is a fundamental principle of holistic care where the individual is viewed as an integration of the body, mind, spirit and the environment and systems in which they operate (Ventegodt et al., 2016, p.1936).

Figure 2.2: Components of holistic care



Adapted from Ndiok, A.E., Oyire, E., & Ncama, B. (2020).
https://www.intechopen.com/chapters/72585

Ndiok et al.,2020 also identify some principles of holistic approach outlined in Box 2.2. The holistic assessment is a tool utilised by nurses to assist patients and their families during the end-of-life phase and in decision-making regarding palliative chemotherapy (Streck & Wood, 2019). This method guides the conversation between the nurse and patient or family and helps to determine whether there is a need for further interdisciplinary services or support from clergymen, social workers or pain management expects (Streck & Wood, 2019).

Box 2.2 The principles of holistic approach

- Every individual possesses natural curative powers.
- The patient should be regarded as a person, not solely as a disease.
- An effective healing therapy needs a collaborative team effort.
- Both the patient and healthcare team work together in the healing process.
- Treatment includes addressing the underlying cause of the illness, not just alleviating the symptoms.

Adapted from Ndiok et al., 2020. The principles of holistic approach.
https://www.intechopen.com/chapters/72585

2.1.4 Palliative nursing care and the nurses' role

Palliative nursing care combines competent clinical skills, deep listening and communication skills and the ability to be present during immense suffering to provide the needed care and support as well as hope to the patient and his or her family even in the face of death (Ferell & Coyle, 2010).

The nursing profession has played and continues to play a vital role in the provision of palliative care (Fitch et al., 2015) where the palliative care nurse's relationship with the patient is characterized by warmth, compassion, and trust which forms the foundation for a healing relationship while paying attention to the patient as a whole person (Ferell & Coyle, 2010). Registered nurses (RN) form a significant percentage of healthcare providers who play a crucial role in the palliative care team and promote patients' autonomy in decision-making globally (American Nurses Association, 2017).

All members of the palliative care team play a significant role in delivering care to patients. However, the presence of a palliative care nurse cuts across all aspects of care. Patients' desire to participate in nursing care decisions in palliative care also indicates the significance of the nurse's role in empowering patients to participate in decision-making about their care. Nurses' role in SDM is worth noting because they are often at the centre of coaching and advocating for patients, assessing the condition of the patient, and serving as a link between the patient and the interdisciplinary team in the dissemination of information (Kousmanen et al., 2021).

Regardless of the specific type of care required, the nurse serves as the primary mediator between the healthcare team, the patient, and the family. They bring the team's plan to the patient's bedside, whether at home, in the clinic, or in a hospital (Ferell & Coyle, 2010).

The palliative care nurse, who is an integral part of the team, contributes significantly to the team and participates in the care planning process. This entails consistent evaluations of the patient's objectives, anticipations, practical interests, and the intricate aspects of familial connections. Moreover, if relevant, the nurse also works to promote reconciliation and understanding when engaging with individuals who have been emotionally distant (Cheluvappa & Selvendran, 2022).

As noted by Sekse et al., 2018, the nurse's roles span multiple areas, such as advocacy to ensure the patient's understanding of information and feedback from the doctor and other care providers, enhancing clear communication between the patient, their family and healthcare providers and assisting patients in discussing topics which they find difficult to talk about. Nurses also act as care coordinators, overseeing the organization of services designed to providing support for both the patient and family. Furthermore, nurses provide support and education to patients and their families as well as the provision of emotional support.

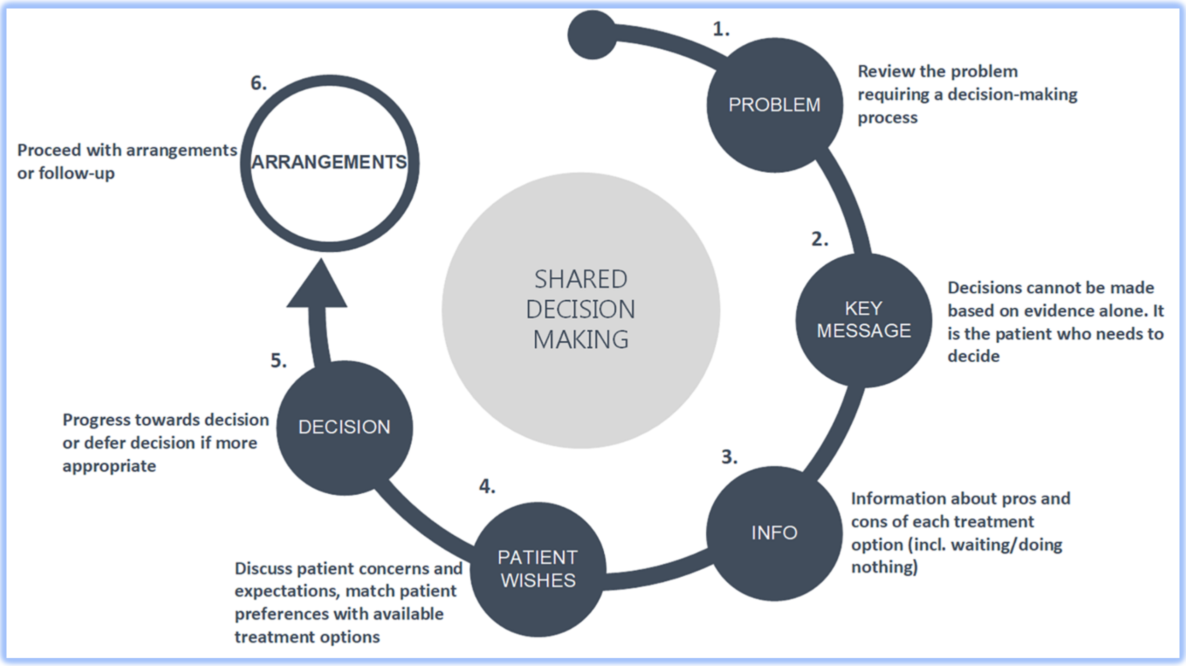
Furthermore, palliative care oncology nurses help to bridge the gap of continuity by delivering both physical and psychosocial support throughout the entire cancer journey and beyond. Oncology nurses champion patients' needs and address various ethical and legal facets of care as they ensure that patients receive palliative care throughout the progression of illness from curative to palliative treatments (Schroeder, 2018).

2.2 Shared decision-making in palliative care

Shared decision-making (SDM) comprises four key features. These include involvement of at least two participants (physician and patient); information sharing between both parties; both parties working together to agree on the preferred decision; and reaching an agreement on the decision to implement. These key characteristics are known as the Charles et al., 1997 model of SDM (Huagom et al., 2023). Rosca et al. 2023 summarize the elements of SDM (See Figure 2.3) in six steps. Nevertheless, it is important to note that as the interaction evolves, the steps initiated at the beginning of a medical encounter may undergo certain changes (Gafni & Charles, 2010).

SDM is based on the premise that healthcare professionals are the experts in medical evidence and patients are their own experts on what matters to them most (Roordink et al., 2019). Basically, SDM includes ensuring patients are informed of reasonable options, providing comprehensive explanations with professional recommendations, exploring the preferences of the patients, and fostering communication to aid patients in deliberation (Huang et al., 2020). The primary responsibility for the effective facilitation of patient participation in SDM in palliative care is held by healthcare professionals and the institutions of palliative care (Kousmanen et al., 2021).

Figure 2.3: Shared decision-making process as described by Makoul and Clayman



Adapted from Rosca et al., 2023. https://doi.org/10.1186/s12910-023-00944-7

In cancer care, healthcare providers must work with patients by demonstrating competence and compassion, to create a practical cancer care plan which should be built on relevant evidence, consider emotional aspects of the problem, and be both achievable and sustainable for the patients. Consequently, SDM is not an extra duty for clinicians; rather, it is a fundamental approach to care akin to activities such as gathering medical history, conducting physical examinations, choosing, and interpreting diagnostic tests, and offering education and counselling to the patient (Shickh et al., 2023).

The following ethical principles underpin the decision-making process: autonomy, beneficence, nonmaleficence and justice. Autonomy is the right of the patient to self-governance which affirms every individual's right to choose what kind of care they wish to receive and to ensure that those choices are acknowledged and respected; Beneficence requires healthcare professionals to act in the best interest of the patient. This denotes the obligation to defend and advocate for the delivery of the most beneficial intervention for the patient; Nonmaleficence is the ethical principle that underscores refraining from causing harm to the patient which is a basic rule of good medical care. While some medical procedures may cause discomfort or some harm, nonmaleficence is based on the moral reasoning for causing harm. There can be justification for harm when the benefits of the medical intervention surpass the harm it poses to the patient and the intervention is not to intentionally inflict harm; Justice involves the guarantee of equal allocation of healthcare resources and fairness in the provision of healthcare services (Akdeniz et al., 2021).

2.2.1 The role of family in shared decision-making in palliative care

The family is an invaluable source of companionship and support for severely ill patients as well as those towards the end of life. They offer emotional support to patients and play a significant role in patients' decisions concerning their choice of an oncologist, hospital, and treatment options. Additionally, family members can either promote or impede a patient's decision to opt for the best supportive care, prioritizing symptom management and quality of life (Laryionava et al., 2018). It is very common for family members to play an essential role in providing care for cancer patients, and they are frequently involved in the decision-making process for cancer treatment (Hobbs et al., 2015). Palliative care patients who have the capacity to make decisions should be able to also demonstrate their autonomy in determining the nature and extent to which family members are involved (Kousmanen et al., 2021).

When family members are involved in the early stages of the decision-making process, they can better adjust to the reality of patients' incurable illness, become more prepared for impending loss, and reduce their psychological distress (Laryionava et al., 2018).

The family has a significant impact on the decision-making process, with patients often making the ultimate decisions after consultations with their family members (Tarberg et al., 2022). It is also common for family members to be called upon to make decisions on behalf of their loved ones at the end of life who are incapacitated and unable to make decisions which may include a decision to determine whether to start, withhold, sustain, or terminate life-sustaining treatments. Making these decisions could however be emotionally draining for family members (Trees et al., 2017).

Furthermore, collaboration is another crucial role of the family in SDM in palliative care. Family members work with the patient's medical team to help with the interpretation of advance directives and prior goals of care discussions, with the aim of making medical decisions that align with the patient's preferences and values. The additional support from close family's advocacy for the patient may alleviate stress and offer comfort even when patients are still capable of making their own medical choices (Sudore et al., 2014).

2.2.2 Benefits of shared decision-making in palliative care

According to Kuijpers et al., 2021 there are several reasons why shared decision-making (SDM) holds great value especially in the oncological field. SDM can assist both patients and their caregivers to comprehend and adapt to palliative care. It enables elaboration on concerns and promotes a patient-preferred goal of treatment as well as the development of effective patient-centred communication with patients. When patients are involved in decision-making for their own care plan it enhances their human dignity and improves satisfaction and compliance (Tseng et al., 2023).

Another significance of SDM in palliative care is that it helps to provide patients with information about the most effective interventions tailored to their specific circumstances while incorporating patients' needs and values into the decision-making process. Additionally, it aims to enhance the dialogue between patients and clinicians which promotes collaborative decision-making (Politi et al., 2012).

While SDM allows patients to actively participate in their own care, it enhances patients' awareness of their health status which increases their motivation to assume responsibility and foster a sense of over their treatment. Patient engagement also has a positive impact on behavioural changes which include lifestyle changes and adherence to preventive measures aimed at reducing the risk of pathology-related complications (Galleta et al., 2022).

Moreover, despite the limited opportunities for patients to effectively participate in the decision-making regarding their care, the results of SDM have been noted to lead to decreased utilization of invasive interventions, increased patient safety, reduced costs in healthcare, enhanced patient satisfaction, empowerment of patients and a better-informed patient population (Kousmanen et al., 2021).

2.2.3 Autonomy and decision-making in palliative care.

The principle of autonomy is a fundamental ethical principle in palliative and end-of-life (Virseda et al., 2020) which acknowledges the rights of individuals to self-determination and comprises the right to hold their own views, make decisions, and act in accordance with their own values and beliefs. Autonomy focuses on the patient's priorities rather than those of healthcare professionals and indicates what health means to the patients themselves (Nicol & Nyatanga, 2017, p.107).

