






ORIGINAL RESEARCH:
EMPIRICAL RESEARCH - QUALITATIVE

The role of hospital nurses in shared decision-making about life-prolonging treatment: A qualitative interview study

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Abstract

Aims: To examine hospital nurses' perception of their actual and potential contribution to shared decision-making about life-prolonging treatment and their perception of the pre-conditions for such a contribution.

Design: A qualitative interview study.

Methods: Semi-structured face-to-face interviews were conducted with 18 hospital nurses who were involved in care for patients with life-threatening illnesses. Data were collected from October 2018-January 2019. The interviews were recorded, transcribed verbatim and analysed using thematic analysis by two researchers.

Results: Nurses experienced varying degrees of influence on decision-making about life-prolonging treatment. Besides, we identified different points of contact in the treatment trajectory at which nurses could be involved in treatment decision-making. Nurses' descriptions of behaviours that potentially contribute to shared decision-making were classified into three roles as follows: checking the quality of a decision, complementing shared decision-making and facilitating shared decision-making. Pre-conditions for fulfilling the roles identified in this study were: (a) the transfer of information among nurses and between nurses and other healthcare professionals; (b) a culture where there is a positive attitude to nurses' involvement in decision-making; (c) a good relationship with physicians; (d) knowledge and skills; (e) sufficient time; and (f) a good relationship with patients.

Conclusion: Nurses described behaviour that reflected a supporting role in shared decision-making about patients' life-prolonging treatment, although not all nurses experienced this involvement as such. Nurses can enhance the shared decision-making process by checking the decision quality and by complementing and facilitating shared decision-making.

Danique W. Bos-van den Hoek and Maureen Thodé contributed equally.

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Impact: Nurses are increasingly considered instrumental in the shared decision-making process. To facilitate their contribution, future research should focus on the possible impact of nurses' involvement in treatment decision-making and on evidence-based training to raise awareness and offer guidance for nurses on how to adopt this role.

KEYWORDS

decision-making, hospice and palliative care nursing, nurse–patient relations, nurses, nursing, palliative care, qualitative interview study, shared decision-making

1 | INTRODUCTION

Patients and healthcare professionals in palliative care often deal with treatment decisions for which difficult trade-offs are at stake (Brom et al., 2014; Epstein & Street, 2007; Shrestha et al., 2019). Given that for these decisions often no clear best strategy exists, the best treatment option depends on patients' values and preferences for treatment (Elwyn, Frosch, & Rollnick, 2009; Wennberg, Fisher, & Skinner, 2002). Therefore, such decisions require shared decision-making (SDM), an approach for involving healthcare professionals' evidence and expertise and patients' values and preferences in treatment decision-making (Charles, Gafni, & Whelan, 1997; Elwyn et al., 2017; Stiggelbout, Pieterse, & De Haes, 2015). Given their strong relationship with patients and unique expertise, nurses are increasingly considered important for and complementary to physicians' role in treatment decision-making (Buiting, Rurup, Wijsbek, van Zuylen, & den Hartogh, 2011; Elwyn et al., 2012; McCarter et al., 2016; McCullough, McKinlay, Barthow, Moss, & Wise, 2010). Importantly, patients want nurses to be involved (NFK, 2019) and report that nurses are valuable and influential in treatment decision-making (McCarter et al., 2016; McCullough et al., 2010). This all suggests that involving nurses in SDM about life-prolonging treatment would promote patient-centred care.

However, despite the potential for their involvement in SDM, the literature points to a gap between nurses' current and potential contribution to the decision-making process (Lewis, Stacey, Squires, & Carroll, 2016; McCarter et al., 2016; Tariman & Szubski, 2015). This gap may be attributed to several institutional and professional barriers nurses face, such as the lack of uniform practice standards or professional training and experience (McCarter et al., 2016). Yet, there is still much that is unknown about the role nurses have—or could have—in SDM about life-prolonging treatment in the palliative phase.

1.1 | Background

Shared decision-making is most relevant for preference-sensitive decisions, decisions for which the best strategy is unclear because of a lack of evidence for the effect of different treatment options, similarity in outcomes and/or more likely individual differences in the weights assigned to the risk and benefits (O'Connor, Legare, & Stacey, 2003; Wennberg et al., 2002). Particularly for decisions

about life-prolonging treatment, such as palliative chemotherapy and antibiotics, difficult trade-offs are at stake. These treatments may have uncertain and limited benefit and may impose a high burden on patients, such as side effects or prolongation of life without sufficient quality (Epstein & Street, 2007; Legare & Witteman, 2013; Shrestha et al., 2019). Consequently, the best strategy depends on patients' preferences (Elwyn et al., 2009; Wennberg et al., 2002).

