

REVIEW

Patient participation in shared decision-making in palliative care – an integrative review

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Abstract

Background: Shared decision-making is a process where the decisions regarding patients' care are done in collaboration with the patient, the patient's family and a healthcare professional or an interdisciplinary team. Shared decision-making is considered to be a part of patient centred care, and it enables patient autonomy which is a cornerstone of palliative care. In the past, research on the experiences of palliative care patients' participation in shared decision-making involving a nurse has been limited as the focus has mainly been on specific medical interventions, rather than holistic palliative care.

Objectives: To synthesise research findings on patient participation in shared decision-making in palliative care.

Research design: An integrative literature review.

Methods: The literature search was conducted by searching computerised databases (CINAHL, PubMed, PsychINFO and COCHRANE). The search resulted in 12 articles. The quality of the included articles was evaluated with JBI checklist, and the data analysis was done using inductive content analysis. Reporting was done according to a PRISMA checklist.

Findings: Patients do participate in shared decision-making and desire to participate in everyday nursing care decisions, treatment-related medical decisions and end-of-life decisions. The prerequisites for patient participation in shared decision-making are interdisciplinary teamwork, open communication, good patient–healthcare professional relationship, a favourable environment and mutual information.

Conclusion: Palliative care patients do participate and desire to participate in decisions that cover a much broader range of topics than just medical interventions and this should be addressed in future research and in practise. The main responsibility for successful patient participation in shared decision-making lies with the healthcare professionals and the organisations providing palliative care. There is a need to conduct more research from the patient's perspective and explore the meaning of participating in shared decision-making from the patient's point of view.

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KEYWORDS

end-of-life decision-making, nursing, palliative care, patient care team, patient participation, teamwork

1 | INTRODUCTION

Palliative care patients have the right to participate in the decisions that are made regarding their own care (European Association for Palliative Care (EAPC) 2009; National Consensus Project for Quality Palliative Care, 2018). In addition, the Council of Europe (CoE) and the World Medical Association (WMA) have stated that patients should have the right to decide about their treatment and these decisions need to be made with the patient being provided with an adequate amount of information (CoE, 2014; WMA, 2011). The right to make an informed decision is also addressed in the Council of Europe's Convention on Human Rights and Biomedicine (CoE, 1997, ETS No.164). Patient's empowerment for participation in shared decision-making should be supported by healthcare professionals (EAPC, 2009), and the patient should be seen as an equal part of the interdisciplinary team (Gómez-Virseda et al., 2019). Shared decision-making where the patient is seen as an active member in making decisions together with the healthcare professionals has also been identified by the patients as an enabler for optimal palliative care (Virdun et al., 2020). In addition, in palliative care patient autonomy should be seen as a diverse entity and patients should be given the opportunity to engage not only in medical decision but also in every day care decisions and decisions regarding end-of-life. (Houska & Loučka, 2019). According to previous research, shared decision-making results in less invasive procedures, increased patient safety, reduced healthcare costs (Castro et al., 2016), improved patient satisfaction (Castro et al., 2016; Shay & Lafata, 2015), patient empowerment and more informed patients (Castro et al., 2016). According to research however, there are too few opportunities for patients to genuinely participate in the decision-making regarding their care (Seibel et al., 2014).

The definition of shared decision-making in research varies (Makoul & Clayman, 2006). However, the main principle of shared decision-making is that the decisions regarding patients' care are done in collaboration with the patient, the patient's family and a healthcare professional or an interdisciplinary team (Légaré et al., 2011). Shared decision-making is considered to be interdisciplinary if at least two healthcare professionals from different professions either simultaneously or sequentially work with the patient (Légaré et al., 2011). According to the model by Legaré et al., (2011), the process of shared decision-making consists of recognising that a decision needs to be made, exchanging information, taking into account the values and preferences of everybody involved in the decision-making process, assessment of the preferred and the actual choice, its implementation and outcome (Légaré et al., 2011). In this model, the roles of the healthcare professionals involved in the team can be versatile (Légaré et al., 2011). Lewis et al., (2016), however, state that

What does this paper contribute to the wider global clinical community?

- Palliative care patients desire participation in decision-making about medical treatment but also about everyday matters that influence their daily life.
- Being involved in seemingly small decisions enables patients to maintain control over their own life and improve the quality of life.
- Patient participation in shared decision-making has numerous prerequisites and the main responsibility for enabling patient participation lies with the healthcare professionals and the organisations providing palliative care.

the role of nurses in shared decision-making is significant as nurses, more often than others, adopt the role of the decision coach and also advocate for the patient, assess the patient's condition and provide information in the interdisciplinary team.

Palliative care (Radbruch et al., 2020) and end-of life care (EAPC, 2009) as terms are used widely and the definitions vary. According to the World Health Organization palliative care aims to improve the quality of life and prevent or relieve suffering of patients enduring a life-threatening illness (WHPCA & WHO Worldwide Hospice Palliative Care Alliance & World Health, 2020). End-of-life care can be defined either as a synonym for palliative care or as the final hours or days of the patient's life (EAPC, 2009). In this review, end-of-life care was defined as the final phase in palliative care consisting of the last hours or days of the patient's life. Palliative care patients might depend more on the competence of the healthcare professionals than patients who have not been diagnosed with a life-threatening illness (Seibel et al., 2014). Therefore, shared decision-making concepts that have been developed in the curative setting might not be directly applicable in the palliative care settings. Palliative care patients who are capable of decision-making should, also, be able to determine the preferred role and amount of participation of family members (National Consensus Project for Quality Palliative Care, 2018). There is a great variety of communicational matters and preconceptions that might affect patient participation (Halabi et al., 2020). For example, it has been established that advanced cancer patients' desire to participate in shared decision-making varies depending on the patients' age, gender, state of the disease (Gaston & Mitchell, 2005) and culture (Cain et al., 2018; EAPC, 2009).