When discussing patients' right to make decisions, we are referring to respect for a patient's autonomy (Tahmasebi, 2022) which involves our obligation as healthcare professionals to tell the truth to the patient, respect their privacy and maintain confidentiality. Furthermore, patients can be supported in exercising their autonomy by teaching them to make their own decisions without force or coercion (Nicol & Nyatanga, 2017, p.107).

Decisions cannot solely rely on evidence; the individual themselves needs to decide. Respecting a person's autonomy demands that they are adequately informed about potential gaps in evidence, its quality, or inconclusiveness, and the fact that the treatment options available may often present various benefits and risks for each patient. It therefore falls upon individuals to determine whether the benefits exceed the risks, and which uncertainties they are comfortable with. If the individual is still uncertain about their preference for a treatment option after discussing all the benefits and risks available, the healthcare provider may either offer a treatment recommendation or postpone the decision to a later time (Rosca et al., 2023).

2.3 Overview of Patient-Centred Care

The Picker Commonwealth Program for Patient-Centred Care (1988) introduced the concept of patient-centred care (PCC) to highlight the need for healthcare that fosters collaboration between health care providers, patients and their families to ensure that decisions align with the desires, preferences, and needs of the patient and emphasizes the need for patients to be provided with the necessary education and support needed to enable them make informed decisions and actively participate in their own care (Edgman-Levitan, 2021).

Barry & Edgman-Levitan (2012), state the following in regard to PCC:

> "*The most important attribute of patient-centred care is the active engagement of patients when fateful health care decisions must be made — when they arrive at a crossroads of medical options, where diverging paths have different and important consequences*" (Barry & Edgman-Levitan, 2012).

The above quote places SDM as the primary focus of PCC, which is also confirmed by Graham et al., 2021 who stated that SDM is a critical part of PCC, highlighting patient's active participation in healthcare decisions as the "responsive" vision of PCC. According to the World Health Organization (WHO), the overall goal of PCC is one where individuals, families and communities are provided for and can engage in trusted healthcare systems that address their needs in a compassionate and holistic way (WH0, 2007).

An early definition of PCC which continues to be widely used is provided by Kitwood (1997) which describes person-centredness as a status or standing conferred unto one human being by others, within the context of interpersonal connections and societal existence which conveys recognition, respect, and trust (McCormack & McCance, 2010). At the heart of patient centred nursing lies four (4) core components namely: 'Being in relation', 'Being in a social world', 'Being in place', and 'Being with self'. McCormack (2004) makes a link (See Table 2.1) between these concepts and Kitwood's definition of person-centredness.

Table 2.1: Relationship between Kitwood's definition and concepts of person-centredness

Concept	Link with Kitwood's definition
Being in relation	Person exists in relationships with other persons
Being in a social world	Persons are social being
Being in place	Persons have a context through which their personhood is articulated
Being with self	Being recognised, respected, and trusted as a person impacts on a person's sense of self

Adapted from McCormack, B., & McCance, T. (2010). Person-centred nursing: Theory and practice. John Wiley & Sons, Incorporated.

Patient-centred care (PCC) involves acknowledging and addressing the unique needs, preferences, and values of each patient in every clinical decision made (Kwame & Petrucka, 2021; Fang & Tanaka, 2022), and is one of the principal elements in delivering palliative care and support to cancer patients and their families from diagnosis to the last days of a patient's life and after the death of the patient (Aghaei et al., 2021).

The Picker Institute identifies eight principles on which person-centred care (PCC) is grounded (See Figure 2.4). The first core element is respect for the values, preferences and expressed needs of the patient. This involves patients' right to participate in decisions about their health care and healthcare providers ensuring that care is delivered in accordance with patient values and needs. Care coordination and integration is another vital pillar of PCC. When care is properly coordinated, vulnerability in the face of illness can be reduced. Clear information, communication, and education form another essential principle. Patients should be provided with information, which is reliable, high quality and easily accessible throughout their care journey.

Furthermore, is the provision of physical comfort such as management of pain, assistance with activities of daily living and providing a comfortable and conducive environment which can impact patients' experiences and outcomes. Emotional assistance and alleviation of fear and anxiety are also integral to this holistic approach which denotes that the provision of care should be empathetic, and the emotional needs of patients should be recognised.

Family and carer involvement is further acknowledged as crucial to PCC. Patients receive wider support from their families, carers, and friends and this must be acknowledged by healthcare providers. Involvement of a wider support system should be welcomed as this could go a long way to impact the emotional well-being of patients. Ensuring continuity of care and facilitating smooth transitions is also significant. Patients meet various care providers during their care journey therefore facilitating smooth transitions including patients' self-care after discharge is essential. Provision of information concerning for example medication, diet, physical activity, etc to the patient should continue. Lastly, access to care is a fundamental right grounded in PCC. The right services must be made available at the right time as this is necessary for high-quality care which aligns with the needs of the individual (Picker Institute Europe, 2023).

3 Research Aim and research questions

In this chapter, a clarification of the primary objective of the thesis which delves into examining shared decision-making within the palliative journey of cancer patients is presented. The specific objectives guiding the research are expounded upon, shedding light on the various aspects to be investigated in order to achieve the defined aim.

3.1 Research aim

The aim of the thesis is to explore and promote the facilitation of SDM in palliative care for cancer patients. This involves examining and understanding patients' perspectives on SDM and identifying ways to facilitate the SDM process throughout their palliative journey. The goal is to ensure patients receive care that aligns with their values, preferences, and goals.

3.2 Research Questions

1) What are the perspectives of cancer patients on shared decision-making in palliative care?

2) What strategies can be used to facilitate shared decision-making among cancer patients in palliative care?

4 Brendan McCormack's Person-Centred Nursing (PCN) Framework

There is a need to address the theoretical framework on which this research is built because nursing theories serve as the foundation for nurses in the determination of care needs and the achievement of goals to help in the advancement of nursing care and delivery. Furthermore, theories offer the opportunity to learn how to provide more comprehensive and holistic care (Arif et al., 2019) which is one of the core contents of this research. The most appropriate and relevant theoretical framework for our research is Brendan McCormack's Person-Centred Nursing Framework which has been classified as a middle-range theory according to Slater et al.,2015 because it draws from two abstract conceptual frameworks, comprises relatively specific concepts and delineates the relationships between these concepts (McCormack & McCance, 2016).

In McCormack & McCance (2016), patient-centred practice is defined as an approach developed through a cultivation of positive relationships among care providers, service users and individuals significant to them. This practice is grounded in values such as respect for individuals, the right to self-determination, mutual respect and understanding. Patient centredness is enabled when the environment promotes empowerment and support continuous development in practice.

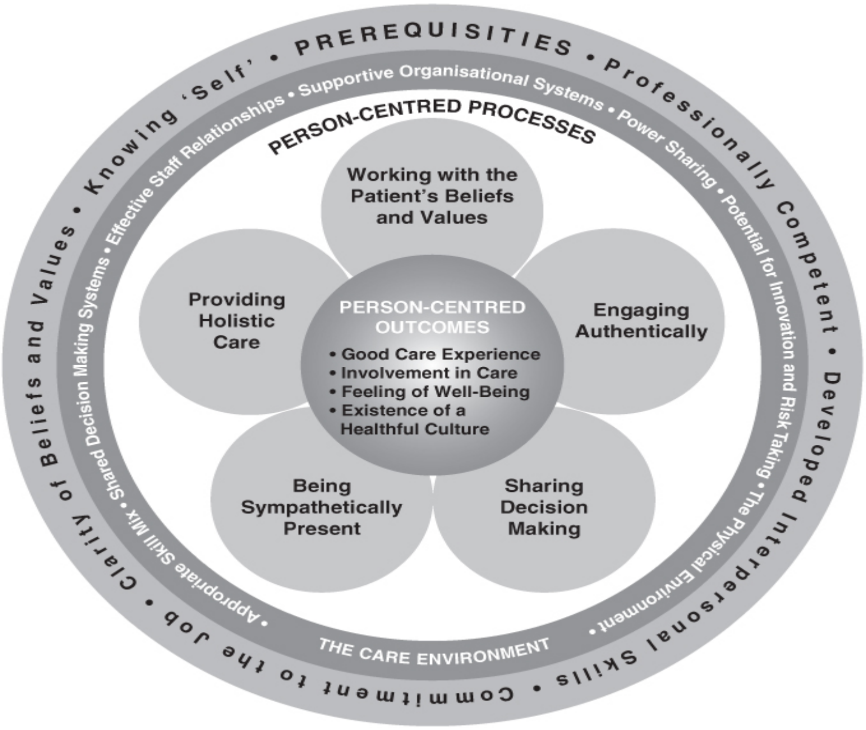
The Person-Centred Nursing (PCN) Framework was formulated by McCormack and McCance (2006) based on earlier empirical studies that focused on person-centred practice among older people (McCormack, 2001) and the experience of nursing care (McCance et al.,2001). Person-centred care has been deeply integrated into nursing practice, which is concerned with treating people as unique individuals, upholding their rights as individuals, fostering mutual trust, and understanding, and building therapeutic relationships. In this regard, nurses are expected to deliver care that aligns with these principles (McCormack & McCance 2010, p.1). The concept of 'person' plays a pivotal role in PCN framework. It captures those attributes that symbolize our inherent humanity and the manner in which persons construct their life experiences; our moral values, how we articulate our political, emotional, and religious beliefs and our interpersonal connections are moulded by our attributes as persons (McCormack & McCance, 2021).

The original framework consisted of four elements (McCormack & McCance, 2010, p.3). The first element termed 'prerequisites' pertains to the quality or attributes of a nurse such as professional competency, effective interpersonal skills, showing commitment to the job, demonstrating a clear understanding of beliefs and values; and knowing self. ‘Care environment’ which is the second element focuses on the environment and context in which care is delivered. This includes appropriate skill combinations; mechanisms that facilitate shared decision-making; effective staff interaction; supportive organisational systems; power sharing; and the capacity for introducing current ideas and embracing risk. The third element, ‘person-centred processes’ and outlines the provision of care through a variety of actions such as aligning with the beliefs and values of patients, promoting engagement, demonstration of empathy, collaborative decision-making, and addressing physical needs. Lastly, ‘expected outcomes’ describes the result of effective person-centred nursing is the core component of the framework, and this includes care satisfaction; participation in care; a sense of well-being; and the presence of a therapeutic environment.

The connection between the elements of the framework as illustrated in Figure 4.1indicates that to reach the core of the framework, it is important to consider the prerequisites. These prerequisites include professional competence, the development of interpersonal skills, job commitment, clarity of beliefs and values and knowing self. This is then followed by the care environment which comprises appropriate blend of skills, systems that promote shared decision-making, power sharing, strong staff relationships, supportive organizational systems, opportunities for innovation and risk-taking and the physical environment which are essential for the delivery of effective care through the care processes. This sequential approach leads to the achievement of the outcomes which lie at the heart of the framework (McCormack & McCance, 2010).

The Brendan McCormack’s Person-Centred Nursing (PCN) framework is notably relevant to this research because it provides a comprehensive and person-centred perspective that aligns well with the goals of exploring and promoting shared decision-making (SDM) in palliative care for cancer patients. It emphasizes care that is in line with patient values, preferences and goals, a holistic approach to care, partnership and relationship-centred care, promotion of autonomy which is vital in decision-making and practical strategies for implementing person-centred care (PCC).

Figure 4.1: The Person-Centred Nursing (PCN) Framework



Adapted from McCormack, B., & McCance, T. (2010). Person-centred nursing: Theory and practice. John Wiley & Sons, Incorporated.

The person-centred processes which embody the core value of this study are centred on delivery of care through a variety of activities that put PCN into practice. These activities include: 'working with the patient's beliefs and values', 'engaging with patients and their beliefs and values', 'collaborating in decision making', 'being present sympathetically' and 'providing holistic care'. This aspect of the framework that specifically focuses on the patient and describes PCN within the context of care provision (McCormack & McCance, 2010).

