

# **Development of Recommendations for Nurses to Prepare Patients and Their Families for Dialysis**

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<p><b>Background.</b> Annually more than 2.5 million people with chronic renal failure around the world receive renal replacement therapy—dialysis. The most common causes that lead to dialysis are diabetes mellitus and hypertension. Against the background of chronic diseases, it is important to conduct timely examination of the kidneys and, if necessary, gradual preparation of patients for the start of renal replacement therapy.</p> <p><b>Objective:</b> improve the quality of nursing by creating recommendations for preparation of patients with end-stage of chronic renal failure and their family members at the beginning of dialysis to reduce the risk of complications and improve quality of life.</p> <p><b>Methods:</b> This qualitative research was conducted from May to November 2018. A total 22 participants (seven dialysis patients, five patients' relatives, five nurses, and five nephrologists) were interviewed. The interviews were analyzed using qualitative content analysis.</p> <p><b>Results:</b> Data analysis led to the production of four main categories, which were selected for each group of respondents separately. 1—Pre-dialysis training helps to reduce possible complications of dialysis issues. 2—Effectiveness of regular counseling of patients and their families at the pre-dialysis stage. 3—The need for psychological help and counseling for patients and their relatives before and at the beginning of dialysis. 4—For further qualitative development of the dialysis service, it is necessary to actively conduct pre-dialysis training jointly with patients with chronic renal failure and with relatives.</p> <p><b>Conclusion:</b> Six common recommendations were developed for counseling: 1—changes in lifestyle, 2—social help, 3—medical interventions, 4—informing patients and their families, 5—psychological preparation, and 6—social life. Developed recommendations for nurses to prepare patients and their families for dialysis were aimed at reducing the risk of developing complications and improving the quality of life of dialysis patients.</p>		
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## 1 Introduction

Annually more than 2.5 million people with chronic renal failure around the world receive renal replacement therapy – dialysis (Al Ismaili, Al Salmi, Al Maimani, Metry, Al Marhoobi, Hola, & Pisoni 2017). Dialysis is a vital procedure, since it helps to purify the blood from toxins and remove fluid from the body, i.e. it performs the physiological work of the kidneys when they themselves are unable to cope with this (Medical encyclopedia 2016; MedlinePlus 2019). Diabetes mellitus and hypertension are the most common causes of chronic kidney disease - a gradual, progressive, and permanent loss of kidney function (Ghaderian & Beladi-Mousavi 2014). Against the background of chronic diseases, it is important to have a timely examination of the kidneys and, if necessary, gradual preparation of patients for the beginning of renal replacement therapy (Clinical protocol of the Ministry of Health of the Republic of Kazakhstan "Chronic kidney disease in adults" 2016).

An important fact is the preparation of patients and their family members for dialysis. Chronic renal failure and dialysis is quite a serious hardship, both for the patient himself and for all members of his family (Walker, Abel, & Meyer 2010). This is due, first of all, to the lack of information, the need to change the family lifestyle, the adaptation of the new regime of the day and nutrition, etc. In this difficult period, patients and their families need moral support, obtaining reliable information necessary to adapt to new conditions of life, which contributes to the effectiveness of replacement renal therapy. (Life on dialysis 2018; Neyhart, McCoy, Rodegast, Gilet, Roberts, & Downes 2010.)

The nurse plays an important role in preparing patients for dialysis (Walker et al. 2010). Important aspects in this case are patient care and compliance with basic vital rules for hemodialysis patients - diet, care for vascular access, etc. (Life on dialysis 2018). A trained nurse who is not only involved in the procedure of hemodialysis and patient care in a hospital environment, but also conducts outreach of the main aspects and rules of life with hemodialysis, helps to gain knowledge and necessary skills. (ibid.; Clinical protocol of the Ministry of Health of the Republic of Kazakhstan "Chronic kidney disease in adults" 2016; Al Nazly, Ahmad, Musil, & Nabolsi 2013.)

The nurse acts as a mentor, educator, and guide, who helps the patients and members of his family to adapt to new conditions of life (Walker et al. 2010). Recommendations received by patients and their relatives should help to reduce the level of stress, and also to prepare for the beginning of hemodialysis, giving explanations of what needs to be done, to observe, the importance of the procedure, care of vascular access, possible complications and consequences, etc. In a word, prepare patients mentally and psychologically for the vital procedure of hemodialysis. (Life on dialysis 2018.)

The purpose of this research is to improve the quality of nursing by creating recommendations for the preparation of patients with end-stage of chronic renal failure and their family members at the beginning of dialysis to reduce the risk of complications and improve quality of life.

## **2 Living with Dialysis**

### **2.1 Chronic Kidney Disease**

Kidney Disease: Improving Global Outcomes (KDIGO) (2017) is a non-profit organization developing and implementing evidence-based guidelines for kidney disease. The organization defines chronic kidney disease (CKD) as abnormalities of kidney structure or function, present for > 3 months, with implications for health. CKD is classified based on cause, glomerular filtration rate (GFR) category (G1–G5), and albuminuria category (A1–A3), abbreviated as CGA (see Figure 1).



**Prognosis of CKD by GFR and albuminuria categories: KDIGO 2012**

				Persistent albuminuria categories, description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30–300 mg/g 3–30 mg/mmol	>300 mg/g >30 mg/mmol
GFR categories (ml/min/1.73 m <sup>2</sup> ), description and range	G1	Normal or high	≥90			
	G2	Mildly decreased	60–89			
	G3a	Mildly to moderately decreased	45–59			
	G3b	Moderately to severely decreased	30–44			
	G4	Severely decreased	15–29			
	G5	Kidney failure	<15			

green, low risk (if no other markers of kidney disease, no CKD); yellow, moderately increased risk; orange, high risk; red, very high risk.

Figure 1. Prognosis of CKD by GFR and albuminuria category (by KDIGO 2017)

The development of CKD is based on the magnitude of GFR (stage G) and the level of albuminuria (stage A). The level of GFR is determined based on the concentration of creatinine or cystatin C in the serum (Murty, Sharma, Pandey, & Kankare 2013). The level of albuminuria is determined based on the daily excretion of albumin in the urine or the albumin / creatinine ratio (Martin 2011). A complete diagnosis of CKD contains the name of the kidney disease (the cause of CKD, if known) along with the assigned appropriate stage G and A (Chapter 1: Definition and classification of CKD 2013). Criteria for determining chronic kidney disease for Kidney Disease: Improving Global Outcomes (KDIGO) (2012) is presented in Appendix 1.

CKD (CKD stages are presented in table 1) leads to the development of renal failure, which in turn leads to a violation of the physiological, psychological, and social well-being of a person (Lindsay, MacGregor, & Fry 2014). Chronic renal failure (CRF) is a nonspecific syndrome that develops as a result of the gradual loss of major renal functions due to the development of sclerosis of the kidney tissue against the background of various progressive kidney diseases (Clinical protocol of the Ministry of Health of the Republic of Kazakhstan Hemodialysis 2013). Chronic renal failure is a progressive and irreversible loss of renal function (Horgan, Rocchiccioli, & Trimm

2012). Chronic renal failure refers to G3-G5 stages of CKD; Stage G5 is the terminal stage of renal failure or uremia (Vaidya & Aeddula 2019). In the absence of appropriate treatment, the patient dies (Clinical protocol of the Ministry of Health of the Republic of Kazakhstan Hemodialysis 2013).

Table 1. International classification of stages of chronic kidney disease CKD (by National Kidney Foundation, Kidney Disease Outcomes Quality Initiative 2002)

<b>CKD Stage</b>	<b>Description</b>	<b>GFR Level (ml/min/1,73m<sup>2</sup>)</b>
I	Kidney damage with normal or elevated GFR	≥90
II	Kidney damage with mild GFR decline	89 – 60
III	Moderate decline in GFR	59 – 30
IIIa	From mild to moderate	45–59
IIIb	Medium to severe	30–44
IV	Severe decline in GFR	29 – 15
V	Kidney failure	≤15

The majority of patients develop the so-called terminal stage of kidney disease (Lindsay et al. 2014). This condition requires the use of substitution therapy methods, which, according to the clinical protocol of the Ministry of Health of the Republic of Kazakhstan for hemodialysis (2013), include: hemodialysis, peritoneal dialysis, and kidney transplantation. According to the Clinical Protocol of the Ministry of Health of the Republic of Kazakhstan "Chronic kidney disease in adults" (2016), the treatment strategy for patients with CKD 4-5 stages is defined as preparation for renal replacement therapy, adequate dialysis therapy: from the onset of dialysis to the achievement of targets, treatment of complications CRF and dialysis therapy.

In this case, chronic kidney disease and subsequent hemodialysis cause a number of problems in various aspects of life (social, psychological, cultural, and spiritual) of patients and their families (Egan, Wood, MacLeod, & Walker 2015).

## 2.2 Hemodialysis

### 2.2.1 Beginning of Hemodialysis

Hemodialysis, by definition of a medical encyclopedia (2016), is a process that removes waste from blood when kidneys can no longer do their job. It is a method of extra renal blood purification from substances with small and medium molecular weight by diffusion and partly convection (ultrafiltration) through an artificial semipermeable membrane (ibid.). During dialysis, the patient is connected to an artificial kidney apparatus (Lindsay et al. 2014). According the Order of the Ministry of Health of the Republic of Kazakhstan dated December 30, 2013 № 765 "On approval of the standard for the provision of nephrological assistance to the population in the Republic of Kazakhstan" the following criteria for the selection and initiation of renal replacement therapy are identified: (the presence of one of the indicators is the reason for the onset of renal replacement therapy):

- 1) Urea of blood serum above 30 mmol / l and / or decrease in glomerular filtration rate (hereinafter - GFR) below 10 ml / min / 1.73 m<sup>2</sup> (in patients with diabetes less than 20 ml / min / 1.73 m<sup>2</sup>) MDRD/CKD-EPI;
- 2)  $GFR (ml / min / 1.73m^2) = 186 \times (\text{plasma creatinine})^{-1.154} \times (\text{age})^{-0.203} \times (0.742 - \text{for women})$ ;
- 3) a decrease in the standard bicarbonate below 20 mmol / l and / or a buffer base deficiency of less than 10 mmol / l;
- 4) Hyperkalemia - over 6.5 mmol / l.

Before taking a patient for hemodialysis, vascular access is provided (Clinical protocol of the Ministry of Health of the Republic of Kazakhstan Hemodialysis 2013). Blood is taken from the body and returned through a surgically formed arterio-venous fistula (Vascular Access for Hemodialysis 2014). The goal of hemodialysis is a life-long support of renal replacement therapy for persons with terminal stage of chronic renal failure (Clinical Protocol of the Ministry of Health of the Republic of Kazakhstan "Chronic kidney disease in adults" 2016). In accordance with Annex 1 to the standard

structure of the Clinical Protocol “Chronic kidney disease in adults” (2016), the standard dose of dialysis is 3 times a week for 4 hours. During these 4 hours, toxins and excess fluid are removed from the body that had been accumulating for two days after the previous procedure. Excessive accumulation of fluid in the body contributes to increased blood pressure and the development of cardiovascular pathology (ibid.) Also, it is necessary to remember about observance of the special diet, limiting consumption of salt, potassium (fruit, etc.), phosphorus (dairy products, fish, etc.) (Medical center BIOS 2018).

### 2.2.2 Quality of Dialysis Patients’ Life

Health is a state of complete physical, mental, and social well-being, and not only the absence of disease and physical defects. Health is one of the factors that affect the quality of human life. (World Health Organization 2014.) The quality of human life is based on the following factors: physical, social, and emotional. A decline in the quality of life can result from a violation of physical health, psychological health, social relations, and the environment. (World Health Organization 2004.)

People do not immediately come to renal replacement therapy. There are various reasons leading to the onset of dialysis. The most common causes leading to chronic kidney disease are diabetes, arterial hypertension, and circulatory system diseases. Over time, these diseases can lead a person to the beginning of renal replacement therapy. (Ghaderian & Beladi-Mousavi 2014.)

Chronic renal failure and the hemodialysis procedure reduce the quality of life of this category of patients (Bonner & Lloyd 2012). At the same time, the quality of life of dialysis patients depends in many respects on the pre-dialysis preparation (Woo & Lok 2016). Patients should be psychologically prepared for dialysis (Egan et al. 2015). This will help them in the future to observe all the recommendations received. The success of dialysis depends a lot on the patient's compliance with the recommended treatment regimen, non-compliance with which leads to a deterioration in the quality of life. (Nagasawa, Tachi, Sugita, Esaki, Yoshida, Kanematsu, Noguchi, Kobayashi, Ichikawa, Tsuchiya, & Teramachi 2018.)

The most important aspect for maintaining the quality of life of dialysis patients is nursing care. Nursing care is completely determined by the features of this category of patients (ibid.). At the same time, to solve various problems of dialysis patients, it is important to strictly follow the prescribed regimen (Alikari, Matziou, Tsironi, Theofilou, & Zyga 2015).

Nurses' knowledge about kidney disease and kidney pathology as well as about the principles of fatigue management contributes to improving the life quality of patients (Horigan et al. 2012). Also, a highly confidential relationship between a nurse and a patient should be formed, so that there is an opportunity to assess the patient's needs clearly. Close and trusting relationships are the key to successful collaboration between a nurse and a patient. At the same time, patients will feel safe and will be able to fully trust the nurse, share their experiences, problems, and needs. (Black 2014, 169-194.)

Thus, the concept of the quality of life will come from the position of the patient and his family, and not from the position of assessment of the medical worker (American Nurses Association 2016). Patients and their relatives must accept the necessity of changing their lifestyle. Moreover, these changes affect various aspects of their life, such as: strict adherence to diet, restriction of fluid intake, regimen of taking medications, studying various symptoms and signs associated with possible complications in dialysis patients, knowledge of care of vascular access support on the part of family members, and changes in social life. (Rambod, Peyravi, Shokrpour, & Sareban 2010.)

It should be noted that human needs, in accordance with the Abraham Maslow pyramid of needs outlined in the book "Motivation and Personality" (1954), are distributed into five basic levels and the satisfaction of higher-level needs is impossible without satisfying the needs of lower levels (Huitt 2017, 356-357). In accordance with this pyramid, the needs of dialysis patients are identified by Bayoumi (2012). *At the first level* for dialysis patients is to learn how to deal with physiological needs, such as thirst - fluid restriction, eating restrictions, and dieting. *At the second level*, there is security, both in the physical and mental sense. The patient should be aware of his safety during the procedure of hemodialysis.

Accordingly, qualitative training of employees on safe management of hemodialysis should be conducted. (ibid.) However, in addition to a sense of security during hemodialysis, it is important for patients to know the rules of their own safety in times of various emergency situations. This knowledge is necessary both for the patients themselves and their families. In such situations it is necessary to keep in touch with the hemodialysis center, and patients always have to have patient's dialysis passport. (Deck 2010.) *At the third level* are the needs for love and comfort (Bayoumi 2012). To meet the needs of this level, dialysis patients need support from relatives. A healthy atmosphere in the family promotes a favorable course of hemodialysis and minimizes various complications. (ibid.) Therefore, during pre-dialysis preparation, it is very important to work not only with the patients themselves, but also with their relatives, with people who will be with them and will be able to help and support at the right moment (Horigan et al. 2012). *At the fourth and fifth levels* are the needs of a person in self-assessment and self-actualization (Bayoumi 2012). For dialysis patients with the satisfaction of the needs of these levels, there are certain difficulties associated with the limitation of social life, the high level of disability, and the severity of the underlying disease (Al Nazly et al. 2013).

