

Experiences of safety among patients on home dialysis therapies

BACKGROUND

For patients, living with dialysis causes many limitations in daily life and a need to accept an uncertain future (Petersson & Lennerling 2017). Due to the complexity of dialysis treatment and care, patients may experience problems with safety, but their experiences can be underpinned with empowering interventions (Finderup *et al.* 2015).

In this study, the focus is on patients' experiences of safety of dialysis treatment and care and the factors connected with the experiences. We assume that experience of safety is positively connected with the wellbeing of these patients and successful outcomes of their treatment and care. Therefore, it is necessary to identify the factors promoting and weakening the safety experiences and create a basis for empowering interventions.

REVIEW OF LITERATURE

Based on the literature, most patients feel safe during their treatment (e.g. Lovink *et al.* 2015; Rygh *et al.* 2015). However, several safety issues have been identified to be associated with the management of dialysis treatment and care, especially with home dialysis, including hygiene, technical issues and medication storage (Peters 2014). Some patients have had feelings of insecurity, fear and discomfort related to dialysis. Moreover, there may be differences between patients' experiences depending on the form of treatment: patients on PD felt safer with the treatment than patients on HD (Pereira *et al.* 2016.) Some studies (e.g. Feroze *et al.* 2012) also indicate a high level of anxiety and depression as well as concerns regarding living with the disease and uncertainty about the future (Tong *et al.* 2009).

Factors promoting dialysis patients' experiences of safety are shown to be related to the availability of a nurse, training of self-care, the care environment and technical realisation of dialysis. Having access to a contact nurse is essential for dialysis patients (Rajkomar *et al.* 2014; Rygh *et al.* 2015; Walker *et al.* 2015), as is having someone available both at the dialysis centre (Lovink *et al.* 2015) and at home (Rajkomar *et al.* 2014; Rygh *et al.* 2015). For promoting safety, sufficient self-care training at the beginning of dialysis treatment and care is crucial for patients living with home dialysis (Rajkomar *et al.* 2014; Walker *et al.* 2015), as is regular additional training (Peters 2014).

Factors weakening patients' safety are related to their own unskilfulness, lack of support, unfamiliar nurses and fears related to dialysis treatment and care. Unskilfulness in self-management, especially at the beginning of dialysis (Vestman *et al.* 2014; Walker *et al.* 2015) and when starting dialysis at home weakens safety (Rajkomar *et al.* 2014; Rygh *et al.* 2015; Walker *et al.* 2015), as does lack of support at the beginning of dialysis (Vestman *et al.* 2014). Furthermore, unfamiliar nurses make patients feel anxious (Feroze *et al.* 2012) and worried about medical mistakes (Garrick *et al.* 2012). Moreover, patients' experiences of safety are weakened by various fears, such as fear of catastrophic events (Lovink *et al.* 2015; Rajkomar *et al.* 2014) and alarms by the haemodialyser (Feroze *et al.* 2012). There are also patients who fear the dialysis process as a whole (Tong *et al.* 2009).

In summary, there is variation in the literature regarding dialysis patients' experiences of safety. Earlier literature indicates some promoting and weakening factors connected to patients' experiences of safety. However, there is still a need for a deeper understanding of patients' experiences of safety in order to make dialysis treatment and care more empowering for the dialysis patient. Thus, the present study was designed to analyse patients' experiences of safety with dialysis and the factors promoting and weakening their safety.

METHODS

STUDY DESIGN AND PARTICIPANTS

A descriptive study design was used. The data were collected in the dialysis unit of one out of five university hospital districts in the southern part of Finland. The patients were recruited to the study by the nurses in the dialysis unit. The patients were included if they 1) had pre-dialysis follow-ups in the dialysis unit or 2) carried out home dialysis, 3) were Finnish speaking, 4) were 18 years or older and 5) were willing to participate in the study (N = 128). The patients recruited from a pre-dialysis phase to home dialysis. Patients in pre-dialysis were included because getting CKD diagnosis and waiting for decision on treatment modality and probable dialysis are stressful and frightening time for patients.