Collaborating with patients regarding their beliefs and values aligns with one of the fundamental principles of PCN, which highlights the significance of developing a clear understanding of what beliefs and values mean to the patient and how they interpret their experiences (McCormack & McCance, 2010). This concept is closely linked to what the first research question of this thesis seeks to address. Furthermore, it is closely intertwined with shared decision-making, where the involvement of patients is facilitated through information provision and integrating new perspectives into practice as noted by McCormack & McCance, 2010 which is pertinent to answering our second research question.

In the middle of the PCN framework (See Figure 4.1 above) is the person-centred outcomes. These outcomes include satisfaction with care, involvement in care, feeling of well-being and creating a healthful environment, all of which are expected results from effective implementation of PCN. Patient satisfaction is a representation of how a patient assesses their healthcare experience which is notably the most widely acknowledged indicator pf quality care. The second PCN outcome which is involvement in care is described as the expected result of participating in the SDM process. Feeling of well-being denotes the sign of a patient feeling valued. Establishing a healthful environment described as one in which decision-making is fostered, staff relationships are collaborative, leadership adopts a transformational approach and innovative practices are supported is the ultimate outcome for teams committed to promoting person-centred cultures in the workplace (McCormack & McCance, 2010).

5 Methodology

This research has chosen a qualitative study research method based on a systematic literature review approach to integrate information from existing literature on shared decision-making among cancer patients in palliative care. This review follows the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA).

Larsseson et al. (2022) described a systematic review as a meticulous process that aims to gather all relevant empirical evidence meeting specific eligibility criteria to answer a research question. It uses a structured approach to minimize bias and produce reliable findings that inform conclusive insights and informed decisions. A literature review is considered systematic when it adheres to a research question and explicitly explains the following processes: identification, selection, appraisal, and synthesis of the relevant literature (Belanger et al., 2011). As indicated by Polit and Beck (2021), once the research problem and research aims have been identified a comprehensive literature review is essential which provide researchers information for guiding a high-quality study including the following: the scope and intricacy of the defined research problem, what previous researchers have discovered regarding the research question, quality and quantity of available evidence, settings in which the research has been carried out, characteristics of individuals who involved in the study, the theoretical basis of concluded studies, methodologies used to address the question and deficiencies in the current evidence base as well as the type of new evidence necessary.

The use of systematic review is on the rise in nursing to inform evidence-based practice. The selection and incorporation of only the most credible and top-quality evidence, has contributed to the development of best-practice guidelines and improving the trajectory of nursing care (Ham-Baloyi & Jordan, 2016).

5.1 Data Collection

The following databases were searched to identify articles relevant to shared decision-making in palliative cancer among cancer patients: EBSCO, PubMed, CINAHL, Springer Link and DOAJ Directory of Open Access Journals. The core concepts searched included shared decision-making, patient participation, palliative care, and person-centred care. The search strings were performed using the following search string combinations: "Shared decision-making" **AND** "Palliative care" **AND** "Cancer patients", "Communication" **AND** "Shared decision-making", "Shared decision-making **AND** patient participation" and "Facilitating shared decision-making in palliative care"

The hits were then screened according to the inclusion and exclusion criteria of the titles and abstracts, peer-reviewed articles, full-texts, and date relevance from 2015 and 2023 to get the articles that were included in the analysis.

5.2 Inclusion and exclusion criteria

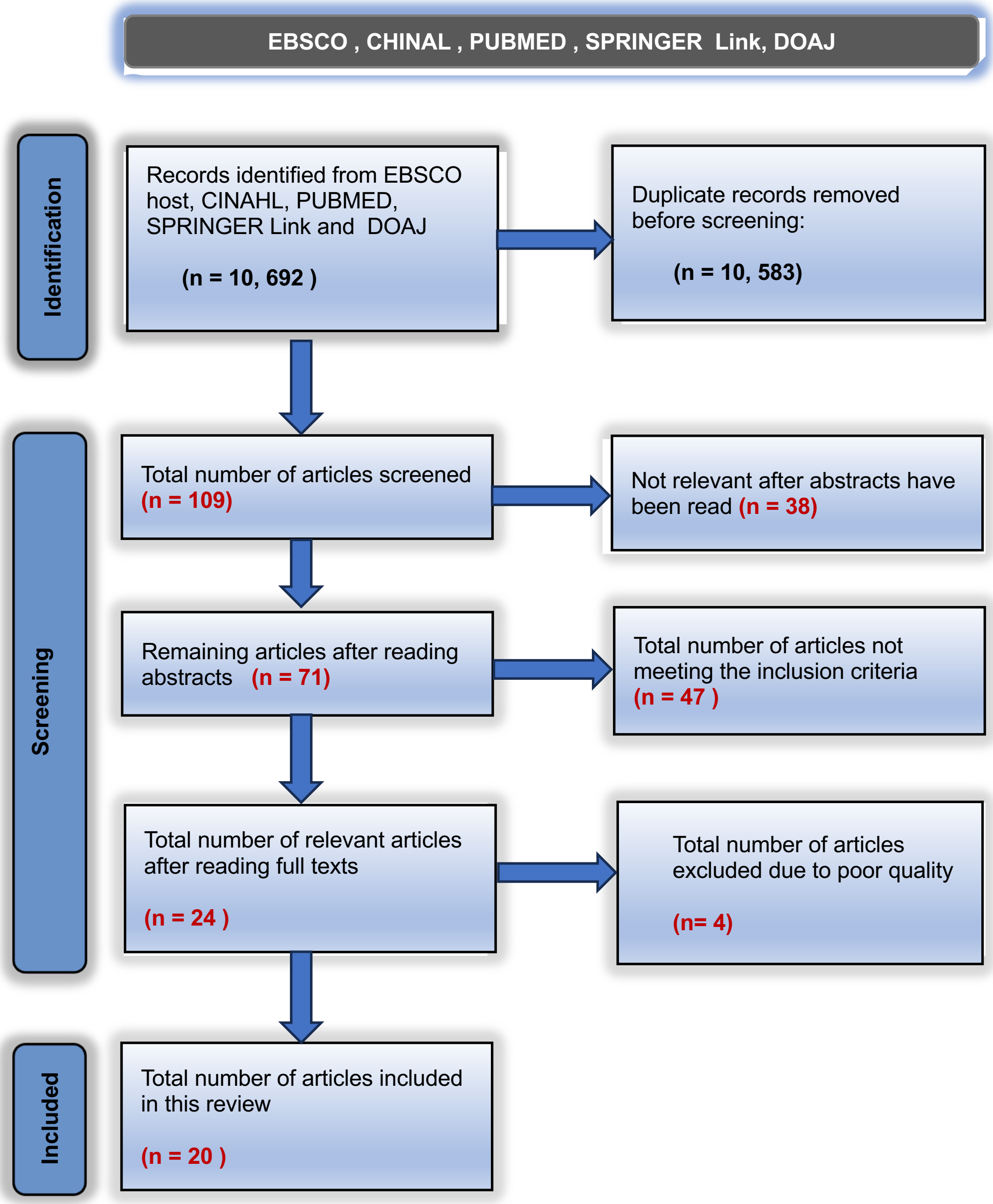
This sub-section offers an overview of the criteria used in the selection of studies included in this study. The general screening process and the flow of selecting relevant literature for this study are presented in Figure 5.1 using a PRISMA flow chart to document the search strategy employed and results. As a researcher, it is important to document record specific information such as search completion date, the quantity of titles retrieved, how many articles are excluded, duplicates, full paper reviewed versions and the number finally included in the study (Holland & Watson, 2021). The inclusion and exclusion criteria (See Table 5.1) used in this study are in line with all the criteria and definitions used.

Studies that have been included in this study are those with full texts, scientifically peer-reviewed, articles in English, studies related to SDM in palliative care nut not limited to a particular geographical location and articles from 2015 to 2023. On the other hand, the exclusion criteria used included the following: articles not directly related to SDM in palliative care, non-peer-reviewed articles, articles about diseases other than cancer, studies employing other forms of design such as systematic reviews, scoping reviews and meta-analysis and articles older than 2015.

Table 5.1 Overview of inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
▪ Full text articles	▪ Articles not related to shared-decision making.
▪ Scientifically peer reviewed articles	▪ Non-peer-reviewed articles
▪ Articles written in English	▪ Articles focusing on other diseases other than cancer
▪ Studies related to shared decision-making and palliative care	▪ Articles using other study designs. E.g., systematic reviews, scoping reviews and meta-analysis
▪ Studies from 2015 to 2023	▪ Articles before 2015

Figure 5.1: Prisma flow chart of the articles



5.3 Data Analysis

The objective of data analysis is to structure, organize and extract meaning from data. Collection of data and analysis often happen simultaneously rather than after all data are collected. When the individual gathering and analysing data is the same person the exploration for essential concepts and patterns starts during the while data collection is in progress (Polit and Beck, 2021).

The data extracted from the included studies was analysed using content analysis to synthesize the data and identify key themes and sub-themes related to the research questions. The analysis was done using a coding process to identify relevant concepts and ideas, which were then grouped based on their relationships with each other. The themes were identified to reflect the main patterns and ideas that emerged from the data. The findings were expressed in a clear and concise manner, using figures to illustrate main themes and sub-themes which can be seen from Figures 6 and 7 and further discussed in context using quotations and references. The overview of the articles included in the analysis (Appendix 4) were presented in a table (Polit and Beck, 2021). The findings of this thesis will contribute to existing literature and research on the development of more patient-centred care approaches to palliative care.

5.4 Ethical considerations for the study

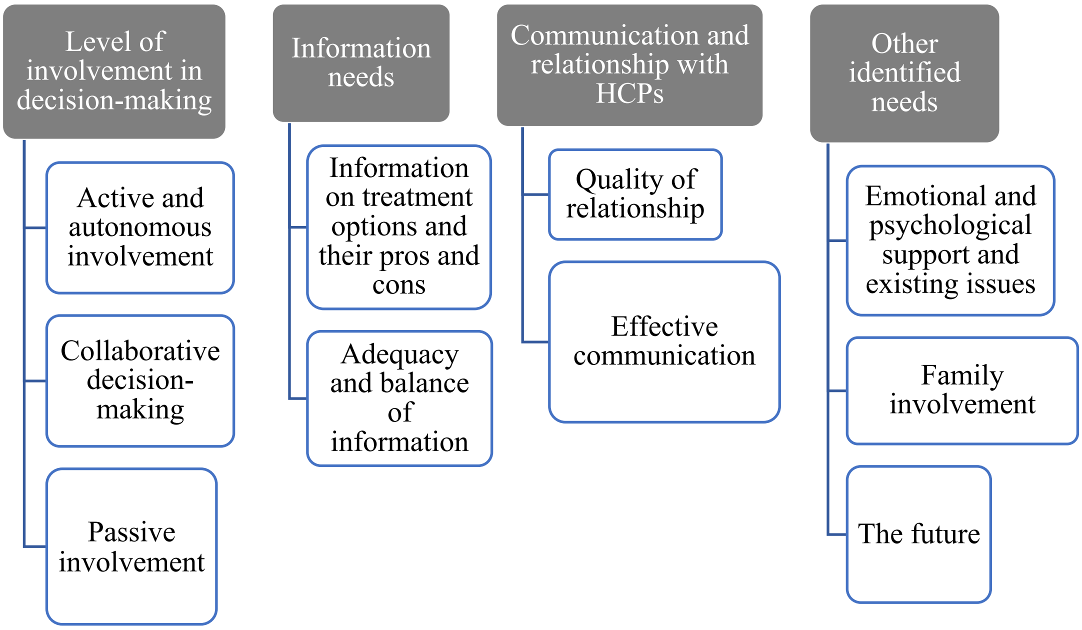
Research ethics are principles that regulate the standards of conduct for scientific researchers (WHO, 2023). It is important to address ethical concerns in nursing research because of the irregularities that are sometimes present when drawing a line between what constitutes expected nursing practice and research data collection. The demarcation between these two components is sometimes vague. In addition, ethics can pose challenges because of the conflict between what is required ethically and the necessity to generate high-quality evidence for practice (Polit & Beck 2010. p.118). For research to be conducted responsibly, it must adhere to the following principles: integrity, carefulness, precision, and ensuring that conducting, recording, presenting, and evaluating the results of the research are done accurately (TENK, 2023). In this study, the methods used are in conformity to scientific criteria and ethical standards. The findings of this research are shared in a clear and honest manner, which is in line with the dissemination of scientific knowledge (TENK, 2023). According to the Finnish National Board on Research Integrity (2021), plagiarism is a serious offence.