Thus, understanding the basic needs of dialysis patients makes it possible for nurses to come to the aid of patients on time, and to advise their relatives, as the duration of hemodialysis changes the needs of patients. In this regard, nurses must provide ongoing care for dialysis patients; assess their status and changing needs, which requires them to develop a clear plan for care at each stage. (Bayoumi 2012.)

### 2.2.3 Quality of Care Provided for Hemodialysis Patients

The level of life quality should come from each patient and the family individually, and not from the medical workers (American Nurses Association 2016).

Unfortunately, patients on renal replacement therapy suffer from severe and incurable kidney diseases that led to the onset of dialysis. The procedure for hemodialysis is not always smooth and calm, takes quite a long time, and entails various consequences and complications. (Bonner & Lloyd 2012; National Kidney

Foundation 2019.) In this situation, quality nursing helps to maintain the physical and mental well-being of patients and their relatives.

Unfortunately, nowadays many elderly patients on dialysis face the problem of the reluctance of medical workers in various fields of healthcare to provide them with high-quality medical care due to their poor attitude to old age (Aghamolaei & Hasani 2011). At the same time, the quality of nursing care for people in program dialysis largely depends not only on the level of the medical personnel's training, but also on the quality of developing clinical protocols for the treatment of patients with hemodialysis (Shnishil & Mansour 2017). It should be noted that in Kazakhstan, the Clinical Protocol of the Ministry of Health of the Republic of Kazakhstan, "Chronic kidney disease in adults", where in annexes 1 and 2 the protocol of surgical intervention hemodialysis and peritoneal dialysis is prescribed, was approved in 2016 and is subject to revision and new approval in 3 years or if there are new methods with a level of evidence. To provide quality care to dialysis patients, it is necessary to create multidisciplinary teams that are an essential component of care (Tulebayev, Turdaliyeva, & Kuzieva 2016). These teams include doctors of various specialties, nurses, social workers, nutritionists, and psychologists. (Tulebayev et al. 2016; Garbin & Chmielewski 2013.)

Cardiologists, neurologists, endocrinologists, oculists, therapists, and nephrologists should work together. This is due to the main diseases that led to the terminal stage of CRF and the beginning of renal replacement therapy. Stabilization of the condition of the dialysis patient and the control of the main one contribute to a favorable course of the hemodialysis procedure, as well as reducing the risk of various complications. (Tulebayev et al. 2016.)

Nutritionists help patients regulate their diet, teaching them how to diversify their diet with useful products to maintain their health. This is necessary both for the patients themselves and for their families, since often there is already a recognized diet in each household, which does not always correspond to the dialysis patient's diet. (National Kidney Foundation 2015; Beto, Schury, & Bansal 2016.) Therefore, the work of a nutritionist with family members is very important - to show a variety of useful foods, as well as methods for their processing, which will contribute to

meeting one of the basic human needs - the need for food. (ibid.; DiaPriva Dialyse Centrum 2018.)

The work of psychologists in pre-dialysis preparation and dialysis management of patients is difficult to overestimate. Proper psychological support and support for patients and their families contributes to a favorable attitude towards hemodialysis and the smooth conduct of these procedures, which contributes to the well-being of patients. This causes a reduction in the risk of complications. The work of psychological support is important for patients and caregivers. Family members have a hard time, especially the first year after the onset of chronic dialysis. During this period, psychological support is especially important for them, since it is this category of people that provides dialysis patients with home care, in other words a comfortable atmosphere in the family. (Corseva, Shishkin, & Asanina 2012.)

Social workers are needed in the work of a multidisciplinary care team, since they are the ones who advise patients on all the issues that arise about disability (Tulebayev et al. 2016; DiaPriva Dialyse Centrum 2018). Also, social workers support and accompany patients to various activities related to supporting the social life of patients. At present in the Republic of Kazakhstan, social workers are provided for First and Second category invalids according to the Order of the Minister of Health and Social Development of the Republic of Kazakhstan dated March 26, 2015 № 165 "On approval of in the field of social protection provision of social services standards of the population ", patients who receive renal replacement therapy by dialysis belong to the first group and are provided with social workers.

Nurses are an integral part of the multidisciplinary care team and its most important part (Tulebayev et al. 2016). Nurses are always next to dialysis patients, whether it is an outpatient clinic or a hospital (Bayoumi 2012). Nurses see patients during each visit; they have the opportunity to observe dynamics of their condition, which enables them to adjust the care plan in accordance with the newly emerging needs of patients. The nurse, as a member of a multidisciplinary team (ibid.; Garbin & Chmielewski 2013), contributes to the implementation of all stages of prevention, both the development of chronic kidney disease, and the complications that occur before and during the procedure of hemodialysis. Also, relatives of such patients are



more likely to discuss the patient's condition with a nurse, since they can see it when accompanying the patient to the procedure of hemodialysis. (Alikari et al. 2015.)

#### 2.2.4 Consequences of Dialysis

Dialysis patients, having various chronic diseases, have a strong emotional tension by the time of starting hemodialysis treatment (Hawamdeh, Almari, Almutairi, & Dator 2017). Fatigue is the most common symptom among dialysis patients (Jablonski 2007). This is due not only to the most debilitating procedure of hemodialysis, but also to the fact that people have been suffering from chronic kidney disease for a long time (National Institute of Diabetes and Digestive and Kidney Disease 2010). It is worth noting that fatigue is by no means the only symptom in dialysis patients. Other symptoms include: decreased appetite, impaired concentration, swelling in the hands and feet, muscle cramps, and itching. (Clinical protocol of the Ministry of Health of the republic of Kazakhstan “Hemodialysis” 2013.) All these symptoms can cause stress in a person and negatively affect a patient's quality of life (Jablonski 2007). There are a number of difficult situations that need to be addressed: fatigue and a desire to relax after a hemodialysis session, while the patient also needs to travel home; the need to be accompanied by a third person due to poor health; difficulties with planning their time, taking into account the frequency and duration of dialysis; difficulties in managing concomitant diseases, in particular with the onset of pain (ibid.).

The main points that patients encounter when starting hemodialysis, according to Al Nazly and others (2013), are: *lifestyle changes* - nutrition, regime, various activities, and so on; *loss of time* - the road to the dialysis center and back, the hours spent at the artificial kidney apparatus; *suffering from symptoms*: poor health immediately after dialysis and weakness the next day, restless legs syndrome, nausea, muscle spasms, and so on; *family and sexual functions*: lack of sexual desire, inability to do household chores; *labor restrictions, support for family and health*: help from family members at home, support for dialysis, medical advice. Many problems can be solved if the patient and his family are properly prepared for hemodialysis (Horigan et al. 2012; Hallock 2014).

### 3 Pre-dialysis Education

#### 3.1 Awareness of the Patient and his Family about Dialysis

Early education can reduce the fear of hemodialysis and the emergence of AV-fistula and care for it (Stolic 2013). Training is conducted with patients and members of his family. Complete information on the preparation for dialysis includes: functional access, patient education, and obtaining laboratory data (Neyhart et al. 2010).

The patient's education should cover not only the patients themselves, but also their family members (Covic, Bammens, Lobbedez, Segall, Heimbürger, van Biesen, Fouque, & Vanholder 2010). People should be aware of the causes of the illness that led to the terminal stage of kidney failure, the possibilities of substitution therapy, the need for diet adjustment, and monitoring of the general condition (Davison & Cooke 2015; Rambod et al. 2010).

Full awareness of his condition contributes to the involvement of the patient and his active participation in improving the quality of life (Jablonski 2007). At the same time, the information provided should be extremely clear and unambiguous in order to avoid conflict situations (Hallock 2014). Also, one should not forget that it is necessary to train not only the patients themselves, but also members of his family, since with the advent of a dialysis patient in the family, it is necessary to change the way of life for the whole family (Covic et al. 2010).

It is important that the sources of information should not only be medical workers, but also other patients, which is very important for newly arrived patients (Bonner & Lloyd 2012; Sondrup, Copland, Black, & Trask 2011). More experienced patients can share their experiences and give some necessary advice on lifestyle, diet, and self-control methods (Beto et al. 2016). However, most patients at the beginning of dialysis therapy want to know only a little about their condition, because it seems difficult for them to absorb a large amount of information all at once; they prefer to learn gradually and in small doses (Bonner & Lloyd 2012; Davison & Cooke 2015; Griva, Li, Lai, Choong, & Foo 2013). At the first stage, too much information can

frighten a person and put him in a state of depression, so it is necessary to develop minimum criteria for "beginners" (Hawamdeh et al. 2017).

On hemodialysis, the patient must develop self-monitoring methods for himself (Liu, Kim, Jung, Arisy, Nicdao, Mikaheal, Baldacchino, Khadra, & Sud 2017). However, there are no clearly defined methods in the literature; there are only general recommendations that do not quite fit dialysis patients (ibid.; Horigan, Schneider, Docherty, & Barroso 2013; Jablonski 2007). The training of patients on hemodialysis should continue and include knowledge of self-monitoring, as well as ways to maintain optimal conditions for concomitant chronic diseases (diabetes mellitus, hypertension), hygiene, sleep, rest, and nutrition (Horigan et al. 2013). However, family members need a greater understanding of these issues, since at first, they will be responsible for changes in the lifestyle and routine of dialysis patients (Covic et al. 2010).

According to a study by Bonner and Lloyd (2012), patients with terminal stage of kidney disease are divided into two types of information perception: one passively accepts information provided by health professionals; others actively ask questions and look for information in various sources. Patients rely on the support of their families, but do not want to become a burden to them. In view of the active support of families, it is necessary to try to raise public awareness of hemodialysis and to educate health professionals about the importance of interaction with families of patients. (Al Nazly et al. 2013.)

In the Republic of Kazakhstan, the Order of the Ministry of Health of the Republic of Kazakhstan is in force as of December 30 2013. The order №765, "On the approval of the standard for the provision of nephrological assistance to the population in the Republic of Kazakhstan", describes the types of diagnostics, stages of development of kidney diseases, treatment methods and protocols for managing patients on renal replacement therapy, and preparations for kidney transplantation. In accordance with this Order, each patient who initiates dialysis therapy should become familiar with the dialysis patient's reminder, presented in Appendix 2.

### 3.2 Patient Safety Issues of Dialysis

At the beginning of hemodialysis patients are faced with specific problems that need to be addressed both by patients and their relatives and the health care system as a whole. This includes self-awareness of patients and their learning. (Plantinga, Tuot, & Powe 2010.) Lack of knowledge and understanding of the course of their illness gives patients a sense of their own helplessness and impotence (Aasen, Kvangarsnes, & Heggen 2011).

The number of patients with CKD is steadily growing (Devi, Prabhu, Bhanumathi, Sequiera, Mayya, Bairy, & Mohan 2012). Dialysis patients come in differing in the severity of their illness and needs. Therefore, it is necessary to improve the quality of education of patients that leads to their involvement in the treatment process, which makes them more competent to track their emotional and physical states. (Neyhart et al. 2010.) This, in turn, contributes to the development of self-sufficiency and independence in this category of patients.

According to the results of the Thomas-Hawkins and others' study (2010), a patient on dialysis may pose a threat to their own safety. This is due to the following factors: requirements for staff (patients are often asked to hurry up), non-compliance with safety regulations during dialysis (absence of limb immobilization with AV-fistula, shelter from visual inspection, etc.), lack of knowledge, and non-participation in care. Lack of knowledge about the illness and lack of participation in the treatment process indicate the unpreparedness of patients for hemodialysis (Thomas-Hawkins, Flynn, Lindgren, & Weaver 2015; Neyhart et al. 2010). The emergence of fear and disbelief in the loss of kidney function can aggravate the patient's condition (Bindroo & Challa 2019).

### 3.3 The Role of the Nurse in Pre-Dialysis Education

Currently, CKD is one of the most important problems in the health system of developing countries. The lack of necessary knowledge about prevention and care measures among the population increases the importance of nurses in this field. In this case, the work of nurses is aimed not only at preventing the disease, but also in

preventing the development of complications, as well as encouraging healing / improving well-being. (Nobahar & Tamadon 2016.)

Thus, four levels of preventive measures are distinguished: primordial prevention, primary prevention, secondary prevention, and tertiary prevention. At each stage, there is elimination of various risk factors for the development of the disease or its complications. At the stage of tertiary prevention, all efforts and developed programs are aimed at improving the quality of life of patients. This is achieved by the following measures: adequacy of dialysis, regular examination, diet therapy, treatment of concomitant diseases, compliance with the adequacy of physical activity, regular psychological and social counseling, as well as consultations of various health professionals. (Adhikari 2011.)

In preparation for hemodialysis, the nurse plays a central role (Walker et al., 2010). A qualified nurse must have critical thinking, know approaches to solving emerging problems, help to find the best solution for the patient and his family, and help to improve the patient's health and quality of life (Gaughey 2009). The nurse helps to improve the life quality of hemodialysis patients, and their tolerability to the procedure (Walker et al. 2010). In this regard, Walker and others (2010) identifies five main roles that a nurse performs. **A holistic assessment of patients** on pre-dialysis prepares for timely referral to hemodialysis, identification of needs, assessment of self-care capacity, housing and social conditions, and patient education. A personal acquaintance with the patient makes it possible to make a holistic assessment of the patient to determine the individual monitoring regime for each patient (Center for Clinical Standards and Quality/Quality, Safety & Oversight Group 2018). Exchange of contact information enables the nurse to keep in touch with the patient and answer questions that arise. **A nurse as an educator** trains and supports the patient at the stage of preparation and receiving of renal replacement therapy. In the new conditions of life, the nurse provides patients and his family with all the necessary information about the disease: the process of the disease, the impact on life, the possible consequences, facilitates patient's adaptation to a new state, to the information received, and answers emerging questions about both medical and social aspects. In this role, the nurse can conduct group sessions with patients and their relatives, which significantly reduces the time spent, and also

positively affects dialysis patients by meeting with other patients and sharing experiences, communicating with each other. The nurse trains and monitors the patient's condition, all vital signs, thereby **preventing** the development of possible complications. At the same time, the care plan is constantly adjusted to meet the newly emerging needs of the dialysis patient. Therefore, the work of a nurse develops her professionalism by working in a multidisciplinary team with various specialists in health care and social protection service. (Garbin & Chmielewski 2013; Tulebayev et al. 2016.)

A nurse has an important role as a controller for performance of physical exercises by patients during hemodialysis. Intradialysis exercises contribute to maintaining the physical health of patients (Painter, Carlson, Carey, Myll, & Paul 2004). A study by Bennett and others (2016) showed the ratio of nurses for the physical exercises of patients on hemodialysis. From the perspective of nurses, there was an incomplete awareness of their responsibilities and, accordingly, little control over patients. It should be noted that this process requires the participation of physiotherapists who develop individual exercise programs for each patient during the hemodialysis session. Nevertheless, these issues directly depend on various financing programs and the organization of the health system in general in different countries (Schütte, Acevedo, & Flahault 2018).

It is necessary to constantly develop and improve the **role of a nurse** caring for dialysis patients, as this is a complex and creative work that requires constant development of professional and personal qualities of a nurse (Shahdadi & Rahnama 2018). The nurse looks after the patient in the dialysis department, and this builds the nurse's confidence as the source of necessary and useful information (Leatherland 2007). Nurses play an important role in obtaining, understanding and using information. During dialysis, patients constantly interact with nurses, and with doctors only occasionally (Bonner & Lloyd 2012).

A nurse has a direct impact on a patient with kidney disease (Hopkins, Kott, Pirozzi, Deppoliti, Pond, Randolph, Zajac, & Côté-Arsenault 2011). Understanding the needs and daily difficulties of dialysis patients helps health workers improve the quality of life of dialysis patients (Al Nazly et al. 2013). Qualified nurses become active

participants in the life of the patient. They help in making difficult decisions. It is nurses who are called upon to provide patients and their families with complete information for making an adequate decision both at the pre-initial stage and at all subsequent stages of receiving renal replacement therapy. (Loiselle 2011.)