DATA COLLECTION

The data were collected with a questionnaire including one structured question and two open questions in autumn 2016 (September–December). The structured question asked whether patients experienced safety in their care on a 4-point scale (1 = no safety at all – 4 = very safe). In the open questions, patients were asked to describe factors promoting and weakening their experiences of safety.

The questions were addressed to the patients during their hospital visit or mailed home if there was more than a month before the next hospital visit, and they were asked to respond to the questions by themselves either at their dialysis unit or at home.

Furthermore, the following demographic background factors were asked: age, gender, dialysis form (pre-dialysis, PD or HHD), close ones' involvement in an education session (yes-no), receiving written education material (yes-no) and searching for information by themselves (yes-no).

DATA ANALYSIS

The patients' answers to the open questions were short, mainly just one sentence. However, the answers were informative enough to identify the factors promoting and weakening patients' experiences of safety. Patients' responses describing the factors promoting and weakening their experiences of safety were analysed separately using inductive thematic analysis (Braun & Clarke 2006) by two researchers (JK & HV). The analysis started with familiarisation with the data. Next, each sentence of the patients' written responses was coded. The codes were sorted and collated into sub-categories, and these were assigned into main categories describing the promoting and weakening factors. After that, the analysis continued by comparing the main categories and grouping them into six overarching themes describing factors that promote or weaken patients' safety.

The responses to the structured question were analysed by descriptive statistics. Differences associated with sociodemographic factors were tested using the χ^2 test. If the groups were small the differences were not tested. All statistical tests were performed by using SAS release 9.1 (SAS Inc, Cary, NC).

ETHICAL QUESTIONS

The principles of research ethics were considered during the whole study process (RCN 2009; TENK 2012). The study was approved by the Ethics Committee of the University of Turku (4 April, 2016) and permission to carry out the study was received from the university hospital of the hospital district. All patients were informed orally or by mail about the purpose of the study as well as about anonymity, confidentiality, voluntary participation and opportunity to withdraw from the study at any time. All the patients gave written informed consent.

FINDINGS

PARTICIPANTS AND THEIR EXPERIENCES OF SAFETY IN DIALYSIS

A total of seventy patients (n=70/128, response rate 55%) participated in the study. The mean age of the patients was 63 years (range 37 - 85). The patients were in pre-dialysis (n=28, 40%) or home dialysis treatment (n=42, 60%) including PD (n=37, 88%) or HHD (n=5, 12%). Due to low number of the patients in HHD, their experiences of safety and promoting and weakening factors were analysed together with PD group. The participants' sociodemographic background variables are described in detail in Table 1.

The patients participated in education sessions, which supported them to engage with their dialysis treatment and to reach self-management. Patient education was started as soon as the probability of dialysis was confirmed. In the pre-dialysis and PD patient education was carried out following the education program of the dialysis unit and taking account patients' condition, needs and resources. In home HD there was six weeks education program for patients. The content of patient education included concrete issues of dialysis treatment (e.g. monitoring kidney function, use of dialysis machine, care of catheter and fistula, hygiene and infection control) and living with CKD (e.g. diet, working while dialysis, hobbies and free time and sexuality and outer appearance). All patients received written educational material, except those (n=4, 6%) who were in such a bad condition that they could not deal with it.

Table 1 about here

On a scale 1 - 4, the participants' average score when answering the structured question of experiences of safety of their treatment and care was 3.6 (SD 0.49). The patients experienced their care as either somewhat safe (n = 28, 40%) or very safe (n = 41, 59%). There were no statistically significant differences in patients' sociodemographic factors and patients' experiences of safety (p= 0.146–0.479).

FACTORS PROMOTING PATIENTS' EXPERIENCES OF SAFETY

The factors promoting patients' experiences of safety formed three overarching themes: certainty of patient's own competence in dialysis self-management, competence of personnel in dialysis treatment and care, and continuity of ensuring patients' state of health (Table 2). In the next paragraphs, the promoting factors will be described in more detail.