Therefore, the works of other researchers and authors have been acknowledged and respected; appropriate citations of their works have been used throughout this research, which includes scientific articles, books, and literature. Additionally, as mentioned earlier, the study is based on systematic literature review to investigate shared decision-making (SDM) among cancer patients in palliative care, therefore there is no breach of the principle of autonomy in the research (TENK, 2023) because there has not been any direct human involvement. The collection of data is credible and reliable and poses no harm.

6 Results

Overall, twenty (20) articles were analysed (Appendix 4). The results from the data analysis were presented according to themes and sub-themes based on the respective research questions. The findings pertaining to the first research question, "what are the perspectives of cancer patients on shared decision-making in palliative care?" have been characterised by four (4) themes and twelve (10) sub-themes. Quotations were chosen to exemplify the themes and sub-themes. Additionally, the findings on the second research question, "what strategies can be used to facilitate shared decision-making among cancer patients in palliative care?" have been summarised through two (2) main themes and six (5) sub-themes as shown in figure 6.2.

Figure 6.1: Perspectives of cancer patients on shared decision-making in palliative care



6.1 Level of involvement in decision making

This theme pertains to the varied levels of engagement expressed by cancer patients regarding their participation in shared decision-making in palliative care**.** It also points out the patients' experiences of how decisions were made during their course of treatment. In this theme, three (3) sub-themes were discussed: 'active involvement and autonomous involvement', 'collaborative decision-making' and 'passive involvement'.

6.1.1 Active and autonomous involvement

Active involvement and autonomous decision-making denote patients' ability to express their preferences and make choices that suits their needs. It indicates that patients have the final say in the choice of treatment. Patients desire to actively participate in the decision-making process (Tamirisa et al.,2017; Windon et al.,2021; Pan et al.,2022; Hopmans et al.,2015) as expressed in the examples below:

> *"I would prefer to know that I am making a decision. I mean after all it is my body, right?"; "It was my decision. My husband was there, my son was there, and it was up to me [...] I decided" (Tamirisa et al.,2017).*
>
> *"Ultimately it was really my decision"; "It's not your risk. It's my risk"; "It's 100 per cent up to me to make my own decision"; "... it was good because [...] I was asked to make a decision"; "so the surgeon said, 'it's your choice,' which [...] I actually would have preferred being told" (Windon et al.,2021).*
>
> *"Since I have been in the hospital, I have been instructed to undergo various checks or tests. It's as if I were a puppet. I want to be able to decide whether or not to do these checks" (Pan, et al.,2022).*

Patients also valued being given the opportunity to voice their own opinion and preferences regarding treatment choices:

> *"The clinician wanted to operate immediately. I said, I wanted to think about that first…."; "……. I felt that my body wasn't ready for another operation. Then I said that I wanted a second opinion…." (Hopmans et al.,2015).*

6.1.2 Collaborative decision-making

This sub-theme describes patients' desire to decide together with the HCPs after exploring the treatment options available as well as the benefits and risks associated. Most patients wanted treatment recommendations from the HCPs (Tamirisa et al.,2017; Hopmans et al., 2015).

> *"Many people get frustrated when a doctor won't tell them what they recommend" (Tamirisa et al., 2017).*

> *"And then my oncologist said to me, it is your decision, what do you want? Then I said, what do you recommend?" (Hopmans et al., 2015).*

Out of 175 participants in a study conducted by Josfeld et al., 2021, 160 participants which represented 91.4% wanted a shared decision-making approach. In Alzubaidi et al.,2022 about half (46.9%) of the participants preferred to work closely with their physician. Most participants according to Windon et al., 2021 described their experience of a shared decision:

> *"The doctor and I made the decision together to do surgery"; "It was something that the doctor and I came up with manually" (Windon et al., 2021).*

6.1.3 Passive involvement

Passive involvement in decision making occurs when the patients entrust decision making responsibility to their HCPs. Some patients described their experiences of passive decisional control in the following examples:

> *"I just followed medical advice… These doctors are experienced and professional" (Pan et al., 2022).*

> *"Is it expected of me not to listen to doctors when I am ill? I have faith in their expertise and skills"; "I have registered a specialist clinic, which is costly and precious. As a result, I would follow the expert's advice" (Pan et al., 2022).*

More than half of the participants according to Alzubaidi et al., 2022 (389 out of 516) representing 75.4% preferred to leave decisions up to the physician:

> *"I prefer to leave decisions about my medical care up to my doctor".*

Trust played a crucial role passive decision making. This can be inferred in the following example:

> *"I'm going to do whatever they tell me to do"; "I think it will be foolish not to go along with the professional that's giving you the advice"; "honestly there weren't any decisions to be made because I was just going to go along with whatever the doctor said" (Windon et al.,2021).*

6.2 Information needs

This theme refers to patients' experiences and preferences in the delivery of information by health care providers which has been further divided into the sub-themes of 'information on treatment options and their pros and cons' and 'adequacy and balance of information'.

6.2.1 Information on treatment options and their pros and cons

This sub-theme pertains to the kind of information patients want to receive such as information on the disease, treatment options and the potential risks and benefits. Patients believe that they should know all the facts of the disease:

> *"I had the impression that the doctor was a bit reluctant when he spoke to me [...] However, since this is a sickness that affects my health, I should be informed" (Pan et al., 2022).*

> *"I genuinely want to be involved in my disease treatment, but no one informed me, and I'm still puzzled. What alternatives do I have for treatment? Which is the more radical and which is more conservative? [...] whatever therapy is more suited [...] I still want more information" (Pan et al., 2022).*

> *"Occasionally, I like to get comprehensive knowledge about the sickness to prepare ahead...." (Pan et al., 2022).*

Patients shared their experiences of not being presented with information on treatment options:

> *"I would say that I have been dictated this treatment. Actually, they didn't mention anything about other treatments" (Netsey-Afedo et al., 2020).*

and being less informed as mentioned in the following quotations:

> *"I hadn't realised just how invasive and intrusive it was, [...] It just seemed as though there was an assumption [...] I just don't understand why I was fully aware of everything through the chemo but not the stem cell" (Gemmell et al., 2022).*

> *"The only thing that bothers me is I'm not being told what to expect, what I'm being treated with and things like that" (Gemmell et al., 2022).*

According to Josfeld et al., 2021 patients were particularly interested in information on the pros and cons of the different treatment options available.

6.2.2 Adequacy and balance of information

Patients reported that sufficient and understandable information was significant:

> *"I think it is important that a clinician is open to a patient. That they do not refrain from providing information [...] I'm lucky because my surgeon explains everything very thoroughly and in a straightforward way. I appreciate that"(Hopmans et al., 2015).*

> *"I think it is important that they explain everything in an understandable way. No fancy Latin names that patients do not understand and that results in saying to yourself when you are out of the office: I have cancer, but I don't know what they are going to do. For me it is important that I understand everything" "(Hopmans et al., 2015).*

Information given to the patients were either too much or too little which made patients feel either overwhelmed or inadequately informed (Josfeld et al., 2021; Windon et al., 2021). This finding paralleled the results reported in Tamirisa et al., 2017 as outlined:

> *"Things in writing always help. Too much paper gets to be a whole lot though" (Tamirisa et al., 2017).*

> *"No one ever asked me what my background was so they could know what level of information I could receive" (Tamirisa et al., 2017).*

> *"It was one of those things where I had to trust doctors and my gut and my heart, but I don't feel like I've been an educated patient" (Tamirisa et al., 2017).*

Windon et al., 2021 reported a large number of participants being well- informed:

> *"I had enough facts"; I've got as much information as there is to get".*

6.3 Communication and relationship with HCPs

In this theme, patients describe the need for and importance of communication and how their relationship with HCPs impact shared decision-making. This is further categorized into two sub-themes which include 'quality of relationship' and 'effective communication'.

6.3.1 Quality of relationship

Patients identified kindness (Hopmans et al., 2015 & Gemmell et al.,2022) respect (Gemmell et al., 2022 & Hopmans et al., 2015) compassion (Hopmans et al.,2015; Tamirisa et al., 2017

& Netsey-Afedo., et al., 2020) friendliness and thoughtfulness (Hopmans et al., 2015) as qualities of HCPs that exhibited SDM as expressed in the following perspectives:

> *"The two things that are most important are the humour and warmth of all the stuff, [...] the fact that everybody looks at you as they walk past, instead of just treating you as an object [...] So these little things become quite big things. Because it makes you feel protected somehow, from the ordeal" (Gemmell et al.,2022).*

> *"... And they forget to feel compassion for a patient [...] When a clinician is very kind, that is 20% of your recovery. Only being nice. And when he is disrespectful, you decline with 20%" (Hopmans et al.,2015).*

> *"There was not so much patient attention [...] without asking "are you with me?" or "anything else you need?" [...] No eye contacts!" (Netsey-Afedo et al.,2020).*

> *"I have had the physician that comes in and they make no contact with me [...] well then, we are all just robots. The doctor should sit and talk to you and listen and ask some pointed questions" (Tamirisa et al.,2017).*

6.3.2 Effective communication

From the patients' viewpoint, it is significant for clinicians to have the ability to communicate effectively with people (Hopmans et al.,2015) because it helps to incorporate patient preferences into the SDM process (Tamirisa et al.,2017).

> *"In my opinion, it is important that a clinician is able to communicate with people, able to talk and to listen. And when you are not able to do that, you are a worthless clinician" (Hopmans et al.,2015).*

According to Tamirisa et al., 2017 physicians who engaged in face-to-face discussions, explained treatment choices verbally, spoke while maintaining eye contact and took the time to answer all questions were considered effective communicators. In a study conducted by Gemmell et al.,2022, openness in communication was emphasised in the following example:

> *"…But I think to some people you'd have to explain exactly what you were offering. Because palliative care, to a lot of people, just does mean, end of life, [...] so, I think sometimes you have to be very open in what you're offering and what it means. And it is not just you're near death".*

Nonetheless, some patients have expressed their satisfaction with clear communication:

> *"They don't sugar-coat anything. But I'm fine with that! Getting a clear message, cause it's worse not knowing" (Netsey-Afedo et al.,2020).*

6.4 Other identified needs

The following results chapter delves into other needs identified by patients to be addressed in SDM other than focusing on their disease and treatment related issues which encompasses three sub-themes, including 'emotional and psychological support and existing issues', 'family involvement' and 'the future'.

