Experiences on Moral Distress among Hospital Nurses while Being Involved in Life Prolonging Treatment

A qualitative study

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SAMENVATTING; "Ervaringen van morele spanningen ten aanzien van levensverlengende behandelingen bij verpleegkundigen werkzaam in het ziekenhuis"

Achtergrond: Betrokken zijn bij levensverlengende behandelingen van volwassenen met een korte levensverwachting of kwetsbare ouderen kan morele spanningen veroorzaken bij verpleegkundigen werkzaam in het ziekenhuis. Morele spanningen die verpleegkundigen ervaren kunnen de kwaliteit van communicatie met andere hulpverleners verminderen evenals hun vermogen om te zorgen. Hoewel verpleegkundigen betrokken zijn bij levensverlengende behandelingen, zijn zij minder betrokken bij de besluitvorming omtrent starten, continueren of stoppen van deze behandelingen. Ondanks dit gebrek aan betrokkenheid, kunnen verpleegkundigen in staat zijn om meer te betekenen binnen de besluitvorming.

Doel: Inzicht krijgen in morele spanningen die verpleegkundigen in het ziekenhuis ervaren in situaties waar zij betrokken zijn bij levensverlengende behandelingen van volwassenen met een korte levensverwachting of kwetsbare ouderen. Daarnaast is onderzocht of het ervaren van morele spanningen bij verpleegkundigen in het ziekenhuis wordt veroorzaakt doordat zij niet betrokken zijn bij de besluitvorming omtrent levensverlengende behandelingen.

Methode: Een kwalitatieve studie werd uitgevoerd waarbij data werd verzameld door middel van semigestructureerde interviews met verpleegkundigen werkzaam in het ziekenhuis. Secundaire analyse werd toegepast op bestaande transcripten. Een topiclijst werd gebruikt om de interviews te ondersteunen. Alle interviews zijn opgenomen en getranscribeerd. Thematische analyse werd toegepast om de data te analyseren.

Resultaten: In totaal werden elf interviews gehouden. Morele spanningen die ontstaan in de situaties waarbij verpleegkundigen betrokken waren bij levensverlengende behandelingen kunnen gekenmerkt worden door gevoelens van machteloosheid, hopeloosheid, frustratie en woede. De mate van betrokkenheid in de besluitvorming werd verschillend benoemd.

Conclusie: Verpleegkundigen werkzaam in het ziekenhuis ervaren morele spanningen in situaties waarbij zij betrokken zijn bij levensverlengende behandelingen. Deels werden deze ervaringen ten aanzien van morele spanningen veroorzaakt door het niet betrokken zijn in de besluitvorming.

Implicaties: Het ervaren van morele spanning en de gevolgen hiervan mogen niet onderschat worden. Verder onderzoek is nodig om verpleegkundigen te kunnen ondersteunen wanneer zij morele spanningen ervaren.

ABSTRACT; "Experiences on Moral Distress among Hospital Nurses while Being Involved in Life Prolonging Treatment"

Background: Being involved in life prolonging treatments during care for adults with a short life expectancy or vulnerable elderly may cause moral distress among hospital nurses. As a result of moral distress nurses quality of communication with other healthcare providers and their capacity to care may decrease. Although nurses are often involved in life prolonging treatments, they are less involved in the actual decision making about starting, continuing or quitting these treatments. Despite this lack of involvement, nurses might be able to participate more during the decision making.

Aim: To explore whether hospital nurses experience moral distress in situations where they are involved in life prolonging treatments of adults with a short life expectancy or vulnerable elderly. Secondary, to explore whether moral distress among hospital nurses is due to not being involved in the decision making about life prolonging treatments.

Method: A qualitative design was used for this study. Semi-structured interviews were conducted with registered hospital nurses working with patients where decisions about life prolonging treatments were taken. Secondary analysis was performed on existing transcripts. A topic-list was used to support the interviews. Each interview was audio-taped, transcribed verbatim and analyzed trough thematic analysis.

