

Review Paper

Shared Decision-making for Cancer Treatment: A Scoping Review



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ABSTRACT

Background: Shared decision-making (SDM) is a key element of client-centered cancer care, involving active collaboration among patients, families, and healthcare professionals (HCPs). Understanding the roles and interactions among these stakeholders is essential to support significant engagement in treatment decisions. This scoping review aims to explore and synthesize the roles and components of SDM in cancer treatment.

Methods: This scoping review was conducted in accordance with the Arksey and O'Malley framework and the PRISMA-ScR (PRISMA extension for scoping reviews) guidelines. A comprehensive literature search was conducted across 8 electronic databases—Scopus, PubMed, ProQuest, EBSCO, Cochrane Library, ScienceDirect, MEDLINE, and Garuda—as well as Google Scholar, a supplementary search engine. The search included studies published between 2015 and 2024 in English and Indonesian languages. Key terms related to decision-making and cancer treatment directed the search strategy. The screening process was carried out using the Rayyan QCRI software to enable independent, blinded review by multiple researchers, and references were managed using Mendeley reference manager. Data extraction focused on synthesizing key themes related to patient participation, family involvement, and HCP roles in SDM within clinical settings.

Results: A total of 52014 articles were retrieved, with 18 studies meeting the inclusion criteria. The included studies comprised 6 quantitative, 11 qualitative, and 1 mixed-methods study. Thematic analysis revealed the emergence of 3 main themes: (1) patient participation (n=18, 100%); (2) family involvement (n=14, 78%); and (3) the role of HCPs (n=16, 89%).

Conclusion: This review emphasizes the importance of collaborative decision-making in cancer treatment, with active roles for patients, families, and HCPs. Effective communication among these parties is essential for patient-centered care, supporting informed, value-aligned treatment choices, and optimizing patient outcomes.

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Highlights

- The level of patient involvement varies, ranging from active to passive, depending on individual preferences and cultural factors. The SDM approach is increasingly popular as it encourages collaboration between patients and HCPs.
- Families provide emotional support, assist in gathering information, and influence treatment decisions. However, conflicts can arise when patient and family preferences differ.
- HCPs serve as information providers, decision facilitators, and emotional supporters.
- Effective communication between HCPs, patients, and families is crucial.
- Collaborative decision-making processes enhance patient and family satisfaction.
- Culturally-sensitive SDM training and decision-support tools are needed to ensure patient-centered care.
- This approach requires integrating the perspectives of patients, families, and HCPs to improve treatment outcomes.

Plain Language Summary

This review examines how cancer patients make treatment decisions, highlighting the roles of patients, families, and healthcare professionals (HCPs). Patients may actively participate or rely on others, influenced by personal and cultural factors, while families provide emotional support, gather information, and influence decisions, though conflicts may arise. HCPs guide the process by offering information, emotional support, and decision-making assistance, with effective communication being crucial. Shared decision-making (SDM) leads to better outcomes and satisfaction, emphasizing the need for culturally sensitive training and tools to support patient-centered care.

Introduction

Cancer is a critical global health challenge among non-communicable diseases, characterized by uncontrolled cellular proliferation that may invade surrounding tissues and metastasize (Magnusson, 2020; American Cancer Society, 2024). The incidence of new cancer cases worldwide rose from 18.1 million in 2018 to 19.3 million in 2020, resulting in nearly 10 million deaths across all age groups, and projections indicate an increase of 61.3% by 2040 (WHO, 2022). Given the high and escalating prevalence of cancer, making informed treatment decisions is imperative. A cancer diagnosis profoundly affects patients and their families, impacting not only physical health but also emotional, social, and financial wellbeing (Khullar et al., 2018). Patients must navigate numerous uncertainties related to diagnostic procedures, complex treatment regimens, remission, palliative care, and unpredictable disease outcomes, a process that can recur throughout their lives (Stone & Olsen, 2022). These challenges significantly influ-

ence the patient's quality of life (QoL) and can lead to heightened levels of stress, anxiety, and depression (Pitman et al., 2018). Therefore, the decision-making process surrounding treatment options is a vital component of the patient's journey through illness.

The decision-making process in healthcare involves a collaborative effort among the patient, their family, and the medical team to identify treatment options that align with the patient's preferences and needs, based on available information (Tariman et al., 2012). An increasing recognition of its significance drives this shift towards a more patient-centered approach (Zucca et al., 2014). Engaging patients more actively in clinical decision-making can enable healthcare providers to accept choices that may not align with their professional judgments but that the patient is willing to pursue (Légaré & Witteman, 2013). Consequently, adopting effective decision-making models in clinical settings could be a beneficial strategy for helping cancer patients evaluate their treatment options.

Previous reviews of decision-making in cancer care have typically focused on specific aspects of the process, such as particular age groups or healthcare providers. For instance, [Dijkman et al. \(2022\)](#) examined treatment preferences among older adults, and [Spronk et al. \(2018\)](#) investigated the availability and effectiveness of shared decision-making (SDM) tools. However, this study was limited to metastatic breast cancer patients. Neither review addressed cancer patients more broadly. Meanwhile, [Pinker and Pilleron \(2023\)](#) focused on the role of healthcare providers in patient decision-making. Similarly, [Covvey et al. \(2019\)](#) explored the barriers and facilitators of SDM in oncology, identifying factors such as patient characteristics, physician roles, and health system influences. However, a comprehensive review that integrates the involvement of patients, families, and healthcare professionals (HCPs) in the SDM process has not yet been conducted.

In contrast to previous studies, this scoping review focuses on cancer patients in general, across diverse clinical settings, rather than limiting its scope to a specific cancer type or treatment phase. Specifically, it aims to explore and synthesize the roles and components of SDM in cancer treatment by examining how patients, family members (FMs), and HCPs participate in and collaborate on the decision-making process. By adopting a broader, more holistic perspective, the review seeks to address gaps in the existing literature and generate insights applicable across various cancer care contexts.

Materials and Methods

This scoping review was conducted using the Arksey and O'Malley framework, in accordance with the [Joana Briggs Institute \(JBI\) \(Aromataris & Munn, 2020\)](#). The process included (a) identifying the research questions; (b) identifying relevant articles; (c) selecting articles; (d) mapping data; and (e) collating, summarizing, and reporting results. Additionally, the PRISMA-ScR (preferred reporting items for systematic reviews and meta-analyses extension for scoping reviews) was used to optimize reporting and increase validity ([Tricco et al., 2018](#)). This research protocol has been registered in the [Open Science Framework \(OSF Ltd. 2026\)](#).

Identifying research questions

We aim to scope the existing literature and specifically answer the research question: how does the treatment decision-making process in cancer care integrate patient participation, family involvement, and HCPs' roles?