To incorporate those preferences, SDM entails the following four steps: (a) informing patients that a decision needs to be made; (b) explaining options with the associated benefits and disadvantages; (c) exploring patients' preferences; and (d) making or deferring the decision (Stiggelbout et al., 2015). Alongside the ethical imperative to deliver patient-centred care and respect patient autonomy, SDM is also associated with positive patient outcomes such as higher satisfaction with the decision and trust in the physician (Shay & Lafata, 2015). In addition, the literature indicates that SDM in palliative care may result in patients receiving less aggressive treatment, possibly resulting in a higher quality of life for both patients and families (Wright et al., 2008; Zhang et al., 2009).

Yet, despite its benefits, SDM is not common practice in all palliative care settings (Belanger, Rodriguez, & Groleau, 2011; Brom et al., 2017; Fitzsimons et al., 2019; Henselmans, Van Laarhoven, Van der Vloodt, De Haes, & Smets, 2017; Jerpseth, Dahl, Nortvedt, & Halvorsen, 2018). This may be for several reasons. SDM in palliative care requires high-level communication skills known to be demanding for clinicians, such as dealing with patients' emotions and coaching patients in constructing a treatment preference. Also, both clinicians and patients have a tendency to focus on the short term and on active treatment (Buiting et al., 2011; de Haes & Koedoot, 2003; The, Hak, Koëter, & Van der Wal, 2000). Nurses might be well-equipped to overcome these barriers in SDM.

Traditionally, decision-making about life-prolonging treatment is considered to take place in a patient–physician interaction. Yet, attention for the role of nurses in treatment decision-making has increased (Joseph-Williams, Elwyn, & Edwards, 2014; Legare et al., 2011; McCarter et al., 2016; Stacey, O'Connor, Graham, & Pomey, 2006; Tariman et al., 2016; Tariman & Szubski, 2015). Among suggested roles for nurses related to decision-making are educating patients about treatment and side effects, advocating on patients' behalf and coaching patients in decision-making (Elwyn et al., 2012, 2017; McCarter et al., 2016; Stacey et al., 2008; Tariman et al., 2016; Tariman & Szubski, 2015). Additionally, nurses may have an important

role in end-of-life discussions with patients (Buiting et al., 2011). This all suggests that nurses potentially contribute significantly to decision-making about life-prolonging treatment.

2 | THE STUDY

2.1 | Aims

This study aims to examine hospital nurses' perception of their actual and potential contribution to shared decision-making about life-prolonging treatment and their perception of the pre-conditions for such a contribution.

2.2 | Design

A qualitative study with face-to-face in-depth semi-structured interviews was conducted. This report adheres to the Consolidated criteria for Reporting Qualitative research (COREQ) (Tong, Sainsbury, & Craig, 2007).

2.3 | Study participants and sampling strategy

Nurses were considered eligible if they: (a) had a vocational or bachelor qualification in nursing; (b) practiced in inpatient or outpatient hospital settings; (c) were involved with the care of patients with life-threatening illnesses for whom life-prolonging treatment decisions were made; and (d) had at least 1 year's working experience.

We used a maximum variation sampling strategy for inviting participants (Suri, 2011). We invited nurses working in different types of hospitals (university and general hospitals), hospital settings (inpatient, outpatient and day care), positions (Registered Nurses, Registered Nurses with additional relevant training and clinical nurse specialists) and with a range of years of working experience. Project group members and participating nursing teams in various hospitals in the Netherlands, with whom collaborations were established before the commencement of the study, were asked to forward an invitation by e-mail to eligible nurses. To reach maximum variation, nurses with particular characteristics were invited if needed. For example, when we observed that many nurses were employed at inpatient settings we invited nurses employed at the outpatient setting more actively. Twenty nurses showed interest, of who 18 eventually participated. Two nurses withdrew because of personal circumstances. The participants did not know the researchers. Prior to the interviews the participants received an information letter.