Results: In total eleven interviews were conducted. Moral distress occurring in situations where nurses were involved in life prolonging treatment can be characterized as feelings of powerlessness, hopelessness, frustration and anger. Different experiences on involvement in the decision making were mentioned.

Conclusion: Hospital nurses experience moral distress in situations where they are involved in life prolonging treatment. Experiences of moral distress were partly caused due to not being involved in the decision making

Implications of key findings: Experiencing moral distress and its consequences should not be underestimated. More research is needed to provide hospital nurses tools and support.

Keywords: Nurses, life prolonging treatment, moral distress, powerlessness

INTRODUCTION

Hospital nurses are often involved in life prolonging treatments during care for adults with a short life expectancy (less than one year) or vulnerable elderly[1-3]. Examples of these treatments are artificial hydration and nutrition or medical treatments such as chemotherapy and antibiotics. Unfortunately, these treatments might deteriorate the quality of life[1-3]. Although nurses are often involved in life prolonging treatments, they are less involved in the actual decision making about starting, continuing or quitting these treatments[4,5]. Despite the current lack of involvement in the actual decision making, nurses might be able to participate more during the decision making[6]. For example, nurses can question if a treatment needs to be continued and might be able to recognize the futile nature of a treatment[6]. In addition, nurses might be able to bring acceptance and realization about the patient being in the end of his life despite maximum clinical support[6]. Hospital nurses can experience moral distress as a result of facing these challenges regarding life prolonging treatments in clinical practice[7].

Moral distress is defined as a phenomenon that brings a negative experience of psychological imbalance[8]. The phenomenon of moral distress in nursing was firstly described by Jameton, who stated that moral distress occurs under specific conditions[5,9]. Firstly, there must be moral certainty; the nurse knows the morally correct action. Secondly, there must be a constraint or obstacle that prevents the nurse from the ability to take the morally correct action[9]. In general moral distress may occur during daily practice when nurses cannot fulfill their moral obligation to a patient or fail to pursue what they believe to be the correct course of action caused by forces that are out of their control[5].

Previous research indicates that moral distress is commonly experienced by nurses in hospital environments[8,10-12]. Investigating moral distress has led to the development of the moral distress scale to measure moral distress as an element of job stress in nursing[8]. A high prevalence of moral distress is found among nurses in critical care and end-of-life care[2,5,13,14]. In addition, earlier research states that the highest level of moral distress among nurses is experienced while performing treatments that are not expected to benefit the patients quality of life[15].

As a result of moral distress nurses can respond with a myriad of biological, psychological and stress reactions[10]. During daily practice this may result in a decreased capacity to care, a decrease in the quality of communication with other healthcare providers, emotional distress, developing symptoms of burnout and a distance between the nurse and the patient[10,11]. Furthermore, experiencing moral distress over time may even lead to reaching a state of burnout and eventually leaving the job as a nurse[12,15].

Current literature towards moral distress is primarily focused on oncology wards or intensive care units. However, the care that is provided to patients on an acute ward often differs from the care that is needed from many elderly patients[15]. Therefore this study is focused on the experiences of hospital nurses on moral distress while being involved in life prolonging treatment during care for adults with a short life expectancy and vulnerable elderly. Further understanding of moral distress is also required in these specific situations given the significant problems that moral distress brings for patient care and nurses wellbeing[12,15].

AIM

The primary objective for this study was to explore whether hospital nurses experience moral distress in situations where they are involved in life prolonging treatments of adults with a short life expectancy or vulnerable elderly. The secondary objective was to explore whether moral distress among hospital nurses is due to not being involved in the decision making about life prolonging treatments while they are involved in the actual treatment.

METHODS

Design

A qualitative design was used to conduct this study[16-18]. The consolidated criteria for reporting qualitative research (COREQ) were used to conduct the final study report[19].

Participants & recruitment

The study population included registered hospital nurses working with patients where decisions about life prolonging treatments were taken. Purposeful sampling was used to select participants[17,18]. Hospital nurses that might seem eligible according to the criteria were approached by the researcher or through a contact person from the participating hospital (peripheral and academic). Participants had to meet the following criteria: 1) Registered hospital nurses; 2) Professional experiences with life prolonging treatments while providing care for adults with a short life expectancy or vulnerable elderly in the past half year; 3) Dutch speaking.