Long-term survival and quality of life of dialysis patients directly depend on both the adequacy of the hemodialysis program and the ongoing care plan (Lim, Ng, Cheng, Cigolini, Kwok, & Brennan 2016). Caring for patients with kidney failure includes the following: nurse prepares a plan for caring for dialysis patients, explains to them and their families the need for hemodialysis and the importance of protecting vascular access sites, as well as fluid management and adherence to diet and exercise. (Allsopp 2011.)

## **4 Purpose, Objectives, and Research Questions**

The purpose of this study is to improve the quality of nursing by creating recommendations for preparation of patients with end-stage of chronic renal failure and their family members at the beginning of dialysis to reduce the risk of complications and improve quality of life.

### **Objectives:**

1. Study experience and basic needs of patients in preparation for hemodialysis.
2. Develop and justify nursing recommendations for counseling patients and their families at the beginning of hemodialysis.

### **Research questions:**

1. What are patients' and their relatives' views on the experiences, basic needs of patients with end-stage of chronic renal failure to create recommendations for nurses to prepare patients and their families for dialysis?
2. What are nurses' and nephrologists' views on the experiences and basic needs of patients with end-stage chronic renal failure to create

recommendations for nurses to prepare patients and their families for dialysis?

## **5 Methodology**

### **5.1 Qualitative Research Approach**

Qualitative research methods are used in social sciences, in particular management and care. Qualitative research attempts to explain human behavior, and to study the causes of such behavior. The purpose of conducting qualitative research is to interpret the behavior and interaction of people in society. (Topping 2015, 159-161.) Studies in nursing are often qualitative. This is due to the evaluation of the quality side in the provision of nursing care (Research in Nursing 2019). As this study was aimed at studying the lived experiences of nursing care for patients with terminal stage CRF in order to learn about patients' needs in preparation for dialysis therapy, qualitative approach is justifiable and gives opportunity to reveal both needs and existing experience of patients in this preparation.

Qualitative research makes observation and develops theory (Jamshed 2014). Qualitative research provided an opportunity not only to collect complete and in-depth information about the needs for pre-dialysis preparation of patients and their families, but also an opportunity to observe respondents, their behavior, reactions to various issues related to their illness (Austin & Sutton 2015). In this research, this is the most important component because it contains sensitive aspects of dialysis therapy. Therefore, the type of research approach for this study is a qualitative one.

### **5.2 Interview as a Data Collection Method**

Interviews are used as a tool of collecting data for both quantitative and qualitative research. Interviews are the most common form of data collection in qualitative studies (Holloway & Wheeler 2010, 87). Interviewing provides an opportunity to collect information about expectations and feelings; preferences of respondents, their experience, and life position, and so on (Edwards & Holland 2013, 1-2). This, in turn, gives a complete picture of the issue of interest and makes possible, after a detailed analysis of the data obtained, to formulate a theory and recommendations



for preparation for dialysis. Therefore, this method has become the most widely used among researchers of quantitative and qualitative data. (Tod 2015, 387.)

Interviewing has been chosen as a tool for gathering the required data in studying patients' needs for dialysis preparation and their families at the level of nursing service.

The application of the interview method enables the researcher to study more deeply the participants in the study. For a deeper study, unstructured and semi-structured interviews are used. It is these types of interviews that are most often used in health and nursing studies (*ibid.*, 391). Semi-structured interviews are used when the researcher has some information about the issue under study (Ploeg 2008, 53-57). Structure of such interview allows to define certain questions that can be open or closed. The researcher guides the interviewee to get maximum information about the area of research and reduces opportunities for discussions on irrelevant topics. This type of interview is often used in nursing research (Bryman 2011, 468-499).

A semi-structured interview provides an opportunity to gather information about the socio-demographic situation of patients and their families and their wishes for teaching patients before the onset of hemodialysis. In addition, a semi-structured interview in this study provided an opportunity to collect the necessary data, while saving time and avoiding the collection of unnecessary information. This was because the researcher asked questions during the free conversation, sending the respondent to receive the necessary information (Yadov 2003, 263-298). Nevertheless, it should be borne in mind that these questions did not interrupt the participant's story.

There are various ways of conducting interviews: face to face, polling through phone or online resources, and online surveys (Tod 2015, 391-392). Considering age features, a face-to-face interview was chosen as the preferred method of interviewing, which provided an opportunity to collect more accurate and complete information, to build a more trusting relationship between the researcher and the respondent, which also gave confidence to the respondent about the non-disclosure of personal data and personal experiences. In this situation, respondents felt more at ease and shared information they preferred to keep silent about when there were

witnesses. It is also worth noting that online surveys and e-mail interviews would have been quite difficult to conduct among the selected category of people. This was because not all respondents among the selected category of patients had computer literacy. (Information and communication technology 2019.)

Thus, as a data collection tool for this study the method of interviewing was used. It should be noted that when conducting qualitative research, it was possible to revise the questions in accordance with the receipt of new ideas and to conduct a conversation again (Holloway & Wheeler 2010, 88). So, the researcher could use different techniques for asking questions. Part of the questions were aimed at studying the respondent's experience. Other questions were aimed on revealing the feelings of the participants, and the third part studied the knowledge that the participants of the study have in the area under study. It was also asking questions aimed at studying information on a wide-ranging (grand-tour) and more specific issues (mini-tour). (ibid., 91.)

Approximate questions for interviewing patients, their relatives and nurses are presented in Appendix 5, which are necessary for interview planning and subsequent data analysis. It was important that the wording of the questions in the interview were changed depending on the response of the study participants and on new issues arising during the current or previous interview. Thus, new questions could arise during the interview, so there were no clearly formulated questions in advance. In accordance with this, there was no similar interview, i.e. each interview was differing from the next one on its questions and duration. However, the first part of the interview was structured since it was necessary to identify general social and demographic data of the patients (age, duration of chronic diseases, timing of CKD detection, dialysis start date, duration of dialysis therapy).

The Republic of Kazakhstan is a secular democratic state with a population of more than 18 million people (Main socio-economic indicators 2019). In accordance with the Law of the Republic of Kazakhstan of July 11, 1997, No. 151-І "On languages in the Republic of Kazakhstan" (Ministry of Industry and Infrastructure 2019), the Kazakh language is the state language - "the language of state administration, legislation, legal proceedings and records management, operating in all spheres of

public relations throughout the territory of the state". At the same time, the population of the Republic has varying degrees of knowledge of the Kazakh language. Therefore, the interview language is determined by the respondent himself - Kazakh or Russian. Kazakhstan is a multi-ethnic state, speaking several languages, and quite often there are people who prefer to mix two languages.

For this research, the mobile voice recorder and making notes were used as methods for collecting data. Recording the interview helped to preserve all the words and comments of the participants, as well as questions of the researcher. Thus, loss of data during analysis was excluded. This provided an opportunity to collect the complete information needed in this research for each participant and conduct a qualitative analysis of the data. In addition, it allowed the researcher to observe the interlocutors during the interview, to establish eye contact without loss of data. (Holloway & Wheeler 2010, 95.) The recording was particularly important when conducting interviews in different languages. It was possible to analyze the responses of participants with a deeper understanding of their speech and language characteristics.

It should also be noted that important memories and facts could often be heard after the interview was over and the recorder was turned off. In such situations, it was important to maintain field notes immediately after the interview. After the end of the interview, the researcher could also record his comments, live impressions, and possible questions for further clarification on the same record. (Yadov 2003, 263-298.)

Considering the contingent of respondents, it was preferable to take notes before and immediately after the interview, since taking notes during an interview could somewhat offend the respondents, and did not allow direct observation of their behavior, eyes, motor reactions and emotional state. Distracting the attention of the researcher to notes can interfere with the development of a trusting relationship with the participant (Holloway & Wheeler 2010, 97), which could lead to the collection of untrue information or the refusal to participate in the study. In the field notes immediately after the interview situation, it was necessary to note moments

such as the description of the situation, the features of behavior, the general reactions to interviews from respondents, and the features of speech, etc.

All received information was stored in the form of audio records in a folder accessible only by the researcher himself, as well as in the form of a transcript of the verbal information with all verbatim statements of the research participants and the nature of their speech (Yadov 2003, 263-298). This did not allow any editing. In the transcript, it was necessary to reflect all the pauses, intonations, emotional interjections. This helped the researcher as much as possible during the processing and analysis of the data obtained.

### 5.3 Data

In this study, the source of information was the data obtained during the interviews. The participants were patients of the hemodialysis center, their relatives, nephrologist, and nurses of the dialysis center, who gave their written consent for the interview. Respondents in this study were from one hemodialysis center in Almaty. As a source of information, the dialysis center of "Zhasandy Buyrek" LLP was chosen. This center was chosen, since it covers patients with hemodialysis from all corners of the city of Almaty and depending on the period and resources of the researcher himself.

For the selection of participants, certain inclusion and exclusion criteria were selected, which are presented below for each group of respondents (patients, relatives, nurses, nephrologists).

For patients:

Including: Important characteristics of patients: gender – did not matter; age – adults; residents of Kazakhstan, at least 3 months of hemodialysis.

Gender. For the research, the gender did not have an important meaning because the end-stage of CRF is the result of different chronic diseases.

Age. Adult people can give objective information.

Residents of Kazakhstan. The participants of the research should be residents of Kazakhstan because they have all the benefits provided by the state.

At least 3 months of hemodialysis. These patients could formulate their difficulties of life with dialysis. The first months of dialysis are the most difficult because of the challenge of accepting a new style of life for patients and their family members.

Excepting: patients who did not give their agreement to take part in the study.

These criteria were due to the need to focus on the patients' needs and wishes, not the researcher's objectives. It was very important to collect good reliable data for the research for the study to have practical significance. Therefore, the findings needed to be truthful.

For patients' relatives:

All without exception, relatives of patients who expressed a desire to participate in the study.

For nurses:

Nurses who had at least six months of experience at the time of the interview and who had agreed to participate in the study. This choice was because in the absence of proper experience with dialysis patients and communication with their relatives, the nurse could not provide the necessary information to the researcher. The year of work in the dialysis center provided more accurate and reliable information, which was a very important aspect in conducting a qualitative study.

For nephrologists:

All without exception, nephrologists who expressed a desire to participate in the study.

#### 5.4 Ethical Issues of the Research

This study is a qualitative research in the field of nursing care. Interviews were conducted with patients who were receiving hemodialysis, their relatives, and nurses and nephrologists at one of hemodialysis centers in Almaty to collect the necessary

information. For this purpose, at first, access to the respondents was obtained (Research Ethics Guidebook), second, consent of the respondents to participate in the study (Code of Ethics 2018).

The data was collected by interviewing. To start data collection, it was necessary to fully define all stages of the study and prepare a plan according to which the entire study was carried out. Before the data collection began, it had been necessary to develop a thorough research plan and receive approval for the next stage from the side of scientific leaders.

In order to come directly with interviews to the participants of the study, at first it was necessary to formulate approximate questions that helped to collect the necessary information for research. Further, it was necessary to submit the study plan to the Local Ethical Commission for approval to conduct the study. Since this study was directly related to living people, it was necessary to go through an ethical committee to harmonize all ethical norms and rules for conducting research with people. For this, it was necessary to prepare an application for conducting an ethical review of the research papers on the research topic (Appendix 3); a study protocol specifying the purpose, objectives of the study, and a brief annotation (Appendix 4); an indicative list of questions for interviewing (Appendix 5); the form of a cover letter to the host organization with a request to participate in the study (Appendix 6); and a form of informed consent to participate in the study (Appendix 7). Permission of the Local Ethical Committee was received in April 2018, protocol 1 from April 20, 2018. Only after receiving a written opinion authorizing the study with living people, according to ethical norms and rules, data was collected. (Research Ethics Guidebook.)

To gain access to patients and employees of the hemodialysis center, the permission was obtained from the management of the center. To do this, it was necessary to conclude an agreement on the cooperation of the researcher, the head of the study, and the host organization (Appendix 6). After receiving the official agreement for the study, cover letters were sent to the dialysis center to determine the voluntary participants. This cover letter (Appendix 6) contained information on the purpose of the study, the ethical aspects of this study, the safety of the information received,

and the contact details of the researcher and his supervisors. Each participant who had expressed a desire to participate in the study was asked to read and sign an informed consent to participate in the study. Informed consent (Appendix 7) was a document in which the participant expressed his / her voluntary consent to participate in the study, acquaints himself / herself with his / her rights and duties, and gave his / her consent for interviewing and using the data obtained for research purposes.

Before the beginning of a semi-structured interview, participants were fully informed of the purpose and objectives of the study, the form of the interview, the methods of recording the information received, the rights of the study participants, and the possibility of rejection at any time. Thus, consent or refusal to carry out this method of gathering information was obtained from the interlocutor. The consent of each participant (Appendix 7) was required for involving him / her in the study, recording the interview in various ways, and using the information obtained for data analysis. In this case, each participant was informed about the security measures and the safety of their personal data, as well as the right to terminate their participation in the study at any time at the request of the participant (Appendix 6).

In the case of a refusal, the respondent was not interviewed. In the case of a written consent for data collection and processing, the respondent was interviewed using audio recording as well as the researcher's notes, in order to avoid the loss of any data and more in-depth study of the information received.

The interview was conducted in compliance with ethical rules and norms: autonomy of personality, voluntariness, vulnerability and justice, and confidentiality. Thus, the implementation of the principles of biomedical ethics in this study were: non-disclosure of personal data, a respectful attitude to patients and their families during interviews, reckon with the opinion of the patient and his relatives, and in the case of a patient's desire to stop the conversation, immediately fulfill his wish.

## 5.5 Data Collection

Data was collected between September and November 2018. General information about the study was given on meeting with the administrator and by an information

paper (Appendix 7). All respondents who agreed to take part in the research signed an informed consent to participate in the study (Appendix 7). Every one of them chose the time and place of the interview. Most of the medical staff and patients decided to have interviews at the dialysis center. Four groups of respondents took part in the research. For medical workers, the interview began with the general question "How long have you been working in the dialysis unit?" And for patients and their relatives, the interview began with the general question "How long have you had to deal with dialysis?"

The first group of respondents are dialysis patients from one of the dialysis centers in Almaty. Seven patients agreed to participate in the study and answered all questions during the interview. Written consent was received for recording all seven interviews. All respondents were interviewed personally at the dialysis center "Zhasanda Buirek". One patient was interviewed before starting dialysis, five expressed a desire to conduct an interview during the dialysis procedure, one patient wished to be interviewed after dialysis. The total duration of all recorded interviews is more than 120 minutes. The average interview duration was 18 minutes. In this case, the longest interview was 26 minutes 10 seconds, and the shortest 8 minutes 42 seconds. All interviews with dialysis patients were converted into printed text. Total number of pages of the printed text was 38 pages, Calibri font, space 1.5.

It is worth noting that the longest interview was conducted with a patient who expressed his desire to answer all the questions before the start of the hemodialysis procedure, as he approached earlier than his time and had time while his apparatus was preparing for the procedure. Shorter interviews were collected from patients both during and after dialysis. After dialysis, the patients were not particularly talkative, which affected the amount of information collected. By the end of each interview, it was quite clear for the researcher that the patients would like to complete the conversation already.

The second group of respondents are relatives of dialysis patients. Five respondents expressed their consent to participate in the study and answered all questions during the interview. Unfortunately, not all relatives agreed to record the conversation. Therefore, only one audio recording was taken, for which a written consent was



obtained. The duration of this interview was 13 minutes 25 seconds. Interviews with the other respondents were transcribed during the interview. Also, after a personal meeting with each of the respondents, verbal consent was given to continue collecting information through any convenient method for them. Thus, with a shortage of necessary information, three respondents were further polled by means of WhatsApp. Answers were provided in the form of audio and text messages. All the information obtained in this way made it possible for a more detailed analysis of the data. The audio recording was translated into text format, all recordings were printed and prepared for further analysis. In general, the printed text of interviewing relatives of dialysis patients was 14 pages, Calibri font, space 1.5.