6.4.1 Emotional and psychological support and existing issues.

According to Netsey-Afedo et al.,2020 patients experienced that their mental health and other existing issues need were not addressed as well as psychologically (Gemmell et al.,2022). The following is how patients narrated their experiences:

> *"Usually, it's about how I am. But, the last time, the doctor didn't really need to ask [...] looking at the [...] PSA level [...] At least physically, right. Well, mentally that's something completely different"; " [...] But they don't ask about mental health and things like that. [...] They're only interested in their own area [...]" (Netsey-Afedo et al.,2020).*

> *"I don't think people who have not gone through chemo or know about it- you know, don't know about hospitals understand [...] It's hard you know, and I think everybody finds it hard; not just me"; "I'm not looking forward to being in hospital.*

> *Being dependent on people you don't really know [...] I like to be in charge and be independent" (Gemmell et al.,2022).*

HCPs did not ask about profound issues:

> *It's strange, really, that they don't ask how I feel. They only ask how you are doing" (Netsey-Afedo et al.,2020).*

A major existing issue described by patients was daily life priorities regarding for example symptom management:

> *"And another thing I would like is best control with the pain management. [...] It's depressing walking around in pain [...] and you don't really understand why it's worse today and not yesterday"; "I mean I was sick, quite sick and nauseous with the treatments" (Gemmell et al.,2022).*

6.4.2 Family involvement

Patients stated that it was important to involve family members in the decision-making process (Hopmans et al.,2015) due to their vital roles as a source of support (Gemmell et al.,2022):

> *"My husband joins me. We complement each other. We all do these things together. When there is something wrong with him, I go along and when there is something wrong with myself, he goes along" (Hopmans et al.,2015).*

However, according to Pan et al.,2022 although family members supported patients emotionally, patients felt that despite having their own opinions, their family held the dominant position in the decision-making process:

> *"My family, relatives, and acquaintances are all aware of my sickness, yet I was an outlier".*

> *"My son informed me last week that I would be having surgery, without providing any other information [...] Additionally, I am concerned about sexual dysfunction.*

> *I want to sustain sexual function [...] I was excluded since my family believed I was helpless due to my vulnerability [...] It was my wife and children who spoke with the doctor".*

Gemmell et al.,2022 noted that the family also faced various challenges and ordeals throughout the treatment process hence the preference of patients to involve them:

> *"It's massively difficult for my wife because she sees me suffering [...] It's often far more difficult for the person who's watching the illness than for the person who's actually suffering from the illness"; "[...] My children were old enough for them to come in but it was very traumatic for them".*

6.4.3 The future

There were fewer future concerns among some patients:

> *" [...] my family members have avoided discussing this subject in front of me out of fear of making me upset. Indeed, I am concerned and saddened. I'm not interested in discussing the future" (Pan et al.,2022).*

> *"When I try to discuss future plans with my wife. She usually urges me not to think too much" (Pan et al.,2022).*

However, others wanted the future to be talked about such as the changes associated with cancer:

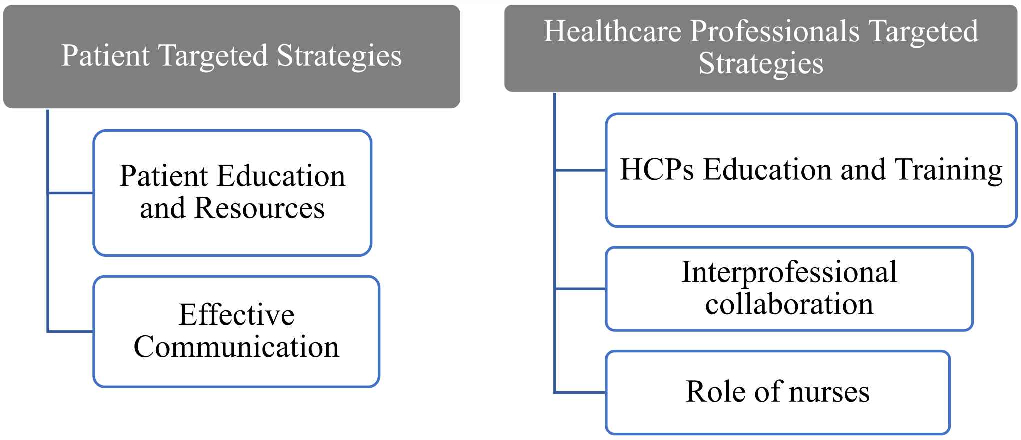
> *"You ought to be talked to about your self-image, cancer changes your whole self-image" (Tamirisa et al.,2017).*

Furthermore, there was also a need for discussion on wishes and plans for an uncertain future as stated in Gemmell et al.,2022 as follows:

"I suppose the only thing nobody's really talked about, for me, is the prognosis […] So that I find a little bit disconcerting. Because I'd like to know roughly how long I've got".

"Well, I'm sure it wouldn't be easy, but it's something we've all got to face. Because as difficult as it is, I think in the long term it would probably help me and maybe others to talk about that […] So yes to talk about it. I think it would help even though it wouldn't be easy".

Figure 6.2: Strategies that can be used to facilitate SDM among cancer patients in palliative care.



6.5 Patient-Targeted Strategies

In the context of palliative care for cancer patients, this thematic exploration underscores the overarching theme of patient-targeted approaches to enhance the participation of cancer patients in SDM. This focus centres on the individualized preferences, aspirations, and circumstances of each patient. Within this theme, two sub-themes have surfaced: 'Patient Education' and 'Effective Communication'.

6.5.1 Patient Education and Resources

This approach involves providing patients with information about their condition, treatment options, and potential outcomes, in order to empower them to make well-considered choices, ask pertinent question and actively participate in the decision-making process.

According to Serpico et al. (2016), Henselmans et al. (2018), Musella et al. (2021), Bagshaw et al. (2021), and Oostendorp et al. (2017), informing patients about their treatment choices, the nature of their illness, potential results, and the resources available for decision-making can enhance their involvement in the decision-making process related to their care.

> *"Describe all potential treatment choices and explain the significance of each to help patients choose the course of care that is right for them, increasing patient empowerment" (Musella et al., 2021).*

In particular, the utilization of decision aids (DAs), as highlighted by Serpico et al. (2016), Henselmans et al. (2018), Bagshaw et al. (2021), and Oostendorp et al. (2017), has proven to be effective in promoting SDM. These decision aids come in various forms, including videos providing information about the disease, treatment options, and expected outcomes (Serpico et al., 2016), web-based decision aids that enable patients to assess different treatment methods, outcomes, and side effects based on their preferences (Bagshaw et al., 2021), and other formats (Henselmans et al., 2018; Oostendorp et al., 2017).

In the study by Musella and colleagues (2021), it is suggested that advocacy groups or organizations have a significant role to play in increasing patient awareness and involvement in SDM by enlightening patients about what resources they can access throughout the progression of their disease.

6.5.2 Effective communication

Communication within this context denotes the process of sharing, relaying, or transferring information, ideas and emotions between the patients and HCPs. Four research studies emphasized the role of effective communication in facilitating SDM for cancer patients in palliative care (Roodbeen et al., 2020; Roze des Ordons et al., 2015; Musella et al., 2021;

Henselmans et al., 2018). The elements identified as core to effective communication included effective time management, communication aids, and customized and holistic communication.

Effective time management plays a crucial role in promoting SDM during discussions between patients and HCPs (Roze des Ordons et al., 2015; Musella et al., 2021; Roodbeen et al., 2020). Having ample time available during interactions with HCPs (Roze des Ordons et al., 2015; Roodbeen et al., 2020) and initiating early communication among HCPs, patients, and family members (Roze des Ordons et al., 2015; Musella et al., 2021) can help eliminate persistent communication barriers, build rapport, and encourage active participation from both patients and their families in the decision-making process regarding treatment.

The following is what an HCP stated regarding offering time to patients to process information given to them:

> *"If you provide information to a patient, you schedule a time-out and offer patients time for reflection, in order for the patient to come up with questions or have discussions with their significant others[...] after the time-out" (Roodbeen et al., 2020).*

According to Henselmans et al. (2018), the use of communication aids, such as questionnaires incorporating elements aimed at facilitating patient involvement in care decision-making, is considered an effective communication strategy conducive to fostering SDM. The components of these questionnaires may encompass informative elements, including patient education about SDM, facilitative aspects such as a question prompt list, and reflective components such as value clarification exercises (Henselmans et al., 2018). Roodbeen et al. (2020) also identified utilizing various resources, including printed materials like leaflets and patient checklists, visual aids such as illustrations and videos, as well as anatomical models, as effective strategies for communication.

In the studies conducted by Roodbeen et al. (2020) and Musella et al. (2021), the importance of customized and holistic communication was highlighted. This approach, which considers individual patient needs, including spirituality, empathy, and comfort, was found to be a key factor in promoting patient participation. Roodbeen et al. (2020) further emphasized that healthcare providers can enhance patient involvement by engaging in empathetic communication, which involves acknowledging and discussing the emotions expressed by patients during interactions. This approach helps patients feel more involved and negotiable in the consultation process (Roodbeen et al., 2020).

HCPs reported the following about how to tailor their communication:

> *" Yes. Some people just don't like talking about death or about illness [...] Well, you have to accept that people don't want to talk about it, at least at that moment, and that they need their own strategy. [.......] " (Roodbeen et al., 2020).*

6.6 HCPs Targeted Strategies

This theme focuses on strategies and approaches designed to enhance shared decision- making (SDM) with a specific emphasis on healthcare professionals (HCPs) while incorporating the role of the nurse and how this contributes to facilitation of SDM among cancer patients in palliative care. Within this overarching theme, we identified three sub-themes as follows: 'HCPs Education and Training', 'Interprofessional Collaboration', and the 'Nurse's Role'. A comprehensive examination of relevant studies reveals the significance of HCPs targeted strategies.

6.6.1 HCPs Education and Training

Educating or training HCPs was identified as an effective method for promoting SDM in palliative care (Ordons et al., 2015; Roodbeen et al., 2020; Henselmans et al., 2018; Goto et al., 2022; Bos van den Hoek et al 2023). Bos van den Hoek et al (2023) revealed that training HCPs in SDM support skills led to improvements in their SDM support skills, knowledge, and confidence. Furthermore, the training was found to enhance HCPs' ability to complement the SDM process (Bos van den Hoek et al., 2023). In the study conducted by Goto et al. (2022), it was found that an Advanced Care Planning (ACP) education program, which included training in SDM skills, led to an improvement in the quality of SDM skills among HCPs who participated in the program. Similarly, Roodbeen et al. (2020) identified that educating HCPs on communication skills emerged as an effective approach to facilitate SDM. Their research revealed that HCPs themselves recognized the value of education in enhancing their communication skills:

> *“Well, a nice thing is that we sometimes have additional training, also in that area. That makes everything livelier again. You can exchange tips, asking, ‘how do you deal with that? [....] ” (Roodbeen et al. 2020).*

> *“……. Every nurse, every doctor, has to deal with this. It’s nice to share things with each other, Then it remains fresh and you think, “oh yes, those people [patients with low health literacy] sometimes need different methods [....]. That is always nice to do, additional training (Roodbeen et al. 2020).*

6.6.2 Interprofessional Collaboration

Several studies (Roodbeen et al., 2020; Ordons et al., 2015) pointed to the significance of HCPs working together to facilitate patient participation in decision-making. To lay the foundation for effective teamwork, Roodbeen et al. (2020) and Roze des Ordons et al., (2015) stated that it's essential to maintain consistent communication among the various healthcare professionals involved in a patient's care. Moreover, role clarity is crucial for both patients and HCPs when discussing goals of care. Having a clear understanding of who does what within the healthcare team streamlines the decision-making process and minimizes confusion (Roze des Ordons et al., 2015). Multidisciplinary family meetings and healthcare team meetings, where the input and expertise of different professionals come together to ensure comprehensive care for the patient, proper documentation of these discussions and decisions emerged as approaches to interprofessional collaboration (Roze des Ordons et al.,2015).

Interprofessional collaboration was illustrated according to specialized palliative care nurses as follows:

> *“Yes. Yes. That we, before talking to the patient, should discuss the things we are going to explain to the patient, and how. And that you, only after discussing this, should approach the patient” (Roodbeen et al., 2020).*

6.6.3 Role of nurses

The roles of nurses have been identified as significant in promoting SDM (Tariman et al., 2017; Bos van den Hoek et al 2021; Fauzan et al., 2019). According to Tariman et al. (2016), nurses can actively encourage patients’ involvement in the decision-making process related to their care. This encouragement is achieved through various means, including advocacy, providing support, and educating patients.

Bos van den Hoek et al (2021) further emphasize the pivotal role of nurses in facilitating shared decision-making. They highlight specific interactions and activities conducted by nurses. These interactions encompass ‘multidisciplinary team discussions’, where patients’ diagnoses and treatment proposals are reviewed, ‘conversations between physicians and patients’, which involve deliberations about commencing or continuing treatment, 'nurse-patient conversations' focusing on emotional support and the discussion of information provided by physicians after consultations, and ‘educational conversations between nurses and patients’. In their research, they underscored the nurse’s role as complementary and facilitative to SDM.