Table 2 about here*CERTAINTY OF PATIENT'S OWN COMPETENCE IN DIALYSIS SELF-MANAGEMENT*

Participants described that their safety was promoted by their own capability in dialysis self-management and using their previous experiences as well as the availability of support for dialysis self-management. Patients' own capability in dialysis self-management was related to their own learning, knowledge and skills during dialysis treatment and care. When patients had enough time to learn self-management skills and to achieve a certain degree of certainty in their self-care they considered it as promoting their experience of safety. Patients also highlighted the importance of a sufficient level of comprehensive knowledge of dialysis and its outcomes for their health.

Knowledge of their own situation and understanding what dialysis treatment and care means for their daily lives was brought up as well. Own skilfulness was mentioned in the realisation of high-level and hygienic self-management as well as in compliance with the right diet.

Using one's own previous experiences of dialysis, including past experiences and habits in self-management, was seen as promoting. The ability to use past experiences over a long time period and the habits developed during self-management increased a sense of safety. Availability of support for dialysis self-management included knowledge of the possibility to contact the dialysis unit and access to dialysis personnel and treatment in hospital. It was essential for the patients to know that support was available from the dialysis unit at any time. This was described by one participant as follows:

“My safety was promoted by a phone number I can always call if there are any issues or concerns” (ID 5)

Safety was confirmed by promise by the staff that the patient could come to the hospital any time if there were problems with dialysis self-management. The participants appreciated having the possibility to go back to the hospital at any time in the case of any problems with their self-self-management or home dialysis.

COMPETENCE OF PERSONNEL IN DIALYSIS TREATMENT AND CARE

Participants described that skilful personnel in dialysis treatment and care and meeting the patient individually promoted safety. Skilful personnel in dialysis treatment and care was a promoting factor focusing on nurses' skills in dialysis treatment and care as well as in patient education. It was important that the nurses knew what was happening in dialysis treatment and were able to describe

the positive effects of the treatment. The skills in patient education included correct timing and a sufficient amount of patient education prior to starting dialysis treatment. Furthermore, education of participants' relatives during dialysis treatment was a promoting factor. The importance of meeting patients individually was evident, especially in terms of the relationship between the patient and staff. The fact that the participants felt that the nurses really knew them and their circumstances was perceived as promoting. As one participant put it:

“The nurse meets me in person at the ward, making me feel that she knows me and my circumstances” (ID 208)

The participants stated that staff's empathy and kindness during the treatment and care process and individual encounters had supported their safety.

CONTINUITY OF ENSURING PATIENTS' STATE OF HEALTH

The participants stated that permanence of personnel in the dialysis unit and continuity of dialysis treatment and care were promoting factors. It was considered promoting that the dialysis unit personnel remained the same and knew the patient. Continuity of dialysis treatment and care, including continuous monitoring and follow-ups, was experienced as promoting. The importance of continuity of monitoring the patient's state of health and disease was highlighted. Regular and adequate follow-ups and control visits at the dialysis unit were mentioned as essential.

FACTORS WEAKENING PATIENTS' EXPERIENCES OF SAFETY

The factors weakening patients' experiences of safety formed three overarching themes: patients' uncertainty of living with CKD, insufficient patient education, and uncertain realisation of dialysis treatment and care (Table 3). In the next paragraphs, the weakening factors will be described in more detail.

Table 3 about here

PATIENTS' UNCERTAINTY OF LIVING WITH CKD

The participants described that problems with self-management, risks of living with CKD and restrictions of the home conditions weakened their safety. Problems in self-management consisted of worries and fear of self-management. The participants were worried about incompetence in self-management and problematic situations with dialysis, especially at weekends. Furthermore, they were

afraid of unexpected alarms given by the dialysis machine and worried about failure in self-management of needle sticks, for example. Risks of living with CKD included risks associated with the disease and dialysis treatment. Some of the participants had experienced changes in medication all the time. Their sense of safety was also weakened by their uncertain state of health. Patients suffering from multiple diseases or multi-dimensional symptoms experienced unsafety due to continuous changes in health and fear of sudden complications. The restrictions of the home conditions included the type of housing, home conditions and the distance between home and hospital. Living alone without daily support from family members was an essential factor in decreasing safety. Problems in family life were mentioned as a cause of unsafety, as was long way to the hospital to get treatment and support.