The third group of respondents are nurses of the nephrology department and dialysis center. Five nurses gave their consent to participate in the study and answered interview questions. However, only one nurse agreed to audio recording. Therefore, four interviews were recorded manually. All respondents chose their workplace – “Zhasandy Buirek” LLP – during their shift as a convenient time and place, explaining their choice by not wanting to lose their free time to conduct an interview. The duration of the recorded interview was 21 minutes 7 seconds. All respondents tried to respond quickly and succinctly enough, were constantly distracted by their work affairs, and at the end, even showed signs of some restlessness and asked to complete the recording as soon as possible because they needed to return to their work duties. All interviews with nurses were converted into printed text. The total number of pages of the printed text was nine pages, font Calibri, and space 1.5.

The fourth group of respondents are nephrologists. Five doctors gave their consent to participate in the study and were interviewed. All respondents chose the convenient time and place – “Zhasandy Buyrek” LLP – in the afternoons, i.e. after the end of their official working day. Only four doctors agreed to the recording, therefore the interview of one of the nephrologists was recorded manually with his consent. The average interview duration was about 23 minutes. The longest interview was 30 minutes 5 seconds, the shortest 19 minutes 2 seconds. All interviews with nephrologists were converted into printed text. Total number of pages of the printed text was 28 pages, Calibri font, space 1.5.

## 5.6 Data Analysis Method

Content analysis is one of the widely used methods for conducting qualitative research. Qualitative content analysis is widespread in nursing research (Elo & Kyngäs 2008). Content analysis is a method of analyzing written and verbal messages, aimed at summing up various forms of content by counting its aspects (Research Methodology 2018). In this study, content analysis of text data was conducted to interpret the general meaning (Hsieh & Shannon 2005).

Like any other method of analysis, content analysis has its advantages and disadvantages. According to Bryman (2011, 304-306), the following advantages of content analysis are highlighted: the transparency of the research method due to the clearly formulated coding scheme and sampling, and that the flexibility of the research method makes it possible to apply it to various types of unstructured information. To disadvantages, it was (ibid., 306) related the following: the quality of content analysis depends on the quality of the analyzed material. In this case, the analyzed documents must meet certain requirements: authenticity—the relevant content of documents, reliability—no distortions in the content of documents, representativeness. When encoding material, it is necessary to adhere strictly to the accepted encoding rules and to minimize the subjective opinion of the encoder.

There are two approaches to conducting content analysis: inductive and deductive (Elo & Kyngäs 2008). In this study, inductive content analysis was used. This method of analysis is determined by the purpose of the study—to improve the quality of nursing by creating recommendations for the preparation of patients with end-stage of chronic renal failure and their family members at the beginning of dialysis to reduce the risk of complications and improve quality of life. In this regard, the data was considered from private to general, that is, during this study, certain stories from the lives of patients, their relatives were analyzed, and general statements derived (Chinn & Kramer 2011, 11).

Inductive content analysis allowed analyzing the interviews of all participants in the study, and the analysis was carried out for each group of respondents separately. It gave an opportunity to identify the main categories and needs for each group that further facilitated the development of criteria for the preparation of patients and

their relatives for dialysis by nurses. When working with the data, all information was depersonalized and encrypted to achieve an objective analysis of the data. All collected information was translated from a digital format into text format as a transcript of the speech information with the transfer of all the emotional tones of speech.

Steps of content analysis (according Elo & Kyngäs 2008) included: preparation of data, defining the unit or theme of analysis, developing categories and coding scheme, coding all the text, assessing the consistency of coding employed, drawing inferences on the basis of coding or themes, and the presentation of the results (Datt 2016).

Total number of pages of the printed text was 89 pages, Calibri font, space 1.5. The process of inductive content analysis is shown in Appendix 8. After studying the entire text, 696 codes were allocated as well as 35 subcategories, which were combined into 11 categories and four abstractions were selected for each group of respondents separately (Appendices 9-12). Abstractions were analyzed to derive two separate views to the development of recommendations in accordance with research questions.

Group of patients. After the content analysis of the interviews with the first group of respondents, 254 codes were received, 28 sub-categories, seven subcategories, two categories and an abstraction were derived (Appendix 9). The main category that was derived during the analysis of interviews with patients is the following: for further qualitative development of the dialysis service, it is necessary to actively conduct pre-dialysis training jointly with patients with chronic renal failure and with relatives.

Group of relatives. During the content analysis of the interviews with the second group of respondents, 86 codes were received, 22 sub-categories, nine subcategories were selected, of which four categories were defined further (Appendix 10). The main category that was derived during the analysis of interviews with relatives of dialysis patients is the following: the need for psychological help and counseling for patients and their relatives before and at the beginning of dialysis.

Group of nurses. During the content analysis of the interviews with the third group of respondents, 79 codes were received, 13 subcategories were identified, and three categories were selected (Appendix 11). The main category, which was derived in the course of the analysis of interviews with nurses, is the following: effectiveness of regular counseling of patients and their families at the pre-dialysis stage.

Group of nephrologists. During the content analysis of the interviews with the fourth group of respondents, 277 codes were received, 32 sub-categories were identified, of which six subcategories were defined further and two categories were selected (Appendix 12). The main category, which was derived in the course of the analysis of interviews with doctors, is the following: pre-dialysis training helps to reduce possible complications of dialysis issues.

## 5.7 Reliability and Validity

Quality evaluation of the study had great importance (Noble & Smith 2015) because the obtained results were necessary for practical public health. Reliability and validity in qualitative research were called upon to answer the following question: "Does the data reflect the truth?" (Polit & Beck 2004, 430). Evaluation of reliability and validity of qualitative research (Noble & Smith 2015) requires the application of critical tools for evaluation of the research. The tools used in this research were validity and reliability.

**Validity** means that the research is justified and reflects the real situation (Leung 2015). According to Azeem and colleagues (2015), the validity of qualitative research cannot be determined by evaluation of participants and real social phenomena. Various methodological strategies (Noble & Smith 2015) are used to ensure the validity of results of qualitative research (Maxwell 2005, 105-106; Leung 2015). In this research, according to Darawsheh (2014), personal prejudice was ignored by the author in order to exclude the impact on results of the research and was constantly keeping critical attitude for provision of reliability at all stages of the research and ensuring deep and correct data gathering and analysis.

The author of the research gave full description of the research methodology in order to increase the reliability of the research, presented detailed description of the

research participants, and provided results of the content analysis (Appendices 8-12). The researcher determined four groups of respondents who could give important information for the research and who are personally familiar with the dialysis therapy, not by hearsay. These groups are dialysis patients, their close relatives, and nurses and doctors of the dialysis center.

**Reliability** is quite a difficult objective considering uniqueness of each planned interview. One person conducted all the interviews in order to ensure congruence of the results. During coding, all the obtained material was transcribed and openly coded by the researcher under guidance of scientific advisors (Appendix 8). Phrases were chosen to be the unit of the analysis that were optimal choices for coding of the obtained research results. The data was grouped until all doublings of meanings were eliminated and absolute difference between categories was achieved. Validity of the obtained data was warranted by the fact that one researcher performed the interviews and interpreted the gathered data as this helped to avoid prejudice and limitations of other people in the process of data collection. The interviews were digitally audio recorded for the purpose of gathering and analysis. Moreover, all the anonymous records were submitted to a second party for analysis (Bucknall & Aitken 2015, 450).

Interpretation of the obtained data was conducted in accordance with the purposes of the research. Two main views for developing of recommendations for pre-dialysis preparation of patients and their families were determined: nurses' and nephrologists' views and patients' and their relatives' views. Also, general recommendations for preparation of CKD patients and their family members were proposed for the beginning of the dialysis therapy. Interpretation of the data is not a researcher's fiction as it is proved by citations from interviews of a relevant respondent group (Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs 2014).

A semi-structured interview method was used for gathering of necessary data. The respondents were often speaking not only about certain topics but sharing their life experience, emotions, difficulties, and support from people around them. A pilot research was organized in order to maximize receipt of inductive data (Elo et al. 2014) and not direct respondents during interview.

## **Pilot Research**

In order to improve the quality of the study, a pilot research was conducted in May 2018. A pilot research was needed because the researcher did not have experience in conducting qualitative interviewing. In this regard, in order to gain a thorough understanding of this data collection method, correctly formulate questions, and obtain additional information during data collection, a pilot interview was conducted with several respondents from different groups.

During preparation of the pilot research, administration of the dialysis center expressed its interest in the results of this study. It was also proposed to expand the number of respondents, namely, to add another group of respondents—nephrologists—as earlier, when preparing the study plan, it was planned to interview three groups of respondents, nurses, patients, and relatives of patients. This proposal was explained by the fact that in Kazakhstan at the present time, the main burden of pre-dialysis training for patients with chronic renal failure and their relatives rests entirely on nephrologists. This in turn restricts both scientific and practical activities for the development of Kazakhstan nephrology. At the same time, conducting consulting work on the main issues of pre-dialysis training for both patients and their relatives can be transferred to the functional duties of a nurse. At the same time, patients and their families will not be denied their rights, and they can get a quality consultant in the person of a nurse. Head of the nephrology department expressed the wish that the obtained results shall be implemented in practice, which would provide a great resource for the development of Kazakhstan nephrology.

During the pilot research, two nephrologists, one nurse, one patient, and one relative of the patient were interviewed. All five respondents agreed to participate in the research and signed an informed consent of the respondents. During the interview, the researcher recorded conversations with the consent of the respondent. After each interview, the researcher made some notes on his observations, which were useful at the stage of transcribing and analyzing the data.

As a result of the pilot research, the researcher received great experience in data collection using the interviewing method, which gave confidence, as well as the

ability to identify questions that were useful and necessary in collecting data. The main goal for the researcher in conducting a pilot research was to gain experience in conducting interviews with various categories of respondents, as well as to identify a range of questions that were helpful in obtaining more complete and detailed information for the research.

The researcher conducted interviews by building rapport first in a friendly atmosphere, which led to the reliability of the data obtained. A semi-structured interview allowed achieving the required level of credibility, as interview questions were aimed at identifying certain aspects of people's lives related to their dialysis experience. Examples of interview questions presented in Appendix 5 were based on the material studied and a literature review. During the research, some problems were identified in collecting data through interviewing: difficulty of getting answers, communication skills, and literacy level.

**Difficulty of getting answers.** This problem is that modern society in Almaty is not accustomed to answering many open questions, where it is necessary for the respondent to speak more instead of the researcher". In this connection, respondents often gave very short and scant answers, without much desire going deep into the memories of their experiences. At the same time, the respondents' unwillingness to spend a large amount of time on the interview was an issue. Therefore, a sufficient interview duration of one and a half to two hours was not achieved in this study, and on average took only 10 to 30 minutes, while many respondents began to repeat and show their unwillingness to continue the conversation.

**Communication skills.** During the interview, there was a rather low level of communication skills on the part of nurses. Many of them even noted this fact themselves, expressing their unwillingness to talk and advise patients and their relatives. It is quite difficult both at the stage of gathering information, and at the stage of transcribing and analyzing the data obtained and the fact that many respondents are bilingual and used a mixture of two languages during the interviews. Often, dialysis patients tried not to answer the specific questions of the researcher

but tried to divert the researcher from the main topic, switching to their philosophical topics.

**Literacy level.** Nursing staff noted an incomplete knowledge of research issues. Also, when interviewing nursing staff, a rather low level of proficiency in certain terms was noted both in relation to the research question and on general medical issues. Therefore, it is important for the researcher to keep not only the audio recording of the interview, but also to take notes whenever possible both during the interview and immediately after it, in order to decipher all the nuances that may arise during data collection.

The society is currently not quite ready for a lengthy interview. Not every respondent is ready to share his innermost thoughts and personal experience, despite all confidentiality measures. Unfortunately, the time of the interview does not reach the recommended duration of one and a half to two hours. In this connection, it is necessary to gradually accustom the public to this kind of data collection.

## 6 Results

### 6.1 Participants of the Study

The study involved 22 respondents. Seven of them were dialysis patients, five relatives of patients, five nurses, and five nephrologists. Among the patients were six men and one woman. Average age of respondents was 48–49 years. The woman was of retirement age, two men of pre-retirement age, the other respondents were of working age 25–48 years. On average, patients receive dialysis therapy for six years (from six months to 13 years of dialysis). Among the relatives were two participants of the retirement age, one man and one woman. In addition, three participants were children of dialysis patients. Among the nurses, one man and four women participated in the study. The average work experience of nurses in the dialysis unit was five years. Among the nephrologists were three women and two men. The average age of doctors was 38 years old. The average length of service by a nephrologist was 7 years.



## 6.2 Patients' and Their Relatives' Views on Recommendations for Nurses to Prepare Patients and Their Families for Dialysis

Dialysis patients and their family members who participated in this study expressed their vision on preparing for dialysis therapy, as well as their recommendations and wishes for patients who are at the stage of preparing for renal replacement therapy (see Appendices 9 and 10). To derive a common view for consumers of this medical service, the two main categories of dialysis patient groups and patient relatives were combined, and the following abstraction was obtained—conducting joint pre-dialysis training for patients and their relatives with constant psychological support to improve the provided dialysis care (see Figure 2). Thus, the views of patients and their families **are** considering the possibility of successfully conducting dialysis therapy, provided that the patients with chronic renal failure and their families are trained correctly and timely.

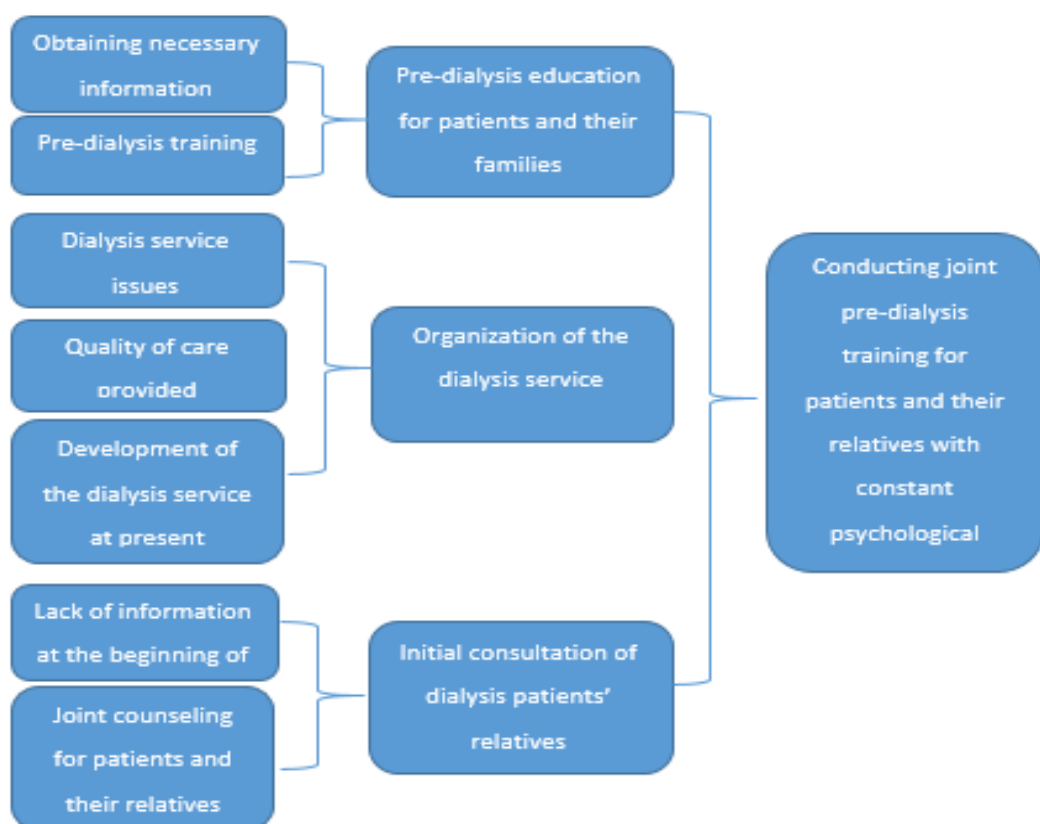


Figure 2. Patients' and their relatives' views on recommendations for nurses to prepare patients and their families for dialysis

### 6.2.1 Pre-dialysis Education for Patients and Their Families

Both patients and their families highlight the great importance of pre-dialysis training for the whole family. This is because many were forced to be acquainted with dialysis in emergencies, when neither patients nor their family members were ready for dialysis. It was this lack of preparation that caused many subsequent problems that all family members had to face.