Participants that were willing to participate received a digital information letter about the study and had the possibility to ask for further information. Before the start of each interview Informed Consent (IC) was verbally explained. Participants gave their permission by signing the IC or by phone that was audio recorded.

Data collection

Data were collected through semi-structured interviews by a novice researcher (SA). Data collection took place between March and May 2020. Since data collection started during the

COVID-19 pandemic it was not achievable to collect data through semi-structured face-to-face interviews as initially aimed. Therefore, semi-structured interviews were held by phone. In an earlier phase of the research project, face-to-face interviews focusing on involvement of hospital nurses in decision making during end-of-life care were conducted by another researcher (MT). Given the similarities in the interview topics and the presumption of the presence of moral distress, that arose from the transcripts, led to performing a secondary analysis on these transcripts for this research. Secondary analysis was performed on six interviews that were held with hospital nurses working in academic and peripheral hospitals.

During the interviews the phone was set on speaker and after agreement from the participant the conversation was audio taped with a voice recorder. Memos were made by the researcher during the interview and directly afterwards to increase credibility and trustworthiness[17].

A topic list was used to guide the semi-structured interviews[17,18]. The topic list was based on existing literature and earlier research (MT)[10,20]. Each interview started with the participant describing a recent situation where they had been involved in life prolonging treatment of adults with a short life expectancy or vulnerable elderly. Furthermore, the topic list intended to seek for experiences on moral distress without explicitly asking. The topic list that was used to support the semi-structured interviews was reviewed after each two interviews. After the first two interviews questions were added to support the researcher (SA) in further questioning experiences.
It was aimed to collect data until data saturation was reached.

Data analysis

Data was analysed following the six steps of thematic analysis as described by Braun & Clarke[21]. I) Familiarization: the researcher (SA) transcribed the audiotapes verbatim and re-read transcripts after each interview. II) Coding: segments of interest were independently highlighted and summarized into codes (SA, MS). Initial codes that derived from the first three transcripts were discussed until consensus was reached (SA, MS). Coding was continued independently by SA and these codes were checked by MS. III) Generating themes: characterised by significance, codes were sorted into potential themes. Potential themes were discussed with the research group (MS, IJ, AF). IV) Reviewing themes: potential themes were reviewed on consistency by the researcher (SA) to ensure that the entire data set was represented. V) Defining and naming themes: themes and subthemes were discussed within the research group (SA, MS, IJ, AF) and further defined if necessary. VI) Writing a report: analysis was completed by the researcher writing a report with a compelling story of the data.

Ethical issues

This study was conducted according to the principles of the Declaration of Helsinki and the General Data Protection Regulation (GDPR)[22,23,24]. Approval that this study did not meet the requirements of the Medical Research Involving Human Subjects Act (WMO) was given by the Medical Ethics Review Committee (METC) of the VU university medical centre (protocol-ID: 2018.551).

RESULTS

Participants & demographics

A total of eleven nurses were interviewed. The duration of the interviews varied between 20 and 67 minutes. Ten participants were female. The age of the participants varied between 23 and 61 years. In total, six participants were working in an academic hospital. The participants were working on the nursing wards of oncology, cardiology, geriatric and internal medicine. One participant was working on a surgical ward. The working experience of the participants ranged from 3 to 44 years. Demographic data is summarized in table 1, this table is admitted in appendix I.

[Table 1 here]

Three main themes derived from the data: involvement in decisions about life prolonging treatment, experiences of moral distress and consequences for patient care. An overview of themes, subthemes and codes is admitted in appendix II.

Involvement in decisions about life prolonging treatment

Participants made it clear that being involved in life prolonging treatments had great emotional impact and that this was influenced by the way that they were involved in the decisions about life prolonging treatment. Participants not only mentioned that they could have a meaningful contribution in the decision making about life prolonging treatments, they also mentioned having other beliefs in decisions about life prolonging treatment than a physician. Despite of seeing themselves as the provider of a treatment, participants mentioned wanting to be involved in the decision making.

