

Patients' experiences and perceptions of safety during haemodialysis treatment – a qualitative study

Naam:	M.H. Lovink
Studentnummer:	3155617
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Opleiding:	Universiteit Utrecht, Masteropleiding Klinische Gezondheidswetenschappen (KGW), Masterprogramma Verplegingswetenschap, UMC Utrecht
Begeleider:	Dr. L. Schoonhoven
Cursusdocent:	Dr. J. de Man-van Ginkel.
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Samenvatting

Titel: Ervaringen en percepties van hemodialysepatiënten met betrekking tot veiligheid tijdens de hemodialyse behandeling – een kwalitatief onderzoek

Inleiding: Er wordt aangenomen dat veilig voelen voor patiënten net zo belangrijk is als veilig zijn. Helaas is bekend dat de helft van de hemodialysepatiënten angst ervaart tijdens de behandeling. Tot nu toe is er geen diepgaand inzicht in de ervaringen en percepties van hemodialysepatiënten met betrekking tot veiligheid en is onbekend wat hun gevoel van veiligheid beïnvloedt.

Doel: Inzicht verkrijgen in het gevoel van veiligheid van hemodialysepatiënten om verpleegkundige interventies te kunnen ontwikkelen die dit gevoel vergroten.

Onderzoeksvragen: Wat zijn de ervaringen en percepties van volwassen hemodialysepatiënten met betrekking tot veiligheid tijdens hun poliklinische hemodialyse behandeling in een ziekenhuis? Wat vergroot en wat vermindert het gevoel van veiligheid van volwassen hemodialysepatiënten tijdens hun poliklinische hemodialyse behandeling in een ziekenhuis?

Methode: Een kwalitatief onderzoek volgens de grounded theory benadering waarin twaalf patiënten zijn geïnterviewd en open en axial coding is gebruikt om tot een thematische beschrijving te komen.

Resultaten: De volgende vijf thema's werden onderscheiden: 'de centrale rol van de verpleegkundige', 'de balans tussen alles overlaten aan de verpleegkundige en eigen toezicht', 'vastliggen aan de machine', 'waargenomen risico's' en 'acute situaties'.

Conclusie: Hoewel hemodialysepatiënten veel risico's waarnemen voelen de meeste patiënten zich veilig. De verpleegkundige heeft een centrale rol in het bevorderen van dit gevoel. De patiënten die zich onveilig voelen zijn de patiënten die zeggen dat ze alles overlaten aan de verpleegkundige, maar tegelijkertijd toezicht houden. Het Monitoring-Blunting model, waarin monitoring betekent aandacht voor en blunting vermijden van bedreigende signalen, lijkt een verklaring te geven voor dit resultaat.

Aanbevelingen: Dialyseverpleegkundigen moeten worden geïnformeerd over hun centrale rol zodat ze aandacht kunnen besteden aan de risico's die patiënten waarnemen. Daarnaast moet er rekening worden gehouden met de coping strategie van patiënten. Om dit te bereiken moet het Monitoring-Blunting model worden onderzocht in relatie tot het gevoel van veiligheid van hemodialysepatiënten.

Trefwoorden:

hemodialyse, patiëntenervaringen, veilig voelen, kwalitatief onderzoek

Abstract

Title: Patients' experiences and perceptions of safety during haemodialysis treatment – a qualitative study

Introduction: It is assumed that for patients feeling safe is equally important as being safe. Unfortunately, it is stated that half of the haemodialysis patients experience anxiety during their treatment. To date, no in-depth understanding of haemodialysis patients' experiences and perceptions of safety exists and it is unknown what influences patients' feeling of safety.

Aim: To gain insight in haemodialysis patients' feeling of safety in order to inform future development of nursing interventions that increase patients' feeling of safety.

Research questions: What are adult patients' experiences and perceptions of safety during their outpatient haemodialysis treatment in a hospital? What increases and decreases adult patients' feeling of safety during their outpatient haemodialysis treatment in a hospital?