2.4 | Data collection

Data were collected from October 2018-January 2019. The interviews were conducted by DB (MSc, background in Health Sciences)

TABLE 1 Topic guide

A. Introduction to the research/interview by researcher
Short explanation of the goal of the interview
Explanation of confidentiality and anonymity
Permission for audio taping
B. Substantive part of the interview
Case of an incurable patient who had to decide on treatment with a life-prolonging yet non-curative intent (given by nurse)
Current role and ideal role for involvement in treatment decision-making
Types of treatment decisions
Points during treatment trajectory at which nurse is involved
Position with respect to other healthcare professionals
Tools/interventions supporting involvement in life-prolonging decision-making
Goals within conversations with patients
Stimulating and restraining factors for fulfilling his/her role
Examples: work culture, organization, knowledge and expertise, type of patient, cooperation with other departments/ healthcare professionals, workflows, communication
Requirements for fulfilling his/her role
Different levels: manager/organization, colleagues, individual
C. Conclusion of the interview
Issues that were not addressed

and MT (MSc, background in Interdisciplinary Social Sciences and a Registered Nurse), both junior researchers with experience and training in conducting interviews. The interviews took place in a private meeting room at the participant's workplace during working hours. Interviews were audio-recorded and lasted approximately between 45 and 60 min. Field notes were made after each interview.

The interview guide (Table 1) contained general questions about the current and desired roles of nurses in treatment decision-making, stimulating and restraining factors and the requirements for fulfilling this role. The interview started with asking participants to provide a case of a patient with a life-threatening illness who had to decide about treatment with a life-prolonging yet non-curative intent. This case allowed nurses to elaborate on their role, the pre-conditions and the requirements for that particular case. Follow-up questions aimed to clarify the underlying reasons for experiencing or desiring roles, pre-conditions or requirements. The interviewers continuously discussed the interview guide during data collection, resulting in minor changes. All interview recordings were transcribed verbatim. Interviews continued until perspectives were being repeated and data saturation was considered to have been reached. Two additional interviews were then conducted and used for checking data saturation; no new themes emerged.

2.5 | Ethical considerations

The Medical Ethical Committee of Amsterdam UMC—location VUmc offered a written exemption for the study from the requirement to

seek formal approval. We followed the Good Clinical Practice guidelines. Written informed consent for participation in the study and publication of the results was obtained from all respondents.

2.6 | Data analysis and rigour

Data were analysed in ATLAS.ti version 7, following the principles of thematic analysis (Boyatzis, 1998; Braun, Clarke, Hayfield, & Terry, 2018). After becoming familiar with the data by reading the transcripts, two researchers (DB and MT) carried out the initial coding, keeping very close to the original transcripts. The first five interviews were double-coded independently by the two researchers, after which each interview was discussed until consensus was reached. As coding agreement was high, the following 11 interviews were coded independently by one researcher and subsequently discussed by the two researchers. The different codes were sorted into groups to develop overarching themes. 2,547 codes were created initially, which were categorized into 36 code families. Themes and corresponding codes were continuously compared and discussed by the two researchers. After this, potential themes were categorized, merged and refined and the content of the themes was analysed to generate definitions and names for each theme in a codebook. Eventually, themes were arranged into four overarching themes (corresponding with the subheadings of the results section), 16 subthemes and 21 explanatory themes related to the subthemes. In the meantime, 'member checks' were sent to the participants, encompassing a summary of the analysis. All participants agreed with the member check and no changes were made to the analyses. Finally, appropriate quotes were selected and translated by a professional translator. The analyses were discussed twice with the research group and on multiple occasions with one of the senior researchers (RP).

3 | FINDINGS

Eighteen nurses participated, mostly Registered Nurses with additional relevant training employed in oncology departments (Table 2). Nurses worked in different clinical settings—inpatient (where patients stay at least one night), outpatient (where patients visit the hospital for one or more appointments) and day care (where patients receive treatment during the day without an overnight stay).

3.1 | Influence on treatment decision-making

Nurses experienced varying degrees of influence on decision-making about life-prolonging treatment. Some nurses said that they had influenced the final decision taken by patients, whereas others mentioned not interfering with such decisions on life-prolonging treatment at all. Many nurses said that the responsibility for such decisions lies with the physician:

TABLE 2 Participants' characteristics

Age (years)	
20–34	5
35–49	5
50–65	8
Sex	
Male	4
Female	14
Working experience (years)	
1–4	4
5–9	3
10–14	3
≥15	8
Nurses' job category	
Registered Nurse (RN)	5
RN with additional relevant training (e.g. oncology or palliative care)	10
Clinical nurse specialist	3
Hospital setting	
Inpatient	9
Outpatient	5
Day care	3
In- and outpatient	1
Department	
Oncology (including neurology-oncology and haematology-oncology)	14 ^a
Cardiology and pulmonary diseases	3
Urology and plastic surgery	1 ^a
Surgery	1
Hospital type	
University hospital	9
General hospital	9

^aOne nurse was employed in two departments

Choosing and making the decision regarding the life-prolonging treatment is definitely a job for the doctors to discuss with the patients. I don't think nurses have a role in that.

