

Experiences of Moral Distress Regarding Life-Prolonging Treatment in Outpatient Nurses

a qualitative study

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ABSTRACT

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Background: Outpatient nurses are confronted with life-prolonging treatment in the last stage of the patient's life. Literature suggests that nurses lack involvement in the decision making of life-prolonging treatment and may experience moral distress, which is negatively associated with compromised care and job satisfaction.

Aim: To explore whether nurses in the outpatient clinic experience moral distress in situations where nurses are involved in life-prolonging treatments of adults with a short life expectancy or frail elderly and whether moral distress is due to not being involved in the decision making about these life-prolonging treatments.

Method: A qualitative design using semi-structured interviews with nurses working in the outpatient clinic. Recruitment was based on purposive sampling, but limited due to the COVID-19 outbreak. Interviews were guided by a topic list and started with a case description. Interviews were audiotaped, transcribed and subjected to thematic analysis.

Results: Interviews with 12 outpatient nurses (5 registered nurses and 7 nurse specialists) led to four themes: i) involvement in the decisions about life-prolonging treatment, in which nurses felt dependent on the physician, ii) experiences of moral distress, which seem to occur if nurses experiences doubt regarding the decision for life-prolonging treatment, if nurses doubt whether the patient's wishes were met or when nurses felt unheard or overruled for their opinion to stop life-prolonging treatment, iii) experienced consequences for patient care, in which some nurses withdrew from care, and iv) experienced support, when nurses shared their feelings about the decision making process and moral distress.

Conclusion and implications: This study gives a first impression of moral distress in outpatient nurses. It is recommended to involve nurses into the decision making regarding life-prolonging treatment and to facilitate opportunities to share feelings regarding the decision making process and moral distress.

Keywords: Moral Distress, Nurses, Outpatient Clinic, Life-Prolonging Treatment, End-of-Life-Care

SAMENVATTING

Ervaringen van morele spanning omtrent levensverlengende behandelingen bij verpleegkundigen werkzaam op de polikliniek

Introductie: Poliklinische verpleegkundigen zijn betrokken bij levensverlengende behandelingen van patiënten in de laatste levensfase. De literatuur suggereert dat verpleegkundigen niet betrokken zijn bij de besluitvorming hierover en mogelijk morele spanning ervaren. Morele spanning heeft negatieve gevolgen voor de kwaliteit van zorg en werktevredenheid.

Onderzoeksvraag: In hoeverre ervaren poliklinische verpleegkundigen morele spanning wanneer zij betrokken zijn bij mogelijk levensverlengende behandelingen van patiënten met een korte levensverwachting of kwetsbare ouderen, en is deze morele spanning gerelateerd aan het wel of niet betrokken zijn bij de besluitvorming voor de levensverlengende behandeling?

Methode: In deze kwalitatieve studie zijn semigestructureerde interviews gehouden met verpleegkundigen die werkzaam zijn op de polikliniek. Doelgerichte sampling werd toegepast, maar werd bemoeilijkt door de COVID-19-uitbraak. Een topiclijst werd gebruikt voor de interviews en elk interview begon met een casusbeschrijving. Interviews werden opgenomen, getranscribeerd en geanalyseerd middels thematische analyse.

Resultaten: Interviews met 5 verpleegkundigen en 7 verpleegkundig specialisten werkzaam in de polikliniek hebben geleid tot vier thema's: 1) Betrokkenheid bij de beslissingen over levensverlengende behandeling, waarbij verpleegkundigen zich afhankelijk voelden van de arts; 2) Ervaringen van morele spanning als a) verpleegkundigen twijfels hebben over de levensverlengende behandeling, b) verpleegkundigen twijfelen of aan de wens van de patiënt is voldaan en c) verpleegkundigen zich ongehoord voelen in hun mening om levensverlengende behandeling te stoppen; 3) Gevolgen van morele spanning voor patiëntenzorg, waarbij sommige verpleegkundigen niet meer voor de patiënt konden zorgen; en 4) Ervaring van steun wanneer verpleegkundigen hun gevoelens over het besluitvormingsproces en morele spanning deelden.