Nurses described engaging in discussions with patients following a dialogue between the physician and patient:

> *“ Then I take the patient aside, after the conversation with the neurologist. Just to hear them repeat what they think they’ve heard- what they think about it. So, I’m really helping them process that discussion, briefly summarizing what the options are” (Bos van den Hoek et al 2021).*

7 Discussion of results

In this chapter, an in-depth discussion of the key findings derived from the systematic literature review conducted to shed light on SDM within the context of palliative care for cancer patients was undertaken. The analysis of the twenty (20) articles included in the study revealed six (6) distinct themes and fifteen (15) sub-themes in total. The discussion revolved around these themes and sub-themes that correspond to the two research questions reflecting the aim of the study which was to explore and promote SDM in palliative care for cancer patients. It is however important to note that all these themes collectively play a vital role in providing guidance to healthcare professionals in delivering comprehensive patient-centred care. Furthermore, the discussion examined how the research findings align with specific components of the Brenden McCormack’s Patient-Centred Nursing (PCN) framework while integrating the study’s background.

7.1 Discussion of main findings

As mentioned, the aim of the thesis was to explore and promote the facilitation of shared decision-making (SDM) in palliative care for cancer patients. This was achieved through an examination and understanding patients' perspectives on SDM and identifying ways to facilitate the SDM process throughout their palliative journey to ensure patients receive care that aligns with their values, preferences, and goals. The background of the study was established by addressing gaps identified in previous research (Brom et al., 2025 & Rocque et al., 2019) related to SDM in palliative care for cancer patients revealing challenges such as the deficient implementation of SDM in daily practice and the differences in perspectives between patients and oncologists. Building on these insights, the review had a specific focus on investigating and advancing the facilitation of SDM within the context of palliative care for cancer patients.

The study's findings provide a precise understanding of the perspectives of cancer patients on SDM, which directly addresses the gaps identified in literature. Notably, the study indicates the high demand among cancer patients for a collaborative approach in decision-making, echoing concerns raised in previous research by Josfeld et al. (2021). Furthermore, the results shed light on strategies to facilitate SDM, emphasizing patient education, decision aids, and healthcare provider training. These strategies directly address barriers outlined in the literature, providing actionable insights for improving the implementation of SDM in palliative care for cancer patients.

Additionally, each background topic addressed, contributes uniquely to the study by providing a comprehensive understanding of the palliative care context. Understanding the broader context of palliative care helps to recognise the unique challenges and considerations in the care of cancer patients, setting the stage for the exploration of SDM. Discussing advance care planning (ACP) is also essential as it touches upon the need for anticipatory decision-making, aligning with the overall theme of SDM in palliative care. Highlighting palliative care as a holistic approach also emphasizes the importance of addressing physical, emotional and psychological aspects of care thereby reiterating the need to consider comprehensively the values and preferences of patients. Touching on the role of nurses and family in SDM contributes to promoting effective collaboration in decision-making. Exploring autonomy and decision-making is crucial, as it addresses the ethical considerations of respecting patients' autonomy in the context of palliative care. Similarly, discussing the principles of patient-centred care underscores the importance of involving patients in decision-making processes and tailoring care to their individual needs and preferences.

7.1.1 Perspectives of cancer patients on shared decision-making in palliative care

To answer the first research question on the perspectives of cancer patients on shared decision-making (SDM) in palliative care, the study revealed that majority of cancer patients in palliative care prefer a more collaborative and shared approach in decision-making which means that they want to actively participate in decisions regarding their health while partnering with healthcare providers. Both parties are then able to contribute their knowledge and expertise and preferences to jointly make informed, mutually accepted decisions that aligns with the values and preferences of the patient. Patient engagement is necessary for SDM and occurs when patients assume responsibility for their own health and address problems using information and guidance from healthcare professionals (Galleta et al., 2022).

However, patients' preferences and styles for SDM may be impacted by a range of factors such as health literacy and health status. A patient's personal capacity and the environmental conditions in which they find themselves empowers them to acquire, comprehend and use information received to make decisions related to their health which enables them to adopt behaviours that will impact their wellbeing. Health literacy encourages the patient's active interactive role with the healthcare professional. Higher health literacy levels may therefore promote increased autonomy, decisional control, and active participation in health-related and medical decisions. On the other hand, when the level of health literacy is low, the possibility of patient involvement in SDM may be reduced and this hinders effective communication (Alzubaidi et al., 2022). The differences in decision-making must however be considered for a successful implementation of SDM among cancer patients in palliative care as patients express more satisfaction with decisions regarding their treatment when they feel they have participated in the decision-making process, irrespective of whether they had an explicit preference for SDM or not prior to their actual consultation (Josfeld et al.,2021).

The study found a high demand among cancer patients for more information especially regarding information on treatment options and their pros and cons. Josfeld et al., 2021 pointed out in their research that other previous research (Gaston and Mitchell, 2005) have also shown a significantly high demand in patients for information regarding their disease and treatment.

Enhancing patients' understanding of treatment options helps to clarify the possible risks and benefits associated with treatments and makes diagnostic choices more consistent with their preferences and values. Informing patients about the pros and cons of available treatments can enhance the safety and quality of diagnostic procedures (Galleta et al., 2022). It also serves as the basis for the provision of recommendations to patients within the context of their clinical characteristics and individual choices (Tamirisa et al., 2017).

Additionally, based on the results of this review it has also been recognised by previous research (Kousmanen et al., 2021) that healthcare professionals need to develop a good relationship with the patient as it helps to make communication more effective. Considering the complex challenges faced by cancer patients, it is crucial for HCPs to be empathetic and supportive especially in decision-making regarding treatment. Empathy affects communication which patients have found to be very helpful (Hopmans et al., 2015). Good relationship between HCPs and cancer patients in SDM could also contribute to building trust and confidence among patients. When patients trust their care providers it can help to make them feel more comfortable and become more open with discussing their concerns and preferences. Cancer patients have also expressed the need for their caregivers to be emotionally available (Netsey- Afedo et al., 2020; Pan et al., 2022; Gemmell et al., 2022). Cancer patients want their care providers to treat them as 'whole persons' and not a symptom mass as it contributes to their emotional wellbeing (Gemmell et al., 2022). This is evident in the principles of holistic care which views the individual as a whole and not just a disease which is also a fundamental value in patient-centred care (Netsey- Afedo et al., 2020).

Other needs were also identified by cancer patients following their experiences in palliative care SDM. The most prominent concern raised was discussion about the future. Future in this case is not limited to a specific timeline; it ranges from days to years. Most cancer patients wish to engage in discussions that involves how to plan an uncertain future including their hopes, wishes and fears (Gemmell et al., 2022) considering the changes associated with cancer both physically and emotionally. The duration for palliative care varies among individual patients prompting some patients to express a wish to discuss with their healthcare providers about their prognosis including their expected longevity in order to plan for potential adverse events. Planning in advance has been said to be beneficial as it promotes for example even less aggressive care and meets the wishes of patients at the end of life which is the final phase of palliative care (Gemmell et al., 2022).

7.1.2 Strategies to facilitate shared decision-making among cancer patients in palliative care

Regarding strategies for facilitating shared decision-making (SDM) among cancer patients in palliative care, this review identified two primary approaches. It emphasized the significance of patient education and resources including access to information and education and training initiatives for HCPs. Educating patients about treatment options, values clarification, and weighing the pros and cons emerges as a key strategy in this review. Patients with cancer have shown according to previous studies (Tamirisa et al., 2017) to feel more engaged in decision-making when they receive sufficient information. Nevertheless, the findings of our review identified the variability among patients in terms of amount of information they prefer. While some patients preferred to have adequate information, others felt overwhelmed with too much information. This could imply that HCPs must ensure that there is some level of balance in the amount of information given to patients.

This aligns with findings from Maher et al. (2008), which emphasized the demand for extensive information by patients concerning their care. Their study indicated that a lack of information for cancer patients could elevate anxiety levels. Likewise, recent research by Edward et al. (2023) further emphasize that patients' knowledge about care goals, treatment options, and the roles of HCPs significantly influences their participation in SDM. Considering these insights, patient education proves to be a valuable approach to facilitating SDM among cancer patients in palliative care. This is underscored by the acknowledgment that informed patients are better equipped to actively participate in decision-making processes related to their care.

In this review, decision aids (DAs) emerged as important tool for patient education. Research conducted by Stacey et al. (2017) and Pena et al. (2019), as mentioned in Bagshaw et al. (2021) emphasizes the effectiveness of DAs not only in educating and informing patients but also in fostering their involvement in the decision-making process regarding their care. This highlights the broad impact of patient education, extending beyond simply just providing information and knowledge to actively empowering patients to contribute collaboratively to the decisions about their care.

The review findings suggest that patients who are well-informed through DAs are better equipped to understand the complexities of their treatment options (Serpico et al., 2016; Oostendorp et al., 2017). By gaining this understanding, patients are not only more knowledgeable about their conditions but are also more likely to take part in meaningful discussions with HCPs regarding their preferences and values. This, in turn, will foster a collaborative decision-making environment, where both the patient and the HCPs contribute to shaping the course of care. Additionally, the diverse impact of educating patients is clear when we consider the positive results linked to using DAs. Patients who engage actively in decision-making, with the help of these aids, frequently express greater satisfaction with the treatment plans they select as reported by Oostendorp et al. (2017) and Serpico et al. (2016). This satisfaction is based on the feeling of independence and empowerment that arises from being actively involved in decision-making process regarding their care. Therefore, as patients become more involved and empowered through education, the potential for shared decision-making to be truly patient centred becomes more probable.

The results of this review consistently underscore the significance of educating and training healthcare providers (HCPs) as a practical method to improve SDM among cancer patients in palliative care. It is highlighted that the training for HCPs should go beyond simply sharing information. Instead, it should include the enhancement of advanced communication strategies and skills to support SDM. These skills are essential for healthcare providers to not only convey information but also actively involve patients in meaningful discussions. This approach helps them understand patients' preferences, values, and concerns, ultimately promoting a collaborative and shared decision-making process

In the study conducted by Hoek and colleagues in 2022, it was revealed that not all healthcare professionals (HCPs) are cognizant of their potential supportive role in SDM regarding palliative cancer treatment. The study further suggested that HCPs need specific knowledge and communication skills to recognize and actively participate in their roles. Similarly, Legare et al. (2018) and Roodbeen et al. (2020) proposed that education and training programs are instrumental in addressing this gap. It is clear that a specific method of educating HCPs is crucial. This requires offering training that goes beyond fundamental concepts, including detailed communication strategies and highlighting the importance of grasping patient preferences. Additionally, tackling the limited awareness among HCPs regarding their role in shared decision-making (SDM) requires tailored educational programs to provide them with the required knowledge and skills.

Furthermore, the results highlighted the crucial role of interprofessional collaboration and the specific contributions of nurses. The findings emphasize the importance of consistent communication, role of clarity and structured healthcare team interactions to enhance SDM. As mentioned earlier, there has not been much research on the involvement of everyday nursing care decisions which is also important in the provision of more holistic and patient-centred palliative care (Kousmanen et al., 2021), however the perspectives of cancer patients expressed in this review spanning from information needs to emotional and psychological needs show that nurses also have an important contribution to make in enhancing patients' involvement in shared decision-making. Nurses are mostly at the forefront of caregiving and have more frequent interactions with patients. Therefore, it is crucial that the role of nurses in this context is defined more comprehensively as it goes a long way into facilitating the SDM process. Nurses, as identified in the literature, actively contribute to SDM through various means, emphasizing the need for advocacy, support, and education to encourage patient participation in decision-making processes. These strategies align with the overarching aim of promoting SDM in palliative care for cancer patients.

7.1.3 Connection between patient perspectives and facilitation strategies

Several overarching themes have emerged while investigating the perspectives of cancer patients on shared decision-making (SDM) in palliative care. The theme of 'information needs' revealed the desire of patients for comprehensive insights into treatment options, including their pros and cons. This recognition further sets the stage for the development of patient-targeted strategies which emerged as a theme on strategies to facilitate SDM. Under the patient-targeted strategies, the sub-theme 'patient education and resources aligns seamlessly with the need for information. Recognising patients' desire for knowledge enables healthcare professionals to advocate for enhanced educational resources that empower patients with the necessary information thereby promoting SDM throughout their palliative journey.