Previously, there have been three reviews published on patient participation in shared decision-making in palliative care (Bélanger

et al., 2011; Feuz, 2014; Gaston & Mitchell, 2005). In Gaston and Mitchell's (2005) review from 2005, the aim was to identify studies that tested ways of improving patient participation in decision-making and giving information to patients with advanced terminal cancer. The study did not limit the patients to only those who were in the palliative care stage. The review also focused only on the impact of information as an enabler for shared decision-making and did not examine any other prerequisites; in addition, the review only addressed decisions regarding medical treatment. In the Belanger et al., (2011) review from 2011, the aim was to synthesise knowledge about the process of making informed and shared decisions with palliative care patients. The selected studies mainly focus on treatment decisions in the patient-physician dyad and there is a lack of decisions other than medical decisions in the studies. However, according to their results Belanger et al., (2011) recognised eight different categories of decisions in which patients participated. The categories were as follows: unspecified treatments, palliative chemotherapy, palliative radiotherapy, palliative surgery, advance directives, place of care, everyday care and alternative therapies (Bélanger et al., 2011), whereas Feuz's review from 2014 aimed to review the legal and ethical issues relevant to Canadian and UK informed consent and shared decision-making practices and how these processes related to the current topical palliative care practices, with a particular emphasis on radiation therapy (Feuz, 2014). The review was limited to patients with a cancer diagnosis and focused on medical decisions and legal aspects and found that patients desire participation in treatment decisions. The review also established that good communication between the patient and the healthcare professionals enables participation shared decision-making.

Previous reviews on shared decision-making in the context of palliative care have been mainly limited to decision-making involving only medical decisions (Bélanger et al., 2011; Feuz, 2014; Gaston & Mitchell, 2005). However, the EAPC and the WHO state that palliative care uses a team approach (WHPCA & WHO, Worldwide Hospice Palliative Care Alliance & World Health, 2020) which consists, at a minimum, of a nurse and a physician (EAPC, 2009). Although it has been established that the role of the nurse is significant in shared decision-making (Lewis et al., 2016), in general, the majority of studies regarding shared decision-making basically focus on the patient-physician dyad (Légaré et al., 2011) with shared decision-making often being limited to only medical decisions (Makoul & Clayman, 2006). This might be due to the fact that majority of the conceptual models of shared decision-making only involve a physician and patient (Légaré et al., 2011). Additionally, the interdisciplinary models of shared decision-making might include nurses but often fail to address them separately from other professionals or define their role in detail (Lewis et al., 2016). Research on the experiences of palliative care patients has also been limited, as it has been thought that the patients are too vulnerable (Bloomer et al., 2018). However, it has been established that palliative care patients should not be assumed to be vulnerable and should be provided with equal opportunities to participate in research and contribute to society, science and future

palliative care (Bloomer et al., 2018). In addition, the need for palliative care is substantial as it has been estimated that each year over 52 million adults worldwide are in need of palliative care at the end of life (WHPCA & WHO, 2020) with the number increasing rapidly and continuing to increase as the population ages and cancer and other severe chronic diseases become more common (WHPCA & WHO, 2020).

This review is part of a broader research project aiming to explore patient participation in shared decision-making, the meaning of participating in shared decision-making and assessing patients' participation in shared decision-making in palliative care from a nursing perspective. Registered nurses (RN) are the largest group of healthcare professionals internationally and have a significant role in palliative care teams and in enabling patient autonomy (American Nurses Association, 2017). Previous reviews did not include everyday nursing care decisions which are significant in providing quality holistic palliative care. This review updates the knowledge gained from earlier reviews and focuses more broadly on patient participation in shared decision-making in palliative care.

2 | AIM

The aim of the review was to synthesise research findings on patient participation in shared decision-making in palliative care. The ultimate goal of this review is to produce new knowledge and build on this to better understand and support patients' participation in shared decision-making in palliative care and improve the quality of care. The research questions were as follows:

1. In what kind of shared decision-making have palliative care patients participated in and what decisions do patients desire to participate in?
2. What are the prerequisites for patient participation in shared decision-making in the context of palliative care?

3 | METHODS

3.1 | Design

An integrative review was chosen as the method for this study to maximise the collection of research data as an integrative review allows inclusion of studies regardless of the original research methodology. This study was conducted based on Whittmore & Knaf's process for an integrative literature review (Whittmore & Knaf, 2005). According to their process, an integrative review consists of an identification of the problem, a literature search, data evaluation, data analysis, forming the synthesis and presenting the results (Whittmore & Knaf, 2005). This review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and the reporting was done following the PRISMA checklist (Supplementary File 1) (Moher et al., 2009).

3.2 | Literature search

The literature searches were conducted in January 2020 and updated in December 2020 by searching CINAHL, PubMed, PsychINFO and COCHRANE computerised databases and by additional ancestry searching and citation index searching (Conn et al., 2003). The search terms used were palliative care, end-of-life, hospice care and patient participation and shared decision-making and nurse or nursing and their synonyms and MeSH-terms. The search phrase is presented in Figure 1. An information specialist assisted in defining the search terms and search phrases. The inclusion criteria were peer reviewed scientific articles, adult patients, palliative care, patient participation in decision-making and decision-making including at least one nurse. The exclusion criteria were intensive care, nursing homes, residential care, dementia, surrogate decision-making, advance care planning, euthanasia, child patients, decision-making not involving the patient and decision-making limited to the patient-physician dyad. There was no limit as regards the year or language of the publications (Figure 1).

After executing the database search, 940 articles were identified. No additional records were identified through ancestry searching or citation index searching. After duplicates were removed, 854 articles remained and after the titles were screened 293 articles remained. Fifty-six full texts were then selected based on the abstracts, and 12 articles were included for this review (Figure 2) (Moher et al., 2009). The titles were screened by one of the authors (LK), and the abstracts and full texts were screened by two of the authors (LK, SA).

3.3 | Data evaluation

The quality of the included studies was evaluated with a JBI checklist for Qualitative Research (Lockwood et al., 2015). Quality appraisal

was done by two of the authors individually (LK, SA) and discussed to produce a consensus. The quality of the included studies was good overall, although there was some variation in the qualitative studies. The overall quality of the studies is presented in Table 1 in the form of total points aggregated from the JBI checklists.