Identifying relevant studies and search terms

A comprehensive literature search was conducted across 8 prominent databases, including Scopus, PubMed, ProQuest, EBSCO, Cochrane Library, ScienceDirect, MEDLINE, and Garuda (an Indonesian database), as well as Google Scholar, a supplementary search engine. The search strategy employed MeSH terms and key phrases to identify relevant publications. The primary search terms included variations of "decision-making" or "choice-making," combined with cancer-related terms such as "neoplasms" or "malignancy," and treatment-related terms such as "therapy." For the Garuda database (Indonesian database), the search utilized the keyword "pengambilan keputusan pengobatan pasien kanker." These terms were applied to the title and abstract fields using appropriate Boolean operators (e.g. AND, OR) to combine concepts and improve the precision and sensitivity of the search. An initial exploratory search was performed to identify additional relevant keywords and their variations across different languages and cultural contexts. The identified terms were then incorporated into the main search strategy ([Table 1](#)). To ensure comprehensive coverage, the reference lists of articles retrieved from Google Scholar were also examined to identify potentially relevant studies that may have been overlooked in the database searches.

Selecting studies

All studies retrieved from the database searches were rigorously screened using predetermined inclusion and exclusion criteria. The initial phase involved reviewing the titles and abstracts of identified studies to assess their relevance, specifically regarding decision-making processes among adult cancer patients in clinical settings. To enhance the efficiency and accuracy of this screening process, [Qatar Computing Research Institute \(Rayyan QCRI\)](#) software was utilized ([Ouzzani et al., 2016](#)) and no single method fulfills the principal requirements of speed with accuracy. Automation of systematic reviews is driven by a necessity to expedite the availability of current best evidence for policy and clinical decision-making. We developed [Rayyan \(Rayyan, 2024\)](#). Two independent reviewers, a researcher and a nursing lecturer, conducted the selection process, resolving any conflicts through collaborative discussion to ensure consistency and accuracy in the final selection of studies.

The inclusion and exclusion criteria for this scoping review were established using the population concept context (PCC) model ([Table 2](#)). Qualitative, quantitative, and mixed-method studies presenting empirical

Table 1. Search strategy

| No. | Database | Keyword | Article |
|-----|------------------|--|---------|
| 1. | PubMed | ((Decision making OR decision making, shared OR decision making, clinical[MeSH Terms]) AND (patients OR cancer survivors[MeSH Terms])) AND (neoplasms OR malignancy OR cancer[MeSH Terms])) AND (treatment OR therapy[MeSH Terms]) | 28680 |
| 2. | Scopus | ((Decision making OR decision making, shared OR decision making, clinical[MeSH Terms]) AND (patients OR cancer survivors[MeSH Terms])) AND (neoplasms OR malignancy OR cancer[MeSH Terms])) AND (treatment OR therapy[MeSH Terms]) | 11650 |
| 3. | EBSCO | ((Decision making OR decision making, shared OR decision making, clinical[MeSH Terms]) AND (patients OR cancer survivors[MeSH Terms])) AND (neoplasms OR malignancy OR cancer[MeSH Terms])) AND (treatment OR therapy[MeSH Terms]) | 426 |
| 4. | ScienceDirect | Cancer patient AND treatment decision | 813 |
| 5. | Cochrane Library | Decision-making OR choice-making AND cancer OR oncology OR malignancy AND treatment OR therapy | 6490 |
| 6. | ProQuest | Title (decision making) AND title(patients cancer) AND title(treatment) | 69 |
| 7. | MEDLINE | Decision making OR choice making AND cancer OR oncology OR malignancy AND treatment OR therapy {including limited related terms} | 3870 |
| 8. | Garuda | Pengambilan keputusan pengobatan pasien kanker | 2 |
| 9. | Google Scholar | Treatment decision-making for cancer patients | 14 |

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data related to treatment decision-making were considered. However, opinions, editorials, commentaries, case reports, letters, literature studies (review studies), parts of books (book chapters), and articles originating from proceedings that do not provide full text, and single-patient studies without broader relevance to decision-making processes were excluded. Additionally, studies that focused solely on cancer prevention, early detection, or technical aspects of treatment, without addressing decision-making, were removed. Only studies published in English and Indonesian within the last 10 years were included, unless they were seminal works offering significant contributions to the field. Through a comprehensive search across eight databases and a supplementary search engine, 52014 relevant articles were initially collected in Mendeley reference manager. After removing duplicates and screening titles and abstracts, 31 publications were selected for full-text review. Ultimately, 18

articles were deemed relevant for data extraction and analysis (Figure 1).

Mapping data

Data were systematically extracted by recording key information on authors, research purposes, study methods, participant characteristics, research context, and major findings. A detailed description of the analyzed variables is provided in Table 3.

Collating, summarizing, and reporting results

After delineating the research focus, SDM in cancer treatment within clinical settings, we systematically gathered data from pertinent articles examining patient participation, family involvement, and the roles of HCPs in this context. Statements and findings relevant to the study's aims were then coded into predefined thematic

Table 2. Eligibility criteria for articles

| Criteria | Inclusion |
|------------|---|
| Population | Adults (18 years and older) diagnosed with cancer, receiving or deciding on treatment options in clinical settings. |
| Concept | Decision-making process related to cancer treatment. |
| Context | Studies are conducted in clinical settings such as hospitals, oncology centers, outpatient clinics, or palliative care centers. |

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categories, including patient engagement, family support, and HCP influence on treatment decision-making. Following the coding phase, the data were subjected to a thematic analysis to identify overarching patterns and insights related to these core themes. The results of this analysis were then organized into a structured, comprehensive report to offer an in-depth understanding of the levels and roles within SDM in cancer care, while addressing gaps identified in the existing literature.

Results

A total of 18 articles were deemed relevant for data extraction and analysis (Figure 1). Of 18 articles reviewed, 6 utilized quantitative research designs (Schuler et al., 2017; Shin et al., 2017; Mokhles et al., 2018; Nakayama

et al., 2020; Gu et al., 2023; Tilly et al., 2023) family caregiver, and their treating oncologist view the risks and benefits of family involvement in cancer treatment decision making (TDM), 11 employed qualitative approaches (Berry et al., 2015; Laidsaar-Powell et al., 2016; D'Agostino et al., 2018; Pozzar et al., 2018; Sattar et al., 2018; Dew et al., 2019; Wang et al., 2020; Holdsworth et al., 2020; Malhotra et al., 2020; McCaughan et al., 2022; Sitanggang & Lin, 2024) and 1 used mixed methods designs (Heuser et al., 2023). The studies were conducted across various countries worldwide: 4 studies were from the United States (Berry et al., 2015; D'Agostino et al., 2018; Pozzar et al., 2018; Holdsworth et al., 2020), 2 each from Germany (Schuler et al., 2017; Heuser et al., 2023) and China (Wang et al., 2020; Gu et al., 2023), 1 study each from South Korea (Shin et al., 2017), Austra-