Simultaneously, the theme, 'communication and relationship with healthcare professionals' highlighted the importance of quality relationships and effective communication which directly influences the strategies targeted at healthcare professionals. The sub-theme 'healthcare professionals' education and training' stems from the patients' perspective on quality of relationship. This approach shows the importance of ongoing education and training for healthcare providers to for example, refine their communication skills and build trusting relationships with patients that are conducive to shared decision-making (SDM).

Delving deeper into the experiences of patients, additional needs and preferences that directly shape the development of facilitation strategies for SDM in palliative care are identified. Within the patients' perspectives, the sub-theme, 'emotional and psychological support' underscores the importance of holistic care which is embedded in the patient-targeted strategies, particularly in the sub-theme 'effective communication'. The recognition that effective communication extends beyond the transfer of medical information emphasizes that emotional support is integral in fostering a collaborative decision-making environment.

In essence, this study review not only identifies patient perspectives on shared decision-making (SDM) but actively translates these insights into targeted strategies. This comprehensive approach demonstrates the interconnectedness between patient perspectives and the development of strategies, reinforcing the study's overarching goal of navigating shared decision-making in the palliative journey of cancer patients.

7.2 Synthesizing main findings with the Brendan McCormack's Person-Centred Nursing (PCN) framework

The main findings of the study aligns with the core elements of the Person-centred nursing (PCN) framework which include: Prerequisites in Person-Centred Nursing, Care environment in Person-Centred Nursing, Person-Centred Processes and Expected Outcomes. Health literacy emerged as a pivotal factor in facilitating SDM aligning directly with the prerequisites for effective person-centred nursing. Patients' ability to comprehend, process, and apply the information provided by HCPs mirrors the prerequisite of professional competence and understanding of the beliefs and values of patients. The framework emphasizes the importance of professional competency and self-awareness, therefore patients' capacity to interpret medical information and actively participate in SDM is a representation of the fundamental prerequisites of PCN (McCormack & McCance, 2010).

Moreover, the study identified the importance of cultivating supportive and empathetic relationships with cancer patients in palliative care reflecting the care environment's requirement for effective staff interactions and supportive organizational systems within the PCN framework. Effective communication and a good relationship resonates with the PCN framework's care environment element. An environment that enhances SDM necessitates good relationships and a conducive setting for power-sharing. Encouraging discussions about the hopes, fears, and future plans of patients within palliative care encapsulates the idea of power-sharing and effective staff relationships (McCormack & McCance, 2010).

Additionally, as revealed in the study, cancer patients in palliative care expressed a high demand for information, especially regarding treatment options and their pros and cons and also sought to discuss issues consisting of the psychological and emotional aspects of their health journey. These desires are at the core of the person-centred processes outlined in the PCN framework focusing on the delivery of care through activities such as aligning with patients' beliefs and values and addressing their information needs. When healthcare providers address these holistic needs, a conducive environment for SDM is nurtured, and involvement in care and patient satisfaction is fostered (McCormack & McCance, 2010).

The study further revealed that patients who actively participated in decision-making through the help of decision aids, expressed greater satisfaction with the treatment plans they selected. This aligns with the PCN framework's expected outcomes, including care satisfaction and involvement in care which reflects the core component of the framework, emphasizing positive outcomes resulting from person-centred nursing. In brief, the synthesis reinforces the importance of prerequisites, a conducive environment, person-centred processes, and expected outcomes, providing insights for healthcare professionals in delivering person-centred care to cancer patients in palliative settings.

7.3 Discussion of method

The discussion of the method used in this review helps us to maintain its quality. It always provides the reader the necessary information to understand and analyse the outcomes and conclusions of the review. The method used for our data collection and analysis are also discussed. As mentioned in the previous chapters the methodology employed in this study was a qualitative study based on a systematic literature review and content analysis. The PRISMA flow chart was used to outline how data was collected and screened for eligibility. 109 articles were screened after duplicates were removed from the initial hits. 38 articles were excluded after abstracts were read with 71 articles remaining. 47 of the articles remaining did not meet the inclusion criteria and were therefore removed bringing it to a total of 24 out of which 20 were selected to be analysed.

This method was the most suitable for the study because of its capacity to explore the multifaceted nature of SDM. It permitted a detailed examination into the differences in the interactions between healthcare providers, patients and their families and emotions that may not be captured through quantitative methods. It also contributed to uncovering the patients' perspectives. The use of content analysis was able to help filter the essence of the narratives of patients while shedding light on the complex dimensions of SDM from the patient's viewpoint. Furthermore, it served as a means to contextualize decision-making factors. The use of content analysis helped to systematically identify and categorize the factors that influenced SDM in palliative care for cancer patients such as clinical information, patterns of communication, and beliefs. Additionally, the method contributed to informing and guiding best practices. This method allowed for the development of insights that can be transformed into practical guidelines for healthcare professionals and policy makers.

The research began with an identification of issues and gaps in shared decision-making (SDM) specifically among cancer patients in palliative care in previous research that had been conducted in this field. After identifying the gaps that needed to be addressed which focused on dwelling more on patients' perspectives in SDM to enhance the SDM process, the research questions were framed and the search for relevant evident based studies related to the aim was made. Data was extracted from the studies and an assessment of quality was conducted. After data was analysed, the evidence was summarized and continued with an interpretation of the main findings.

To ensure the trustworthiness of qualitative data, otherwise known as the quality criteria, a set of five (5) criteria has been suggested by Lincoln and Guba (1994) namely: credibility, dependability, confirmability, transferability, and authenticity (Polit & Beck, 2021). 'Credibility' refers to having confidence in the accuracy of data and their subsequent interpretations which is the primary goal of qualitative research. This review has been carried in a way that enhances the believability of the findings and has taken the necessary steps to validate the reports in this research as both credible and evidence based (Polit & Beck, 2021). The detailed presentation of direct quotes and references from the studies, enriches the analysis and enhances it credibility. 'Dependability', the second criterion for assessing rigor of qualitative research signifies the stability and consistency of data over time and situations. However, without dependability, credibility remains unattainable (Polit & Beck, 2021).

Moreover, within this qualitative review, the data reflects viewpoints of cancer patients on SDM as discussed in the main results. The interpretations of these perspectives have not been fabricated by the researcher, establishing that, the third criterion, 'confirmability' has been enhanced (Polit & Beck, 2021). 'Transferability' refers to the extent to which the findings of this review can be transferred or applied in different settings or groups (Polit & Beck, 2021). The elements highlighted in the themes and sub-themes of the study such as desire for comprehensive information and importance of effective communication, among others are crucial aspects of SDM that may be applied to other healthcare settings or patient groups who are faced with similar challenges. An example may be patients with other life-threatening diseases other than cancer. Ultimately, the research has brought to light various realities in the perspectives of cancer patients which makes the study authentic. As noted by Polit and Beck, (2021), 'Authenticity' becomes evident in a report when it reflects the emotional essence of how participants experience their lives.

8 Strengths and limitations of the study

A significant advantage of this study is that it is the first qualitative systematic review literature research to delve into both cancer patients' perspectives and concurrently exploring strategies to promote shared decision-making (SDM) in their palliative journey. This unique perspective provides an in-depth understanding of patients' viewpoints while directly linking these perspectives to strategies for facilitating SDM. A typical example is patients' need for comprehensive information which aligns with a key strategy of educating the patient and granting them access to adequate information. This creates a valuable correlation between the two research questions. This interconnection enhances the depth of understanding, providing a holistic view of patient needs and the facilitation of effective SDM. Additionally, this review meets the five (5) criteria for trustworthiness which makes it credible, dependable, confirmable, transferable, and authentic (Polit & Beck, 2021).

The review's main limitation is generalizability, in that, it may not be directly applicable to cancer patients in palliative care who may be cognitively incapacitated for decision-making such as those living with dementia and may face challenges in expressing their preferences. More research could however be undertaken in this field to provide tailored insights that guide the development of strategies and interventions sensitive to the unique needs of this population.

9 Conclusion

In conclusion, this review has meticulously explored shared decision-making (SDM) in the context of palliative care for cancer patients. The analysis of diverse perspectives has emphasized the significance of patients' active participation in the decision-making process. By following the Brendan McCormack's Person-Centred Nursing (PCN) framework, the study examined patient beliefs and values which is included in the person-centred process. The analysis of the twenty (20) articles uncovered six (6) key themes and fifteen (15) sub-themes, underscoring the importance of a collaborative and shared decision-making approach that extends beyond mere medical treatments. Emphasizing patient education and healthcare professional training as critical strategies, the study recognizes empowerment as vital for both patients and healthcare providers in decision-making processes.

Notwithstanding, a clear understanding of experiences, values, and preferences of cancer patients helps in the development of tailored strategies in facilitating the shared decision-making process, ultimately enhancing a more holistic and patient-centred approach to palliative care. The findings of this review contribute to the existing knowledge in healthcare by advocating for more patient-centred care models, aiming to transform palliative care practices by creating an inclusive environment, prioritizing patient values, and ensuring care delivery that aligns with patients' needs. Furthermore, a paradigm shift in healthcare and promoting a holistic care has also been instigated.

This systematic literature review contributes to the development of best practice guidelines for shared decision-making (SDM) among cancer patients in palliative care. By selecting and incorporating only the most credible and top-quality evidence, this review provides a rigorous and structured approach to minimize bias and produce reliable findings. The findings inform healthcare providers, policymakers, and other stakeholders on patients' perspectives on SDM and strategies to facilitate SDM among cancer patients in palliative care, improving the quality of care and patient outcomes while considering patient values and preferences.

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Appendices

Appendix 1

Tables

Figures

Boxes

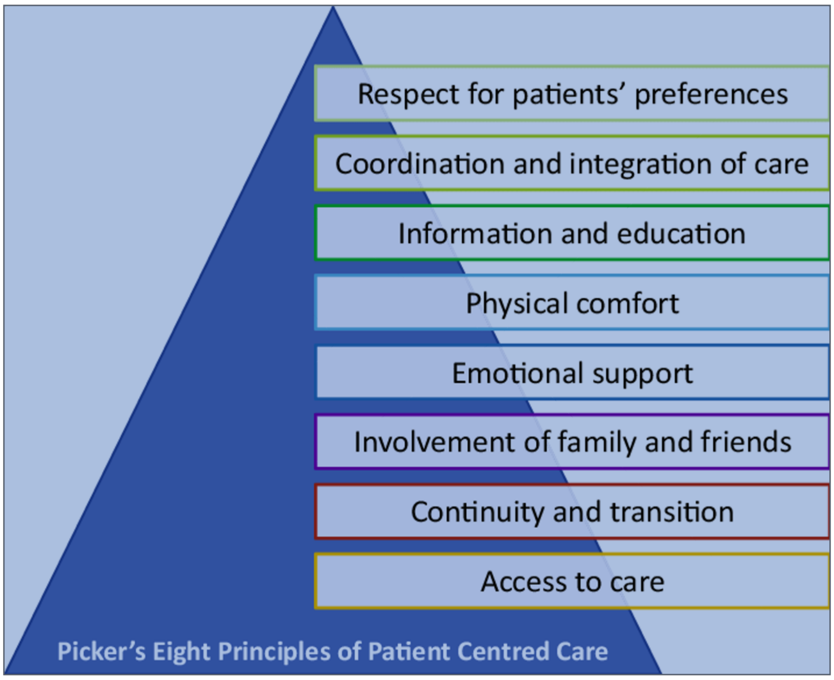
Appendix 2

Database for the selected articles used for the analysis

Databases	***Selected Articles***
CINAHL Complete EBSCO	9
EBSCO Academic Search Elite	5
PubMed	4
Springer Link	1
DOAJ	1
Total	**20**

Appendix 3

Picker’s principles of patient-centred care



Barret et al., 2019. Adapted from ResearchGate. https://www.researchgate.net/publication/337458760_Artificial_intelligence_supported_patient_self-care_in_chronic_heart_failure_a_paradigm_shift_from_reactive_to_predictive_preventive_and_personalised_care