Conclusie: Deze studie geeft een eerste indruk van morele spanning van poliklinische verpleegkundigen. Het wordt aanbevolen om verpleegkundigen te betrekken bij de besluitvorming over levensverlengende behandelingen en hun gevoelens met betrekking tot morele spanning te delen.

Kernwoorden: *Morele spanning, Verpleegkundigen, Polikliniek, Levensverlengende behandelingen*

INTRODUCTION

Advances in medicine have greatly improved possibilities to treat seriously ill patients and to prolong life of patients with a short life expectancy or frail elderly. The extension of life however, should not always be the desirable goal of end-of-life care.(1) Life-prolonging treatments, such as artificial ventilation, chemotherapy, dialysis, antibiotics and artificial nutrition and hydration may prolonging the last stage of the patient's life, but may also produce more burdens than benefits and negatively affect quality of life.(2,3) Evidence based criteria of burdens and benefits of life-prolonging treatment are not always available, which can lead to difficult ethical decisions for healthcare providers.(2,3) Discussing no further curative treatment was reported as one of the biggest ethical challenges for oncologists in clinical practice.(4)

Nurses are often ideally positioned to contribute in end-of-life care and decisions regarding life-prolonging treatment. Nurses often have more frequent and closer contact with patients than physicians. Nurses can therefore function as an important source of information about the patient's situation and wishes at the end of life.(5,6) Nurses also wish to be involved in end-of-life decision making.(5,7,8) However, literature suggests that nurses lack involvement in the decision making. (5,7–10)

Dealing with end-of-life decisions can cause moral distress.(11,12) Moral distress is described as the negative experience of psychological imbalance related to a moral event. It occurs in situations where healthcare providers cannot act according to their core values and perceived obligations.(13) Moral distress especially occurs when providing ineffective treatment in the end of life.(11,12,14) Moral distress is negatively associated compromised care, risk of burn out and job satisfaction.(10,11,15,16) Studies indicate that nurses even had left or considered leaving their position due to moral distress.(17,18) However, most studies on moral distress regarding life-prolonging treatment focus on the inpatient setting (intensive care, oncology or geriatrics) and no studies focus on moral distress in the outpatient setting.(7,10,12,15,17,19)

Nurses in the outpatient clinic may also experience moral distress since they are involved in the patient's life-prolonging treatment. In the outpatient clinic, nurses work closely with the physician in their consultation and are involved in the treatment for the patient.(20) Nurses may administer treatment, perform minor medical procedures, and primarily provide patients with information, guidance and support.(5,6,21) During their contact with the patient, nurses may also be in a position to discuss the patients preferences and therefore be an important

source of information during medical decision making.(21) Therefore, it is important to explore the experience of moral distress in outpatient nurses and their involvement in the life-prolonging treatment of adults with a short life expectancy or frail elderly.

OBJECTIVE

The objective of this study is to explore whether nurses in the outpatient clinic experience moral distress in situations where nurses are involved in life-prolonging treatments of adults with a short life expectancy or frail elderly. The secondary objective is to explore whether moral distress is due to not being involved in the decision making about these life-prolonging treatments.

METHOD

Design

This study used a qualitative design to explore the experiences of moral distress in outpatient nurses regarding life-prolonging treatments. Data collection took place between March and June 2020 during the COVID-19 outbreak. The consolidated criteria for reporting qualitative research (COREQ) were used to describe data analysis and to report the findings.(22)

Participants and recruitment

Participants were recruited from two academic and three regional hospitals in the Netherlands. Eligibility criteria included: i) being a registered nurse or nurse specialist, ii) working in an outpatient clinic, iii) having professional experience in the past half year with life-prolonging treatments in adults with a short life expectancy and/or frail elderly.

Initially, eight contact persons (seven team managers and one nurse) of four hospitals were approached to invite participants who were deemed most appropriate for providing useful data.(23–25) This purposive sampling resulted in 26 nurses who received an invitation to participate. Due to limited recruiting during the COVID-19 outbreak, additional sampling based on convenience was performed. The researcher (MS) consulted her personal network and LinkedIn, which led to an additional contact person (nurse) and 10 additional eligible participants of three hospitals (appendix).