Nurses beliefs in decisions about life prolonging treatments

Participants mentioned having other beliefs than a physician when it comes to making a decision about starting, continuing or quitting a treatment in adults with a short life expectancy or vulnerable elderly. Nurses defined their beliefs in decisions about a life prolonging treatment as follows: I) the patient needs to be comfortable during treatment, II) the treatment must not harm the patients quality of life and III) the treatment needs to be in

line with the patients wish. Despite these three beliefs, participants described noticing that most physicians have other values and are primarily focused on curing a patient resulting in continuing or starting a treatment even when this is only prolonging life.

"I have noticed that physicians are actually focused on curing. There are a lot of physicians that are finding it hard to agree on a palliative policy. They want to continue treatments as long as possible." – Nurse;05

Treatments were mentioned as life prolonging by the participants when a treatment was started or continued while knowing the patient would die despite treatment. For example, treatments such as administering antibiotics, implanting pacemakers, artificial nutrition or chemotherapies were named by nurses as life prolonging treatment. Performing a treatment to combat symptoms, such as administering diuretic medication, was not mentioned as life prolonging. Nurses also marked a treatment differently when performing this treatment was the explicit wish of the patient.

Nurses wanting to participate in decisions about life prolonging treatment

Differences in nurses contributions and involvement in decisions about life prolonging treatments were found. Where some participants experienced being poorly involved, others were satisfied with their contribution and involvement in the decision making. Most of the participants see themselves as the provider of the treatment that is prescribed by the physician. Nevertheless, nurses believe they can have a meaningful contribution during the decision making and therefore wanting to be involved in the decision making. Participants mentioned that a patient might give other information to them because of their close relationship with the patient. Furthermore, participants described that their observations during patient care and their adequate knowledge can have a meaningful contribution in decisions about life prolonging treatment. However, every participant mentioned that the final responsibility in decisions about life prolonging treatment lies with the physician.

"You can have a contribution as a nurse because you are the one that observes the patient the entire day. And the physician only observes the patient for two minutes and that's is. They [physicians] see the lab results but we [nurses] observe how the patient felt during the day." – Nurse;01

Experiences of moral distress

Several feelings that were expressed in the interviews could be marked as experiences of moral distress. Feeling powerlessness, hopelessness, anger and frustrations were often mentioned by participants when being involved in life prolonging treatments of adults with a short life expectancy or vulnerable elderly. Participants described different situations in which these feelings occurred.

Feeling powerlessness while being involved in life prolonging treatments

Participants mentioned witnessing their patient suffer from a treatment that is only prolonging life and not being able to intervene causing a feeling of powerlessness. Moreover, they mentioned that the same feeling of powerlessness was caused when they marked a treatment as futile care. Not supporting the treatment that has been prescribed by the physician while having to perform this treatment also caused feelings of powerlessness. Feeling hopeless was often mentioned together with the feeling of powerlessness.

"So I have performed the treatment. But I think it gave me a strong feeling of powerlessness and the feeling that I was going to perform a treatment that I did not supported and which really went against my feelings." – Nurse;01

"It also was difficult witnessing this patient lying in his bed, fighting for his and being uncomfortable. I stood with my back against the wall, not being able to intervene" – Nurse;05

Feeling powerlessness was mentioned as well when nurses were not feeling heard while sharing important information with a physician or when nurses felt that their information was not taken seriously. Participants described that physicians might not be aware of the outcomes that these treatments bring for patient care and that nurses are the ones dealing with this outcomes. Being confronted with harmful outcomes for a patient also causes feelings of powerlessness and hopelessness.

"Sometimes symptoms and side effects can be so serious and eventually we [nurses] are the that are cleaning up the mess. Sometimes that is heavy." – Nurse;V07

And then they [physicians] want to continue chemotherapy. That makes me think… Eventually we [nurses] stood there, we are performing these treatment, because she [patient] cannot do this without us. It makes me think: "what are we doing?" – Nurse;V07

Some participants described that experiencing powerlessness might have bigger impacts on unexperienced nurses.