Method: The grounded theory approach was used and in-depth interviews were conducted with twelve participants. Open and axial coding was used to develop a thematic description.

Results: Five themes were identified describing haemodialysis patients' experiences and perceptions of safety: 'the pivotal role of the nurse', 'balance between leaving everything to the nurse and own monitoring', 'being hooked up to the machine', 'perceived risks', and 'acute situations'.

Conclusion: Although haemodialysis patients perceive multiple risks, most patients feel safe during their treatment. The nurse has a pivotal role in promoting this feeling. The patients who feel unsafe are the patients who say that they leave everything to the nurse, but meanwhile monitor their treatment. The Monitoring-Blunting model, in which monitoring refers to attention to and blunting to avoidance of threatening signals, provides a possible explanation for this result.

Recommendations: Dialysis nurses need to be informed about their pivotal role so that they can pay attention to patients' perceived risks. Furthermore, patients' coping strategy should be taken into account. To achieve this the Monitoring-Blunting model should be explored in relation to haemodialysis patients' feeling of safety.

Keywords:

haemodialysis, patients' experiences, feeling safe, qualitative study

Introduction

Patient safety is an important aspect of quality in patient care and is defined as 'the prevention of harm to patients' by the Institute of Medicine of the United States(1). In the Netherlands, potentially avoidable harm during hospital admission affected 2.8 percent of patients in 2008(2). The risk for harm to patients increases when health care becomes more complex(3). Haemodialysis treatment can be seen as complex care. In the Netherlands 5,333 patients received this complex care in 2011(4). During haemodialysis, a machine partly replaces the kidney function of patients with severe chronic kidney insufficiency by circulating patients' blood through an artificial kidney(5). Various aspects of the treatment cause it to be complex and consequently increase the risk of errors. For instance, the technical equipment(6) and risk of vascular access related infections(7-9). To enhance patient safety, these risks need to be reduced. Dialysis nurses have a key role in this reduction since they provide direct patient care(10). In addition to the physical risks for patients there is also the psychological risk that haemodialysis patients might experience anxiety(11,12). To gain insight in how to reduce this risk patients' experiences of safety should be an important topic in patient safety studies(13,14).

It is assumed that for patients feeling safe is equally important as being safe(15). Based on intensive care patients' experiences and perceptions, Russell(16) described feeling safe as a condition during which a patient perceives that there is no risk of physical or emotional injury. Although the term feeling safe is not always mentioned explicitly in survey studies of haemodialysis patients' experiences and perceptions, Garrick et al.(11) described that half of the haemodialysis patients worried someone would make a mistake during their treatment and Feroze et al.(12) showed that half of the patients experienced anxiety during their treatment. Situations engendering anxiety were: a new or unknown dialysis nurse connecting the patient to the machine and alarms on the machine(12). Anxiety during the haemodialysis treatment may result in increased distress in patients who already experience a psychological burden due to their severe chronic illness and complex treatment(12).

It is unknown what influences haemodialysis patients' feeling of safety, but there are indications of what might be important. First, in a study at medical and surgical wards(17) and in a study at intensive care units(15), nurses appeared to be very important to enhance patients' feeling of safety. Second, family, friends, and fellow haemodialysis patients might be able to make patients feel safe(18)(19). Third, some patients express the desire to receive more education about the haemodialysis treatment(18), but it is unclear whether more knowledge about the treatment increases patients' feeling of safety. Finally, Garrick et al.(11)

showed that haemodialysis patients' views about safety were not influenced by their involvement in care, but some patients declare that they retain personal autonomy when they participate in their care(20,21).

Problem statement

It is stated that half of the haemodialysis patients experience anxiety during their treatment. This feeling may increase the psychosocial burden for patients. To date, no in-depth understanding of haemodialysis patients' experiences and perceptions of safety during their treatment exists. There are some indications about what influences patients feeling of safety but these indications have never been explored.

Aim

The aim of this study was to explore patients' experiences and perceptions of safety *during* their haemodialysis treatment and what increases and decreases patients' feeling of safety, in order to gain insight in how to create a feeling of safety in these patients. *During* the haemodialysis treatment means: the treatment itself including all actions related to the treatment like for example puncturing the arteriovenous fistula and weight control before and after the treatment.