A total of 36 eligible participants received an email from the researcher with the purpose of the study and the participation information letter. Of the 36 nurses, 22 nurses did not respond, four nurses felt they did not meet the criteria and 1 nurse declined due to not having

time to participate. Interviews were planned with the nine nurses who indicated a willingness to participate. The researcher had no relationship with the participants and identified personal interests in the research topic at the introduction of the interview to improve transparency.(22)

Ethical considerations

All participants received verbal and written information about the purpose and procedure of the study. Written informed consent was obtained. Data collected was treated confidentially in accordance with the Dutch Personal Data Protection Act. Ethical approval was obtained from the medical ethics review committee (METC) of the VU university medical center (protocol ID 2018.551). The METC verified that this study does not fall under the scope of the Medical Research Involving Human Subjects Act (WMO) and does adhere to the principles of the Declaration of Helsinki.

Data collection

Semi-structured interviews were considered most appropriate for data collection given the explorative character of the objective. Face-to-face interviews were not attainable and interchanged with interviews by telephone, because of COVID-19 measures.(26) Interviews were held by telephone by a master student in nursing sciences (MS) who received training in qualitative methodology and interviewing techniques.(22,27,28)

Face-to-face interviews focussing on the involvement of nurses in decision making during end-of-life-care were conducted in a previous part of the project (protocol ID 2018.551) and led to the exploration of moral distress. As these interviews showed similarities in topics, a secondary analysis was performed for the three interviews that were held with nurses working in the outpatient clinic to integrate these in the present study and increase data collection.

To offer a framework for the interview, interviews started with a description of a recent case in which the participant was involved in life-prolonging treatment in adults with short life expectancy and/or frail elderly. Furthermore, a topic list (appendix) guided the semi-structured interviews.(23–25) The topics ‘decision-making process’, ‘involvement’, ‘desired role’, and ‘effect’ were derived from the Moral Distress Scale-Revised and adjusted based on interim analyses of the interviews.(14)

Interviews were audio recorded and transcribed verbatim by MS. Immediately after the interview, MS made field notes about communication and thoughts to enhance the credibility and trustworthiness.(22,23,25)

Data analysis

The analysis was carried out using the six principles of thematic analysis to offer a thick description of data. Important themes arising from interim analysis were further explored in subsequent interviews.(29) i) *Familiarization*: After each interview, MS transcribed the audiotape verbatim, re-read transcripts and wrote theoretical memos. Three transcripts were checked for accuracy (SA, IJ).(22,28) ii) *Coding*: MS and SA independently highlighted segments of interest and summarized them into codes. The codes contained the essence of the raw data and context. After discussing differences in segments and codes for the first three interviews and reaching consensus, MS continued coding and codes were checked by SA and IJ. iii) *Generating themes*: Codes were sorted into potential themes characterised by its significance independently for three interviews by MS and SA. Hereafter, MS sorted codes into potential themes using a thematic map to create a visual representation. iv) *Reviewing themes*: MS and SA reviewed themes by checking them against the entire original data set, other themes and the contours of the coded data. v) *Defining and naming themes*: Themes, subthemes and the coding tree were reviewed and discussed with the research group (MS, SA, IJ, AF) to improve the quality of the analysis. Then, MS refined themes by identifying sub-themes, naming themes and describing the scope and content of the theme in a couple of sentences. MS highlighted one or two citations for every theme in order to enhance the transparency and trustworthiness.(29) vi) *Writing up*: In the final analysis MS created an analytic narrative and vivid thematic map to provide an overall picture of the entire data set, which was reviewed and discussed with the research group (MS, SA, IJ, AF). Furthermore, generated themes were returned to the participants to validate the results and enhance trustworthiness. In this member checking, participants should be able to recognize their experiences within the synthesized themes.(30) The analysis was supported with the computer data analysis software ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, version 8.4.20).

RESULTS

Interviews were held with five registered nurses (RN) and seven nurse specialists (NS) working in the outpatient clinic.(Table 1) The interviews lasted between 25 and 55 minutes. Of the participants nine were female and eight worked in a university hospital. The participants' age was between 30 and 60 and their experience varied from 0 to 20 years.

One participant was included in the study, but was found not to fit the criteria. The participant worked as a nurse specialist, primarily in the inpatient setting. Regardless, this interview was included in the analysis as data derived from this interview fitted the themes and collected data.