> *"Then there was my unexperienced colleague who was not fully aware of the situation and was scared. She witnessed her patient collapsing and harms herself for this." – Nurse;03*

Feeling frustrated caused by involvement in life prolonging treatment

Feelings of frustration and anger were noticed while participants described their opinion towards a life prolonging treatment and the communication between the patient and the physician. Nurses explicitly mentioned that communication between a physician and a patient is not fair. Hereby, hope is created by the physician that is no longer there. For example, when treatment is started in a situation where it is expected that this treatment is only prolonging life. Furthermore, one participant expressed frustrations by stating multiple times that prescribing and performing life prolonging treatment is criminal and in violation with the law.

> *"And the physician offered the patient the possibility to continue treatment. I think that is inhuman. I think that is in violation with the law. I think that is criminal." – Nurse;03*

Feeling supported when sharing experiences of moral distress

Sharing feelings and emotions with colleagues after experiencing moral distress caused by involvement in life prolonging treatment was mentioned as helpful in dealing with moral distress. Also participating in a moral deliberation and discussing cases with colleagues was described as helpful and supportive.

"I share my feelings with my colleagues when I notice that I am overthinking a situation and then I can usually leave the feelings behind after sharing this with my colleagues" – Nurse;04

Consequences for patient care

Experiencing moral distress among nurses is influencing their ability to provide optimal patient care. Some nurses refused to perform the prescribed treatment and forced the physician to reassess their decision. Other nurses expressed difficulties in caring for other patients when they had to deal with moral distress earlier during their shift.

Withdraw in involvement treatment

Some participants mentioned they refused performing a treatment that they did not support since it was only prolonging life and the patient was visibly uncomfortable. Other participants mentioned wanting the physician to reassess their decision before the nurse performed the

prescribed treatment. One participant mentioned she stopped artificial nutrition given her observations of the patient being uncomfortable before consulting the physician.

"On the moment when treatment became futile, I told the physician that I had difficulties with administering fluid through intravenous therapy and that I quit performing this treatment." – Nurse;03

"And then I observe my patient suffering because he has a full stomach. He is experiencing serious pain in his stomach and I am not seeing any quality of life. And I might be rebellious, but then I am going to stop this artificial nutrition and let the physician determine further policy the next day." – Nurse;04

Difficulties in patient care

One participant expressed difficulties in continuing care for other patients and acting like everything is normal after experiencing moral distress in an earlier situation during their shift caused by involvement in life prolonging treatment and the patients death.

"And on a certain moment, when the patient dies, you have to continue your daily practices. You see a new patient and just act like nothing happened. Sometimes I find that difficult. Then life can be cruel. Life actually continues fast while a life just has been ended" – V07

Difficulties in patient care were expressed while communicating with the patient. Knowing that a treatment was only prolonging life and might harmed the patients comfort and quality of life, when this was not discussed between the patient and the physician, created these difficulties. This resulted in the nurse not knowing how to answer a question or not knowing how to give information about a treatment.

DISCUSSION

Main findings

Nurses experiences of moral distress in situations where they were involved in life prolonging treatments of adults with a short life expectancy or vulnerable elderly can be characterized as feelings of powerlessness, hopelessness, frustration and anger. Not being involved in the decisions about life prolonging treatment and a treatment not being in line with nurses beliefs can be seen as a moral constraint preventing nurses from the ability to take the morally correct action. Nurses had different experiences about their involvement in the decision making regarding life prolonging treatment. This might indicate that there is no clear role typology for hospital nurses in situations where they are being involved in life prolonging treatments.

Findings compared with literature

In this study, nurses expressed wanting to be involved in the decision making about life prolonging treatments in adult patients with a short life expectancy or vulnerable elderly. However, it was mentioned that nurses might had other believes in the decision making than the physician. A study of Oberle described similarities with these findings by mentioning that physicians and nurses might perceive ethical problems differently and also might use different reasoning and decision making frameworks in decisions surrounding end-of-life care[25]. Nurses place high values on the perspective of caring while physicians value a major concern with the disease and its cure[25].