(RN with additional relevant training, day care, university hospital)

It sometimes happens that there are different opinions between a physician and patient. Then my role is just to find out what the patient thinks. Sometimes I try to pass along information to physicians. I tell them I had a conversation with the patient and what they think.

(RN with additional relevant training, outpatient, general hospital)

3.2 | Involvement in decision-making process

Nurses described interactions at different points in time with patients and physicians. We identified these interactions as potential opportunities for a conversation about – and thus involvement in – treatment decision-making. Despite differences in the interactions depending on hospital settings, nurses' job category and departments in the hospital, some general findings can be reported.

The different types of interactions (Table 3) that were identified are: (a) multidisciplinary team discussions; (b) patient–physician conversations; (c) nurse–patient conversations directly after the physician–patient conversation; (d) educational conversations; (e) formal conversations; (f) informal conversations; and (g) conversations between physicians and nurses.

Nurses said that many decisions about life-prolonging treatment were made in *outpatient settings*, with a leading role for the physician and that they usually did not have conversations with patients before the decision was made. Clinical nurse specialists were an exception as they did mention having conversations about treatment decisions with patients at this stage:

I mainly outline what patients find important in their lives, what they expect from the treatment, what they know about the diagnosis. (...). And then the physicians often continue about what to expect from the treatment in this situation.

(Clinical nurse specialist, outpatient, university hospital)

In contrast, in *inpatient settings*, some nurses, especially clinical nurse specialists, said that they talked to physicians about the patient's treatment when attending multidisciplinary team discussions. Furthermore, nurses were sometimes present during physician–patient

conversations about the treatment on admission. Nevertheless, their role during these conversations was perceived to be limited:

The doctor often then runs the whole conversation, right? They get it going, then there are a few questions from the patient and it goes back and forth a bit. Sometimes there are also a couple of action points for us at the end, or we can give them some tips, but we don't really have much to say during the conversation.

(RN with additional relevant training, inpatient, general hospital)

Both nurses in the *inpatient* and *outpatient setting* explained having conversations with patients directly after a physician–patient conversation:

Then I take the patient aside, after the conversation with the neurologist. Just to hear them repeat what they think they've heard – what they think about it. So I'm really helping them process that discussion, briefly summarizing what the options are.

(RN with additional relevant training, outpatient, general hospital)

Both *day care* nurses and nurses in the *outpatient setting* described systematically having educational conversations with patients about the treatment. These offered opportunities to discuss treatment decisions:

But that kind of conversation usually takes place first [before the start of the treatment], as an informational

TABLE 3 Occasions of contact with potential for conversation about treatment decision

Type	Who	Description	When
Multidisciplinary team discussion	Nurse(s), physician(s), other team members involved	Conversation with multiple team members in which patients' diagnoses and treatment proposals are discussed	Usually before the start of (new) treatment
Conversation between physician and patient	Physician, patient, with or without nurse present	Conversation about starting or continuing treatment, in which decisions may be made	Multiple occasions in the period around the treatment decision
Nurse–patient conversation directly after the conversation between physician and patient	Nurse, patient	Emotional support and discussion about information from physician after conversation with physician	Multiple occasions in the period around the treatment decision
Educational conversation	Nurse, patient	Informational conversation about treatment and side effects	Before the start of (new) treatment
Formal conversation	Nurse, patient	Official, organized conversations between patient and nurse about treatment	Multiple occasions in the period around the treatment decision
Informal conversation	Nurse, patient	Unofficial, unorganized conversations during care or the admission for treatment	Multiple occasions in the period around the treatment decision
Conversation between physician and nurse	Nurse, physician	Conversation about patient and his/her progress/wishes/etc	Multiple occasions in the period around the treatment decision

conversation. So that the patients only decide for definite they're going to go ahead with it after the side effects really have been explained. Sure, they've often already made up their minds – I'm going to have this treatment and I'll get those side effects – but you do also often see people saying that's something they don't want and they're not going to do it. So yes, you do often see that in a discussion. That they only genuinely get the information then that makes an impression on them, that they then start to get a feeling that they might not have made the right decision about this therapy.