[Insert Table 1]

A total of 515 codes were derived from the interviews, which led to four themes: i) involvement in the decisions regarding life-prolonging treatment, in which participants felt dependent on the physician, ii) experiences of moral distress, which were subdivided into three subthemes (experiencing doubt, doubting the patient's involvement, and feeling unheard or overruled), iii) experienced consequences for patient care, in which participants withdrew from care, and iv) experienced support, when participants shared their feelings about the decision making process and moral distress.(Figure 1)

[Insert Figure 1]

Involvement in decisions regarding life-prolonging treatments

Participants felt the need to be involved in the decision-making regarding life-prolonging treatments to be able to provide the patient with information and support. However, half of the participants expressed not feeling involved in the decision-making regarding life-prolonging treatment. These treatments varied from routine blood transfusions to surgery, tumor-specific treatment (chemotherapy and immunotherapy) to hospital readmission. Participants were either not asked for their involvement, not able to share their opinion or involved in the decision making too late.

Although half of the participants did express feeling involved in the decision-making regarding the life-prolonging treatment, participants felt dependent on the physician. Participants stated that the physician is either responsible for the decision making, and therefore has final say, or needed to successfully execute the decision. In the decision making regarding life-prolonging treatment by physicians, almost all participants expressed too much focus on treatment and too little awareness for the option of withholding treatment.

“I think our doctors [...] think if this treatment doesn't work, maybe there will be a new treatment or a new research and then we'll try that. So, they are really 100% in that treatment mode.” –NS4

Experiences of moral distress

Experiences of moral distress seem to occur in different situations: i) if the participant experiences doubt regarding the decision for life-prolonging treatment, ii) if the participant doubts whether the patient's wishes were met in the decision for life-prolonging treatment, and iii) if the participant felt unheard or overruled in their opinion to stop life-prolonging treatment.

Doubting the decision for life-prolonging treatment and seeing the patient suffer

Some participants expressed doubt regarding the decision for life-prolonging treatment and described not knowing if the life-prolonging treatment was the best option for the patient.

“It was difficult, because initially it was more of a feeling I had, and some other people with me. Like, [...] that patient will not be able to handle surgery. But again, that's a gut feeling, I can't really argue why that is the case” – NS7

Two participants indicated that life-prolonging treatment remains an ethical dilemma in some cases.

“It was a bit of a dilemma. Because, if you wouldn't take it [tumor] out, it would continue to grow. And if you do operate, it would grow again. Well, and this patient chose to take it out. But I thought, oh dear, what that lady has to go through...”- RN5

Four participants indicated that experiencing doubt regarding the life-prolonging treatment is facilitated by seeing the patient suffer in terms of pain or other complications. Seeing the patient suffer resulted in moral distress as they doubted the patient's quality of life and therefore the decision for life-prolonging treatment.

“The moment I see someone, transferred by ambulance two, three times a week, who can only lie in bed. Then, I see suffering. If you really can't do anything anymore, if you are too tired to do anything, and it doesn't help to give a blood transfusion, then it is enough for me.” – NS8

One participant described that seeing the patient suffer due to performing a painful life-prolonging procedure almost made her emotional during the treatment.

“I almost cried while I was working on that needle [...] Because when I do that procedure, I already know what the result is” – NS10

Doubting the patient's wishes were met in the decision for life-prolonging treatment

Some participants described that they doubted if the patient's wishes were met in the decision for life-prolonging treatment. All participants stated that patients need to be able to choose their own course of treatment and therefore need to be properly informed about the life-prolonging treatment. However, multiple participants indicated that it varies how the decision making regarding life-prolonging treatment is discussed with the patient.

"If you're talking about withdrawing treatment for example. I know that some doctors will always name it and others, they tend more towards offering or motivating them to do so." – NS2

Participants described doubt as to whether the patient's wishes are met in the decision for life-prolonging treatment especially occurred when the participants was not present during the decision making.

Feeling unheard or overruled in the decision making to stop life-prolonging treatment

Participants seem to experience moral distress when they discussed stopping the life-prolonging treatment with the attending physician, but felt that their opinion regarding the life-prolonging treatment was not taken into account during the decision making.