3.4 | Data analysis

Data analysis was initially done by one of the authors (LK) using inductive content analysis (Elo & Kyngäs, 2008), then discussed by the research team to reach an agreement. First, the data from the studies included in this review that included information about the review questions was transferred to a spreadsheet. The data were colour coded, and the original expressions were reduced and similar reductions were combined into sub-categories. The subcategories were then combined to form the main categories. The original articles and the spreadsheet were rechecked several times to ensure the reliability of the analysis. After this, a conceptual map was made and the categories obtained were compared and arranged.

4 | RESULTS

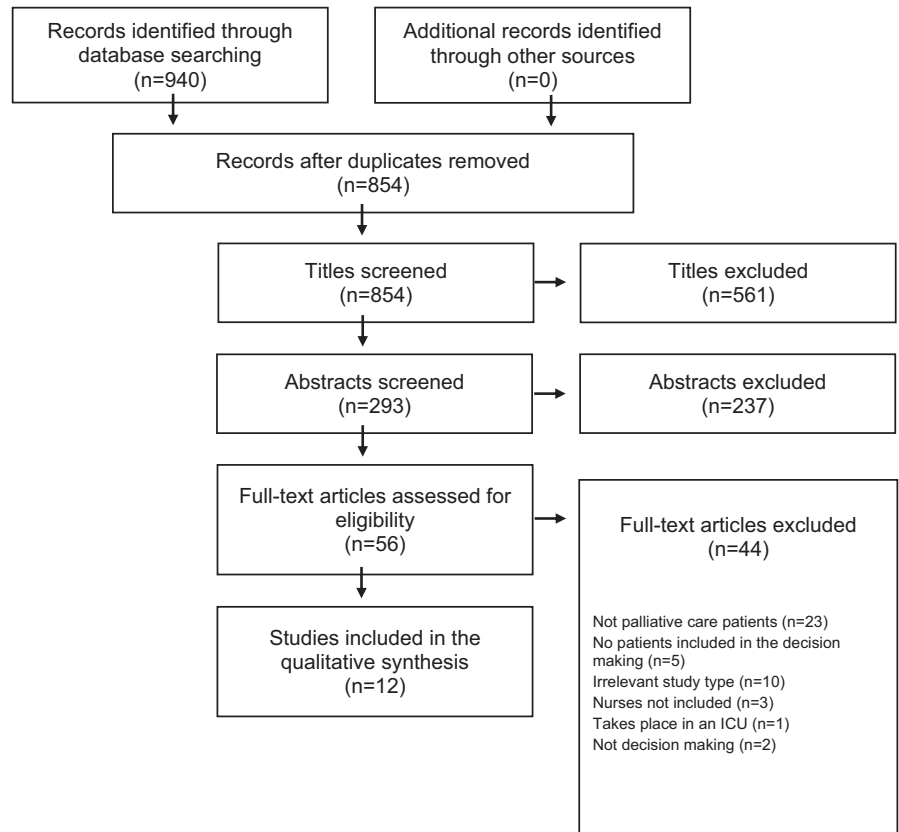
4.1 | Description of the studies

Overall 12 studies were included for this review (Table 1). The included studies were published between 1996–2018, and they were conducted in the USA, Australia, the Netherlands, New Zealand, Norway, Sweden and Canada. One of the studies had been conducted in several different countries (Belgium, the Netherlands and the United Kingdom). All of the included studies were qualitative. The sample size varied between 7–80, and the data were obtained from patients, family members or healthcare personnel. In nine of

("terminal care*" OR "hospice care*" OR "end-of-life care" OR "end of life care" OR EOL OR "palliative care*" OR (MH "Palliative Care") OR (MH "Hospice and Palliative Nursing") OR (MH "Terminal Care+") OR (MH "Hospice Care"))
AND
("patient* participa*" OR "consumer* participa*" OR "patient involv*" OR "involving patient*" OR shared OR sharing)
AND
("decision making" OR decision-making OR (MH "Decision Making+") OR (MH "Decision Making, Shared") OR (MH "Decision Making, Patient+"))
AND
(nurs* OR "nurse specialist*" OR "nurse practitioner*" OR "nursing staff*" OR (MH "Nurses+") OR (MH "Nursing Staff, Hospital") OR (MH "Staff Nurses"))

FIGURE 1 Search phrase

FIGURE 2 PRISMA flow diagram of the study selection



the twelve studies, the data were obtained from patients. In four of these nine studies, there were also other informants, who were either healthcare professionals or family members.

Out of the twelve studies that were included in this review five studies included only patients that were diagnosed with cancer. One of the studies focused solely on chronic obstructive pulmonary disease (COPD) patients and one did not specify the diagnoses of the patients being cared for. In five studies, the majority of the patients were diagnosed with cancer but they also included patients suffering from AIDS, heart diseases, respiratory diseases and neurological disorders. The data were obtained mainly by interviews and observation, but surveys were also used. The analysis had been carried out using different qualitative approaches according to the research methodology. All the articles that were included in this review were published in English.

4.2 | Decisions in which palliative care patients have participated and decisions patients desire to participate in regarding shared decision-making

Based on the analysis, three categories of decisions in which patients have participated and those they desire to participate in were identified. The identified categories were everyday nursing care decisions, treatment-related medical decisions and end-of-life decisions (Figure 3). Even though patients seem to have participated in decision-making in all of these categories, the desired level of participation was not always achieved (Bottorff et al., 1998; Clover

et al., 2004; Jerpseth et al., 2018; Lee et al., 2009; Richardson et al., 2010). The included studies did not report which healthcare professional took part in any specific decision but all of the studies had physicians and nurses involved in the patient's care and in the shared decision-making.