(RN with additional relevant training, day care, university hospital)

After treatment started, nurses described having formal and informal conversations with patients. 'Formal' conversations include planned, organized conversations; 'informal' means having conversations with patients while in the course of providing care, during the admission for treatment or by deliberately taking a seat at the patient's bedside. During these conversations, nurses could receive important information related to the treatment decision, such as experiences with the treatment or patients' views on their end of life:

Well, with this one woman it happened a lot while I was washing her. It just so happened [...] that we were talking a bit about [the end of life]. But I do also regularly go round to the patients and have a chat, sitting on the edge of the bed [...] If the patient hasn't been entirely clear [during the talk with the palliative team] about what they do or don't want, that can help you to get things clearer. I often notice that the patients are more open with us than during a formal discussion.

(RN with additional relevant training, in/outpatient, general hospital)

Additionally, nurses described talking to physicians to share information they perceived as important for treatment decision-making that emerged during previous conversations with patients. That way, physicians could consider this information during physician–patient conversations or during multidisciplinary team discussions:

So yeah, you size up how the patient is doing, how they feel about it and depending on that you tell the doctor and, well, the conversation or the timing of the decision will be changed to suit.

(Clinical nurse specialist, outpatient, university hospital)

3.3 | Roles of nurses in treatment decision-making

Although many nurses did not recognize their influence on treatment decision-making, most of them nevertheless described behaviour that might have influenced the treatment decision-making process when discussing patient cases during the interviews. Nurses' descriptions of behaviours that potentially contribute to shared decision-making were grouped into three different roles—checking the quality of the treatment decision, complementing SDM and facilitating SDM.

3.3.1 | Checking the quality of the treatment decision

Nurses looked at the quality of a treatment decision. They checked the extent to which the treatment choice had been made consciously, was based on complete information and an understanding of this information and fitted the needs, values and preferences of the patient. This was mainly done by asking patients all sorts of questions and assessing patients' reactions:

What I actually do, I guess, is get a clear picture of how someone feels about their life, what they expect from the treatment, whether they know what the diagnosis means and so whether they actually understand what we're talking about and what the life expectancy is and the purpose of the treatment, so that things can be weighed up properly.

(Clinical nurse specialist, outpatient, university hospital)

Some nurses mentioned that checking the quality of the decision is particular importance in palliative care:

Look, treatments in the palliative phase are about extending your life. But it's the patient who determines the quality of life. We're not the ones who can say whether it's good or bad. [...] [Our job is] to pick up the signals correctly if it's troubling the patients.

(RN with additional relevant training, day care, university hospital)

All nurses considered checking the decision quality to be present in all conversations with patients, before and after the start of treatment, although it was most clearly present in conversations directly after the physician–patient conversation. Besides, nurses mentioned that as the treatment progressed, they repeatedly asked about the patient's perception of the balance between the quality of life, satisfaction with the treatment choice and end-of-life wishes. This way, they could monitor whether values or treatment preferences had changed:

I see it as a nurse's responsibility to [...] flag up how that balance is working out. Whether people are still happy with the life that they are leading, as far as possible. In combination with the treatment.

(RN with additional relevant training, day care, university hospital)

3.3.2 | Complementing shared decision-making

In response to identified patient needs or deficiencies in the quality of the decision-making process, nurses mentioned behaviour that complemented the SDM-process. This could partly involve the same behaviours as were described for checking the quality of the decision (e.g. asking questions about patient values), yet now with the intention to support patients in constructing a treatment preference.

Nurses reported that they may create choice awareness or inform patients about treatment options and the benefits or disadvantages of such treatments:

I think it's important to discuss with patients that they can choose to start chemotherapy and that they can always reconsider their decision when they notice that the chemotherapy leads to many complaints and a terrible decline in their quality of life.

(RN with additional relevant training, outpatient, academic hospital)

For example, nurses provided of their complementary role included answering questions, repeating or clarifying information given by the physician, adding information about their own experiences with the treatment and side effects as observed from other patients or mentioning the option to refrain from life-prolonging treatment. The latter option was mentioned by only a few nurses; some nurses said that if the physician did not mention the option to refrain, they were not in the position to interfere:

But it's not as if I ask very specifically whether they might not want anything done at all. I don't ask that specific question. [...] Because I think that can be pretty confusing if we mention that as one of the options, or it might scare them off.

(RN with additional relevant training, inpatient, general hospital)

Additionally, nurses mentioned helping patients by exploring their values and treatment preferences. Several nurses said they supported

patients in choosing or evaluating a treatment by encouraging them to weigh the treatment or treatment proposal against the patient's values or quality of life:

So I sometimes then ask them what's actually important to them. What can you still get genuine moments of pleasure from?