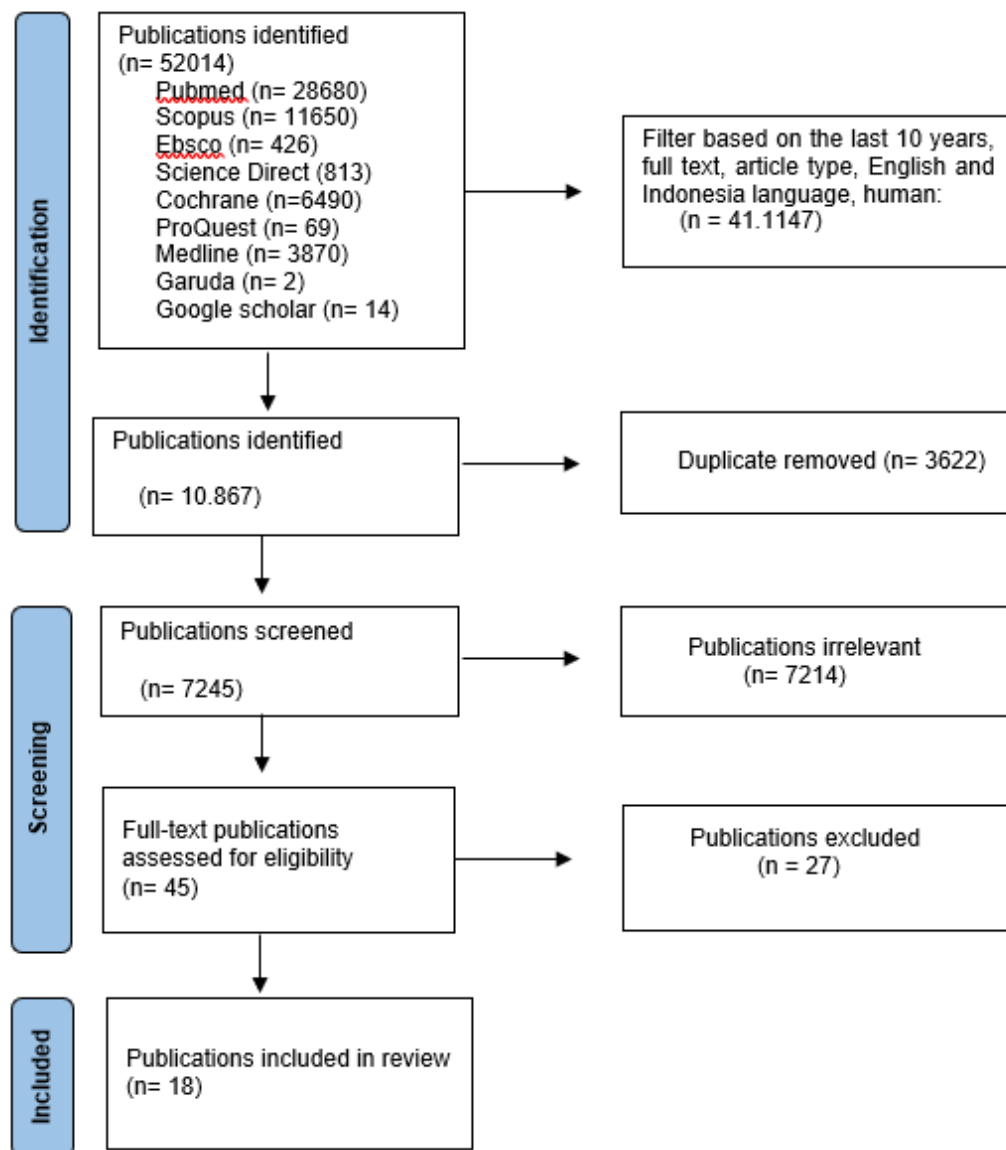


Figure 1. PRISMA-ScR chart

Table 3. Exploring articles on treatment decision-making in cancer patients

| Author(s), Year, Country | Study Objectives | Design and Methods | Sample | Setting | Main Findings |
|--|---|---|--|--|--|
| D'Agostino et al. (2018), USA | To identify factors influencing treatment choices and understand the shared experiences of patients and caregivers in the context of early-stage papillary microcarcinoma (PMC) | Qualitative methods, including focus groups and individual semi-structured interviews | 21 participants: 15 PMC patients (4 from the surgery subsample and 11 from the active surveillance subsample) and 6 caregivers | Endocrinology outpatient clinic | The complexity of treatment decision-making in PMC patients emphasizes the need for personalized communication from healthcare providers to align treatment options with patients' values and preferences. |
| Shin et al. (2017), South Korea | To explore and compare attitudes toward family involvement in cancer TDM among patients, caregivers, and oncologists | A cross-sectional survey was conducted using questionnaires linked as patient-caregiver-oncologist triads | 134 oncologists recruited 725 cancer patients and their family caregivers from an initial pool of 960 invited dyads (75.5% participation rate). | A multicenter survey was conducted across 13 cancer centers in Korea, including the National Cancer Center and 12 regional cancer centers. | The results indicated varying preferences for family involvement in TDM, with a significant proportion of participants agreeing that it is beneficial. |
| Sattar et al. (2018), Canada | To explore the decision-making experiences of older adults with cancer regarding chemotherapy and radiation treatment. | A qualitative design using semi-structured interviews | 20 older adults aged 65+ who recently made treatment decisions regarding chemotherapy or radiation for cancers like breast, prostate, colorectal, and lung | Princess Margaret Cancer Centre and Odette Cancer Centre in Toronto, Ontario, Canada | The importance of trust and expected outcomes in the TDM process among older cancer patients. |
| Laidsaar-Powell et al. (2016), Australia | To explore patient, family, and clinician attitudes and experiences regarding family involvement in cancer TDM | A qualitative study design was employed, utilizing semi-structured interviews to gather in-depth insights from participants | 30 patients (response rate 54%) 33 FMs (response rate 67%) 11 oncologists (response rate 61%) 10 oncology nurses (response rate 48%) | A tertiary metropolitan hospital oncology clinic and a breast cancer patient advocacy group | Participants' experiences of family behaviors during the decision-making process. Attitudes towards family involvement in decision-making. Perceptions of factors influencing family involvement. |
| McCaughan et al. (2022), UK | To explore the perspectives of patients with chronic hematological cancers regarding TDM and to identify factors that promote or impede this process | A qualitative, descriptive study was conducted using semi-structured in-depth interviews | 35 patients were interviewed, with the option for them to invite a relative to participate, enhancing the depth of the data collected | UK's Hematology Malignancy Research Network (HMRN) | The findings emphasize the importance of patient and public involvement in TDM, showing that the participation of relatives improves data quality and adds valuable perspectives |