INSUFFICIENT PATIENT EDUCATION

Insufficient patient education covered insufficient knowledge received from the dialysis unit.

Patient education was perceived as insufficient due to lack of knowledge or only a small amount of knowledge on treatment and its effects on daily living. Patient education in the emergency unit was experienced as particularly challenging because of the nurses' lack of knowledge of dialysis treatment and care.

UNCERTAIN REALISATION OF DIALYSIS TREATMENT AND CARE.

The participants described that uncertain operation of the dialysis machine weakened their safety. In particular, concern about the operation of the dialysis machine at night and in exceptional circumstances, such as thunderstorms, decreased their safety. One patient described this as follows:

“Problematic situations – if the machine does not work, if the fluid does not pass through the tubes, if the machine sounds an alarm” (ID 236)

The presence of new staff at each follow-up visit was described as problematic because it meant that the staff members were not familiar with the patients and their individual circumstances.

DISCUSSION

In this study, the aim was to analyse patients' experiences of safety with dialysis and the factors promoting and weakening their safety. We analysed the promoting and weakening factors separately, but here they are discussed together because both types of factors were connected with three common areas of dialysis treatment and care (Figure 1).

Figure 1 about here

Our main finding was that patients' safety was connected with the realisation of patients' self-management and personnel's support for patients' self-management. Furthermore, the delivery of dialysis treatment and care was an essential factor for patients' safety. These findings are in line with previous studies highlighting patients' management with dialysis and the support provided by nurses for promoting patients' safety (e.g. Rajkomar et al., 2014; Lovink et al., 2015). However, the present study increased our understanding of patients' safety, providing insight into the pre-dialysis phase.

Thus, patients' self-management was essential for their safety. This study showed that facilitating self-management was essential for patients' safety whereas the opposite was true for hindering self-management. This finding is in line with earlier studies (Rajkomar *et al.* 2014; Walker *et al.* 2015) showing that sufficient self-care promotes patients' safety while unskilfulness weakens it (Vestman *et al.* 2014; Walker *et al.* 2015). However, this study showed the importance of patients' own capability, knowledge and skills in dialysis self-management, referring to patient empowerment. Our finding is encouraging since dialysis patients' empowerment is increasingly required in health care according to the current health policy (WHO 2013).

In addition, the importance of personnel's support for patients' self-management was evident to patients' safety. This study showed that delivery of high-quality dialysis treatment and care as well as realisation of patient education were essential in promoting patients' safety, as were individual encounters with patients. Instead, insufficient patient education and constant changes of personnel in the dialysis unit were seen to decrease safety. These findings demonstrate the importance of professional skills and especially the recognition of patients' individuality in dialysis treatment and care.

Furthermore, this study showed that continuity of ensuring patients' state of health by the same personnel working in the dialysis unit as well as continuity and good functionality of treatment and care were experienced as essential for safety. This finding may demonstrate a need to invest more in organisational resources concerning dialysis machines and personnel so that each patient in the dialysis unit has the opportunity to experience high-level dialysis treatment and care.

However, all patients in different phases of dialysis perceived their dialysis treatment and care as safe. This is noteworthy since the patients experienced safety regardless of the phase of their dialysis.

However, the longer a person is treated, the more probable is that they will have had a negative experience, also negative experience in the early stages of treatment may be more frequent due to uncertainty, and patient expectations. This finding may expand previous findings which have shown HD patients to perceive safety in routine treatment (Lovink *et al.* 2015) and home haemodialysis patients to feel safe as long as they have easy access to the hospital (Rygh *et al.* 2015). Our finding on patients' safety experiences may indicate that dialysis patients may manage with their dialysis treatment and care although it may cause restrictions for them.

This study has some limitations concerning the data collection method and procedure. First, validation of the questionnaire was assessed with researchers and clinical nurses specialised in dialysis care and pilot tested with five patients from the dialysis unit. No changes were made based on piloting.