(RN with additional relevant training, inpatient, general hospital)

3.3.3 | Facilitating shared decision-making

Nurses mentioned various behaviours that could be classified as facilitating SDM—organizing contact between patients and physicians (sometimes in the presence of the nurse) and preparing patients for these conversations:

I generally then say that it's useful for us to have a talk – what questions have they got. And I often give them a pen and paper so that they can write things down too and then don't get overwhelmed in the formal conversation because they've run out of time. Or because they just don't think of something. It means they won't forget things.

(RN with additional relevant training, inpatient, general hospital)

Additionally, nurses described facilitating the SDM process by passing on important additional information or doubts in conversations with the physician so that the physician could adapt the treatment proposal or conversation with the patient accordingly. Some nurses referred to this intermediary position as patient advocacy. Mainly inpatient nurses and nurse specialists mentioned being able to contact the physician directly or by attending multidisciplinary team discussions; day care nurses described using electronic notes to communicate with the specialist. By having these conversations, nurses and physicians were able to align their understanding of patients' health and mental status and, consequently, the quality of the treatment decision:

I did do it once, by the way and I was proud of it: simply emphasized the fact that I didn't think this was a good quality of life. And I thought that we [the care providers] all ought to think carefully about how we tackle this discussion; we have to be open, of course, but we also need to see not giving treatment as one of the options.

(RN, inpatient, university hospital)

3.4 | Pre-conditions for nurses' role in SDM

Six pre-conditions for nurses' participation in the decision-making process were deduced from nurses' responses.

A first pre-condition is the transfer of information among nurses and between nurses and other healthcare professionals so that they all stay informed about the patient's health and mental status:

If you want to make the most of each other's capabilities and the knowledge you've built up during the process, then you – well, actually, you have to pass that knowledge on to each other. [...] We make very little use of each other's input and know-how. Sure, a doctor can read the notes I've made, but that's as far as it goes.

(RN with additional relevant training, outpatient, university hospital)

Many nurses mentioned that working part time and changing shifts have a negative effect on their ability to stay informed about the patient's current situation and be involved in the treatment decision:

I think that it [working full-time] is sometimes helpful and sometimes not, because I think that continuity... it's often nice for the patient if you keep seeing the same face – provided you can get on with that person, at any rate. And I reckon that you then automatically have more meaningful conversations.

(RN with additional relevant training, inpatient, general hospital)

As a way to improve the transfer of information, some nurses mentioned the need for more structural involvement in the decision-making process, for example by having more organized conversations with patients. Additionally, assigning case managers to patients would help improve the transfer of information, as nurses would then closely monitor the patient and have direct contact with him/her from the start of the treatment.

Secondly, a positive and supportive hospital or departmental culture towards nurses' involvement in SDM may facilitate this. For example, some nurses said that psychosocial care was considered important in their departments, providing space for investing time in conversations with patients and the opportunity to influence the treatment decision-making process.

A third pre-condition is nurses' relationship with the physician. Nurses often said that if physicians were open to nurses' contribution to the decision-making, they dared to give their opinion sooner. Several nurses mentioned that clarity and recognition of their role in treatment decision-making would help them to position themselves better with respect to contributions by other healthcare professionals:

I sometimes find it awkward to see where the role of the nurse starts and the role of the doctor ends. The extent to which I can stand my ground, as it were. I mean, it's fine to be forthright – but you have to think whether this is your role at that moment.

(RN, inpatient, university hospital)

Knowledge and skills were considered a fourth pre-condition for being involved in the treatment decision-making process. Nurses mentioned that experience in and knowledge about SDM, opportunities in palliative care and conversation techniques helped in starting conversations about treatment decision-making and discussing end-of-life issues with patients.

Time was a fifth frequently mentioned pre-condition as time is needed for starting in-depth conversations, especially for informal conversations. However, some nurses mentioned making time for these conversations as they considered it an investment for ensuring a good treatment relationship.

Lastly, a good relationship and personal connection with the patient influenced the conversations as well. Nurses mentioned that if they supported patients socially and emotionally, that enabled open and valuable conversations about the treatment decision. It helped SDM as nurses gained a better understanding of patients' motives, thereby allowing nurses to support value clarification and preference construction. Besides, it helped patients feel more at ease in asking questions:

And really being there for them, because they often get emotional [in nurse-patient conversations] and then they start really thinking about it. And you often provide support for them [...] You reassure them or get them thinking a bit... that's more our role.