| Author(s), Year, Country | Study Objectives | Design and Methods | Sample | Setting | Main Findings |
|------------------------------------|--|--|---|--|--|
| Dew et al. (2019), New Zealand | To provide insight into the mechanisms of decision-making in cancer care consultations by identifying the elements of epistemic and deontic rights and their interplay | Qualitative study, based on recordings of cancer care consultations | 18 patient participants and 8 specialists | 4 hospitals in Aotearoa/New Zealand | Decision-making in cancer care consultations is a dynamic process influenced by the interplay of epistemic (knowledge-related) and deontic (decision-making authority) rights. The study reveals that clinicians often maintain epistemic authority and limit patients' deontic rights, especially when clinical benefits are clear. |
| Pozzar et al. (2018), USA | To pilot-test the procedures for recruiting unpaid caregivers and the interview protocols for a planned grounded theory study of the ovarian cancer treatment decision-making process. | A cross-sectional, descriptive study using a qualitative approach | 6 out of 8 invited patients, 4 out of 6 unpaid caregivers (partner, daughter, niece, or cousin of the patient participant), and 3 physicians were interviewed | A National Cancer Institute (NCI)-designated cancer center located in the Pacific Northwest of the United States | The study identified 3 major categories of concepts describing the process of ovarian cancer treatment decision-making: Choosing a provider, choosing a facility, and choosing a treatment. Geographic location was noted to influence treatment decisions, and physicians reported encounters with patients declining recommended treatment. |
| Wang et al. (2020), China | To explore the TDM, family influences, and cultural influences of Chinese breast cancer survivors | Qualitative study, expressive writing method to explore the experiences of breast cancer survivors | 44 participants who were diagnosed with stage 0 to III breast cancer | Weifang People's Hospital | Three themes were identified: TDM, family influences, and cultural influences. TDM included subthemes of preference for mastectomy, passive involvement, and active involvement. Family influences included subthemes of financial burden, family expectations, and family support. Cultural influences included subthemes of fatalism, barriers to expressing emotions, and stigma related to cancer. |
| Sitanggang & Lin (2024), Indonesia | To explore the TDM process for Indonesian women with breast cancer, highlighting the care needs and the importance of nurses' roles in this context | Qualitative research design, in-depth interview, and online semi-structured interviews with each participant via the Zoom platform | 15 women aged 30 to 60 years old | Breast Clinic in a private hospital in Banten | The study highlights the importance of nurses in providing clear information and support to patients and their families during the decision-making process. It emphasizes the need for nurses to be trained in knowledge and skills related to the decision-making process for cancer patients. |
| Gu et al. (2023), China | To investigate factors affecting patient involvement in TDM, particularly focusing on demographic and clinical characteristics, patient awareness of CRC risk factors, and the role of family and HCPs in the decision-making process. | Quantitative research design using a nationwide, multicenter, cross-sectional survey | 3824 patients who submitted self-reported efficacy evaluations during treatment | Henan Cancer Hospital and the First Affiliated Hospital of Baotou Medical College | Gender, age, education level, family economic income, marital status, bearer of treatment expenses, type of hospital, and treatment method were independent factors affecting patient involvement in TDM. Males, younger patients, those with higher education and income, and married patients were more involved in making treatment decisions. |

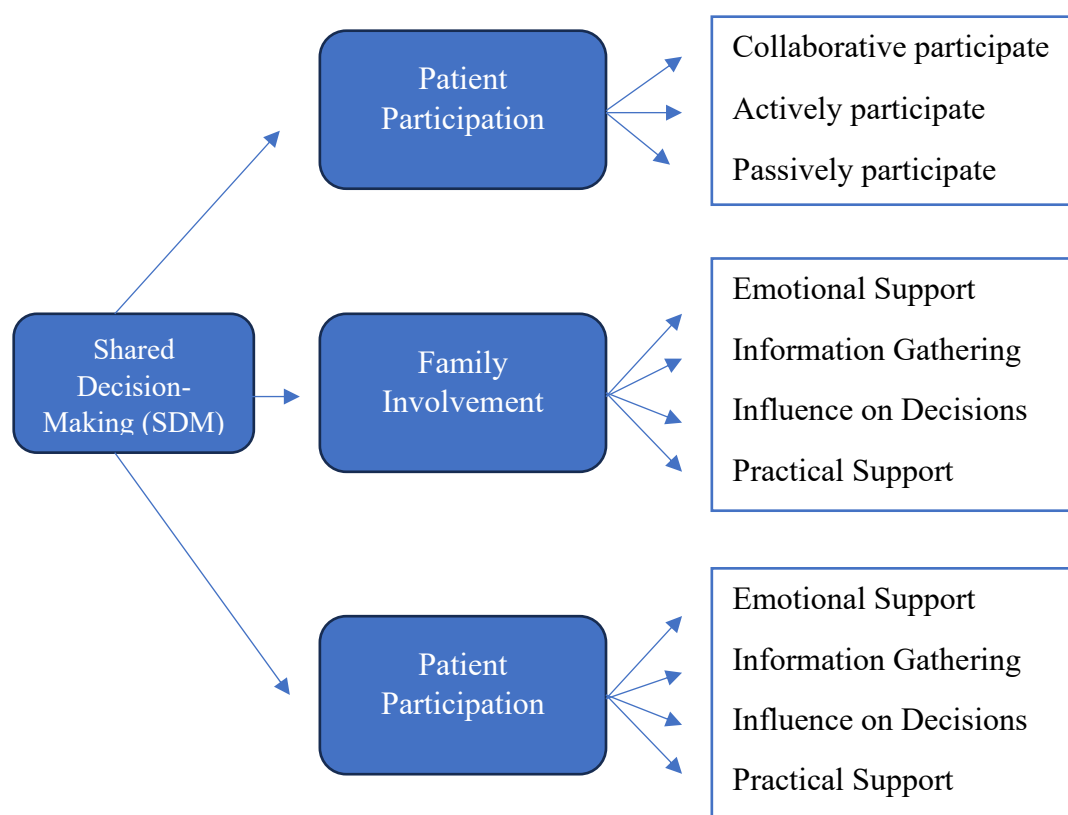
| Author(s), Year, Country | Study Objectives | Design and Methods | Sample | Setting | Main Findings |
|-----------------------------------|--|---|--|--|---|
| Tilly et al. (2023), Malawi | To explore decision-making preferences among cancer patients in Malawi, focusing on patient participation, family involvement, and the role of HCPs in the decision-making process | Quantitative study, a survey method | 50 cancer patients in the oncology clinic | Oncology clinic at Kamuzu Central Hospital in Lilongwe, Malawi | The majority of participants (70%) preferred SDM regarding their cancer treatment. About half of the participants (52%) felt their medical team did not involve them in decision-making as much as they would have liked. Nearly all participants (94%) preferred to be informed by their medical team about the likelihood that treatments would lead to a cure. |
| Mokhes et al., 2018), Netherlands | To investigate patient involvement in TDM, perceived patient knowledge of treatment options, and experiences with clinical decision-making | Quantitative method, prospective observational study | 84 patients with early-stage non-small cell lung cancer (NSCLC) | Erasmus University Medical Center, Erasmus MC-Cancer Institute, or Amphia Hospital Breda | Dutch early-stage NSCLC patients find it important to be involved in TDM. A substantial proportion of patients experienced decisional conflict and felt uninformed. SDM is crucial for patient-centered cancer care, allowing patients to be active partners in treatment decisions. |
| Nakayama et al. (2020), Japan | To evaluate the relationship between perceived SDM, physicians' explanations, and treatment satisfaction in patients with prostate cancer receiving hormone therapy | The study was designed as a cross-sectional survey conducted using an online panel in Japan | 124 patients and 150 physicians | Hospital | The study suggests that providing comprehensive information and engaging patients in decision-making processes enhances their satisfaction with treatment and physicians' explanations. |
| Heuser et al. (2023), Germany | To analyze patients' perceived SDM experiences over 4 weeks between patients participating in or not in multidisciplinary tumor conferences (MTCs), and to analyze the association of patients' active participation in and organizational variables of MTCs with patients' perceived SDM experience directly after MTC. | Mixed method, combining quantitative patient survey data, qualitative passive participatory observation in MTCs | Data were collected from a sample of 317 patients diagnosed with breast or gynecologic cancer. | The study was conducted across six breast and gynecologic cancer centers in North Rhine-Westphalia, Germany. | The study provided insights into patients' SDM experiences in MTCs, indicating that MTC environment variables were associated with these experiences. |
| Schuler et al. (2017), Germany | To assess patients' DCP in medical decision-making and their association with various patient-reported outcomes (PRO) in a clinical setting | Quantitative study, a cross-sectional design | 126 patients, out of which 102 (81%) completed the DCP items | Comprehensive Cancer Center, University Hospital Dresden | Among the cancer patients assessed, 49% preferred SDM, 29% wanted to leave control to their physician, and 22% wished to be in control of their treatment decisions. |