Nurses being in the situation where they were not involved in the decision making and performing the prescribed treatment, while they did not supporting this treatment, was described as a situation causing feelings related to moral distress. Literature confirmed this finding. In the same study of Orbale is stated that nurses experienced moral distress in the uncertain situations where they believed that the wrong course of action was being followed and therefore they were contributing to a patients' misery[25]. Moreover, this study described that conflicts with physicians, that result in nurses having an inability to influence decision and decision making processes, were mentioned as a source of experiencing moral distress among nurses[25].

With the results of this study, moral distress can partly be characterized by nurses experiencing a feeling of powerlessness in situations where they were being involved in life prolonging treatment of adults with a short life expectancy of vulnerable elderly. Experiencing a feeling of powerlessness is often mentioned together with moral distress in literature[7,25-26]. A study towards experiences of moral distress among nursing home staff while caring for residents at the end-of-life described that a feeling of powerlessness was found as the nature of experiencing moral distress[26].

Most of the participants contributing in this study were female. Remarkably, a study of McCarthy, that reconsidered moral distress, mentioned that perhaps greater moral griefs are experienced in the nursing profession since this profession is largely being a female profession[27]. Unfortunately, this statement could not be confirmed or rejected with the results of this study. The study of McCarthy also described that it is the nurse who is witnessing the results of ethical failure in treatments while being at the bedside of a patient which is resulting in nurses experiencing moral distress[27]. Witnessing patients suffer of a treatment that is only prolonging life resulting in experiencing moral distress was also mentioned by the participants of this study.

Strengths & limitations of the study

A strength of this study is that each interview started with the participant describing a recent situation where they were involved in life prolonging treatment of adults with a short life expectancy or vulnerable elderly. This created a framework through which specific questions could be asked and specific answers could be given about the experiences in these situations.

Unfortunately, data saturation was not achieved. Only eleven interviews could be conducted for this study and regrettably no further interviews could be conducted to confirm data saturation. Not achieving data saturation might reduce the generalizability of the study findings[17,18]. However, participants have been approached in different hospitals and different regions in the country.

Another limitation is that only five interviews fully addressed the aim for this research. Luckily, the transcripts on which secondary analysis was performed had similarities in the interview topics. Furthermore, these transcripts partly addressed the aim of this research because they were focused on giving insight in nurses involvement in decision making surrounding life prolonging treatments. Despite this limitation, insight in experiences on moral distress among hospital nurses while being involved in life prolonging treatment could be given with the collected data.

Implications

Moral distress among hospital nurses should not be underestimated in situations where they are involved in life prolonging treatments of adults with a short life expectancy or vulnerable elderly. More research is needed to provide hospital nurses tools and support in these moral complex situations. Furthermore, research is needed to investigate how nurses can get involved in the decisions about life prolonging treatments.

Conclusion

The results of this study indicate that hospital nurses experience moral distress while being involved in life prolonging treatments of adults with a short life expectancy or vulnerable elderly. Moral distress in these situations can be characterized as a feeling of powerlessness, hopelessness, frustration, incomprehension and anger. Experiences of moral distress were partly caused due to not being involved in the decision making about life prolonging treatments while they are involved in the actual treatment.

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APPENDIX I

Table 1 Demographic characteristics

N = 11

Characteristic		*(n=)*
Gender		
	Female	*10*
Age	***[range]***	***[23 - 61]***
	< 30	*4*
	30 – 40	*1*
	41 – 50	*3*
	> 50	*3*
	Unknown	-
Hospital		
	Academic	*6*
	Peripheral	*4*
	Unknown	*1*
Nursing ward		
	Oncology	*2*
	Cardiology	*2*
	Geriatric	*1*
	Internal medicine	*1*
	Other[1]	*1*
	Unknown	*4*
Working experience (years)		
	< 10	*2*
	> 10	*3*
	Unknown	*6*
Religious believes		
	None	*5*
	Unknown	*6*