(RN with additional relevant training, inpatient, general hospital)

Nurses reported taking into account differences between patients to have fruitful conversations, such as differences in the attitude towards death, mental capacity, ethnicity and religion.

4 | DISCUSSION

This study aimed to examine hospital nurses' perceptions of their contribution to decision-making about life-prolonging treatment and the pre-conditions for such a contribution. The results showed that nurses experienced varying degrees of influence on the treatment decision. We identified different points of contact in the period around the treatment decision that could lead to involvement in treatment decision-making. Nurses described behaviour that reflected three roles in treatment decision-making: checking the quality of the decision, complementing SDM and facilitating SDM. We

identified several pre-conditions for fulfilling the aforementioned roles: (a) the transfer of information; (b) a culture where there is a positive attitude to nurses' involvement in decision-making; (c) a good relationship with physicians; (d) knowledge and skills; (e) sufficient time; and (f) a good relationship with patients.

4.1 | Involvement and roles in treatment decision-making

Most nurses initially had difficulties in describing their role in decision-making. The degree of perceived influence on treatment decision-making seemed to depend at least partly on differences in setting and types of interactions. For example, nurses initially reported to have limited influence on decision-making in the out-patient setting, where physicians have a prominent role. This corresponds with the suggestion that nurses mainly contribute to the decision-making process during day-to-day care and clinical activities (McCullough et al., 2010). However, when invited to discuss their own experience with a specific patient case, all nurses described different behaviours that could be classified as related to supporting SDM. This implies that nurses are not always aware of their actual and potential contribution to SDM about life-prolonging treatment.

Our results suggest that checking the quality of the decision, complementing SDM and facilitating SDM may be considered important roles for nurses in decision-making about life-prolonging treatment. When adopting these tasks in their work, nurses can support physicians in ensuring high-quality decisions—decisions that are made consciously, informed by the best available evidence and based on values of patients (Stacey et al., 2008).

In the palliative phase, some aspects of nurses' roles in decision-making seem to be of particular importance. Firstly, nurses reported various attitudes towards mentioning the option to refrain from life-prolonging treatment if the physician did not communicate this to the patient first. In practice, physicians appear to focus on life-prolonging treatment options and often do not address the alternative (Brom et al., 2017). A previous study concluded that nurses may be more inclined to express their doubts concerning further treatment (Buiting et al., 2011). The current study shows that some nurses indeed take on this role while others perceive barriers to do so. This hesitation may reflect a need for training on how to raise choice awareness without causing unnecessary confusion. Secondly, nurses described checking patients' attitude towards the impending death. Previous work also showed that nurses were more focused on making best use of the time that is left, in contrast with physicians' and patients' mutually reinforcing attitudes of 'not giving up' (Buiting et al., 2011). These findings stress the importance of nurses' role in SDM about life-prolonging treatment.

Stacey and colleagues (2008) introduced the concept of the decision coach, which Legare et al. (2011) defined as 'the health professional who is trained to support the patient's involvement in healthcare decision-making but who does not make the decision

for the patient'. Among the tasks of the decision coach are: (1) assessing decisional conflict; (2) identifying and addressing decisional needs such as a need for information value clarity and support; and (3) accommodating these needs by providing information, verifying understanding, clarifying values, facilitating access to decision aids and building skills in deliberation, communication and accessing support (Stacey et al., 2008). These tasks largely correspond to the roles of nurses identified in this study, which support the assumption that nurses could take on the role of decision coach (Stacey et al., 2008). Currently, decision coaching is rarely embedded into clinical practice (Stacey et al., 2008). Factors such as unclear expectations, a lack of structured processes and low patient awareness of nurses' possible decision coaching role may impede implementation of decision coaching (Stacey, Pomey, O'Connor, & Graham, 2006). One way to implement decision coaching for patients in hospitals would be to make use of the contacts nurses already have with patients, as identified and categorized in the current study. O'Connor and colleagues (2008) recognize that the linkage of decision coaching to care has various benefits, among which better identification of cases of decisional conflict, tailoring of coaching to the patient's clinical needs and involving the patient's own physician more closely.