Second, the factors associated with the experiences of safety were collected using open-ended questions. These questions provided mainly short answers, which might be seen as problematic without informative descriptions. However, the questions resulted in several factors connected to patients' experiences of safety. The quality of the answers might be dependent on the open-ended questions, because they allowed the patients to tailor their answers individually. Third, it may be difficult to know whether the questions were answered by the patients or their family members because the patients had the possibility to answer the questions at home. However, based on the nature of the answers, it seems likely that the answers were written by the patients themselves.

IMPLICATIONS FOR PRACTICE

In order to ensure patients' safety in dialysis treatment and care, the following changes are recommended:

- 1) Patients' safety in dialysis treatment and care should be seen more broadly and profoundly compared to the definition of WHO (2018) which mostly regards safety as the prevention of errors and adverse effects to patients.
- 2) Patient education should be more empowering to ensure patients' feelings of safety in dialysis treatment and care.
- 3) Safety issues in dialysis treatment and care should be invested in already when patients are preparing for dialysis.

CONCLUSION

This study provided new insight into understanding patients' experiences of safety. We were able to show that the factors connected with patients' safety were related to the successful realisation of self-

management, support for the self-management, and delivery of dialysis treatment and care anticipating high-level outcomes. In light of this study, there are development needs in dialysis treatment and care as a whole in order to ensure patients' safety.

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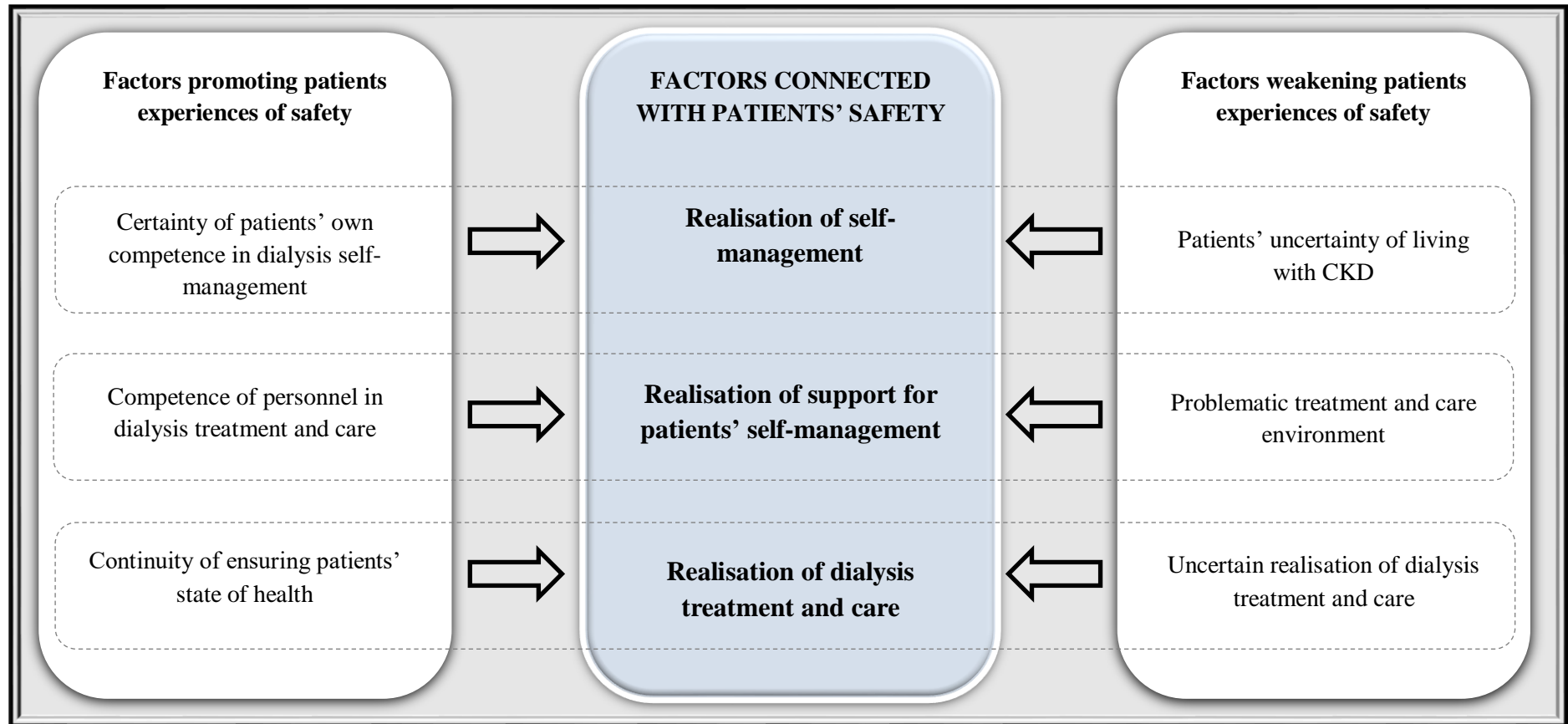