#### 6.2.1.1 Obtaining Necessary Information

This category consists of several subcategories which enable patients with chronic renal failure and their families to obtain the necessary information. These subcategories are: what need to know and understand before dialysis, patient awareness, pros and cons of dialysis therapy, negative effects of dialysis, help and support for dialysis patients.

**What need to know and understand before dialysis.** This category reveals what is necessary to know and do, according to patients, before starting dialysis. Dialysis patients noted the importance of understanding their condition and also clearly know what is necessary for dialysis therapy. Respondents offered the most important recommendations: a balanced diet, adherence to water-drinking regime, the right attitude to a new stage of life. At the same time, one of the patients emphasized several times the importance of the fact that it is impossible in any case to constantly think about his illness and his condition. It is necessary to look to the future and always remember that life goes on, that there is an opportunity to stay alive. As another recommendation, patients suggested not to dwell on their illness, but to occupy themselves with something, for example, to think of a business, a hobby, think only of good things and drive bad thoughts away.

*"And the most important thing about the disease is not to think. One must live, look ahead." (P2)*

*"I have to do something, do something, I have my own tools at home, I find, although they watch me at home: why do you need it?" (P3)*

All patients noted the importance of making the inevitable lifestyle change. At the same time, the changes relate to food preferences, changes in the daily routine, the need to accept support. With regard to dieting, many patients identified this aspect of life as important, but under the condition, that diet cannot be strictly followed. At the same time, they argued their opinion by the fact that a strict restriction in nutrition only worsens the general psychological state of a person. Therefore, as an option, patients consider some dietary restrictions, but at the same time constantly listen to their body. At the same time, the basic rules apply that one should never forget: you should not overeat, you need to eat fractionally, if you wish, from time to time allow yourself some bans in the diet, but in small quantities.

*"Observe course diet. But how to follow a diet? Observe is not so quite ... little by little, little by little, a little bit of everything, little by little I now eat, eat and don't say that it is there. Who is home eating everything three times a day, I can sit down four times, eat a little five times. Because overeating is the worst thing." (P3)*

*"Therefore, we must already explain to people that they have already adhered to a salt-free diet." (P5)*

*"Do not give a lot of fluids!!!" (P7)*

The next recommendation offered by dialysis patients is to seek medical care in a timely manner, to undergo the necessary examination and treatment in time. According to the opinion, a timely appeal for medical assistance contributes to the maximum extension of the pre-dialysis stage. All respondents noted that if there is a need to start dialysis therapy, then you should not put it off until later, worsening your condition. This will contribute to the safe conduct of dialysis therapy and the preservation of patient well-being. One respondent noted that it is important to retain what you have and release any fears of dialysis therapy.

*"The most important time to receive a course of treatment and examination. What kind of examination the doctor will write, you need to pass such an examination, take the medicine on time, everything will be fine." (P2)*

*"What if there is an opportunity to prolong his life without dialysis as much as possible!" (P6)*

*"The sooner this procedure begins, the easier it will be transferred and not so much as they say will cause a sore." (P7)*

Dialysis patients say that it is necessary beforehand, at 3-4 stages of chronic renal insufficiency, to start teaching people the correct understanding of their condition and gradually get used to a new lifestyle. Because the correct mental attitude, the acceptance of one's condition, and an understanding of the basic principles of diet contribute to the adaptation of dialysis patients to a new life with dialysis. But you should never give up and think that it's all over. All recommendations made by patients are aimed at maximizing the pre-dialysis period, as well as maintaining the well-being during the dialysis period and reducing the development of possible complications of dialysis due to the patients themselves. This, according to dialysis patients, is necessary to know and understand before starting dialysis therapy.

**Patient awareness.** Many respondents noted the importance of obtaining complete information about dialysis therapy and everything connected with it. Relatives of dialysis patients shared their sad experience of the appearance of dialysis in their lives, noting that at the beginning of dialysis therapy they did not have any information about what was happening to the body with CRF and were absolutely not ready for the start of renal replacement therapy. Relatives noted the importance of understanding the diagnosis and treatment. To this end, they wished to be informed about the various types of renal replacement therapy in order to make an informed decision in favor of a particular method. In turn, this reduces the fear of dialysis, which can have a negative impact on the entire course of dialysis therapy.

*"Preparation, of course, it is always and in everything needed ... some community where people meet, facing this problem, and jointly receive information, share, communicate." (R1)*

*"I think it could be like courses, say, like birth courses for expectant mothers." (R2)*

*"Very necessary! It is necessary to tell what it is, for which an approximate principle of work is necessary, so that there is a clear understanding of the need to undergo the prescribed procedures in time." (R4)*

Patient relatives noted the importance of providing care and support between the dialysis patients themselves. They suggested that patients could share their experiences, their history. Moreover, perhaps, to new dialysis patients this experience will help to understand and accept their condition more likely. Also, one of the wishes was to organize the so-called preparation courses for dialysis, in which people can familiarize themselves with the basic rules of nutrition and the regimen, the principles of dialysis therapy.

**Pros and cons of dialysis therapy.** Respondents noted that dialysis, like any other medical intervention, has its advantages and disadvantages. According to the relatives of dialysis patients, the following are the downsides of dialysis: a serious condition after the procedure, restless legs syndrome, sleep and appetite disturbances, inability to have a good rest with your family, etc. At the same time, they also highlighted the advantages of dialysis, in that the person continues to live with his relatives, and that dialysis patients have the opportunity to choose a more convenient schedule of the received therapy with the positive effect of dialysis.

*"... when mom is suffering after dialysis ... it is very difficult for me, I think other patients also..." (R1)*

*"Dialysis is an option to continue living. It is important to start in time so that there are as few complications as possible. Therefore, what can be the attitude! Thanks to dialysis, I have a mother, she is there, talking to me, watching her grandchildren grow up. She is alive!" (R4)*

**Negative effects of dialysis.** Dialysis patients also noted the negative effects of dialysis therapy: a complex emotional state, lack of time to communicate with the family, and the need to purchase expensive drugs at their own expense. Respondents noted that recently there has been a problem of providing dialysis patients with original drugs. Mostly ineffective drugs are given. One of the patients also stated that

because of dialysis, there is no time and energy left for his own family and household chores.

*"Hemodialysis still takes a lot of time from the family. And then sometimes the strength is not enough for a family." (P7)*

*"Now in Kazakhstan we don't give the original medicine. Yes, these are the Nobel company - these drugs do not work at all in our direction. And to us ... That's when the original were, then we did not suffer from pressure. And when now these drugs began to give out, constant pressure. They ... And you have to buy yourself to keep the pressure a little bit." (P5)*

Many respondents noted that they had to face these problems personally, since dialysis in their life began on an emergency basis and there was no time to adapt and get used to a new life right away. Patients declared their absolute unpreparedness for the start of dialysis therapy. Therefore, the first months after the start of dialysis patients noted as a very difficult period in their lives.

**Help and support for dialysis patients.** Almost all respondents noted the importance of additional assistance and support from both relatives and from the state and medical staff. At the same time, patients warmly speak about their loved ones, they say that it is thanks to their relatives that they decided to continue to struggle and live, that it is care and involvement in the life of the family that helps them to distract from their illness. However, one of the patients noted that care and guardianship should not annoy so that patients would not be able to relax and sit down with their families. Patients said it was necessary to think about their relatives, because they have a hard time in this situation.

*"Relatives understand everything. Even myself sometimes ... I know that dialysis is tomorrow, and sometimes I forget that dialysis is today." (P2)*

*"These are the moments, it's all the same, when the attention is paid to you, it's very nice. But too much..." (P3)*

*"Looking at me they suffer, it seems to me that they don't fall of sight... well, it's also hard for them. When I am particularly ill, after dialysis it is sometimes bad for them to look at me..." (P7)*

Also, respondents noted that state support is very important and is manifested in providing patients with dialysis care and necessary drugs, providing the first group of disability, prescribing a disability benefit and, if necessary, appointing a social worker.

*"... the state that we ... are paid for the first group—financial support, we get for the assistant. The rest is all. Hemodialysis come here, more that ..." (P1)*

#### 6.2.1.2 Pre-dialysis Training

This category includes several subcategories about pre-dialysis training. These are: pre-dialysis preparation of patients and their relatives, patient security, and psychological attitude of patients.

**Pre-dialysis preparation of patients and their relatives.** All respondents noted the importance of conducting joint training for patients with CKD and their relatives who can help and support them. To this end, they expressed a desire to know about the causes leading to dialysis, as well as the various problems that develop in patients with health in the absence of dialysis therapy. At the same time, patients suggested that their relatives should retain the same attitude towards them, excluding pity and over-care. Many respondents wanted to know about different types of OST to decide whether a transplant is possible and whether relatives can be donors and choose the best therapy.

*"... when a person starts having kidney problems, then you need to prepare him and relatives." (P6)*

*"I know that this is shortness of breath, excess weight, it is difficult to walk. It is therefore necessary to receive dialysis. This without dialysis cannot in any other way." (P2)*

*"Mother wants to give ... but mother ... she will be 55, too, under the old age, she will be reluctant." (P1)*

*"Oh no, I do not want, I do not want this donor of some kind, why do I need him? How do I know who he is, what he is. And I don't want to leave my relatives ... no, I don't need it, all the more cadaverous, thanks, don't. I'm better on dialysis train." (P4)*

**Patient security.** Respondents noted that currently in the Republic of Kazakhstan, dialysis patients are provided with social assistance from the state in the form of registration of the first group of disability with the payment of pensions, the appointment of a social assistant, the provision of medicines, and the provision of free dialysis therapy. Patients receive therapy with maximum comfort from dialysis centers.

*"... special lifts for the elderly, well, for those whom it is hard to climb." (R1)*

Unfortunately, there are some difficulties with the employment of dialysis patients in view of their basic condition, as well as the specific schedule of dialysis therapy. However, some patients have the opportunity to continue their work experience in conditions suitable for combination with dialysis procedures.

**Psychological attitude of patients.** The respondents separately noted a psychological state of readiness for the start of dialysis therapy. Many patients noted their depression and feelings of despair in the first months, which only aggravated their serious condition. Patients complained about their dependence on the artificial kidney apparatus. At the same time, all respondents stated that with this everything must be reconciled, and they must live on, continuing to interact with their environment.

*"I saw. I understand that for the first time in my life I was depressed..." (P1)*

*"You cannot go anywhere, you cannot go anywhere, because you are limiting everything." (P6)*

*"Well, hemodialysis, I think, is already the limit, which ... you can't get away from this, you have to put up with it and live in peace." (P3)*



Both patients and their relatives noted that communication between patients helps brighten up the time spent on dialysis. Moreover, patients find in the face of each other new good acquaintances; they help each other to cope with certain difficulties.

### 6.2.2 Organization of the Dialysis Service

The quality of organization of the dialysis service is directly dependent on the level of development in the country of the health care system. To assess the quality of care provided, it is necessary to identify the level of satisfaction of patients and their relatives with the organization of the whole dialysis service. This category consists of the following subcategories: dialysis problems, quality of care provided, and development of the dialysis service at present.

#### 6.2.2.1 Dialysis Service Issues

Many respondents expressed their negative attitude towards nursing staff, which is the result of the sad experience that patients have gained living with dialysis. Many of them faced inappropriate treatment by medical staff. Many patients noted that there are doctors and nurses who are unable even to have an adequate conversation with their patients. On the part of the medical staff, patients noted illiteracy and non-compliance with medical ethics and lack of professionalism.

*"See, there, frankly, rudely cost the first time." (P3)*

*"Was she trying to explain to me? She explained after I drove her with a tripod along the ridge! What turns out to be such a disease. If I do not get on dialysis, then I will die ... But she started a little bit from the other side. You die, damn... She almost died before me..." (P6)*

At the same time, patients note that they prefer to talk and receive advice only from the medical staff, and not from the nursing staff. They explain this by the fact that nowadays not every nurse deserves their full confidence, and doctors are usually trusted more.

### 6.2.2.2 Quality of Care Provided

Many relatives noted the different levels of medical care in different medical organizations that deal with dialysis patients. They expressed their dissatisfaction with one of the city hospitals in Almaty. Also, one of the respondents spoke in favor of developing dialysis services in Kazakhstan by studying international experience in the management of dialysis patients and the application of certain aspects in our country. For relatives of dialysis patients, it seems important to timely identify the pathology of the kidneys, provide all the necessary modern equipment and provide qualified medical assistance from all medical professionals.

*"In Almaty, thanks to an organized network of dialysis centers, everything is much more civilized ... I like the way it is organized in Sunkar, and I don't like the way they feel about their work in Kalkaman." (R3)*

*"Professional from the beginning should identify, treat and prevent such a situation." (R1)*

### 6.2.2.3 Development of the Dialysis Service at Present

More than 50% of patients noted that the dialysis service is currently developing, saying that today it has become much easier to receive and transfer dialysis procedures. They also stated that at the present time, each patient can freely choose a dialysis center and his doctor. Therefore, patients expressed a desire to know about the organization of dialysis services in their region.

*"In my opinion, the death rate was high ... well, hemodialysis is much better now." (P5)*

*"... for all dialysis centers so that the patient knows what is happening in another dialysis center." (P6)*

The patients explained their attachment to a particular dialysis center as their preference for choosing a new family, because the medical staff becomes close and dear to them and the relationship is more like a family trip. Patients trust such staff and follow all suggested guidelines.

*"I go out when I get up from hemodialysis, when I get up, they correct my slippers. Daughter, go away, say, I'm still in the state. Aka what are you going through?!" (P3)*

*"And some even care about a special relative, because she knows that she is fighting for life. Like this." (P2)*

### 6.2.3 Initial Consultation of Dialysis Patients' Relatives

All the relatives surveyed noted that at the critical moment their family member was on dialysis was very difficult for them because of their ignorance and misunderstanding of everything that was happening at that moment. Therefore, they considered it necessary to hold consultations on dialysis specifically for relatives, in order to have a deep understanding of the situation that occurred with their family member.

#### 6.2.3.1 Lack of Information at the Beginning of Dialysis

Relatives of dialysis patients noted that the lack of information might play a negative role in the management of dialysis patients. Relatives noted that they did not know anything about the rules of compliance with the diet or about the lists of permitted and prohibited products before the start of dialysis. On the contrary, one of the respondents thought that it would be better to give a product that a person wants and did not think at all that this could lead to rather sad consequences.