Three participants explicitly described feeling unheard which resulted in moral distress.

"I am very much standing on the sideline, you know. They really don't listen to me. I find that difficult, because of course, I feel powerless, and also would like to take a bigger role, but that's not expected of me at all."- NS4

Two of the participants added that they felt overruled and not taken seriously by the physician when they advocated for stopping life-prolonging treatment.

"And I know that it [nurses' plan for palliative care] was neatly described as well, which could be seen by the doctor [...] But that was completely overruled. She was told that what can be offered, to put her on medicines that stimulate the heart, to put her on heart monitoring."- RN3

Experienced consequences for patient care

When participants disagreed or doubted the decision for life-prolonging treatment, participants expressed difficulties in providing care for the patient.

“At that moment, I also express that I cannot provide good care and that I cannot support the decisions” – NS8

For example, one participant expressed not being able to support the patient in the psychosocial area and two other participants stated not wanting to perform the life-prolonging treatment and withdrew from care due to moral distress.

“That's why I'm not going to do the bone marrow puncture myself anymore. That was so painful to her. [...] The suffering I see with her is too great for me.” – NS10

One participant even admitted that she temporarily reported sick due to the experience of moral distress as she felt unheard and not appreciated for her opinion in the decision making regarding the life-prolonging treatment.

Experienced support when sharing feelings

Participants described it as beneficial to share feelings about the decision-making and moral distress. Participants expressed experiencing support when they were able to share their feelings.

“It won't change the decision [for life-prolonging treatment], but sharing, it helps.” – NS10

Although some nurses stated they can share their feelings with the physician, participants often shared their feelings with fellow nurses (or other informal contact) as they experienced this to be more accessible.

“I find it important to have accessible contact with your colleagues. And to regularly discuss cases with each other.” –NS8

DISCUSSION AND CONCLUSION

In the first definition of moral distress, moral distress arises when one knows the right thing to do, but it is made impossible to pursue the right course of action due to institutional constraints.(31) In this study, this definition is expanded and moral distress is also considered to arise when one does not know how to deal with all interests and values at stake.(13) Participants showed signs of moral distress when they doubted the decision for life-prolonging treatment, both in situations with and without constraints.

In this study, moral distress also occurred when outpatient nurses doubted whether the patient's wishes were met in the decision for life-prolonging treatment. In a questionnaire among hospital nurses in Italy, it was found that the experience of moral distress when continuing life support can also be related to the provision of truthful information to the patient.(19) This finding was also described in a study among ICU nurses in the USA, where they reported frustration with the way physicians communicated with patients about end of life care and felt physicians occasionally withheld information about diagnosis or prognosis from their patients.(18) Furthermore, studies among nurses in the inpatient setting show that moral distress especially occurs if nurses believe the treatment the patient received was non-beneficial or futile.(12,14,15,18,32) This is in compliance with the results of this study in the outpatient setting. A possible reason for the difference in opinion can be that nurses tend to focus on the suffering of patients, whereas physicians are concerned with the patient's survival.(12,18)

Several studies suggest that the lack of involvement in the decision making and poor communication regarding the decision making contributed to the experienced moral distress.(8,32,33) In this study, outpatient nurses express the importance of being involved in the decision making regarding life-prolonging treatment in order to fulfil their role as nurse and provide the patient with information and support. The wish for involvement in end of life decision making was also expressed by Dutch nurses working in hospitals, home care or residential elderly care.(5) Nevertheless, half of the nurses in this study indicated not being involved in the decision making or expressed being dependent on the physician. This sentiment is also expressed by inpatient nurses, who indicated that the attending physician was seen as the final decision maker.(8,10,33) In one qualitative study among ICU nurses, nurses even described being 'on the side-lines' or 'the middle man'.(8) In this study, moral distress seems to be triggered if nurses feel unheard or overruled in their opinion in the decision making regarding life-prolonging treatment. Studies indicate that nurses lack involvement in the decision making process.(8–10,12,18,19,32,34) In addition, nurses do not have a clear role in end of life decision making.(33,35)

Lastly, moral distress can negatively affect patient care. Several nurses in this study withdrew from care due to moral distress and one nurse temporarily reported sick. In critical care nurses, moral distress resulted in poor communication or inadequate nursing support.(10) Moral distress is also negatively associated with risk of burnout and job satisfaction, and can result in nurses leaving or considering leaving their position.(10,11,15–18)