| Author(s), Year, Country | Study Objectives | Design and Methods | Sample | Setting | Main Findings |
|-----------------------------------|--|--|--|--|---|
| Malhotra et al. (2020), Singapore | To assess the elements of SDM in oncologist-patient consultations, focusing on the involvement of patients and caregivers in decision-making processes | A qualitative study involved audio-recording oncologist-patient consultations | 13 patients consented, of whom 100 completed a pre-consultation survey and had their consultations audio-recorded. Of these, 77 had a primary informal caregiver accompanying them. The sample for analysis included 41 consultations that involved decision-making about new treatment options or changes to the current treatment plan | Clinical setting, consultation rooms where oncologist-patient interactions took place | 46% of the analyzed consultations focused on only one aspect of treatment choice, while 54% focused on two or more aspects. Stopping active life-prolonging treatments and referral to palliative/hospice care were discussed in 12% of the consultations. There were no significant differences in patient and caregiver characteristics between the analytic and overall samples. |
| Holdsworth et al. (2020), USA | To understand the overall experience of cancer care, particularly focusing on access to care, communication, coordination, information, and involvement in decision-making | Qualitative design, in-depth interviews | 37 cancer patients and 7 caregivers | One academic cancer center, the National Cancer Institute | The study found that decision-making in cancer care involves understanding the presence or absence of options during care, information needs, and involvement in decision-making. It highlighted the importance of patients feeling involved in their care and being able to participate in decisions, reflecting their preferences and values. |
| Berry et al. (2015), USA | To explore the TDM process in patients with bladder cancer, focusing on their experiences and the factors influencing their decisions | The study employed a qualitative approach using a descriptive cross-sectional design and Grounded Theory methods for data generation and analysis. | 60 participants, including 45 men and 15 women | A multidisciplinary genitourinary oncology clinic (Dana-Farber Cancer Institute) and two urology clinics (Brigham and Women's Hospital and Beth Israel Deaconess Medical Center) | Participants primarily focused on the decision of where to receive care, favoring locations that offered the highest level of physician expertise. Those with early-stage tumors generally recognized only one treatment option and adhered closely to their physician's recommendations. In contrast, participants with stage II-III tumors were more aware of multiple treatment options. For stage IV participants, a key consideration was balancing QoL with treatment outcomes. Additionally, personal preferences, such as age and activity level, significantly influenced decisions related to bladder reconstruction. |

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lia (Laidsaar-Powell et al., 2016), Netherlands (Mokhles et al., 2018), Japan (Nakayama et al., 2020), Singapore (Malhotra et al., 2020), Indonesia (Sitanggang & Lin, 2024), New Zealand (Dew et al., 2019), Canada (Sattar et al., 2018), Malawi (Tilly et al., 2023), UK (McCaughan et al., 2022). The results are organized into three interrelated components that shape SDM in cancer care: Patient participation, family involvement, and the role of HCPs. These components operate interactively

across clinical and sociocultural contexts, rather than following a fixed sequential process. As illustrated in Figure 2, each stakeholder contributes distinct but complementary functions. Of the included studies, 100% (n=18) addressed elements of patient participation, 78% (n=14) addressed family involvement, and 89% (n=16) explored the role of HCPs.



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Figure 2. A model illustrating the roles of patients, FMs, and HCPs in SDM for cancer treatment

Patient participation in decision-making

This review highlights the diverse ways in which patients participate in SDM, ranging from active, collaborative engagement to more passive roles. Studies across various cancer types indicate that SDM has increasingly become a primary approach in treatment-related decision-making. Across various countries, including the Netherlands, Japan, Germany, Malawi, Singapore, the UK, and Canada, patients demonstrated a strong preference for collaborative models, actively engaging in discussions alongside HCPs (Schuler et al., 2017; Mokhles et al., 2018; Sattar et al., 2018; Malhotra et al., 2020; Nakayama et al., 2020; McCaughan et al., 2022; Tilly et al., 2023) little is known on factors, which may influence cancer patients' decision control preferences (DCP). Effective triadic communication and patient inclusion in multidisciplinary consultations were identified as enablers of significant SDM (Laidsaar-Powell et al., 2016; Heuser et al., 2023).