*"When the catheter was first made, there the doctor talked about nutrition, even the whole list made up what to eat, what not to eat. Not that it is impossible, but is contraindicated. But we don't pay much attention to him, we eat a little of everything." (R5)*

*"... he believed that hemodialysis is the end, that he has lived with him for two years and all ..." (R4)*

Relatives noted that in many ways it would be easier for them to go through a difficult period of adaptation to life with a dialysis patient, if they were ready for this in advance. One of the relatives said that he didn't even remember whether he was given counseling on dialysis in the first days. Another respondent said that the

information was provided in the first days, but nothing was remembered, as everyone was in despair and was not able to perceive anything.

*"The doctors said something ... but as if in a fog, you know, then everything was so scary and difficult ..."* (R3)

*"I even remember on the 3rd or 4th day of my stay in the hospital I called my relatives and almost cried: how could this have happened?!"* (R2)

Relatives of dialysis patients wished to be fully informed and prepared for the onset of dialysis therapy for one of their family members. They want to receive the necessary information on the care of dialysis patients at home: recommendations on diet, adherence to water and drinking regime, care of fistula, how to provide psychological assistance to dialysis patients, and how to receive social assistance from the state.

#### *6.2.3.2 Joint Counseling for Patients and Their Relatives*

Joint counseling for patients and their relatives is aimed at joint pre-dialysis training of patients with CKD and their families. This category includes the following subcategories: training relatives, the need to change the lifestyle of the whole family, preserving patient activity, and effective communication.

**Training relatives.** Relatives, as well as the dialysis patients themselves, expressed their need for professional advice on dialysis. At the same time, they noted that these consultations should cover such areas of knowledge as providing care for dialysis patients, emergency care in critical situations, and knowledge of possible complications and the risks of dialysis. Relatives of dialysis patients expressed their hope that all these recommendations will help them not to feel helplessness in the future and will be able to provide full care and help to their relatives.

*"... tell what it is, how to behave, how it can help, how to change lifestyle, what risks, options, opportunities can be..."* (R5)

*"It is very difficult to see when mom suffers after dialysis and at the same time does not know how to help."* (R1)

*"We need to talk in advance about these dangerous conditions and treatment options!" (R4)*

**The need to change the lifestyle of the whole family.** First of all, the relatives wanted to know that with the advent of the dialysis patient in their family, there is an urgent need for lifestyle changes for absolutely all family members because this fact concerns the planning of family time and may even entail difficulties in a full-fledged working day. Relatives noted that they often have to change jobs or work schedules in order to accompany patients on dialysis. At the same time, family members are forced to create a safe and comfortable home environment for dialysis patients in which the person can rest.

*"Husband was tied to the dialysis schedule for a while because he took his mother to the procedures and we could not leave for a long time..." (R1)*

*"Now we have a night light at night just in case, suddenly something will be needed so that mom does not stumble and does not hurt herself once again... if at home conditions are fully created for the patient..." (R4)*

Therefore, many respondents said that a dialysis patient in a home is a rather difficult life for the whole family, especially in the first months after starting dialysis therapy, in addition to the fact that all family members need to adapt to the schedule of dialysis. It is important not to be discouraged so that at any moment there is an opportunity to support your loved one.

**Psychological problems of dialysis patients.** With the advent of a terrible disease in a person's life, all values in life are re-evaluated. With the onset of dialysis therapy, many psychological problems arise in patients. This is the unwillingness to continue life as a disabled person of the first group, the difficulty to continue adequate communication, and the awareness of oneself as a heavy burden in one's own family. These psychological problems are associated with the unstable nervous system of patients. They become more labile and subject to sudden mood swings.

**Preserving patient activity.** Almost all respondents noted the importance of maintaining the physical activity of dialysis patients. They explained their opinion by

the fact that an adequate “motor mode” helps to improve well-being, and also makes it possible to feel toned and gives a lot of strength to dialysis patients. This in turn helps to reduce the unpleasant effects of dialysis, such as disturbed sleep and appetite. Relatives also noted that adequate physical activity stimulates the human body not to gain excess weight and thus maintain its shape.

*“...what exercises are best to do in the days of dialysis...” (R4)*

*“It is important for me to know that she was, there was an improvement, that her sleep returned to normal, normal was that nothing bothered her... Just so that it does not gain weight, the main.” (R5)*

**Effective communication.** Respondents stated that it is very important for dialysis patients to continue communication with their environment. At the same time, they understand that the presence of dialysis in life somewhat limits movement in various social meetings and can even completely exclude them from the lives of heavy patients. However, it was said that currently there are various ways of communication for all.

For many of the relatives surveyed, it is sad that the restriction of mobility affects the ability to travel. In their opinion, this problem arises due to the difficult transportable state of dialysis patients. Another reason is the availability of dialysis in various regions and countries.

*“Actually, it depends, just more communication is necessary with her. And here she is sitting alone at home, not going anywhere, but she also wants to talk, find out what's going on with relatives, how they are doing. Mostly need more communication.” (R5)*

*“... to go to the next town the problem must be met in the days without dialysis, to seize the moment when the patient can safely transfer the road.” (R3)*

### 6.3 Nurses' and Nephrologists' Views on Recommendations for Nurses to Prepare Patients and Their Families for Dialysis

The nurses and nephrologists of the dialysis center expressed their wishes and their vision on the management of the pre-dialysis period of patients with chronic renal failure (see Appendices 11 and 12).

To derive general trends, the two main categories for the nurse group and nephrology group were combined and the following abstraction was obtained—pre-dialysis training and regular counseling for patients and their families prevent dialysis complications (see Figure 3). Thus, the nursing view is considering the possibility of successfully conducting dialysis therapy, provided the patients with CKD and their families are trained correctly and timely.



Figure 3. Nurses' and nephrologists' views on recommendations for nurses to prepare patients and their families for dialysis

### 6.3.1 Pre-Dialysis Training for Patients and Their Families

Both the dialysis nurses and the nephrologists speak about the importance of pre-dialysis training for patients with CKD and their family members. At the same time, both groups of respondents note the importance of timely training, which should be conducted jointly for patients and their relatives. This is due to the fact that in the management of dialysis patients an important role is played by close relatives, as well as the degree of preparation for the beginning of the dialysis period. Thus, pre-



dialysis education of patients and their families contributes to a smooth start of dialysis therapy and preservation of the psychological stability of dialysis patients.

#### *6.3.1.1 Pre-Dialysis Patients' Preparation*

Pre-dialysis patients' preparation includes the following subcategories: early preparation of patients with chronic renal failure for dialysis and pre-dialysis patient preparation.

**Early preparation of patients with chronic renal failure for dialysis.** Absolutely all nurses were in favor of conducting early preparation of patients with CKD to the start of dialysis. At the same time, they noted the most important points that, in their opinion, are key when working with such patients. Thus, they identified the most important early detection of various stages of CRF for timely treatment with the aim of maximally prolonging the pre-dialysis period. Next, the nurses highlighted the fact that patients should clearly understand and be aware of their condition, which depends largely on the patients themselves and the support of relatives. In this regard, it is important to prepare patients together with their relatives. The nurses shared their opinion that patients, as well as their relatives, should be informed about their diagnosis. Therefore, the consultations should be held by the nephrologist, during which they receive all the necessary information about renal replacement therapy, as well as the need to form a so-called vascular access. In this case, the nurses said that these consultations should be conducted only by professionals who are familiar with dialysis because the source of information for this category of patients must be reliable and able to gain patients' confidence. The nurses suggested that during the consultation the whole family had the opportunity to receive information about the physiology of the kidneys, the reasons for their disruption, the concept of glomerular filtration and under what circumstances it is necessary to start dialysis therapy, as well as what complications of CRI may arise in the absence of timely treatment.

*"Relatives, patients, too, sometimes happen of course also, but rarely, of course, some already prepared come here, and some do not know come." (N4)*

*"Provide all necessary information to both the patient and his relatives, as well as to prepare the vascular access, so as not to injure the patient once more!.. Nephrologists in the nephrology hospital." (N5)*

*"Who should provide this information? Probably, medical staff who understand and know this problem, who can explain, advise, and answer all questions." (N3)*

The nurses expressed their hopes that the knowledge and understanding of all these moments form a positive attitude in people towards dialysis. Because one of the main problems of each dialysis patient and his family in the first days of the start of dialysis therapy, according to nurses, is precisely fear due to complete ignorance and misunderstanding of dialysis. So, one of the respondents said that a positive attitude before starting dialysis therapy helps to acquire timely psychological support for patients and their relatives. In this case, the nurses noted that the advance preparation for dialysis includes not only the advice of various specialists with conducting explanatory conversations about dialysis. In their opinion, it can also include broadcasting demonstration videos in order to acquaint a person with an artificial kidney apparatus, study memos for patients with basic rules of nutrition, and see question-answer conversations.

*"And it's already visible on the video, especially now there's everything to show ... It is able to do that, prepare some bright colorful brochure with the basic nuances of dialysis... and then answer the questions." (N4)*

So, as an early preparation of patients for the start of dialysis therapy, nurses identified the following points: early formation of arterio-venous fistula, timely consultation with a nephrologist to provide patients with complete information about the structure and functioning of the kidneys. It is also important for patients with chronic renal failure to know that complications may occur associated with their basic condition, and what these complications can lead to and in what situations it is necessary to start dialysis therapy. At the stage of early training, both patients and their relatives should receive information about dialysis and about the basic rules of

its conduct, as well as about social support for dialysis patients as persons with disabilities of the first group.

**Pre-dialysis patient preparation.** Nephrologists said that a properly prepared patient comes to dialysis in a planned manner. He or she is familiar with all the nuances, and the person is ready to start dialysis therapy without fear, which contributes to the smooth implementation of the procedures and the patient's well-being. At the same time, according to doctors, patients should know certain rules of behavior when conducting procedures. Failure to do so can lead to various complications during dialysis. Respondents noted that, first of all, patients should know what dialysis is and how it is performed. It is for this purpose that counseling and case management are conducted at the pre-dialysis stage, where the patient can become familiar with the rules of nutrition, the installation of vascular access, and dialysis. However, as nephrologists say, ignorance of all this can cause difficulties in dialysis and poor health during out-of-dialysis days.

*"Probably it should be too. Those. How should they behave during the hemodialysis procedure and after it." (D1)*

*"... we explain that the disease is chronic, that the patient will be forced to receive the procedure at least, well, at least, but 1 to 3 times a week there for 4 hours." (D3)*

At the same time, nephrologists also talk about the need to comply with all the recommendations offered to patients. This is necessary to maximize the pre-dialysis period and preserve the residual excretory kidney function as long as possible. Doctors noted that non-compliance with the recommendations entails the progression of renal deterioration, which leads to complete attachment to the artificial kidney apparatus.

*"Well, a violation of the D2 diet, a violation of all the recommendations that you give them. You give an extract, and ... do not obey ..." (D2)*

*"Look, today you like your appearance, these edemas, this swelling, these bags under the eyes. No I do not like. Did you know that salt will retain fluid in the*

*body? Even if we still have the excretory function, and you can lose all this in the toilet, you will hold this liquid. And you will keep it for a long time if you..."*  
(D4)

#### 6.3.1.2 Relatives in the Patients' Life

This category consists of next subcategories: counseling patients and their relatives and significance of relatives in dialysis therapy.

**Counseling patients and their relatives.** Nephrologists expressed their opinion that counseling patients and their relatives at the pre-dialysis stage and at the beginning of dialysis therapy can be carried out by various medical personnel, both nurses and doctors. However, they noted that the main requirement for these consultants is a deep knowledge and understanding of dialysis. Otherwise, in the case of consultant incompetence, patients will not listen, which can cause inadequate patient behavior outside and on dialysis. Unfortunately, for nephrologists, there is currently some biased attitude of patients and their families towards nurses. In this connection, patients and their relatives seek to communicate only with medical personnel. Nephrologists themselves say that nurses can provide comprehensive counseling to patients and their families, as they interact with them most often. They note that this in turn will provide an opportunity for continuous monitoring of patients, to promptly suggest how to act in certain situations, and periodically reiterate the importance of adherence to diet and water-drinking regime.

*"We have a good nurse here, and he is now studying to be a doctor. It happens yes, that is why salty, why you do that, someone brought kirieshki and chips for dialysis. Why do you do this? The same is impossible, salty ... Your pressure will be jumping, something else ... The attitude was on the part of the patients - who are you? Are you a doctor?"* (D5)

*"... in fact, even in the nursing department, we have more contact with patients and relatives, and therefore ... to say in part somewhere that they drink less water, they already do this, for example. They are trying to perform some functions anyway, because they have a lot of contact with the patient and they see that now he has a two-liter bottle on the table and that of course he has it*

*... when he drank it, the nurse will report to me, for example ... and she can tell him you need to drink less water or salt in it, for some.” (D3)*

Nephrologists expressed their assumption that, in order for patients to listen specifically to the nurse, she must be qualified and an expert in her work. To obtain this kind of qualification, it is necessary to complete a training course and training for dialysis nurses. The respondent acknowledged that at the present time, not every nurse, even in a dialysis center, is able to conduct an adequate conversation with patients and their relatives. They expressed their opinion that the reasons for this lie in the lack of manners of the staff, the lack of communication skills, as well as the experience of communicating with patients and the inability to explain. Therefore, it is necessary to train nurses to talk with patients and their relatives.

*“It seems to me, just teach them this and let them work.” (D2)*

*“... information about what is happening with the patient ... well, ideally, of course, it would be good for the nursing staff to explain.” (D3)*

*“... it will be necessary to prepare, of course, because ... According to different nosologies, if nurses talk to patients, it would be super! At the moment, doctors will work. Gradually train, of course, and nurses need to deal with them.” (D5)*

Many doctors try to establish work in dialysis centers so that patients feel comfortable. This is achieved due to the fact that the same patients usually go to the same shift. In dialysis centers, respondents note the possibility of close communication between patients and all medical personnel. At the same time, doctors noted that the nurse always has the opportunity to talk with each patient in order to determine his needs at the present time. In their opinion, nursing consultation does not exclude the importance of periodic medical consultations. Because it is the doctor who prescribes and in the future corrects the treatment of patients, the nurse provides care, promotes adherence to the regimen, and explains the patient's condition. Therefore, it is important for nephrologists that patients should be not only said what is bad and what is good, but also showed by example, repeatedly repeat information, since different information is assimilated in different ways.

*"All the same, patients are becoming more familiar, they do not change, they are the same from year to year. They become family and you are worried about them, trying to improve their quality of life, improve their well-being." (D4)*

*"... of course, share the experience. There is such." (D2)*

*"I have already shown her ... And I think the information should be given every time and explained. There are people who, even if this moment is now explained, after a while they forget about it. If these people are there, you just need to explain it every time, remind you ... And I think the information should be given every time and explained. There are people who, even if this moment is now explained, after a while they forget about it. If these people are around, you just need to explain about it every time, remind." (D5)*

However, according to the doctors themselves, they are not yet ready to fully transfer the consulting function to the nurse. But at the same time, they note the importance of working in the same team—a nurse and a doctor. According to the doctors, the joint work will allow to pay close attention of the relatives and the patients themselves to issues important specifically for them, as well as to provide full information about dialysis. And some topics can be fully covered exclusively by a nurse.

*"... Nurse, I think she can. The main thing to learn ... A trained nurse in emergency situations, she will not be confused, she will act well. Generally possible, necessary..." (D5)*

*"... this is usually discussed, I believe, at some meetings of the medical staff, i.e. Doctors, nurses get together and discuss that this, that, that, that, that, it is necessary to prepare it, to talk to his relatives, i.e. I think that this should be interconnected, because somewhere the relatives asked the nurse something, they did not understand the question, somewhere they asked the doctor something and now together we should form some common solution in the team that we are giving some information, we are preparing this, and then the nurse is just doing it. those. the decision because what exactly to give can be made together with the doctor." (D3)*

*"It would be possible to transmit information on the water balance, diet, ... A nurse, yes, she can do diets, can do water exchange - explain what it is. Maybe some, maybe a moment for some kind of social payments, something, something, such too ... we are not very good at this and still have to give some direction to patients." (D3)*

For doctors, it is important to prepare patients using not only conversations, but also broadcasting various videos. The polynomial examples are not excluded. If possible, at the pre-dialysis stage, it is better for each patient to be shown the artificial kidney apparatus, and on the spot explain the principles of his work, given the opportunity to see him at work and to get acquainted with dialysis patients.