4.2.1 | Everyday nursing care decisions

Everyday nursing care decisions are decisions in which palliative care patients participate on a daily basis. Patients participate in shared decision-making as regards nursing care routines (Bottorff et al., 1998, 2000; Clover et al., 2004) for example, by participating in planning their daily schedules such as when to go to the bath or participating on decisions on whether to use a bedpan or to go to the bathroom (Bottorff et al., 2000). Patients also participate in decisions about nutrition (Bottorff et al., 1998; Clover et al., 2004; Volker & Wu, 2011), who (Bottorff et al., 1998; Clover et al., 2004) and when (Bottorff et al., 1998) to ask for help, when to sleep or get out of bed and when to be left alone (Bottorff et al., 1998). Patients desire to participate in these everyday nursing care decisions and, in addition, have control over the extent of their own participation in care (Bottorff et al., 1998, 2000; Clover et al., 2004; Richardson et al., 2010). Participating in decision-making enables patients to maintain control over their own life, comfort and social life, as well as the opportunity to maximise their quality of life (Bottorff et al., 1998). Being involved also helps patients to feel empowered (Bottorff et al., 1998; Clover et al., 2004; Richardson et al., 2010).

TABLE 1 Studies included in the review

Authors	Year	Country	Purpose	Sample	Data collection methods	Data analysis methods	JBI scores
Volker D and Hung-Lan W	2011	USA	To explore the meaning of control and control preferences in a group of racially and ethnically diverse patients with an advanced cancer diagnosis	Hospice patients (n = 20) diagnosed with cancer	Short demographic survey and active interview	Hermeneutic phenomenological analysis	8/10
Hermesen M and ten Have H	2004	Netherlands	To explore two aspects of the decision to (dis)continue treatment, and discuss the ways in which caregivers deal with these problems	Caregivers (n = 15) (doctor, nurse, attendant) All palliative care patients	Semi-structured interviews	Inductive content analysis	6/10
Richardson K, MacLeod R and Kent B	2010	New Zealand	To explore issues of empowerment and daily decision-making from the perspectives of people who are terminally ill	Community hospice patients (n = 14). Majority of patients were diagnosed with cancer	Individual interviews	Hermeneutic analysis	8/10
Barry B and Henderson A	1996	Australia	To explore the degree to which 'incurable' oncology patients desire participation in decision-making with respect to treatment modalities and, secondly, to ascertain whether these patients perceived that they were able to enjoy this desired participation	'Incurable' patients (n = 7) diagnosed with cancer	Informal conversation-style interviews (demographic data) A picture-card tool was used as an objective measure of the patient's response Interviews (multiple/patient)	Longitudinal analysis	6/10
Bottoff J, Steele R, Davies B, et al	2000	n/a	To describe the strategies nurses use to facilitate or restrict patient participation in making choices about personal and nursing care routines	Patients and their caregivers in two hospital-based palliative care units and 23 transcripts of interviews with participating nurses and patients. Majority of patients were diagnosed with cancer	Non-participatory observation and open-ended interviews	Inductive content analysis	7/10
Jerpseth H, Dahl V, Nortvedt P, et al.	2017	Norway	To explore the illness experiences of older patients with late-stage chronic obstructive pulmonary disease and to develop knowledge about how patients perceive their preferences to be taken into account in decision-making processes concerning mechanical ventilation and/or non-invasive ventilation	Patients (n = 12) diagnosed with COPD	Qualitative in-depth interviews	Analysed within the three interpretative contexts described by Kvale and Brinkmann	10/10
Clover A, Browne J, McErlain P, et al.	2004	Australia	To explore patients' understanding of their discussions about end-of-life care with nurses in a palliative care setting	Palliative care patients (n = 11), Majority of patients were diagnosed with cancer	Semi-structured interview	Modified grounded theory analysis	8/10

(Continues)

TABLE 1 (Continued)

Authors	Year	Country	Purpose	Sample	Data collection methods	Data analysis methods	JBI scores
Sahlberg-Blom E, Ternstedt BM and Johansson JE	2000	Sweden	To describe variations in patient participation in decisions about care planning during the final phase of life for a group of gravely ill patients, and how the different actors' manner of acting promotes or impedes the process	Palliative care cancer patients' relatives (n = 37)	Qualitative research interviews	Qualitative analysis	7/10
Bélanger E, Rodriguez C, Groleau D, et al.	2016	Canada	To explore how do healthcare providers and their patients discursively construct patient participation in palliative care decisions?	Patients (n = 18) diagnosed with cancer and physicians in a mobile palliative unit	One year of participant observation	Qualitative analysis	9/10
Lee S, Kristjanson L and Williams A.	2009	Australia	To describe the significant issues that influence the processes of care decision-making, from the perspective of patients with advanced illness	Patients (n = 14), family members (n = 7) and health professionals (n = 18). Majority of patients were diagnosed with cancer	Interviews and field observations	Grounded theory analysis	7/10
Robijn L, Seymour J, Delliens L, et al	2018	Belgium, the United Kingdom and the Netherlands	To describe the decision-making process preceding continuous sedation until death with particular attention to the involvement of the person who is dying	Physicians (n = 26), nurses (n = 30), relatives (n = 24) caring for cancer patients in palliative care	Semi-structured interview	Qualitative analysis	9/10
Bottoff JL, Steele R, Davies B, et al.	1998	n/a	To explore and describe patients' experiences of making choices related to their personal and nursing care routines on a palliative care unit	Nurses and patients (n = 16) observation and patient (n = 10) and nurse (n = 12) interviews. Majority of patients were diagnosed with cancer	Observation & in-depth interview	Qualitative analysis	7/10

Data evaluation done using JBI checklists for Qualitative Research.