Active patient participation in cancer TDM often depends on the availability of adequate information and the patient's confidence in evaluating the available treatment options. Evidence from multiple studies highlights variations in how patients engage in decision-making, reflecting individual preferences and contextual influences. Research conducted in South Korea has confirmed that patients tend to take an active role in treatment decisions (Shin et al., 2017). Similarly, early-stage papillary thyroid cancer patients were found to be more proactive in choosing surgical interventions, driven by concerns about disease progression (D'Agostino et al., 2018). Furthermore, personal preferences have been shown to significantly influence treatment choices among bladder cancer patients, affecting decisions about treatment locations and reconstruction options and reflecting high levels of patient engagement (Berry et al., 2015). However, variability in engagement patterns has also been observed, with some patients choosing active participation while others preferred to defer decisions to their HCPs (Holdsworth et al., 2020).

Conversely, passive participation is more common in specific cultural contexts, where social norms shape patients' attitudes towards decision-making. For instance, in China and Indonesia, breast and colorectal cancer (CRC) patients often entrusted decisions to family or physicians, influenced by sociocultural norms and limited health literacy (Wang et al., 2020; Gu et al., 2023; Sitanggang & Lin, 2024). Even in Western countries, such as the United States, there are cases where ovarian cancer patients rely more on their physicians' expertise to make urgent treatment decisions (Pozzar et al., 2018). Likewise, a study found that some patients favor a passive stance, placing full trust in their HCPs' clinical knowledge (Dew et al., 2019).

Family involvement

Family involvement constitutes a foundational element in enhancing the quality of care and overall wellbeing of cancer patients. This scoping review identifies four primary dimensions of family engagement: Emotional support, information gathering, influence in decision-making, and practical support. Firstly, emotional support from FMs contributes significantly to the patient's psychological resilience, as their presence, empathy, and moral support alleviate the anxiety and stress often associated with cancer treatment (Shin et al., 2017; Sattar et al., 2018; Nakayama et al., 2020) family caregiver, and their treating oncologist view the risks and benefits of family involvement in cancer TDM. Secondly, families frequently serve as advocates, proactively seeking information on diagnoses, treatment options, and care plans, thereby facilitating more informed and meaningful decision-making by the patient (Berry et al., 2015; McCaughan et al., 2022). Moreover, FMs play a critical role in influencing treatment decisions, especially when patients experience cognitive or physical limitations, thereby ensuring that chosen interventions align with the patient's values and preferences, which ultimately enhances the appropriateness of clinical care (Dew et al., 2019; Malhotra et al., 2020; Wang et al., 2020). Finally, practical support, ranging from assistance with mobility and daily living tasks to medication management, plays a pivotal role in alleviating patients' burdens, thereby enabling them to focus on recovery (Berry et al., 2015; Dew et al., 2019; Sitanggang & Lin, 2024). In summary, these aspects underscore the integral and multidimensional role of family involvement in supporting patients through the complexities of cancer treatment.

HCPs' roles

HCPs play a pivotal role in supporting cancer patients and their families by serving as primary sources of information, facilitators of decision-making, providers of emotional support, and experts in clinical care. To begin with, HCPs serve as crucial information providers, ensuring that patients and families receive clear and comprehensive explanations regarding diagnoses, treatment options, and care plans (Berry et al., 2015; Laidsaar-Powell et al., 2016; Shin et al., 2017; Schuler et al., 2017; D'Agostino et al., 2018; Pozzar et al., 2018; Sattar et al., 2018; Dew et al., 2019; Wang et al., 2020; Malhotra et al., 2020; Nakayama et al., 2020; McCaughan et al., 2022; Sitanggang and Lin, 2024). As noted by several studies, effective communication from HCPs encourages patient and family engagement and promotes active participation in the care process (Schuler et al., 2017; Malhotra et al., 2020; Nakayama et al., 2020). In addition to this role, HCPs facilitate decision-making by guiding patients and families through complex choices, thereby reducing ambiguity and fostering confidence in treatment pathways (Heuser et al., 2023; Tilly et al., 2023). A further role is the provision of emotional support, in which HCPs contribute to a calm, empathetic environment that helps reduce anxiety and enhance emotional resilience among patients (Laidsaar-Powell et al., 2016; Sattar et al., 2018; Wang et al., 2020). Finally, the clinical expertise of HCPs is essential to delivering safe, evidence-based, and high-quality care. This expertise allows HCPs to accurately diagnose, assess, and implement clinical interventions aligned with current best practices, contributing to optimal care outcomes (Pozzar et al., 2018; Dew et al., 2019; McCaughan et al., 2022). Taken together, these roles underscore the integral role of HCPs in holistic patient and family wellbeing in cancer care.

Discussion

Based on the findings of this review (Table 4), there are three main themes regarding SDM levels in cancer treatment in clinical settings: Patient participation, family involvement, and the role of HCPs.

Patient participation in decision-making

Patient involvement in decision-making is a fundamental component of effective SDM, reflecting a broader shift toward patient-centered care. Evidence from the literature indicates a strong trend toward adopting collaborative, or SDM approaches in various clinical settings (Laidsaar-Powell et al., 2016; Schuler et al., 2017; Mokhles et al., 2018; Sattar et al., 2018; Malhotra et al.,