Appendix 4

Overview table of articles included in the analysis

No	Author(s) & year	Title	Aim	Method	Results
1	Bos van den Hoek, D.W., Smets, E. M. A., Ali, R., Baas-Thijssen, M. C. M., Bomhof-Roordink, H., Helsper, C. W., Stacey, D., van Laarhoven, H. W. M., & Henselmans, I. **(2023)**.	“A blended learning for general practitioners and nurses on skills to support shared decision-making with patients about palliative cancer treatment: A one-group pre-posttest study”.	This study assessed the effectiveness of a newly created learning programme healthcare professionals in facilitating SDM about palliative cancer treatment.	A pre-posttest design. HCPs participated in e-learning and online training sessions. They completed surveys and engaged in simulated consultations.	The training showed a significant improvement in SDM support. Observers also rated SDM support more positively and HCPs exhibited increased proficiency, knowledge, and confidence.
2	Alzubaidi, H., Samorinha, C., Saidawi, W., Hussein, A., Saddik, B., & Scholl, I. **(2022).**	“Preference for shared decision-making among Arabic-speaking people with chronic diseases: a cross-sectional study”.	To assess the preference of involvement in SDM among patients with chronic diseases.	A cross-sectional quantitative study using surveys was conducted in the outpatient clinics.	Contrary to findings in Western nations, this research showed that most Arabic speaking patients with chronic diseases wanted a paternalistic approach to decision-making. However, women and other

					unemployed patients preferred a stronger level of participation.
3	Gemmell, R., Halley, A., Stevens, A., Allam, A., Perkins, M., Ethell. M., … Droney, J. **(2022)**.	“Palliative care for patients around the time of haematopoietic stem cell transplant: a qualitative study of patients’ perceptions and experiences of unmet need and attitudes towards palliative care involvement”.	Identifying ways in which a palliative care team can assist patients undergoing stem cell transplant and to investigate attitudes and perceptions of palliative care patients during this process.	Qualitative investigation. The use of interviews and focus group patients before and after their transplant. Discussions were transcribed and themes were analysed.	Themes of ‘identified information and decision-making’, ‘importance of relationships’, ‘changing perceptions of the meaning of palliative care’, and ‘the future’ arose from the study. Patients were receptive to palliative care once the purpose was clearly explained and when emotional and physical needs were addressed.
4	Goto, Y., Miura, H., Yamaguchi, Y., & Onishi, J. **(2022).**	“Evaluation of an advance care planning training program for practice professionals in Japan incorporating shared decision-making skills training: a	Aimed to evaluate the impact of advance care planning training programme on HCPs knowledge, skill, disposition, and self-assurance in initiating ACP.	Use of the novel Japanese educational program to assess the impact of 8-month training program at eight community sites known as the ACP project. Workshop	95% of the participants forming the majority of the expressed their satisfaction with the training and stated that it was useful for the practice of ACP. There was also an improvement in SDM skills.

		prospective study of a curricular intervention”.		included courses on SDM and an evaluation of participants’ satisfaction and comprehension of the training.	
5	Pan, S., Mao, J., Wang, L., Dai, Y., & Wang, W. **(2022).**	“Patient participation in treatment decision-making of prostate cancer: a qualitative study”.	An investigation of how patients perceive and experience the process of making treatment decisions.	Qualitative interview investigation. Participants included 30 patients with prostate cancer. The use of thematic analysis.	A wide range of needs for patients arose which were classified according to themes and sub-themes. The main themes included the following: ‘Less involvement in treatment decision making’, ‘Information on treatment condition and treatment options’, and ‘future consideration and ACP’.
6	Bagshaw, H. P.., Martinex, A., Heidari, N., Scheinker, D., Pollack, A., Stoyanova, R., … Buyyounouski, M. K. **(2021).**	“A personalized decision aid for prostate cancer shared decision making”.	To develop an automated decision support for patient centred treatment decision-making.	Construction of a patient centred medical decision-making template which included inputs on risk group for prostate cancer,	A decision aid tool which focused on the unique needs of prostate cancer patients was developed which examines and incorporates patients’ preferences and wishes in order to prioritize treatment

				treatment alternatives, side effects, etc.	choices based on achieving the desired outcome.
7	Josfeld, L., Keinki, C., Pammer, C., Zomorodbakhsch, B., & Hubner, J. **(2021).**	“Cancer patients’ perspective on shared decision-making and decision aids in oncology”.	To examine the information needs of oncology patients, satisfaction, the decision aids they prefer and preferred approach to decision making.	Development of questionnaires.	Strong desire for information associated with level of education but also an overwhelming feeling by the amount of information. The use of DAs enhanced information satisfaction.
8	Musella, A., DeVitto, R., et al. **(2021).**	“The importance of Shared Decision-Making for Patients with Glioblastoma”.	This study summarized a discussion by advocacy leaders on the significance of SDM among glioblastoma patients.	Gathering insights and perspectives from advocacy leaders who have an experience in interacting with patients and caregivers dealing with glioblastoma cases.	Six ways in which SDM can positively impact patients were identified and well documented.
9	Windon, M. J., Le, D., D’Souza, G., Bigelow, E., Pitman, K., Boss, E., Eisele, D. W., & Fakhry, C. **(2021).**	“Treatment decision-making among patients with oropharyngeal	To understand the needs of patients in order to enhance engagement, patient satisfaction, quality of life	Qualitative study. Use of one-on-one semi-structured interviews	The study revealed fourteen (14) themes with participants expressing concerns about diagnosis, decisional uncertainty, and a variety of decision-making roles including

		squamous cell cancer: A qualitative study”.	and health outcomes in SDM.	and focus group discussions.	physician-controlled, shared, and autonomous.
10	Bos van den Hoek, D. W., Thode, M., Jongerden, I. P., Van Laarhoven, H. W. M., Smets, E. M. A., Tange, D., … Pasman, H. R. **(2021).**	“The role of hospital nurses in shared decision-making about life-prolonging treatment: A qualitative interview study”.	Investigating nurses actual and possible contribution in SDM regarding life-prolonging treatments and their views on why their participation is necessary.	Qualitative interview study. Semi structured interviews with 18 hospital nurses caring for patients with life-threatening sicknesses.	Nurses classified their contributions to SDM as follows: evaluating the quality of decisions, facilitating SDM and complementing the decision-making process.
11	Netsey-Afedo, M. M. L., Ammentorp, J., Osther, P. J. S., & Birkelund, R. **(2020).**	“No time for reflection: Patient experiences with treatment-related decision-making in advanced prostate cancer”.	Exploring the experience of communication between patients with advanced prostate cancer and HCPs and their encounters with the decision-making process related to treatment.	Phenomenology and hermeneutics methodology. Qualitative interviews, and participants observations within a urological outpatient clinic. Analysis using Ricoeur’s theory of interpretation.	Patients experience of the course being routine and treatment related decisions made in advance. Three themes emerged: Fast track diagnosis and treatment; It’s only natural to have this treatment and existential issues were not addressed.

12	Roodbeen, R., Vreke, A., Boland, G., Rademakers, J., van den Muijsenbergh, M., Noordman, J., … Soundy, A. **(2020).**	"Communication and shared decision-making with patients with limited health literacy; helpful strategies, barriers and suggestions for improvement reported by hospital-based palliative care providers".	To examine the strategies, barriers, and suggestions HCPs have regarding communication and SDM among palliative care patients with low health literacy.	Qualitative interview study with 17 HCPs which included 11 physicians and 6 nurses.	Five (5) themes arose regarding strategies, barriers, and recommendations. They included the following: management of time, communication skills of HCPs, tailoring of information, patients' attributes and what medical information contains.
13	Fauzan, A., Setiyarini, S., Effendy, C., & Kristanti, M.S. **(2019).**	"Perception of nurses in decision-making process in palliative care for patients with cancer in public health centers".	The goal of this research was to explore how nurses perceive the decision-making process and to acquire an understanding of the types of decisions made by healthcare providers in palliative care.	Descriptive explorative qualitative study. Use of purposive and snowball sampling. Focus group discussions and interviews.	The study revealed eight (8) themes. They included: information collection on patients' psychological status, development of alternative measures aligning with patients' current psychological condition, determining what type of implementation to perform, information provision to the patients, patient and family decision-making discussions, selection, or rejection of actions by patients, executing chosen actions and assessing outcomes.

14	Henselmans, I., Smets, E. M.A., de Haes, J. C. J. M., Dijkgraaf, M. G. W., de Vos, F. Y., & van Laarhoven, H. W. M. **(2018).**	“A randomized controlled trial of a skills training for oncologists and a communication aid for patients to stimulate shared decision making about palliative systemic treatment (CHOICE): study protocol”.	An examination of the individual and combined effect of training for oncologists and the use of a patient communication tool on SDM during palliative systemic treatment discussions for cancer patients with life expectancy less than one year.	The method used was in conformity with the CONSORT guidelines for reporting parallel group randomized trials.	The trial showed multiple strengths and it was the first study to assess both individual and combined impacts of interventions at both patients and physicians on SDM in palliative care for cancer treatment. The training and communication aid can be applied in both initial and follow-up consultations.
15	Tamirisa, N.P., Goodwin, J.S., Kandalam, A., Linder, S.K., Weller, S., Turrubiate, S., … Riall, T. S. **(2017).**	“Patient and physician views of shared decision making in cancer”.	Explore patients and physicians’ perception of SDM clinical interactions related to the care for cancer.	Open- ended questions using interviews which were coded and analysed for themes on SDM.	Four main themes emerged about factors that influence SDM. They included: provision of information, patient autonomy, effective communication and priorities of physicians and recommendations of physicians.
16	Oostendorp, L. J. M., Ottevanger, P. B., Donders, A. R. T., van de Wouw, A.J., Schoenaker, I. J.H.,	“Decision aids for second-line palliative chemotherapy: a	To assess the safety and effectiveness of DAs for advanced cancer patients	Randomized controlled trial. Random allocation of patients to the control	DAs containing comprehensive risk information had no negative effects on patient well-being. Positive outcomes

	Smilde, T. J., … Stalmeier, P. F.M. **(2017).**	randomized phase II multicentre trial".	contemplating second-line chemotherapy.	group or intervention group in a ratio of 1:2.	during consultations were also reported by nurses.
17	Tariman, J.D., Mehmeti, E., Spawn, N., McCarter, S.P., Bishop-Royse, J., Garcia, I., … Szubski, K. **(2016).**	"Oncology Nursing and Shared Decision Making for Cancer Treatment".	This study aimed to describe the current roles of oncology nurses in guiding patients through the entire cancer SDM process.	Descriptive cross-sectional design employing semi-structured interviews.	Main themes on the nurses' role during cancer SDM included: education, advocacy, information role and psychological support
18	Serpico, V., Liepert, A.E., Boucher, K., Fouts, D.L., Anderson, L., Pell, J., & Neumayer, L. **(2016).**	"The Effect of Previsit Education in Breast Cancer Patients: A Study of a Shared-decision-making Tool".	To encourage participation of breast cancer patients in the decision-making process, while reducing emotional distress.	Observational study. This included two groups who watched the breast cancer video (BCV). No use of questionnaires for the sake of confidentiality.	The BCV was well- received and demonstrated feasibility for implementation into clinical practice.
19	Roze des Ordons, A.L., Sharma, N., Heyland, D.K., & You, J.J. **(2015).**	"Strategies for effective goals of care discussions and decision-making: perspectives from a multi-centre survey of	Evaluating strategies for communicating effectively and making decisions about care goals for serious illness medical interventions as	Cross-sectional survey using closed-and open-ended questions. Responses were	The following themes arose: patient and family-related factors, healthcare provider and patient communication,

		Canadian hospital-based healthcare providers”.	perceived by hospital healthcare providers.	analysed using thematic content analysis.	interprofessional collaborative efforts, education, and resources.
20	Hopmans, W., Damman, O.C., Senan, S., Hartemink, K.J., Smit, E.F., & Timmermans, D. R. M. **(2015).**	“A patient perspective on shared decision making in stage I non-small cell lung cancer: a mixed methods study”.	Studying the perception of SDM of patients with stage I NSCLC and their view on various aspects of SDM.	Sequential mixed method involving qualitative interviews. Analysis was done descriptively and exploratively.	Of all the themes identified, the most significant to stage I NSCLC patients was clinician guidance.