**Significance of relatives in dialysis therapy.** Doctors noted that close relatives are the main stimulating and supporting factor for dialysis patients. It is the relatives and friends who are constantly nearby and can provide various kinds of support, ranging from the initial decision-making to start dialysis therapy to the provision of care at home. At the same time, doctors noted that for many patients it becomes problematic to stick to their own diet. In such situations, it is necessary that family members are fully informed about the principles of nutrition for dialysis patients.

*"... sometimes the patient refuses to carry out the formation of an arterio-venous fistula without consulting five to ten people from his family, without a family meeting." (D3)*

*"Elementary help in terms of can cooking, care..." (D4)*

*"After talking with his wife, for example, this patient, he corrected immediately. Diet is not exactly he who is watching the diet, but his wife - his wife." (D5)*

Therefore, doctors believe that it is necessary not only to prepare patients for dialysis therapy, but also to give full information to their families about the diseases leading to dialysis, possible difficulties and complications, how to provide proper care at home and provide all kinds of help and support. According to nephrologists, the help of relatives is irreplaceable. Indeed, without a clear understanding of what is happening and what it can bring, the patient will not make any effort to maintain

his/her health. It is here, in the opinion of the doctors, that the maximum help and support of relatives is needed so that patients arrive in a positive psychological mood. Because this category of patients may become depressed when they become acquainted with their diagnosis, suicidal mood is possible for some patients. At the same time, the doctors noted the psychological preparation of the relatives themselves, helping them not to fall into despair, but to find the strength to support dialysis patients since patients can even refuse to accept treatment, without realizing their true state. Nephrologists have offered to work more with relatives in preparation for dialysis, as they will be able to fully support future dialysis patients, help them to quickly adapt to new living conditions, and calmly respond to the emotional instability of patients.

*“... first of all, it seems to me it is necessary to prepare them. More than their relatives.” (D2)*

*“...also the fact that the very nature of a person can change a little bit, we also explain this to relatives, because the disease is severe and chronic, it still leads to a change in this background mood...” (D3)*

*“...because patients do not take themselves, this disease so seriously ... They do not take this disease so seriously. Many of them do not correct sugar, do not take anti-hypertensive therapy...” (D4)*

#### *6.3.1.3 Patient Counseling and Care*

This category includes two subcategories that give information about counseling and care for the patents. These subcategories are medical consultation and nursing care for dialysis patients.

**Medical consultation.** Unfortunately, nephrologists have recognized that many patients prefer medical consultations and do not believe the advice and tips of nurses. At the same time, doctors understand that it is the nurses who should carry out the main consultative load. In this case, the nurses themselves say that they understand their important role in counseling because of their constant contact with patients, however, they note that it would be better for the doctor to do this work. This is explained by the fact that medical consultations are more understandable to



people, more accessible, because the doctor speaks a language understandable for patients. Therefore, the nurses believe that they listen to the doctor and begin to follow his/her recommendations. In society, the doctor has more authority than the nurse.

*"... someone listens and someone refuses to listen, they prefer to talk only with doctors ..."* (N3)

*"... I think they are doctors ... doctors are doctors, they have to explain more, well, they still explain in an accessible way."* (N4)

**Nursing care for dialysis patients.** Respondents recognize that they can provide timely and high-quality advice to patients and their relatives. At the same time, they substantiate this by the fact that they spend the most time right next to the person in need of care. Thus, a nurse may not only provide all the necessary information on nursing but can also directly show on the spot how to properly care for a fistula. Also, nurses do not exclude the fact that they can talk to many patients during dialysis sessions.

*"... it seems to me that the nurse could ... If the nurse knows everything, then it seems to me that she could explain everything."* (N4)

*"We help with what we can - we measure pressure both according to indications and at their request, because they immediately talk about changes in their state of health, measure blood sugar, not unimportant during dialysis!"* (N3)

However, the nurses themselves point out that in order to conduct this kind of high-quality nursing counseling, they must possess the necessary knowledge about dialysis in order to provide complete information to people, as well as to give qualified answers to the questions asked. However, at the present time, the nurses themselves note the lack of their knowledge to fully advise patients and their relatives. Often, nurses do not have knowledge of the various possibilities of renal replacement therapy.

### 6.3.2 Advice for Patients and Their Families

All the nurses surveyed believe that for the effective conduct of hemodialysis procedures, primary training is needed for both the patients themselves and their families to begin dialysis. Preparation is to provide all the necessary information, as well as recommendations on adherence to diet and water-drinking regime. This category includes: possible problems in dialysis patients, the role of relatives in the lives of patients, and the rules of nutrition.

#### 6.3.2.1 Advice for Relatives

Advice for relatives is very diverse. That is why this advice could be in different subcategories. These subcategories are the following: the role of relatives in the life of patients and preparing relatives for the start of dialysis.

**The role of relatives in the life of patients.** Respondents note the importance of relatives who have a heavy share. However, according to the nurses, it is they who can help dialysis patients with, for example, moral support, material assistance, and donation issues. On the other hand, nurses talk about situations where relatives are either so selfish or just get very tired of their role that they simply refuse to provide any assistance to dialysis patients.

*"I think the role of relatives is important, emotional support, financial, as our patients do not work." (N3)*

*"I think the families of these patients sometimes have a hard time. Our patients are quite capricious, sometimes depressed, especially difficult for them in the first months on dialysis, when it is necessary to get used to a new life. Some patients require maintenance at a dialysis center." (N2)*

*"...can sometimes donate." (N1)*

*"... but there were cases when relatives refused to care for such people. It's not easy with these patients." (N5)*

**Preparing relatives for the start of dialysis.** Relatives should be prepared for the start of renal replacement therapy no less than the patients themselves. This is due

to the fact that in many cases, relatives can provide full moral and material support to dialysis patients. Therefore, their readiness, full awareness of both patients and relatives, will speak about a calm atmosphere in the house.

*"... most, well, initially they ask about dialysis." (N4)*

#### *6.3.2.2 Advice for Patients and Their Families*

This category consists of six subcategories which are: possible problems in dialysis patients, food regulations, control underlying disease, dialysis patients' needs, dialysis start, and health of the patient.

**Possible problems in dialysis patients.** According to nurses, dialysis patients have a number of problems that they have not met before. At the same time, they note that these problems are related to the patient's lack of the necessary information about his condition and hemodialysis. So, it affects during the procedures. One nurse recalled situations in which patients had certain difficulties while receiving dialysis and they needed emergency measures.

*"Basically, dialysis patients often have hypotension, hypoglycemia, problems with AVF, and at the same time, some have hypertension and rarely a coma!" (N1)*

*"Depressive condition. Aggression. Apathy. They understand it is very difficult to be disabled." (N5)*

*"In my practice, I am faced with situations such as lowering pressure during dialysis, with a drop in blood sugar levels in diabetics. It is necessary to quickly administer glucose to them so that their condition is stable, and they can continue to lie on the device." (N2)*

The nurses noted that the start of dialysis therapy causes a state of stress, depression, and apathy in patients. A person does not understand his condition and does not perceive any information. Some respondents were faced with situations where patients rejected their diagnosis and showed complete indifference to their condition. So, the nurses suggested that the most difficult problem for all patients is

not only the fact of dialysis therapy in their lives, but the fact that they become disabled. Disability at any age is a difficult psychological barrier for a person.

*"... it is for the patient, maybe indifferent or what ... probably lay for two days and left us. And how much we persuaded her, how many of us here..." (N4)*

*"It is important during this period to provide maximum psychological support so that the patient understands that the onset of dialysis and the disability associated with this is not the end, but only a new stage." (N5)*

Therefore, at this stage, help and support from relatives and friends are also necessary, and they also need to prepare and provide complete information about the patient's condition and dialysis.

**Food Regulations.** Nurses noted the importance of proper nutrition, which contributes to the stabilization of the basic condition, as well as reducing the risk of various complications. Some respondents gave examples: non-compliance with the drinking regime, non-compliance with the recommendations on nutrition can contribute to the retention of excess fluid in the body, gaining weight. The nurses also noted restraint in the diet, restriction of fluidity, and stabilization of the general condition of the patients. According to the nurses, relatives can take on the responsibility for cooking, while preparing everyone the same, but with a limited amount of salt. Thus, patients will not feel hurt or deprived of anything.

*"It is important to follow a diet and water-drinking regime. Where without it?! Otherwise, a person will feel bad when he gets a lot of excess fluid." (N3)*

*"You need to know what you can eat, what needs to be limited, and the importance of compliance with the water-drinking regime..." (N2)*

**Control underlying disease.** According to the nurses, patients are required to monitor their condition. This may include constant monitoring of blood pressure, blood sugar levels. The nurses noted that these indicators are the most important, because the most frequent reason leading to the need for renal replacement therapy is diabetes and arterial hypertension. Accordingly, it is necessary to take prescribed drugs on time.

*“And regular use of nephroprotective drugs, control of antihypertensive therapy, glycemia control!” (N1)*

**Dialysis patients’ needs.** The nurses expressed their assumption that, due to the onset of dialysis therapy, new needs emerge in a person’s life. In their opinion, this is reflected in the fact that now a person is forced to go on dialysis on his/her own schedule and is forced to completely change his/her schedule, habits, and lifestyle. It is not easy. One of the respondents noted that some patients could not cope with it. Most dialysis patients experience strong internal contradictions and conflicts, and therefore they need counseling from a psychologist at various stages of treatment.

*“I think a psychologist is needed in the hemodialysis unit! What would have a conversation at least once a week or a month.” (N1)*

**Dialysis start.** Nurses believe that the start of dialysis therapy in the event of an emergency and unprepared patients threatens the emergence of various complications in patients. Respondents encountered untrained patients in their work and noted that such patients do not have the necessary information about the importance of the dialysis procedure, about the rules of behavior during the procedures; they are not psychologically prepared for this. It is especially difficult for patients in the first months after the start of dialysis therapy. At the same time, the nurses noted that many points could be avoided if future dialysis patients are gradually prepared for the onset of renal replacement therapy, warned about various nuances of therapy, possible difficulties, so that the person does not fall into a state of panic and despair but has information to handle this.

*“In my practice, dialysis most often comes on an emergency basis.” (N3)*

*“They are capricious, not all, but many. Especially in the first time of adaptation to hemodialysis procedures.” (N5)*

**Health of the patient.** Respondents noted that it is important for patients to monitor their health and to clearly listen to the recommendations of doctors. Often, the medical staff in the dialysis centers, by the patient’s appearance alone, can calmly

determine the extent to which all the recommendations on the same limitation of fluid intake have been observed.

*“Sometimes during a conversation, it turns out that someone did not follow a diet or water-drinking regimen—although this is immediately clear by their appearance and weight gain ...” (N3)*

### 6.3.3 Ability to Communicate

Communication is one of the key moments in the development of any personality. The interaction of people in society contributes to the development of each individual, and society as a whole. For dialysis patients, communication becomes somewhat difficult due to their regular and special treatment schedule, as well as poor health after hemodialysis procedures. But it is these communications that these people lack, they need it, perhaps even more than other categories of patients. This category includes the following subcategories: relationships with dialysis staff and interaction with others.

#### 6.3.3.1 Relationship with Dialysis Staff

According to the nurses, it is very important for patients to feel comfortable and to have “homely” conditions in the conditions of conducting dialysis therapy. Therefore, in the dialysis centers, the nurses are trying to create a completely friendly environment in which each patient will feel comfortable so that for them, several hours spent on detoxication of ~~organism~~ their blood? will pass unnoticed.

*“... you know, here we are trying to maintain a friendly atmosphere...” (N3)*

#### 6.3.3.2 Interaction with Others

Each nurse surveyed noted that for each dialysis patient, human communication is of enormous importance. In the dialysis center, patients communicate with each other, with the medical staff, discuss the latest news and events in the world, and are interested in each other’s affairs. This way, time on dialysis goes by faster. Interaction with people contributes to the fact that patients are a little distracted from their routine dialysis procedures, and indeed from their condition. Therefore, for such patients it is very important not to let their circumstances get the best of

them, but to take an active part in the life of their family, relatives, and friends as before. It is important for them to learn something new and useful for themselves to not feel completely disabled, unnecessary, abandoned, and useless.

*"... something patients want to share, talk about their lives, someone, naturally, more closed ... I think they need to communicate with us, with each other, it does not matter, the main thing - live human communication." (N3)*

#### 6.3.4 Problems Associated with the Advent of Dialysis

Dialysis is an invasive procedure and can be difficult for a person to carry, not only physically, but also psychologically. This is the source of various problems that people may have in connection with the advent of dialysis therapy in their lives.

##### 6.3.4.1 Negative Effects of Dialysis

According to respondents, one of the most difficult situations is non-compliance by the patients with the recommendations received. This applies to recommendations on diet, compliance with the water-drinking regime, and control of the main state. Nephrologists have suggested that the reasons for non-compliance with the recommendations are both the psychological attitude of the patients, and general carelessness, and a frivolous attitude to their condition. Doctors say that patients do not follow the recommendations, because they live only once and are not going to spend their lives on various restrictions. At the same time, many patients strive to live their lives to the fullest—to try absolutely everything regardless of the damage they can do to their condition.

*"... noncompliant patients who do not comply with any recommendations that were originally given to them." (D4)*

*"... Well, a violation of the diet, the violation of all the recommendations that they give. You give an extract, but ... they disobey ... yes, there are such ... Some say, we live here, I don't care." (D2)*

Doctors note that excessive weight gain in such patients threatens with a sharp deterioration of the condition, as well as the appearance of possible problems during the dialysis procedure. At the same time, doctors often face situations when patients

may feel unwell during inter-dialysis periods and this negatively affects their psychological state and entails a negative attitude towards dialysis as a whole. Naturally, doctors face difficulties during the dialysis procedure. At the same time, nephrologists say that various complications from other organs and systems, as well as severe metabolic disorders that are very difficult to correct, may gradually appear.

*“Suppose ... just ... let's say water restriction - they start to gain big weights. There are patients to whom we have already talked about this more than once, not a year already, but they continue to do this, their condition worsens.” (D5)*

*“...it happens that if there is already no urine, and then they themselves take on a lot of fluids, heart problems. So basically, a big problem, it seems to me, this failure may not be a failure, but it is just for correcting renal anemia, hypertension, everything is fine, but it is mineral KOS disorders, which then manifest with age, it becomes a bit complicated.” (D2)*

#### 6.3.4.2 Starting Dialysis Therapy

Respondents note the importance of the way the patient came to dialysis. Unfortunately, most patients come to dialysis therapy on an emergency basis. In doctors' opinion, this negatively affects the general condition of patients. Patients are not morally or physically ready for dialysis. Nephrologists note difficulties in conducting a conversation with patients: they do not perceive the information received because of blurred consciousness, refuse to believe in what is happening, and react inadequately to the treatment they receive. Doctors, in the event of a planned start of dialysis therapy, feel a completely different situation: the patient is fully prepared, familiar with the procedure, and is treated as if they are now necessary in their lives.