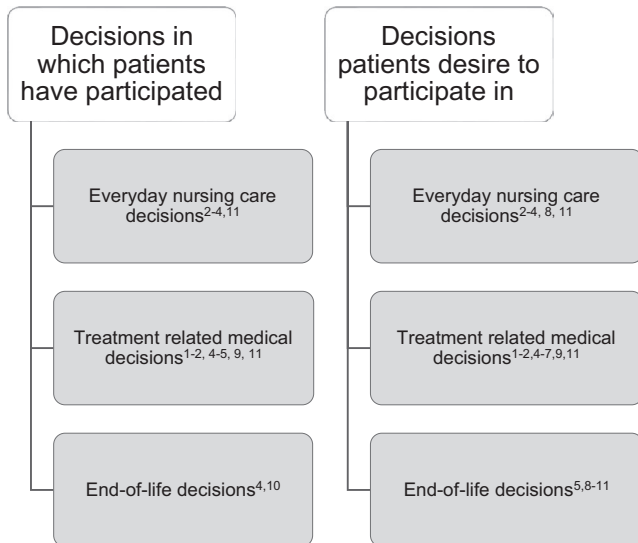


FIGURE 3 Shared decision-making in which patients have participated and decisions patients desire to participate in

4.2.2 | Treatment-related medical decisions

Patients have participated in shared decision-making about treatment (Bélanger et al., 2016; Bottorff et al., 1998; Hermsen & ten Have, 2005; Robijn et al., 2018), medication (Bélanger et al., 2016; Bottorff et al., 1998; Clover et al., 2004; Robijn et al., 2018) and tests (Bélanger et al., 2016). More specifically, patients have been involved in decisions about the continuation of treatment (Hermsen & ten Have, 2005), treatment of pain and other symptoms (Hermsen & ten Have, 2005; Robijn et al., 2018), chemotherapy (Volker & Wu, 2011) and medication scheduling (Bottorff et al., 1998; Clover et al., 2004). Patients desire participation in all these decisions. Particularly when making decisions about medication, patients feel that it is important that they are being heard about their own experiences (Bottorff et al., 1998; Clover et al., 2004; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Lee et al., 2009; Robijn et al., 2018; Volker & Wu, 2011) and have control over medication scheduling (Clover et al., 2004). Patients feel that since they know their body best they should be involved in the decision-making process affecting their own body (Barry & Henderson, 1996; Bottorff et al., 1998; Volker & Wu, 2011). Being excluded from treatment decisions might make the patient feel insecure and fearful (Jerpseth et al., 2018).

4.2.3 | End-of-life decisions

Palliative care patients also feel the need to control matters near the end of life. Patients have been involved in decision-making about the place of death (Clover et al., 2004; Sahlberg-Blom et al., 2000), which is seen as important to ensure their own comfort and that family members can cope (Clover et al., 2004; Sahlberg-Blom et al., 2000; Volker & Wu, 2011). In addition, patients desire a broader participation in the decision-making that enables them control

over unfinished business, such as saying their goodbyes (Hermsen & ten Have, 2005; Robijn et al., 2018). For example, patients might be willing to undergo further treatment as an attempt to buy time (Hermsen & ten Have, 2005; Robijn et al., 2018). Patients also desire to control care after death (Richardson et al., 2010; Sahlberg-Blom et al., 2000; Volker & Wu, 2011), which might help in finding spiritual peace (Volker & Wu, 2011).

4.3 | Prerequisites for patient participation in shared decision-making in the context of palliative care

Based on the analysis, the prerequisites enabling patient participation in shared decision-making were identified. The identified prerequisites were divided into five categories: interdisciplinary teamwork, open communication, good patient-healthcare professional relationship, favourable environment and mutual information (Figure 4).

4.3.1 | Interdisciplinary teamwork

Interdisciplinary teamwork is a crucial factor in patient participation in shared decision-making in palliative care. Patients rely extensively on healthcare professionals' recommendations in decisions and often need suggestions and a reasonable number of alternatives from which to choose (Barry & Henderson, 1996; Bélanger et al., 2016; Bottorff et al., 1998; Bottorff et al., 2000; Clover et al., 2004; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Lee et al., 2009; Robijn et al., 2018; Sahlberg-Blom

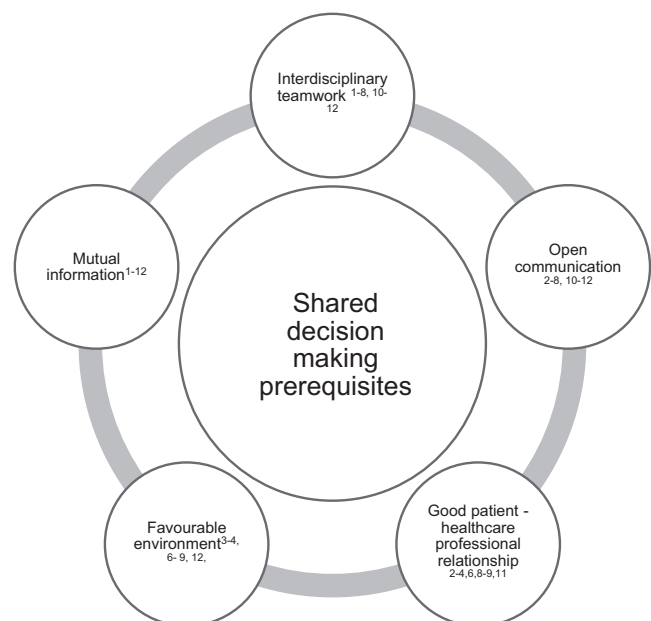


FIGURE 4 The prerequisites for patient participation in shared decision-making in palliative care

et al., 2000; Volker & Wu, 2011). Being offered an appropriate number of options helps the patient to make an autonomous choice (Hermsen & ten Have, 2005) and to not feel overwhelmed (Bottorff et al., 1998). Despite the fact that patients rely on the recommendations and suggestions made by the interdisciplinary team, it is important to affirm the patient's autonomy and try to prevent patients from leaving the decisions to healthcare professionals (Bélanger et al., 2016; Bottorff et al., 1998; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Robijn et al., 2018). However, in some cases, it might help the patient to make a difficult decision if responsibility for the decision is shared with the interdisciplinary team and not left solely as the responsibility of the patient (Bélanger et al., 2016; Bottorff et al., 1998; Robijn et al., 2018; Sahlberg-Blom et al., 2000).