Within a dialysis unit dialysis nurses are responsible for the execution of the treatment. The insight gained by this study can inform future development of nursing interventions that improve patients' feeling of safety.

Research questions

- What are adult patients' experiences and perceptions of safety during their outpatient haemodialysis treatment in a hospital?
- What increases and decreases adult patients' feeling of safety during their outpatient haemodialysis treatment in a hospital?

Method

Design

This qualitative study was conducted using a grounded theory approach, which intends to generate a theory from data(22). As in this study the target population only represents a part of the whole haemodialysis patients population, the findings are presented as a thematic description and not as a theory(23). This thematic description provides a framework that describes and explains the to date unknown experiences and perceptions of safety of

haemodialysis patients. This framework may inform further theory development. The research proposal of this study was presented to the medical research ethics committee (MREC) of the academic hospital in which this study took place. The committee judged that the study did not fall within the scope of the Medical Research Involving Human Subjects Act (WMO). Furthermore, approval was obtained from the research commission of the regional hospital.

Sampling

The target population consisted of patients (≥ 18 years old) who were on haemodialysis for more than half a year and received their outpatient treatment in a haemodialysis unit in a hospital. The study population was purposively selected at two haemodialysis units in the Netherlands, one in an academic and one in a regional hospital, from January 2013 up until April 2013. Patients were eligible for selection when they had a thorough command of the Dutch language.

Exclusion criteria were:

- Patients on home haemodialysis (training) or nocturnal haemodialysis
- Hospital inpatients
- Patients with a low cognitive state
- Patients with another life threatening disease or patients who had decided to phase out or stop their haemodialysis treatment

The sampling strategy maximum variation was used to select the first seven participants. Participants who were quite different from each other on the following characteristics: *gender, years receiving haemodialysis treatment, and comorbid conditions* were included. This enhanced the likelihood that findings cover different views(24). After partial analyses of the first seven interviews, theoretical sampling was used for the selection of subsequent participants(22). In this phase participants with high and low levels of knowledge about and involvement in the treatment were selected, as these characteristics appeared to influence patients' perceptions of safety. This approach was used to saturate the emerging themes as much as possible with the additional interviews(24). Given practical limitations, the maximum number of subsequent participants was five. In total twelve patients were interviewed.

Recruitment and consent

Because the researcher worked as a dialysis nurse at the haemodialysis unit in the academic hospital, patients in this unit were not recruited, informed, and asked for informed consent by the researcher but by the nursing specialist of this unit to ensure that participants offered their non-coerced willingness to participate. At the haemodialysis unit in the regional hospital

the recruitment and consent procedure was conducted by one of the dialysis nurses. Before patients were asked for consent they received information about the study verbally and in writing by means of an information form. From all participants written informed consent was obtained.

Data collection

The data were collected by individual, one-time in-depth interviews of approximately one hour conducted by the researcher. Participants were interviewed at their unit before, after or during the treatment or at their home, depending on their own preference. To focus the data collection a topic list was used (Table 1)(23). Topics were based on the literature used in the introduction and the knowledge of the researcher and supervisor. Preliminary analysis and memos of the completed interviews directed the course of subsequent interviews(22). The interviews were audio taped and transcribed verbatim on the computer.

[Table 1. Topic List]

Data analysis

The computer program NVivo was used for analysis. Analysis of the transcribed interviews consisted of open and axial coding(23). During the theoretical sampling process new data were compared with the emerging main categories (themes) and, if necessary, new codes were added and themes were modified according to constant comparison analysis(24). Two interviews were coded by the researcher and the supervisor independently. All other interviews were coded by the researcher. During meetings the codes were compared and discussed until consensus about the codes and their interpretation was reached; intercoder agreement(24).