4.2 | Pre-conditions for contributing to SDM

Several of the identified pre-conditions for contributing to SDM are recognized in the existing literature as well (Lewis et al., 2016; Tariman et al., 2016; Tariman & Szubski, 2015). When applying an inter-professional approach to SDM where at least two healthcare professionals are involved, the transfer of knowledge and a good relationship and cooperation amongst these healthcare professionals are essential (Tariman et al., 2016). Healthcare professionals should cooperate and determine which health professional is best prepared with knowledge and skills to address the particular needs of patients at different time points (Lewis et al., 2016). Earlier research has also pointed out the importance of a facilitating hospital or department culture for implementation of SDM by, for example, allowing flexible use of decision aids and fostering an amicable and safe work environment (Nibbelink & Brewer, 2018; Scholl, LaRussa, Hahlweg, Kobrin, & Elwyn, 2018). In this study, nurses' knowledge and skills were found to influence their perception of and confidence in participating in treatment decision-making, which corresponds with findings described in literature (Nibbelink & Brewer, 2018; Stacey, Pomey, et al., 2006; Tariman et al., 2016; Tariman & Szubski, 2015).

4.3 | Strengths and limitations

A strength of this research is the variation in the sample on clinical setting, job type and type of hospitals. This allowed us to provide a broad picture of nurses' potential involvement in treatment

decision-making. Another strength is the qualitative design, which enabled us to elaborate with participants on what they and what we meant and understood by SDM; as they did not always realize they were contributing to the decision-making process.

A limitation is the restricted variation between hospital departments—nurses were employed predominantly in oncology departments. This could have influenced the results since decision-making processes and nurses' involvement in decision-making may vary between departments. Given that many previous studies on this topic were conducted among oncology nurses too, future research should investigate whether these findings apply to other departments as well. However, the few nurses in the present study who were employed in non-oncology departments did not seem to perceive a different role compared with those in oncology departments.

4.4 | Impact

Our findings point to the potential for nurses' involvement in SDM about life-prolonging treatment if they were to be more aware of the roles they could adopt. Involving nurses sooner and more systematically in the SDM process, preferably before the treatment decision is made, could improve the quality of the decision. Presumably, more cases of decisional conflict could be detected, and more patients could be supported in making a high-quality decision. For example, nurses could help assess the appropriateness of life-prolonging treatment or support patients in articulating their aims and preferences before decisions are made (Bolt, Pasman, Willems, & Onwuteaka-Philipsen, 2016). This corresponds with previous calls to apply an inter-professional approach and involve decision coaches (Legare et al., 2011; Stacey et al., 2008). Formal involvement may not always be necessary, as nurses could also be made more aware of their potential role during standard care.

Training in the skills and knowledge required for conversations about the decision-making process is needed. Other studies have already confirmed the successfulness of such training in decision coaching for nurses (Stacey, O'Connor, et al., 2006), coaching patients in decision-making for nurses (Lenzen, Daniels, van Bokhoven, van der Weijden, & Beurskens, 2018) and applying SDM about palliative chemotherapy for medical oncologists (Henselmans et al., 2019). Training may also increase awareness and clarity about nurses' supporting role in the decision-making process. Preferably, there is a common conceptual understanding of the roles, expertise and responsibilities in SDM of all the healthcare professionals involved (Legare et al., 2011). Articulation of nurses' behaviour and attributes would help clarify their expected tasks and purposes (Lewis et al., 2016).

For a better understanding of nurses' roles in SDM, further research should focus on other healthcare professionals' perceptions of nurses' position when deciding about treatment. Furthermore, research should focus on how checking the quality of the decision and complementing and facilitating SDM by nurses has an impact on treatment decisions in clinical practice. Lastly, research should focus on effective training for nurses

to improve their awareness and skills in supporting SDM about life-prolonging treatment. Bos – van den Hoek, Visser, Brown, Smets, and Henselmans (2019) conclude that, although implementation of communication skills training for healthcare professionals is widely advocated, evidence for the effectiveness of such training is often lacking.

5 | CONCLUSION

Nurses described behaviour that potentially supports SDM about life-prolonging treatment, although not all nurses were aware that they were contributing to decision-making. This study revealed three roles that nurses could adopt for supporting SDM, that is, checking the quality of a decision, complementing SDM and facilitating SDM. Research on nurses' actual impact on treatment decision-making and on evidence-based training is needed to raise awareness and give guidance for nurses on how to adopt this role.

CONFLICT OF INTEREST STATEMENT

None.

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AUTHOR CONTRIBUTIONS

Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data (DB, MT, IJ, HL, ES, DT, IH, HRP); Involved in drafting the manuscript or revising it critically for important intellectual content (DB, MT, IJ, HL, ES, DT, IH, HRP); Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content (DB, MT, IJ, HL, ES, DT, IH, HRP); Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved (DB, MT, IJ, HL, ES, DT, IH, HRP).

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