Table 4. SDM levels in cancer treatment

| Aspect | Sub-aspects | Key Descriptions From Studies | Ref. |
|-----------------------|---------------------------|--|--|
| Patient participation | Actively participate | Patients ask questions, seek information, and express treatment preferences. | Berry et al. (2015); Shin et al. (2017); D'Agostino et al. (2018); Holdsworth et al. (2020) |
| | Collaborative participate | Patients share views and preferences and negotiate options with HCPs | Laidsaar-Powell et al. (2016); Schuler et al. (2017); Mokhles et al. (2018); Sattar et al. (2018); Malhotra et al. (2020); Nakayama et al. (2020); McCaughan et al. (2022); Heuser et al. (2023); Tilly et al. (2023) |
| | Passively participate | Patients defer decisions to doctors or families, often due to low health literacy or emotional stress. | Pozzar et al. (2018); Dew et al. (2019); Wang et al. (2020); Gu et al. (2023); Sitanggang & Lin (2024) |
| Family involvement | Emotional support | Families provide reassurance, motivation, and presence during consultations. | Laidsaar-Powell et al. (2016); Shin et al. (2017); D'Agostino et al. (2018); Sattar et al. (2018); Nakayama et al. (2020); Wang et al. (2020); McCaughan et al. (2022) |
| | Information gathering | Families seek explanations from HCPs and help translate complex information. | Berry et al. (2015); Laidsaar-Powell et al. (2016); Shin et al. (2017); Sattar et al. (2018); Dew et al. (2019); Malhotra et al. (2020); McCaughan et al. (2022) |
| | Influence on decisions | Families dominate decision-making or persuade patients toward certain choices. | Berry et al. (2015); Laidsaar-Powell et al. (2016); Shin et al. (2017); D'Agostino et al. (2018); Pozzar et al. (2018); Sattar et al. (2018); Dew et al. (2019); Wang et al. (2020); Holdsworth et al. (2020); Malhotra et al. (2020); McCaughan et al. (2022); Gu et al. (2023); Sitanggang & Lin (2024) |
| | Practical support | Families assist with hospital visits, medication, and managing appointments. | Berry et al. (2015); Shin et al. (2017); D'Agostino et al. (2018); Pozzar et al. (2018); Dew et al. (2019); Wang et al. (2020); Sitanggang & Lin (2024) |
| HCPs roles | Information providers | HCPs provide diagnosis, prognosis, and treatment options | Berry et al. (2015); Laidsaar-Powell et al. (2016); Shin et al. (2017); Schuler et al. (2017); D'Agostino et al. (2018); Pozzar et al. (2018); Sattar et al. (2018); Dew et al. (2019); Wang et al. (2020); Malhotra et al. (2020); Nakayama et al. (2020); McCaughan et al. (2022); Sitanggang & Lin (2024) |
| | Decision facilitator | HCPs help patients weigh pros and cons based on personal and clinical values. | Laidsaar-Powell et al. (2016); Schuler et al. (2017); Shin et al. (2017); D'Agostino et al. (2018); Mokhles et al. (2018); Pozzar et al. (2018); Sattar et al. (2018); Dew et al. (2019); Wang et al. (2020); Malhotra et al. (2020); Nakayama et al. (2020); McCaughan et al. (2022); Tilly et al. (2023); Heuser et al. (2023) |
| | Emotional support | HCPs provide empathy, listen actively, and acknowledge patient emotions | Laidsaar-Powell et al. (2016); Shin et al. (2017); D'Agostino et al. (2018); Sattar et al. (2018); Nakayama et al. (2020); Wang et al. (2020); McCaughan et al. (2022) |
| | Clinical expertise | HCPs interpret test results, recommend suitable options, and clarify outcomes. | Laidsaar-Powell et al. (2016); Schuler et al. (2017); D'Agostino et al. (2018); Mokhles et al. (2018); Pozzar et al. (2018); Sattar et al. (2018); Dew et al. (2019); Malhotra et al. (2020); Nakayama et al. (2020); Wang et al. (2020); McCaughan et al. (2022); Tilly et al. (2023); Heuser et al. (2023) |

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2020; Nakayama et al., 2020; McCaughan et al., 2022; Heuser et al., 2023; Tilly et al., 2023). SDM has emerged as a well-established strategy in healthcare settings, designed to involve patients actively in decision-making. This approach is instrumental in enhancing patient autonomy and promoting a more patient-centered model of care (Barry & Edgman-Levitan, 2012; Stiggelbout et al., 2012). In oncology, SDM is particularly crucial, fostering collaborative communication between patients and

healthcare providers, which is essential for optimizing treatment outcomes and patient satisfaction in complex therapeutic decisions (Shickh et al., 2023).

Despite its recognized benefits, SDM implementation is not uniform across settings, with variations influenced by patient demographics, such as age, education level, and cultural background. Research indicates that younger, more educated patients are more likely to actively engage

in treatment decisions, while older patients often prefer a more passive role, relying predominantly on medical guidance (Gieseler et al., 2019; Pyke-Grimm et al., 2020). Factors such as health literacy, decision-making dynamics, and the intricacies of cancer treatment modalities play a significant role in shaping these engagement patterns (Chang et al., 2019; Gieseler et al., 2019). In many cultural contexts, particularly in Asian countries, prevailing social norms often lead patients to defer decision-making responsibilities to FMs or HCPs (Wang et al., 2020; Sitanggang & Lin, 2024). These considerations highlight the need for a more nuanced approach that respects diverse cultural norms while upholding patient autonomy in the SDM process.

The movement towards SDM in clinical practice represents a significant advancement in modern healthcare, particularly in oncology, where treatment adherence and clinical outcomes are closely linked to patient engagement. Engaging patients in therapeutic decision-making enhances the personalization of care, enabling healthcare providers to more effectively respond to individual patient needs and preferences. However, many patients remain reliant on professional expertise, and a growing inclination toward active participation underscores the need for a balanced approach that integrates patient autonomy with professional guidance in cancer care.

Given the complexity of implementing SDM, there are considerable implications for practice, policy, and research. Clinically, HCPs must adopt communication frameworks that support SDM, incorporating decision aids and culturally tailored resources to meet local and individual needs. Health education programs would benefit from incorporating SDM-focused training, with emphasis on cross-cultural sensitivity and ethical decision-making. At the policy level, healthcare systems should advocate for patient-centered policies that incentivize SDM practices, alongside supporting the development of digital and informational infrastructures that facilitate informed decision-making. Future research should aim to validate SDM models that address cultural variability and assess their impact on long-term outcomes and patient satisfaction. This multifaceted approach holds significant promise for improving the quality of patient care, satisfaction, and health outcomes, particularly in diverse patient populations and complex care settings.

Family involvement

The findings of this review highlight the crucial role of family involvement in SDM in cancer treatment, where families often provide emotional, informational, decisional, and practical support to patients. Studies consistently

show that FMs act as key advocates, helping patients navigate complex medical information and making more informed treatment decisions (Shin et al., 2017; Malhotra et al., 2020; McCaughan et al., 2022). This active involvement of families can significantly influence the patient's treatment pathway by offering a support system that reduces anxiety and enhances the patient's confidence in their choices (Shin et al., 2017; Sattar et al., 2018).

Family involvement in medical decision-making aligns with the principles of patient-centered care, which emphasize collaborative relationships between patients, families, and healthcare providers. According to the theory of relational autonomy, patients' decisions are not made in isolation but are influenced by their relationships and the social context in which they live. This concept supports the idea that FMs' roles in decision-making contribute to a shared understanding of the patient's values and treatment goals, thus enhancing the decision-making process (Elwyn et al., 2012).

In cancer treatment decisions, families serve both as supporters and influential participants. Prior research indicates that families often assume primary or SDM roles, which substantially affects treatment choices and outcomes. For instance, a national survey by Dionne-Odom et al. found that 87.6% of family caregivers engaged in treatment decisions, with 53.9% sharing decision-making responsibilities (Dionne-Odom et al., 2023). This significant role is especially prominent among adult children of older patients, who frequently facilitate SDM, leading to more informed treatment choices (Dijkman et al., 2022). However, it is essential to maintain a balance between family involvement and patient autonomy (Hobbs et al., 2015). This family role highlights the need for clear and open communication among all parties involved, ensuring that patient autonomy is upheld while valuing family contributions.

Although family involvement generally enhances the SDM process by providing emotional, informational, and practical support, it is essential to maintain a patient-centered approach in which the individual's preferences and values remain central. While families often serve as advocates and sources of strength, their influence should not override the patient's autonomy, especially in decisions with significant personal implications. HCPs play a crucial mediating role in balancing these dynamics by facilitating open dialogue that respects both the patient's choices and the family's perspectives, aiming to reach a consensus aligned with the patient's best interests.