Healthcare professionals can reduce the anxiety, and insecurity patients might otherwise feel by supporting the patient's decision-making process and the choices that are made (Bélanger et al., 2016; Bottorff et al., 1998, 2000; Clover et al., 2004; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Lee et al., 2009; Robijn et al., 2018; Sahlberg-Blom et al., 2000). Patients' anxiety can also be reduced by reassuring the choice being made is the right one and showing respect for the patient's choice (Bélanger et al., 2016; Bottorff et al., 2000). Previous studies have also stated that patients want to take family members and healthcare professionals into consideration when making decisions (Bélanger et al., 2016; Bottorff et al., 1998, 2000; Clover et al., 2004; Sahlberg-Blom et al., 2000; Volker & Wu, 2011). One study indicated that patients might feel the need to portray themselves as a 'good patient' in order to not seem too demanding as they are aware of the nurses' workloads and want to take this into account. This might lead to not voicing all of their hopes and desires or consenting to compromises (Bottorff et al., 1998).

4.3.2 | Open communication

Open communication between the patient, the interdisciplinary team and family members is an essential requirement for patient participation in shared decision-making. Communication with the patient might be verbal but in two of the studies (Bottorff et al., 1998; Robijn et al., 2018), the meaning of non-verbal communication also became evident.

The healthcare professionals' role in open communication includes asking open-ended questions, listening (Bélanger et al., 2016; Bottorff et al., 1998, 2000; Clover et al., 2004; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Lee et al., 2009; Robijn et al., 2018; Sahlberg-Blom et al., 2000) and giving the patient opportunities to discuss and consult. Especially, matters concerning the patient's daily life and the forthcoming final days and hours of life are the most common subjects palliative care patients need to discuss (Bottorff et al., 2000; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Volker & Wu, 2011). The patient's willingness to talk about issues might, however, differ, and this should also be taken into consideration (Clover et al., 2004; Jerpseth et al., 2018; Robijn et al.,

2018; Sahlberg-Blom et al., 2000). Healthcare professionals need to truly try to get to know, understand and respect patients' preferences (Bélanger et al., 2016; Bottorff et al., 1998; Bottorff et al., 2000; Hermsen & Have, 2005; Jerpseth et al., 2018; Lee et al., 2009; Robijn et al., 2018; Sahlberg-Blom et al., 2000; Volker & Wu, 2011). Various communicational skills are required from the healthcare professionals in order for the communication to be open (Bélanger et al., 2016; Bottorff et al., 1998, 2000; Clover et al., 2004; Hermsen & Have, 2005; Jerpseth et al., 2018; Lee et al., 2009; Robijn et al., 2018; Sahlberg-Blom et al., 2000).

Patient's might share their desires and feelings non-verbally in facial expressions or other behaviour and healthcare professionals need to be especially alert and sensitive to these messages (Bottorff et al., 1998; Robijn et al., 2018). Non-verbal communication also works both ways.

4.3.3 | Good Patient – Healthcare Professional Relationship

Patient participation in shared decision-making also requires a good relationship between the healthcare professionals and the patient. Good relationships are built on mutual trust and getting to know each other (Bélanger et al., 2016; Bottorff et al., 1998, 2000; Hermsen & Have, 2005; Jerpseth et al., 2018; Lee et al., 2009; Sahlberg-Blom et al., 2000). The relationship between the patient and healthcare professionals might affect the decisions the patient makes. Patients might feel that they cannot make certain decisions if they cannot trust the healthcare professionals (Bottorff et al., 1998; Lee et al., 2009), and on the other hand, if the nurses do not know the patient well enough, some decisions might be misunderstood (Bottorff et al., 1998). The healthcare professionals also need to be approachable (Bottorff et al., 2000; Jerpseth et al., 2018; Lee et al., 2009; Richardson et al., 2010; Volker & Wu, 2011). Patients need to feel that they are treated as individuals and their needs are at the centre of the healthcare professionals focus (Lee et al., 2009). From the patient's perspective, the other crucial factors in forming a good relationship are the healthcare professionals' behaviour (Lee et al., 2009; Richardson et al., 2010) and trustworthiness, and the feeling of being heard and understood (Lee et al., 2009).

4.3.4 | Favourable environment

Environmental factors are also important for the patient. These factors include the need for the physical environment to be favourable (Bottorff et al., 2000; Hermsen & ten Have, 2005; Lee et al., 2009; Richardson et al., 2010) and privacy (Hermsen & ten Have, 2005). These factors can be achieved through giving the patient time (Bottorff et al., 2000; Lee et al., 2009) and creating a sense of leisure, sitting down with the patient on their level (Bottorff et al., 2000), appropriate touching to communicate caring (Lee et al., 2009) and making the patient feel welcome (Richardson et al., 2010).

4.3.5 | Mutual information

All of the included studies emphasised the importance of information in shared decision-making. Patient's need an adequate amount of information to make decisions and healthcare professionals also need sufficient information to understand the patient's preferences, needs and ultimately the choices that the patient makes (Barry & Henderson, 1996; Bélanger et al., 2016; Bottorff et al., 1998; Bottorff et al., 2000; Clover et al., 2004; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Lee et al., 2009; Robijn et al., 2018; Sahlberg-Blom et al., 2000; Volker & Wu, 2011).

4.3.6 | From the patient's point of view

From the patient's point of view, information is needed about the aims and consequences of the treatment (Bottorff et al., 2000; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Volker & Wu, 2011), treatment options (Bélanger et al., 2016; Bottorff et al., 1998, 2000; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Robijn et al., 2018), disease (Bottorff et al., 2000; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Robijn et al., 2018), prognosis (Bélanger et al., 2016; Hermsen & ten Have, 2005; Jerpseth et al., 2018; Robijn et al., 2018), organisational factors (Bottorff et al., 1998, 2000; Lee et al., 2009), time schedule factors, nursing care factors and institutional factors (Bottorff et al., 1998, 2000). It is the healthcare professionals' responsibility to assess whether the patient has understood and accepted the information given (Hermsen & ten Have, 2005).

In decisions that concern treatment, it is clear that the patient's disease, treatment consequences, possible side effects and the prognosis all affect the decisions. Patients and physicians also seem to be more positive towards making shared decisions when there is uncertainty about the medically best alternative (Bélanger et al., 2016). Therefore, exposing uncertainty is important. Patient's also need information about adverse news and end of life (Hermsen & ten Have, 2005; Volker & Wu, 2011). When sharing information, healthcare professionals should take into account that patient's might not want to share all the information with family members (Sahlberg-Blom et al., 2000; Volker & Wu, 2011). It is also important to recognise that patient's aptitude for dealing with new information might vary as well as their ability to receive it (Bottorff et al., 1998; Clover et al., 2004; Hermsen & ten Have, 2005; Jerpseth et al., 2018).