Strengths and limitations

Face-to-face interviews are preferred when conducting interviews for a natural encounter and the use of non-verbal communication.(36) However, due to the COVID-19 outbreak, face-to-face interviews were not attainable and replaced with telephone interviews. The COVID-19 pandemic has probably also led to less response during recruitment.(26) The small sample size and limited recruitment likely affected maximum variation between characteristics and may have affected the transferability of results. Furthermore, transferability is also limited by focussing only on Dutch nurses. Although data saturation is not reached due to limited participation, this study gives a first exploration of moral distress regarding life-prolonging treatment as experienced by nurses working in the outpatient clinic. In addition, collected data was analysed by two researchers and discussed with an expert on qualitative data during the entire process and participants were able to recognize their experiences within the synthesized themes.(30)

Conclusion

The objective in this study was to explore whether nurses in the outpatient clinic experience moral distress in situations where they are involved in life-prolonging treatments of adults with a short life expectancy or frail elderly, and to explore whether this moral distress is due to not being involved in the decision making about these life-prolonging treatments. Moral distress in outpatient nurses occurs when nurses doubt the decision for life-prolonging treatment, when nurses doubt whether the patient's wishes were met in the decision for life-prolonging treatment and especially when nurses feel unheard or overruled for their opinion to stop life-prolonging treatment. This study also suggests that the lack of involvement of nurses in the decision making regarding life-prolonging treatment may influence the experience of moral distress. It is interesting to note that the experiences of moral distress in nurses working in the outpatient clinic in this study appear to be similar to the experiences of moral distress in nurses working in the inpatient clinic described in literature.

Clinical and scientific implications

This study gives a first impression of moral distress as experienced by nurses working in the outpatient clinic. Although further research is needed to fully understand moral distress regarding life-prolonging treatment, it seems that moral distress occurs when nurses feel unheard or overruled for their opinion to stop life-prolonging treatment or when nurses doubt whether the patient's wishes were met in the decision for life-prolonging treatment. For these reasons, it is recommended to involve nurses into the decision making regarding life-

prolonging treatment. A more detailed role description for nurses might be beneficial to acknowledge the nurses' involvement in the decision making regarding life-prolonging treatment and for nurses to advocate for their patient.(7,35) However, more research is required in order to provide these nurses with tools to be more involved in the decision making. Additionally, in this study moral distress seems to occur when nurses doubt the decision for life-prolonging treatment and nurses indicate that that sharing feelings regarding moral distress is experienced as beneficial. Therefore, facilitating opportunities to share feelings regarding the decision making process and moral distress should be considered as an intervention. This intervention has also been proposed in earlier studies.(12,35) Nevertheless, additional research is needed in order to provide nurses with effective alternative interventions to cope with moral distress.

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Table 1. Characteristics of participants

Age (years)		
	30-39	2
	40-49	4
	50-59	6
Sex		
	Female	9
	Male	3
Nurses' job category		
	Registered nurse (RN)	5
	Clinical nurse specialist (NS)	7
Hospital type		
	University hospital	8
	Regional hospital	4
Department		
	Oncology	5
	Haematology	3
	Geriatrics	2
	Surgery (vascular)	1
	Cardiology	1
Years of experience (in current job)		
	0-4	4
	5-9	2
	10-14	2
	>15	2
	Unknown	2