Trustworthiness

To reflect on her role during this study and to record methodological issues, the researcher wrote methodological memos during the whole study process(23). The researcher's interview style was peer reviewed by the supervisor to enhance the quality of data collection. During the analytic process the researcher wrote theoretical memos(24) and member checks(23) were carried out after the first seven interviews to enhance the trustworthiness of the study.

Results

Achieved sample

Twelve patients were interviewed, six from both hospitals. The characteristics of the participants can be found in Table 2. In the academic hospital three men refused to take part in this study and two women in the regional hospital.

[Table 2. Participants' characteristics (n=12)]

Themes

Patients defined safety as being safe or feeling safe. Being safe was described as a safe treatment and feeling safe as an internal calm feeling. In addition to this definition five main themes were identified: 'the pivotal role of the nurse', 'balance between leaving everything to the nurse and own monitoring', 'being hooked up to the machine', 'perceived risks', and 'acute situations'.

The pivotal role of the nurse

The dialysis nurse had a pivotal role in patients' feeling of safety. It was important to patients that nurses were skilful. Characteristics of a skilful nurse were: experience, knowledge, professionalism, and ability to take action. Furthermore, nurses' personal attention enhanced patients' feeling of safety. In contrast, not giving attention, in the form of the nurse not being present or not having time, was judged as unsafe.

Patient 3 (man): "That gives a lot of confidence at that moment, you are not alone, there is someone with you who holds you and not only the doctors who are busy, but also someone who pays attention to you. That is very important at that moment and that gave me a real safe feeling, I will never forget that."

A lot of patients reported the checks nurses performed as crucial to a safe feeling. Some patients stated that all nurses were equal and that they fully trusted the nurses, while others stated that their feeling of safety depended on which nurse took care of them. These patients worried about mistakes nurses would probably make and an insecure nurse gave them an unsafe feeling. The role of the doctor in safety was outlined as prescribing the treatment.

Balance between leaving everything to the nurse and own monitoring

All patients reported that the nurse had the final responsibility in a safe execution of the treatment, but some patients *monitored* their treatment and some of these patients also had an active role in their treatment. *Monitoring* included controlling the machine, the blood pressure, the medication, and the nurse. Reasons for this involvement were saving time, making time pass faster, and knowing what is going on. Some patients indicated that their involvement depended on which nurse took care of them and/or they saw their involvement as a responsibility to themselves. In contrast, some other patients said that safety was not a reason for their involvement. All patients reported that their involvement gave them a safer feeling. Some patients did *not monitor* their treatment but left everything to the nurse. Reasons for this non involvement were the fact that it was all well done by the nurse and they did not feel capable. Patients who *monitored* expressed a greater need for information and a higher level of knowledge about the treatment than the patients who left everything to the nurse. The balance between leaving everything to the nurse and own *monitoring* could change within a patient. One patient who had been on home haemodialysis reported that she *monitored* everything while she was on home haemodialysis but that she now left everything to the nurse.

Patient 10 (woman): "But now if there is an alarm about the pressure or anything, yes, I will let it squeak, come on. At home it went like, hop hop, but here I do not do that. Only if it is serious then I can, then I would know."

All patients stated to feel safe during their treatment except for the patients who said that they left everything to the nurse, but meanwhile *monitored* their treatment. They felt unsafe or experienced anxiety sometimes. One patient who first stated that she left everything to the nurses because they had the knowledge later stated:

Patient 5 (woman): "Yes sometimes I hear them say, this is too high, or this is too high, then I think, what does she mean? In such situations I think I have too limited knowledge."

Being hooked up to the machine

Being hooked up to the machine and not being able to get away in case something might happen, like fire, was experienced as unsafe by all patients. Patients said that they did not really worry or think about fire, but that they were insecure about the procedure in case of fire. Patients would like to learn more about these procedures, for example about the emergency disconnection procedure. Some patients reported that they were able to free themselves and that this gave them a safe feeling.

Patient 11 (man): "In case of fire not every patient can be helped at the same time. I always carry scissors with me. Then I would close these clips and cut these lines. Then I would run to the exit."