4.3.7 | The healthcare professionals' awareness

Based on the included studies, it is crucial for healthcare professionals to be comprehensively aware of the patient's situation at all times as it might fluctuate. This can be achieved through ongoing assessment of the patient's condition, patient's views and psychosocial factors. As situations might change rapidly the patient's capacity to make choices (Bottorff et al., 1998, 2000), their symptoms (Bélanger et al., 2016; Bottorff et al., 1998), ability to tolerate

treatment (Hermsen & ten Have, 2005), response to care (Bottorff et al., 1998; Volker & Wu, 2011) as well as the medical feasibility of treatment options (Hermsen & ten Have, 2005) should be evaluated often. Patient safety should also be taken into consideration and safeguarded (Bottorff et al., 2000). Patient safety should not, however, be used as a justification for overriding the patient's right to self-determination. Sometimes patients might make decisions that will eventually cause pain, discomfort or a feeling of failing as a result of overestimating strength or capability. In these situations, it is important that the healthcare professionals support the patient (Bottorff et al., 1998).

Patient's expectations and their realism also need to be assessed and corrected if necessary (Hermsen & ten Have, 2005). Expectations can be affected by the patient's history and their own experiences or experiences related by the patient's family members (Bélanger et al., 2016; Bottorff et al., 1998). In addition, the patient's ability to accept their own disease and current situation has an effect (Hermsen & ten Have, 2005; Richardson et al., 2010; Volker & Wu, 2011).

Patient's views on quality of life should always be the basis for the decision-making process (Bélanger et al., 2016; Bottorff et al., 1998; Hermsen & ten Have, 2005; Jerpseth et al., 2018). The healthcare professionals also need to take into consideration other factors that might affect patient's willingness to participate (Lee et al., 2009); for example, the patient may have other plans for the day (Bottorff et al., 1998). It is also important to frequently check patient preferences since patients might change their minds rapidly (Bottorff et al., 1998, 2000; Lee et al., 2009; Robijn et al., 2018). Psychosocial factors (Bottorff et al., 1998; Hermsen & ten Have, 2005) like the ability of the patient's family members to care for their relative undergoing the treatment should also be assessed.

5 | DISCUSSION

5.1 | Main findings

The aim of the review was to synthesise research findings on patient participation in shared decision-making in palliative care. This review updates the knowledge gained from the previous reviews and focuses on a broader view of patient participation in shared decision-making involving nurses and not limiting the patients based on their diagnosis.

The studies included in this review were conducted in Europe, Australia and North America. Therefore, the results of this review might not be generalisable culturally. The lack of Asian, South American and African research might be due to that fact that palliative care services are still in their development phase according to the mapping by the WHO & WHPCA of palliative care development (WHPCA & WHO, 2020). According to the WHPCA and WHO (2020), only 12% of the need for palliative care is being met globally and the accessibility of palliative care is most insufficient in low- and middle-income countries. In addition, in some of the Asian cultures

the role of the family members is strongly emphasised in decision-making (Back & Huak, 2005; Tang et al., 2005). Nine of the twelve included studies focused on the patient's point of view, and the information was obtained from palliative care patients. All of the included studies were qualitative.

Based on the results of this review, it is clear, and has been recognised in previous literature (Houska & Loučka, 2019), that palliative care patients want to participate more extensively in decision-making and not solely on medical decisions. In this review, the decisions in which patients participated or desired to participate in were divided into three categories: everyday nursing care decisions, treatment-related medical decisions and end-of-life decisions (Figure 3). This review also confirms the fact that even though patients might desire to participate in shared decision-making this desire is not always met by the healthcare professionals. This finding is in line with previous literature (Seibel et al., 2014). Previous reviews have all recognised patient participation in medical decisions (Bélanger et al., 2011; Feuz, 2014; Gaston & Mitchell, 2005), but they have also focused mainly on decisions regarding the patient's treatment. The Bélanger et al., (2011) review identified also non-medical decisions and these partly overlap with the everyday nursing care decisions identified in this review. The lack of end of life decisions in the previous reviews might be explained by the limited studies on the decisions made in the final hours or days of life.

The more extensive categories for the decisions in which the patients participate or desire to participate found in this review is probably due to the fact that this review included the nursing perspective and excluded studies focusing only on patient-physician dyad. In the past the nurses' role has not been clearly defined and nurses have often been dismissed in the conceptual models of shared decision-making (Lewis et al., 2016). Additionally, in this review shared decision-making was defined as including all of the decisions that involved a healthcare professional and the patient. The identified decision categories are not profession-specific as nurses give medications and physicians might be for example involved in decisions about activities of daily living and nutrition.

Palliative care patients might want to be included in deliberation about whether to use antibiotics in case of an infection or not but it might be as important to have control over decisions about everyday events such as taking a bath in the evening when they might feel more alert or when to have their medication so the side effects will not disrupt their plans for the day. These decisions enable patients to maintain some control over own body, its functions and their remaining life. The decisions palliative care patients want to be involved in might sometimes seem insignificant but being involved improves the patient's quality of life and feeling of self-worth. When patients get to be involved in the decisions regarding their care on a daily basis they also might be more satisfied with the care received. This is why shared decision-making should be considered more comprehensively in palliative care than it often is when researched in curative settings.