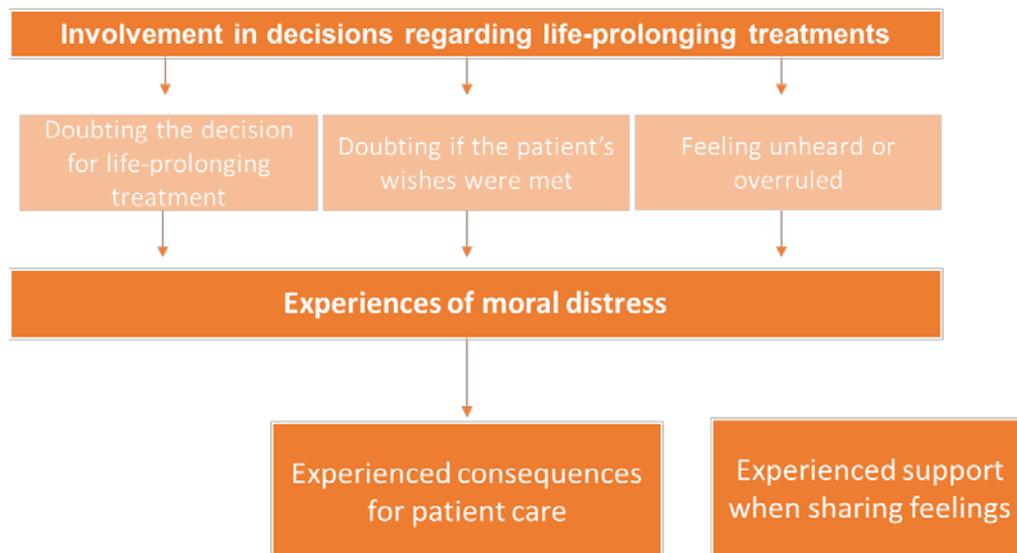


Figure 1. Thematic map of themes.

APPENDIX

A. Recruitment

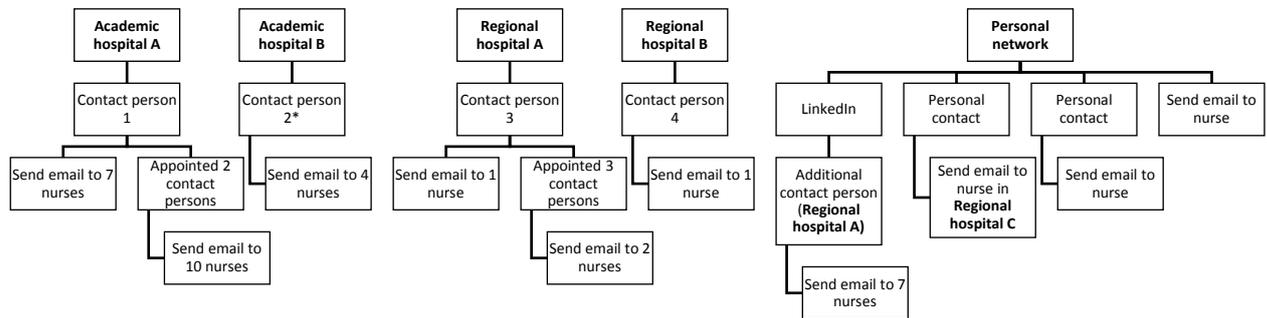


Figure 2. Flowchart of Recruitment

B. Topic list

Table 2. Topic list

Topics	Questions
Case description	Describe a recent case in which you were involved in life-prolonging treatment in adults with short life expectancy and/or frail elderly
Involvement (in life-prolonging treatment)	In what way were you involved in the life-prolonging treatment? ‘ What is your experience regarding your involvement in life-prolonging treatment?’
Decision-making process	Describe the decision-making process What is your experience regarding the decision-making process? To what extent did you feel involved in the decision-making process? What made you feel involved in the decision-making process? How come you were (not) involved in the treatment decision? How do you like to be (not) involved in the decision-making?
Desired role	How would you like the decision to be made? How would you like to see your role / involvement in the case? And would this also apply to other situations?
Effect of moral distress	How does this feeling affect you?