[1] **Surgical ward**

APPENDIX II

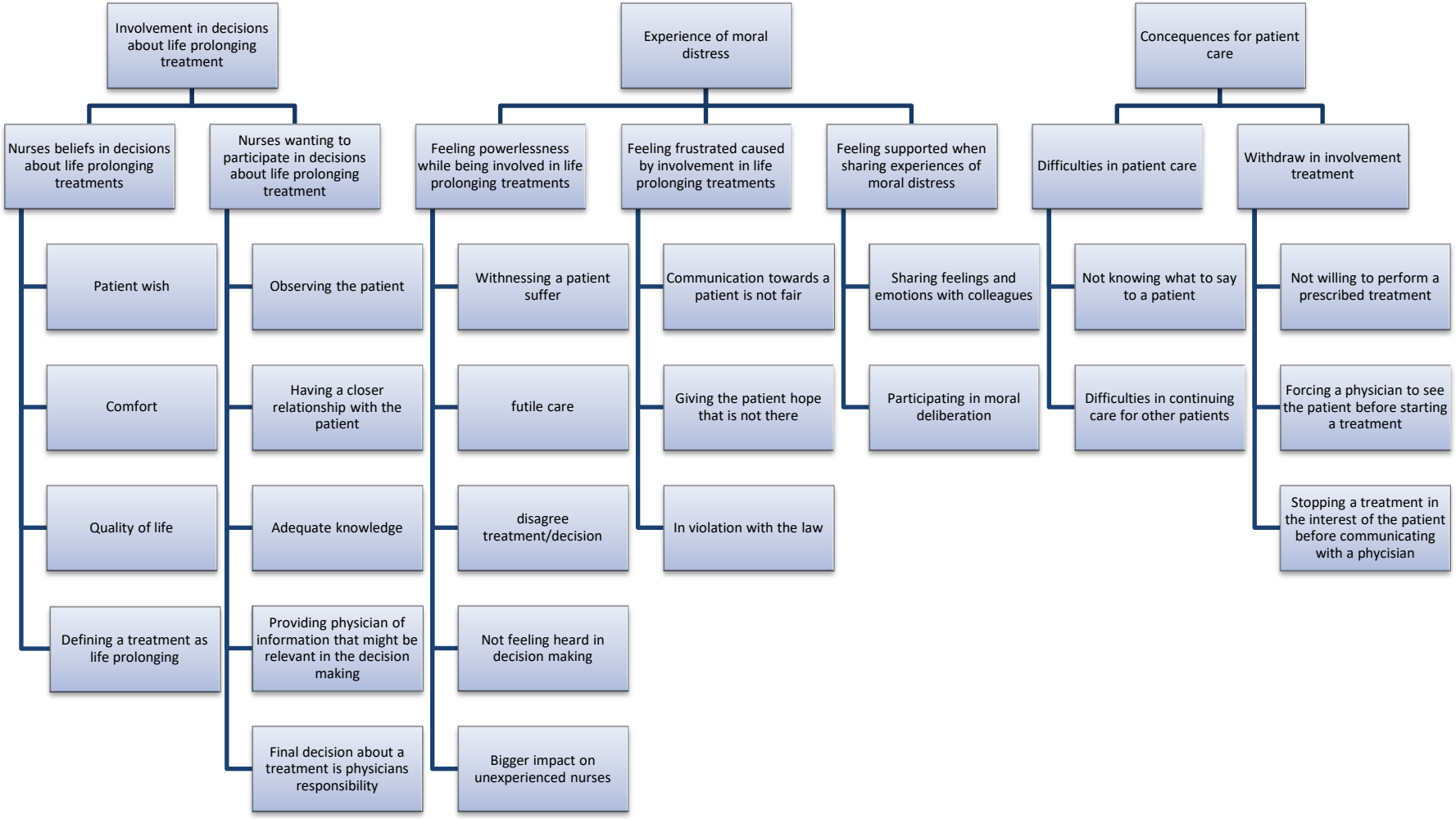

Figure 1 Overview of themes, subthemes and codes