In this review, five categories of prerequisites for patient participation in shared decision-making were identified (Figure 4). The

categories consisted of interdisciplinary teamwork, open communication, good patient-healthcare professional relationship, a favourable environment and mutual information. These results are in line with the prerequisites for good quality palliative care (EAPC, 2009). On the basis of these results, it was established that patient participation in shared decision-making has numerous prerequisites and they are all interconnected with each other and some of them are preconditions to other conditions. The responsibility for enabling patients to participate in shared decision-making mainly lies with the healthcare professionals and the organisations providing palliative care, which is in line with the EAPC (2009) standards for quality palliative care. Healthcare professionals must ensure that the interdisciplinary teamwork is functional and that the communication is open and honest. In addition, patients must be provided with adequate information and healthcare professionals need to ensure that the patient can understand and accept the given information. Healthcare professionals also need a great deal of information from the patient, for example preferences, desired involvement of the family members, attitudes and previous experiences. It is both the patient's and the healthcare professionals' responsibility to assure that all of the needed information has been shared. The information gained from the patients and the decisions made together with the patient need to be documented in an appropriate manner. Information (Bélanger et al., 2011; Feuz, 2014; Gaston & Mitchell, 2005), communication and interdisciplinary teamwork (Bélanger et al., 2011; Feuz, 2014) have also been established as prerequisites for patient participation in shared decision-making in the results of the earlier reviews. The EAPC (2009) and the Council of Europe (2014) also address the importance of these factors. Healthcare professionals should take into consideration that patient's capacity to comprehend new information might be limited and that too many options might lead to anxiety.

Additionally, healthcare professionals need to form a good relationship with the patient, which is also stated by the National Consensus Project for Quality Palliative Care (2018). It is important to recognise that in palliative care the patient's situation might fluctuate and their willingness and capability to be involved in decision-making might vary depending on the patient's current state or the decision to be made. Therefore, healthcare professionals need to frequently assess the patient's willingness and capacity to be involved in decision-making in collaboration with the patient and family members. Healthcare professionals should enable patient's participation in shared decision-making in all decisions possible. The higher number of prerequisites identified in this study compared to the previous reviews might be explained by the fact that this review looks at the issue more broadly; the nursing perspective has been addressed and patient groups were not excluded based on their diagnosis.

Based on the results, palliative care patients depend on the recommendations of the healthcare professionals. Patients' dependence on physicians' recommendations has been identified also in previous reviews (Feuz, 2014; Gaston & Mitchell, 2005) and studies (Seibel et al., 2014). Healthcare professionals should not, however, use their authority to override patient's preferences. Patient's view

on quality of life should always be in the basis of the decision-making process even if it might deviate from the healthcare professionals' views on what is best for the patient. It is the healthcare professionals' responsibility to ensure that the patient has all the information necessary in order to make the best decision.

5.2 | Strengths and limitations

Good scientific practises were followed in every phase of this review. The review was conducted according to the process of integrative literature review by Whitemore and Knafl (2005). The search phrase was formed with the help of an information specialist, and the selection of the articles was done by two authors. The quality appraisal of the included articles was done by two authors with the JBI checklist. The overall quality of the included articles was good, and however, there was some variation. The data analysis was performed according to the model of Elo and Kyngäs (2008) and initially conducted by one of the authors and later discussed by the research team with an agreement being reached.

However, this review has some limitations. The factors that threaten the reliability of this study are mainly related to data. Only a limited number of studies have been conducted on the subject, all of the included articles were qualitative, and the samples were small. The studies were all conducted in Australia, Europe and North America, and therefore, possible cultural differences might not appear in this review. Healthcare professionals were not limited only to physicians and nurses, but the included studies only addressed these two occupations. In this review, the focus was on cognitively alert patients and patients with cognitive impairments were excluded. This might affect the results as more than 12% of patients in need of palliative care suffer from dementia (WHPCA & WHO, 2020) and there are numerous other illnesses and circumstances that can affect palliative care patients' cognitive functions. Nevertheless, this exclusion was done because the process of decision-making differs between patients with cognitive impairments and cognitively alert patients. No articles were excluded based on the language, but all of the eligible articles were published in English. Additionally, the diversity of the terms and concepts and their varying use in previous research was a challenge. This may have allowed some studies to have been overlooked in the searches.

Due to the small number of studies, small samples and cultural bias, it may not be possible to draw broader conclusions from this review. This review, however, covers the current research on the topic and therefore gives as comprehensive a description of the subject as possible.

6 | CONCLUSIONS

Research is very limited on patient participation in shared decision-making including a nurse in the context of palliative care.

However, it would seem that patients generally do participate in shared decision-making in fairly broad terms even though not as extensively as they desire. Overall, most palliative care patients seem to desire to participate in shared decision-making and the decisions patients want to be involved in are wide-ranging. Patients' desire control in seemingly small things as this helps them to feel they have some control over their lives and are being seen as individuals.

The identified prerequisites were numerous, and they are all issues that patients, family members and healthcare professionals can all contribute to. However, the primary responsibility for enabling patient participation in shared decision-making lies with healthcare professionals. Organisations providing palliative care should recognise their responsibility in providing a suitable environment for palliative care as well as a well-resourced, educated and motivated personnel, adequate facilities and a care culture that enables the family members' participation in care.

Patient participation in shared decision-making in palliative care is a complex issue and an area where more research is needed. There is a need to conduct more research from the patient's perspective and explore the meaning of participating in shared decision-making from the patient's point of view. Even though the majority of the included studies focused on the patient's point of view, the research is still limited. There is also a need for intervention research and quantitative research as it would be important to look in more detail at the implementation of shared decision-making and its effects in a wider context.

7 | RELEVANCE TO CLINICAL PRACTICE

According to the results, the main responsibility for enabling patient participation lies with the healthcare professionals and the organisations providing palliative care. There is still a need to further invest in developing nurses' knowledge about patient participation in shared decision-making in palliative care. Nurses are often seen as partners and advocates for palliative care patients and this important role needs to be acknowledged. The results will be useful for nurse managers and policymakers in organising and planning nursing education and palliative care nurse education as well as when managing palliative care staff.

AUTHOR CONTRIBUTIONS

Study concept and design: Lotta Kuosmanen, Maija Hupli and Elina Haavisto. Analysis and interpretation of data: Lotta Kuosmanen, Maija Hupli, Satu Ahtiluoto and Elina Haavisto. Drafting of the manuscript: Lotta Kuosmanen. Critical revision of the manuscript for important intellectual content: Lotta Kuosmanen, Maija Hupli, Satu Ahtiluoto and Elina Haavisto.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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