Figure 1. Factors connected with patients' safety

Table 1. Participants' sociodemographic background

Variable	n	%
Gender (n = 70)		
Female	26	37
Male	44	63
Dialysis type (n = 70)		
Pre-dialysis	28	40
Home dialysis (PD & HD)	42	60
Close ones involved in education sessions (n = 55)		
Yes	24	44
No	31	56
Received written education material (n = 68)		
Yes	64	94
No	4	6
Search for information on one's own (n = 69)		
Yes	50	72
No	19	28

Table 2. Factors promoting patients' safety

Sub-category	Main category	Theme
Expectation of comprehensive knowledge	Patient's own capability in dialysis self-management	Certainty of patient's own competence in dialysis self-management
Knowledge on outcomes of dialysis		
Sufficient knowledge of own situation		
Own understanding on dialysis treatment and care		
Own skillfulness in self-care		
High level of self-care		
Hygiene of self-care		
Compliance with right diet		
Enough time to learn self-care		
Certainty in self-care		
Previous experiences of dialysis	Using own previous experiences of dialysis	
Habits based on patient's previous experiences		
Knowledge on getting support from staff	Availability of support for dialysis self-management	
Knowledge on reachability of a familiar dialysis expert		
Opportunity to ask questions all the time		
Promise of care in a hospital in a problem situation		
Feeling of nurse's knowing me		
Skilled staff in dialysis treatment and care	Skillful personnel in dialysis treatment and	Competence of personnel in dialysis treatment and care
Professional skills of the staff in dialysis unit		
High quality patient education provided by the staff		
High quality dialysis treatment and care carried out by the staff		
Satisfaction with patient education provided by the staff		
Good patient-physician relationship	Meeting the patient individually	
Individual encounter between patient and nurse in dialysis		
Feeling of nurse's knowing me		
Empathetic staff		
Kindness of staff		
Continuous opportunity to contact dialysis unit	Permanence of personnel in dialysis unit	Continuity of ensuring patients' state of health
Opportunity to telephone contact		
Permanence of staff in the dialysis unit		
Access to treatment in hospital in problematic situations		
Continuous monitoring of state of health	Continuity of dialysis treatment and care	
Continuous monitoring of the disease		
Regular follow-up visits in dialysis unit		
Continuity of treatment and care		
Continuity of follow-ups		

Table 3. Factors weakening patients' safety

Sub-category	Main category	Theme
Worry about patients' own incompetence	Troubles in self-management	Patients' uncertainty of living with CKD
Worry about in a problematic situation in self-management		
Fear of failure of self-management		
Risks of the disease	Risks of living with CKD	
Potential risks of dialysis		
Change of medication all the time		
Changes of the state of health	Uncertain state of health	
Fear of the complications		
Living alone	Restrictions of the home conditions	
Inadequate home conditions		
Long distance from home to treat		
Insufficient knowledge from dialysis unit	Insufficient patient education	Insufficient patient education
Operation of the dialysis machine in exceptional circumstances	Uncertain operation of dialysis machine	Uncertain realization of dialysis treatment and care
Surprising malfunction of dialysis machine	Changing of the personnel	
Continuous change of personnel		