Several patients reported that machine problems or a machine change during their treatment gave them an unsafe feeling. They feared that the machine had done something wrong. The technical service was sometimes mentioned to have an important job in guaranteeing the safety of the machines. Alarms on the machine were perceived as an important sign to warn you something is wrong. It was important to patients that alarms were quickly solved. Either by the nurses or by patients themselves. Most patients said that they felt safer when they received their treatment in a room with more patients instead of in a room for themselves. More attention from the nurses and more distraction were the main reasons for this. Fellow patients and visitors could bring such distraction, although patients had only shallow contact with their fellow patients.

Perceived risks

The perceived risks patients mentioned were: coagulation of the dialysis system, a bleeding through the vascular access side (arteriovenous fistula or tesio-catheter) or through the dialysis system, (miss)cannulation of the arteriovenous fistula, infection (of the vascular access side), and the ultrafiltration of too much fluid. The perceived effects of these risks were respectively, early termination of the treatment, losing a large amount of blood, pain and anxiety, getting ill, and low blood pressure. Furthermore, patients worried about the durability of their arteriovenous fistula or tesio-catheter. In most cases patients mentioned risks that they had already experienced.

Acute situations

Besides the perceived risks mentioned above patients mentioned not feeling well or fainting during the treatment. Most patients expressed that they experienced unpleasant feelings in an acute situation. It was vitally important to all patients that the nurses could help them quickly, adequate and with personal attention. Patients felt safe when the nurses were in their close surroundings or when they were able to quickly reach the nurses by calling, an alarm system, or baby phone.

Patient 9 (woman): "If there is someone in my close surrounding, yes then I feel safe. If there is someone who can intervene immediately."

Patients also found it important that the doctor was available in case of emergency. Moreover, fellow patients in an acute situation also engendered an unpleasant feeling. Patients reported that they always noticed such situations because they saw nurses running and curtains being closed. Some patients had a need for talking with a nurse or a doctor during or after such a situation.

Discussion

The results show that the nurse had a pivotal role in haemodialysis patients' feeling of safety. In addition to the role of the nurse, some patients monitored their treatment to feel safe while others left everything to the nurse. Despite this dichotomy, a lot of things were universally perceived as a risk to safety, like being hooked up to the machine in case of fire, a bleeding, and fainting. Nevertheless, most patients reported to feel safe. The patients who felt unsafe were the patients who said that they left everything to the nurse, but meanwhile monitored their treatment.

Similarly to our results, intensive care patients described nursing care as an important factor related to their feeling of safety(15,16,25). Whereas intensive care patients are obliged to leave everything to the nurse, it turned out some haemodialysis patients also did this but some monitored their treatment to create a feeling of safety. An explanation for this dichotomy can be found in Miller's Monitoring-Blunting model(26). Monitoring is defined as the extent to which patients attend to threatening signals. High monitors scan for and amplify threatening signals. Blunting is defined as avoiding threatening signals and high blunters distract themselves from these signals(26). Although it is not known whether in our study the patients who monitored their treatment were real *monitors* or whether the patients who left everything to the nurse were real *blunters*, the Monitoring-Blunting model seems to fit the results. To subdivide patients into *monitors* and *blunters* the Dutch Threatening Medical Situation Inventory (TMSI) can be used(27). In the TMSI monitoring and blunting are two independent scales both with a range from low to high. In this manner there are four coping strategies: low monitor-low blunter, high monitor-high blunter, high monitor-low blunter (*monitor*), and low monitor-high blunter (*blunter*)(27). Patients who use the low monitor-low blunter strategy do not worry about threat. Patients who use the high monitor-high blunter strategy are alert for threatening signals but at the same time try to avoid them. These patients experience anxiety. It might be that in our study these were the patients who said that they left everything to the nurse but meanwhile monitored. Nurses should give a lot of attention to these patients to enhance their feeling of safety. The current study shows that

the patients who monitored expressed a greater need for information than the patients who left everything to the nurse. To give *monitors* and *blunters* a safe feeling the information given should be tailored to patients' coping strategy(26). Moreover, it might be that tailoring medical circumstances to patients' coping strategy also enhances patients' feeling of safety because monitors feel better when they are given more responsibility in their treatment(26)(28).