The insights from this review highlight the need for healthcare systems to adopt a more structured and culturally responsive framework for incorporating family involvement into SDM. It includes equipping HCPs with communication competencies that are sensitive to diverse familial roles and expectations, particularly in collectivist cultures where family input is traditionally more dominant. Additionally, integrating guidelines and decision-support tools that explicitly address family dynamics could improve the quality and transparency of the decision-making process. Prioritizing family engagement in SDM not only promotes holistic, person-centered care but also strengthens the therapeutic alliance between patients, families, and clinicians—ultimately contributing to better treatment experiences and outcomes.

Role of HCPs

The findings of this review suggest that HCPs play multifaceted roles in SDM. Across the included studies, HCPs were consistently involved as providers of clinical information, facilitators of decision-making, sources of emotional support, and contributors of clinical expertise throughout the treatment process. These roles are essential in helping patients navigate the complexities of cancer care, ultimately enhancing their confidence and satisfaction with the chosen treatment pathway.

These roles align closely with the principles of SDM, which advocate for collaborative communication between patients and healthcare providers. Effective communication emerged as a fundamental element, enabling patients to fully comprehend their diagnoses and treatment options, thereby supporting informed, value-based decision-making (Kehl et al., 2015; Dew et al., 2019; Heuser et al., 2023). High levels of trust in HCPs also shape how patients engage, especially in complex or urgent care (Hariati et al., 2021). HCP engagement significantly influences the implementation of patient- and family-centered care (Hariati et al., 2023). This approach also reflects the core of patient-centered care, where patients' preferences, goals, and values are integrated into clinical decision-making (Elwyn et al., 2012).

Previous studies support these findings, emphasizing the importance of HCP communication skills in improving clinical outcomes. For instance, studies have shown that patients who perceive their healthcare providers as effective communicators report lower anxiety levels and greater satisfaction with their care (Faller et al., 2016). Additionally, studies have identified barriers to implementing SDM, including time constraints and limited formal training in communication and decision-making

techniques (Légaré et al., 2008). These challenges have been further explored in recent research, particularly within the context of the UK's National Health Service, highlighting the need for ongoing initiatives to equip HCPs with the skills necessary to engage patients effectively in treatment decisions (Joseph-Williams et al., 2017), which examined the implementation of SDM in the UK's National Health Service. Similarly, a qualitative study in Indonesia found that nurses face challenges in education due to the absence of standardized policies, limited training, and a lack of educational resources (Hariati et al., 2022). Also, a qualitative study in Indonesia highlights the challenges nurses face in providing effective discharge education due to the absence of standardized guidelines and limited training (Hariati et al., 2021). These studies collectively indicate the need for ongoing efforts to equip HCPs with the skills to engage patients in their treatment decisions effectively.

In this context, structured orientation and training programs have proven effective in improving HCPs' clinical readiness and interpersonal skills. A recent scoping review emphasizes that well-designed onboarding initiatives for nurses significantly strengthen their confidence, communication skills, and role adaptation within hospital settings (Ernawaty et al., 2024). These findings support the implementation of structured training programs to prepare nurses for such interventions. As shown by Erfina et al. (2024), nurse-delivered multimodal interventions not only address physical and psychological symptoms but also enhance the therapeutic alliance between patients and providers, an essential component of effective SDM. This finding highlights the importance of equipping nurses with both clinical and communication competencies to deliver meaningful, patient-centered cancer care.

Therefore, a more structured approach is needed to strengthen HCPs' role as facilitators in patient treatment decision-making. Although HCPs are strategically positioned to guide patients in choosing treatment options, their effectiveness is often hindered by systemic barriers such as a lack of training in SDM practices and time constraints within clinical settings. Addressing these obstacles can significantly enhance patient engagement, resulting in more personalized and satisfying healthcare experiences.

The findings of this review underscore the importance of healthcare systems prioritizing the development of training programs to improve HCPs' communication and decision-making skills. By integrating SDM principles into medical education and clinical practice, healthcare

providers can bridge the gap between professional recommendations and patient preferences. Additionally, the use of digital decision aids and culturally sensitive communication strategies can promote a more inclusive and patient-centered approach across diverse healthcare settings.

These findings present several implications for clinical practice. First, adopting a more holistic approach to patient care that integrates the perspectives of patients, families, and HCPs can enhance the SDM process. Implementing SDM tools that accommodate cultural nuances can improve patient engagement, particularly among diverse patient populations. Additionally, equipping HCPs with training in cultural sensitivity and communication skills will foster more effective and empathetic interactions with patients and their families.

While this scoping review provides a comprehensive overview, certain limitations should be acknowledged. The review was limited to articles published in English and Indonesian, potentially excluding relevant studies in other languages. Moreover, most of the included studies were conducted in high-income countries, which may not fully represent the experiences of patients in low- and middle-income settings.

Future research should examine the SDM process across diverse cultural contexts and healthcare systems to provide a broader perspective. Additionally, longitudinal studies examining how interactions among patients, families, and HCPs evolve could offer deeper insights into optimizing SDM in cancer care.

Conclusion

This scoping review examined the roles of patients, families, and HCPs in the SDM process for cancer patients in clinical settings. Three primary factors emerged: Patient participation, family involvement, and support from HCPs. Active patient engagement and family involvement were shown to enhance patient confidence and satisfaction, while HCPs played critical roles as information providers and decision facilitators. Balancing patient autonomy with family input was highlighted as essential, facilitated through effective communication by HCPs. Structured frameworks and culturally sensitive training for HCPs are recommended to improve SDM, ensuring decisions are both patient-centered and value-aligned across diverse healthcare settings. These findings present several implications for clinical practice. First, adopting a more holistic approach to patient care that integrates the perspectives of patients, families,

and HCPs can enhance the SDM process. Implementing SDM tools that accommodate cultural nuances can improve patient engagement, particularly among diverse patient populations. Additionally, equipping HCPs with training in cultural sensitivity and communication skills will foster more effective and empathetic interactions with patients and their families.

Ethical Considerations

Compliance with ethical guidelines

There were no ethical considerations to be considered in this research.

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Authors' contributions

Conceptualization: Fadiah Izzati Salim and Suni Hariati; Methodology: Fadiah Izzati Salim and Andi Masyitha Irwan; Investigation and data curation: Fadiah Izzati Salim and Andi Masyitha Irwan; Data analysis, validation and visualization: Suni Hariati and Erfina Erfina; Writing the original draft: Fadiah Izzati Salim, Suni Hariati, and Andi Masyitha Irwan; Review, editing and final approval: All authors; Supervision: Suni Hariati.

Conflict of interest

The authors declared no conflict of interest.

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