C. Coding Tree

Table 3. Coding Tree

Theme -subtheme	Code group	Codes (in Dutch)	Number of quotes	Cited by
Involvement in decisions about life-prolonging treatments	Feeling involved	Voelt betrokkenheid bij behandelbeslissing	23	RN1, NS4, RN5, NS9, NS10, NS12
		Voelt betrokkenheid bij behandelbeslissing: door aanwezig bij gesprek	6	NS4, RN5, RN6
		Voelt betrokkenheid bij behandelbeslissing: door aanwezig bij overleg	9	RN1, NS2, NS12
		Voelt betrokkenheid bij behandelbeslissing: door uitleg behandelbeslissing	5	RN1, NS8
		Voelt betrokkenheid bij behandelbeslissing: door vpk kan gevoel delen	1	NS10
		Voelt betrokkenheid bij behandelbeslissing: door vpk kan mening delen	9	NS2, NS8, NS9, NS10
		Voelt betrokkenheid bij behandelbeslissing: door vpk voelt zich gehoord	5	NS10
		Voelt betrokkenheid bij behandelbeslissing: door vpk wordt gevraagd om mening	8	NS8, NS9, NS10, NS12
	Good communication	Afstemming met arts, positief: regelmatig, laagdrempelig, openheid	25	RN1, RN3, NS8, NS9, NS10, NS12
		Samenwerking goed	7	NS2, NS8, NS9, NS10, NS12
	Nurses' role	Rol van vpk in aanspreekpunt, voorlichting, begeleiding en aandacht voor psychosociaal welzijn	56	RN1, NS2, RN3, NS4, RN5, NS8, NS9, NS12
		Betrokkenheid vpk bij pt: vpk is de rode draad en kent pt goed door:	67	RN1, NS2, RN3, NS4, RN5, NS9, NS10
	Not feeling involved	Voelt niet betrokken bij behandelbeslissing	10	RN1, NS4, RN5, NS9
		Voelt niet betrokken bij behandelbeslissing: te laat	5	NS4, NS9
		Voelt niet betrokken bij behandelbeslissing: door niet aanwezig bij gesprek	5	NS2, RN3
		Voelt niet betrokken bij behandelbeslissing: geen ruimte om mening te delen	3	RN1, NS2, NS4,
		Voelt niet betrokken bij behandelbeslissing: niet geluisterd	1	NS4

		Voelt niet betrokken bij behandelbeslissing: wordt niet gevraagd om mening/betrokkenheid	5	RN3, NS4
		Wisselend op welk moment betrokken bij behandelbeslissing	9	RN1, NS2
		Wisselend betrokken bij overleg	3	RN1, NS2, NS9
		Afstemming met arts, negatief: te weinig	11	RN1, RN3, NS8, NS9
	Focussed on treatment	Waarden vpk: Niet behandelen als optie	31	RN1, NS2, RN3, NS4, NS8, NS12
	Focussed on treatment	Waarden vpk: Te veel focus op behandelen	38	RN1, NS2, RN3, NS4, RN5, RN6, NS8, NS9, NS12
	Dependent on physician	Arts geeft sturing in behandelbeslissing	11	RN1, NS2, NS4, RN5
	Dependent on physician	Afhankelijkheid van arts	20	RN1, NS2, RN3, NS4, RN5, NS9, NS10
	Dependent on physician	Wisselend hoe behandelbeslissing door arts wordt besproken	26	RN1, NS2, RN3, NS4, RN5, NS8, NS9, NS10, NS12
Experiences of moral distress				
- Doubting the decision for life-prolonging treatment and seeing the patient suffer		Twijfels over behandelbeslissing: doet men pt goed met behandelen	35	RN3, NS4, RN5, RN6, NS10, NS12
		Vpk ziet pt lijden, moeilijk	7	NS4, RN5, NS8, NS10
- Doubting the patient's wishes were met in the decision for life-prolonging treatment		Waarden vpk: Pt moet kunnen kiezen	29	RN1, NS2, RN3, NS4, RN5, RN6, NS8, NS12
		Lastig voor vpk als pt hoop blijft zoeken	13	RN1, NS2, RN3, RN6, NS8, NS12
- Feeling unheard or overruled in the decision making to stop life-prolonging treatment	Feeling overruled	Vpk wordt overruled	4	RN3, NS4, RN5, NS8
	Feeling unheard	Vpk voelt zich niet gehoord	4	RN3, NS1
Experienced consequences for patient care	Not able to support patient	Bemoeilijkte begeleiding als vpk niet achter keuze staat	11	NS4, NS8, NS9, NS10
	Withdraw from treatment	Vpk trekt zich terug van behandeling (vanwege zien lijden pt)	5	NS8, NS10
		Tijdelijk ziek gemeld	1	NS4

Experienced support when sharing feelings		Vpk deelt gevoelens (met collega's)	9	NS2, NS8, NS9, NS10
		Afstemming collega vpk: open, laagdrempelig	2	NS9