The strength of this study is that the researcher worked as dialysis nurse. Her knowledge about the treatment enhanced mutual understanding during the interviews. A limitation is that the researcher worked in one of the participating hospitals. Although the researcher attempted to start the interviews with an open mind, the fact that she knew patients might have influenced the course of the interviews. The researcher underlined the separation between her two roles at the beginning of each interview. Nevertheless, her double role might have engendered that patients did not feel free to say everything during the interview because they were afraid this would change the relation with the researcher. On the other hand, the fact that some patients refused to take part in this study shows that patients felt free to decline. Another limitation of this study was the preset maximum number (twelve) of participants. Nonetheless, by applying theoretical sampling, saturation was reached after eleven interviews. The twelfth only confirmed our themes. Due to the homogenous sample it is not known whether the themes do apply to patients who have just started on haemodialysis and to patients who undergo a form of haemodialysis treatment in which they are more independent than the patients in our sample. To generate a theory a more heterogeneous sample should be studied, like new haemodialysis patients, patients on home haemodialysis, and patients on nocturnal haemodialysis(24).

The results of this study have implications for dialysis nurses in daily practice. Nurses should be aware of their pivotal role in patients' feeling of safety and they should pay attention to patients' perceived risks. Furthermore, patients' coping strategies should be taken into account. The Monitoring-Blunting model might be useful to accomplish this.

Conclusion

Although haemodialysis patients are aware of a lot of risks of their treatment, most patients feel safe during their treatment. The nurse has a pivotal role in this feeling. The results further suggest that patients' coping strategy may engender that some patients feel anxious, especially when patients use a monitor and blunter coping strategy at the same time.

Recommendations

First, this study should be carried out with a broader group of haemodialysis patients to generate a theory. Second, to develop nursing interventions, it should be investigated whether the Monitoring-Blunting model can fully explain the way haemodialysis patients experience their safety and whether tailoring information and medical circumstances to a patient's coping strategy truly enhances his feeling of safety. Furthermore, it is an absolute necessity that patients are informed about the procedure in case of fire.

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Tables

Table 1. Topic List

Opening question:	
•	How do you experience your safety during your haemodialysis treatment?
Further topics	
•	Patient's definition of safety
•	Causes of an (un)safe feeling
•	Perceived risks
•	Patient's knowledge about the haemodialysis treatment
•	Patient's involvement in care
•	Patient's role in safety
•	Influence of others (like dialysis nurse, doctor, family, fellow patients), the machine, and the environment on patients' feeling of safety

Table 2. Participants' characteristics (n=12)

Age in years Mean (SD)	65.3 (10.3)
Gender Male (n)	5
Marital status Married (n)	7
Widow(er) (n)	3
Single (n)	2
Ethnicity Dutch	12
Years receiving haemodialysis treatment ½-2 (n)	4
3-5 (n)	4
6-8 (n)	2
9-11 (n)	1
12-14 (n)	1
Comorbid conditions* CVD (n)	1
CVD+ Other(s) (n)	3
CD+ DM2 + Other(s) (n)	2
Other(s) (n)	3
None (n)	3
Level of education** Low (n)	5
Medium (n)	6
High (n)	1
Vascular access Arteriovenous fistula (n)	10
Tesio-catheter (n)	1
Arteriovenous fistula and Tesio-catheter (n)	1

*CVD: Cardiovascular Disease, DM2: Diabetes Mellitus type 2, Other(s): bilateral above knee leg amputation, carpal tunnel syndrome, coxarthrosis, diverticulitis, gout, hernia cicatricalis, ileostomy, meningionmia, morbus kahler, multiple skin malignancies, overweight, prostate problems, stomach ache, tertiary hyperparathyroidism, unilateral above knee leg amputation, unilateral below knee leg amputation

**Low: elementary education, Medium: high school or middle-level applied education, High: higher professional or academic education