*“... his path to programmed hemodialysis is already increasing, this is an arterial-venous catheter installation, and then after a while the formation of a fistula and improvement in well-being ... this all leads to a very long time being lost and ...” (D2)*

It is important for nephrologists that patients begin dialysis with prepared vascular access, which eliminates the need for emergency catheterization of the central



vessels. The prepared patient behaves adequately, complies with all the necessary recommendations, monitors the main indicators of his health, and has full information about the procedure underway.

#### 6.3.4.3 Factors that Have a Negative Effect on Receiving Dialysis Therapy

According to the respondents, there is currently no uniform statistics on accounting for cases of chronic renal failure in Kazakhstan. Nephrologists do not know what number of new patients they should refer to. Doctors are worried, because this figure cannot even be predicted. This is due to the fact that there is only a small percentage of early detection of CRF in stages 2-3. Nephrologists expressed their opinion that many of these questions arose due to the lack of a nephrologists in polyclinics. The nephrologist could engage in the early detection of these patients, as well as provide the necessary treatment for maximum prolongation of the pre-dialysis period.

*“The detectability of patients in our country is very low, and due to this, it is very late and the detectability is already mainly in the fourth or fifth stage of renal failure, when patients have a rather serious condition. This is a big problem, and probably the main one. We do not have epidemiology and therefore we do not even know how many patients to expect with renal insufficiency” (D3)*

*“There are no nephrologists at the PHC level, to be honest. And I think the preparation should be such, but now ... I do not know there ... we all learn about their condition, when they already get to Kalkaman. We have a large number of patients who go through Kalkaman or there through the regional hospital. There, patients are already getting everything, unconscious, urgently. Although there is an additional examination, there are no nephrologists before ... there is a large turnover there, apparently the doctors do not have time to do it. Therefore, hard.” (D2)*

Respondents noted that local doctors, due to their overwork in the workplace, do not cope with the identification and treatment of patient data. Not to mention the nurses who do not have time to serve their outpatient patients, physically they

simply cannot provide full advice to people at risk for CRF, as well as patients diagnosed with CRF of various stages of development. Thus, nephrologists state the fact that many patients do not have any information about their condition and possible outcomes. The late detection of end-stage CRF leads to an emergency start of dialysis therapy and leads to the development of various difficulties during the procedures. And at the same time, doctors say that in such a grave condition, patients and their relatives may also face the ill will of medical personnel, failing to answer questions of deontology. Although it was in the early days of the start of dialysis that moral support was so important not only from relatives, but also from nursing staff who were always there.

*“Patients are not informed about the stages of development of their disease, about the attendant changes in their body, depending on the progression of renal failure.” (D3)*

*“All of this is from a family or not taught in colleges - ethics; deontology ... There is no elementary subordination. Even the age chain of command! Here is a patient - an adult man, they can make such stupid jokes out there for which I make comments. I make a remark, and they do not even understand why they made a remark!” (D4)*

#### 6.4 General Recommendations for Patients and Their Families in Preparation for Program Dialysis at the Nursing Level

Patients and their families expressed a lot of suggestions and requests as recommendations for preparation to dialysis as well as some of their own hopes and expectations for further development of dialysis service in the Republic of Kazakhstan in general. Main recommendations from the conducted interviews with patients and their families are summarized in Table 2. All comments for each of these recommendations are presented in Appendix 13.

Table 2. Recommendations for nurses on how to prepare patients and their families for dialysis according to dialysis patients' and their families' opinions

#	Recommendations
1	Mutual psychological preparation of patients and their families for beginning of dialysis therapy
2	Informing patients and their families
3	Recommendations about nutrition for the whole family
4	Timely seeking for medical assistance
5	Distraction from personal condition
6	Choosing dialysis center
7	Social help
8	Working with families separately
9	Continuing moving

Nurses' and nephrologists' view of developing the recommendations for nurses on how to prepare patients and their families for dialysis is based on opinion and experience of nurses and nephrologists. This category of respondents expressed certain requirements to such recommendations and expectations to their implementation in real life. Medical and nursing staff define the following recommendations (see Table 3 and Appendix 14) that must be known by the CKD patients and their families.

Table 3. Recommendations for nurses on how to prepare patients and their families for dialysis according to nurse and medical staff

#	Recommendations
1	Psychological preparation of patients and their families for beginning of dialysis therapy
2	Informing patients and their families about dialysis
3	Forming access to blood vessels
4	Recommendations about changing lifestyle
5	Social help and support
6	Socializing

Specialists, i.e. people who are well familiar with the dialysis and ways to accept and live with it, must present all these recommendations. It should be emphasized that such specialists can be doctors and nurses that were specially trained in this area. With this, doctors-nephrologists also expressed their readiness to transfer part of consultancy aid to the trained nurses and noted this will significantly speed up development of dialysis service in the Republic of Kazakhstan. The doctors also noted that currently the training of nurses does not provide them with all the skills necessary for comprehensive consultancy aid to patients and their families. That is why implementation of nurse consultancy aid for patients and their families requires training of qualified nurses who will be able to not only communicate but also to provide necessary information that will be properly received and followed. In order to do this, nurses must know all the material and possess certain authority among patients and their relatives.

All the proposed recommendations about preparation for dialysis therapy must be presented by a specialist knowledgeable in dialysis. Such specialist can be not only a doctor but also a qualified medical nurse. However, on the one hand, not all questions are available for nursing consultancy when preparing for beginning of the dialysis therapy. On the other hand, main necessary information can be provided by medical nurses, and doctors will consult on more narrow issues. These recommendations are directed on early diagnosing of CKD and timely preparation of patients and their families for dialysis therapy. It is worth noting that many patients understand how hard it is for their relatives, and they greatly appreciate their help and support.

In the dialysis center, quite often patients try to regard with favor the work of all medical personnel. It is important for them to receive dialysis in a team with kind attitude to each other, where a person can get advice about dialysis or simply talk about different issues. Both patients and relatives know that in the dialysis center that they chose they will always get all possible support from doctors and nurses. When comparing the view of nephrologists and nurses and the view of patients and their families, a definite relationship can be found between the suggested recommendations. These comparisons and relationship are presented in Figure 4.

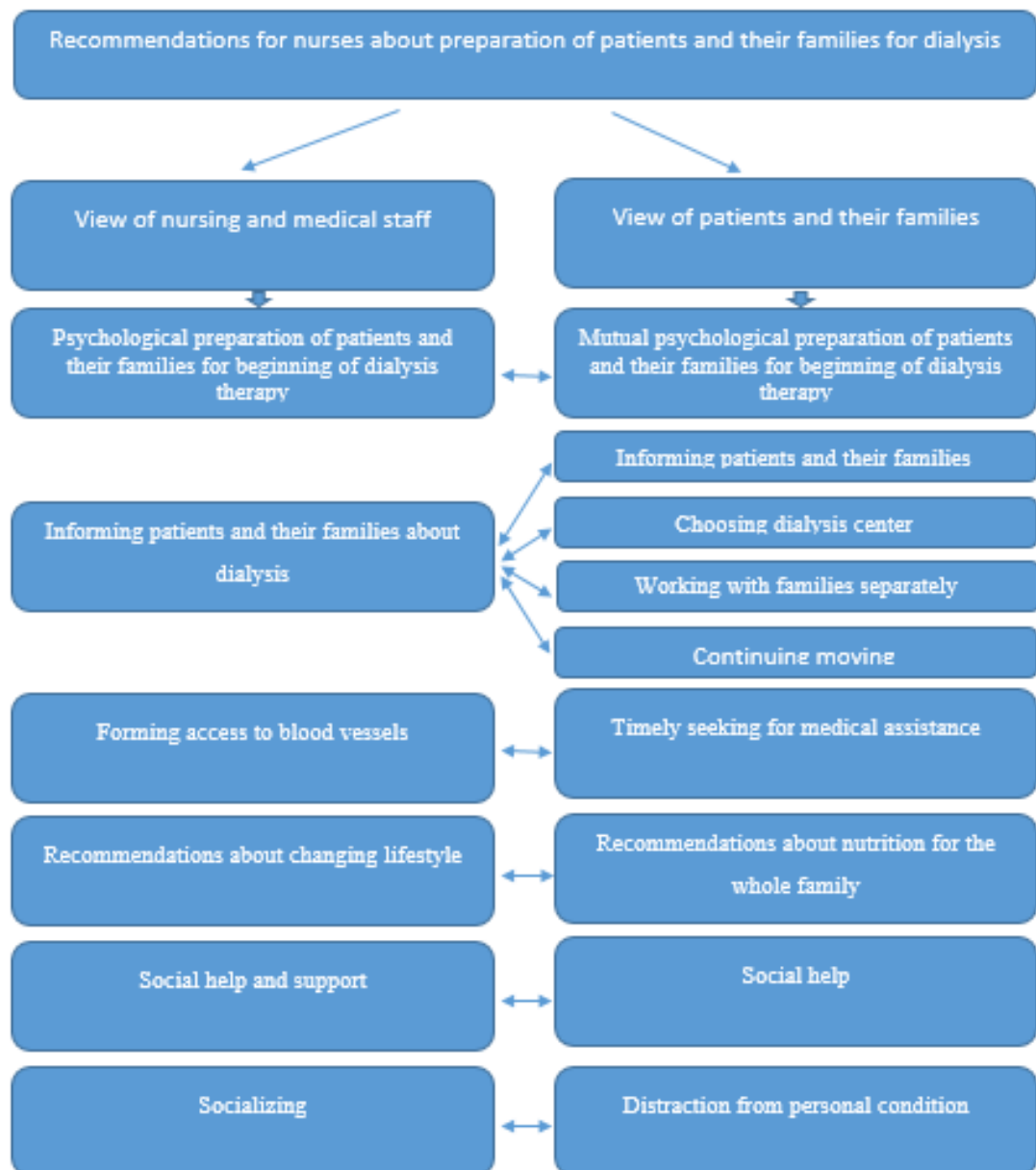


Figure 4. Comparison of advice for nurses on preparing patients and their families for dialysis

At the same time, it is worth noting that the category of informing patients and their families about dialysis in terms of nephrologists and nurses combines several categories from the vision of patients and their families, such as: informing patients and their families, choosing a dialysis center, and preservation of physical activity. Thus, it is possible to highlight the main recommendations for nurses on preparation of dialysis patients and their families for dialysis (see Figure 5).

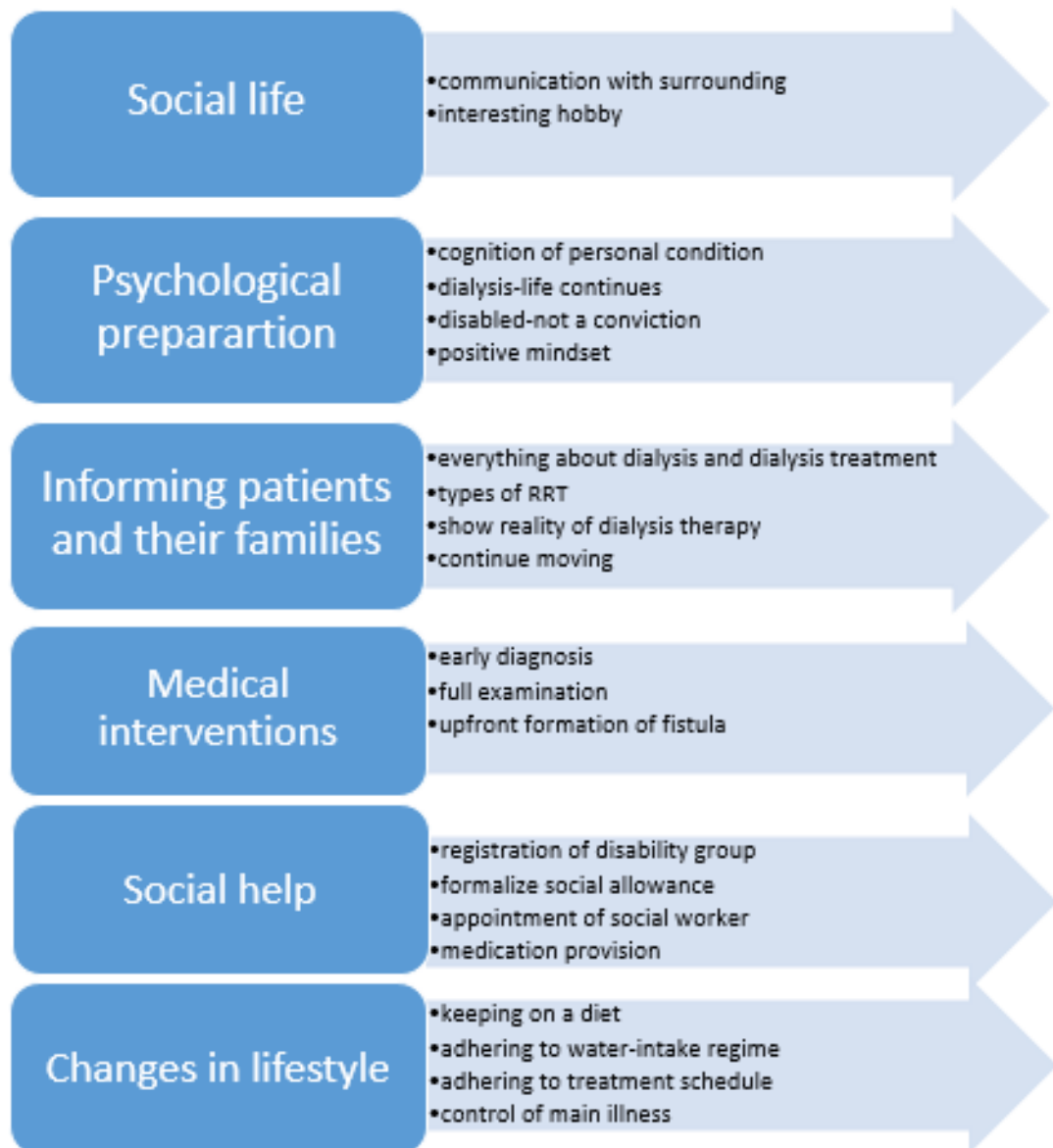


Figure 5. Developed recommendations for nurses on preparing patients and their families for dialysis

### ***Social life***

**Communication with surrounding:** dialysis patients should not turn away from society. They need to continue communicating with their surroundings, even if this is rather difficult due to the need to adhere to the treatment schedule. At the same time, joining an active social life is possible through the possibilities of the global Internet. **Interesting hobby:** an interesting hobby, a favorite thing that brings not

only pleasure to dialysis patients, but also able to distract them from their condition. A hobby encourages people to think as little as possible about their illness.

### ***Psychological preparation***

**Cognition of personal condition:** rapid adaptation to new living conditions. A person needs to understand and accept a new life with dialysis. **Dialysis—life continues:** understanding that dialysis is an opportunity to continue living should be present at every consultation. A person needs to come to terms with this and continue to live. **Disabled—not a conviction:** disability is not a sentence. This is just a social status in which a person may well continue to work ahead of schedule and maintain their leading position in the family. **Positive mindset:** the positive attitude and type of treatment is aimed at improving the psychological state of patients and reducing the fear of dialysis, which in turn reduces the risk of developing complications of dialysis therapy.

### ***Informing patients and their families***

**Everything about dialysis and dialysis treatment:** both patients and their relatives should be provided with information about the conditions that lead to dialysis therapy, about the rules of dialysis and the rules of behavior during and between sessions, possible risks and complications of dialysis therapy, and the need for a timely start of dialysis. **Types of RRT:** patients and their families need information about the possibility of various options for renal replacement therapy. At the same time, full information about the RRT contributes to the early start of the search for donors, or to a balanced refusal of kidney transplantation. A knowledgeable person makes an adequate decision for his/her situation. **Show reality of dialysis therapy:** the demonstration of the reality of conducting dialysis therapy helps reduce the fear of starting dialysis therapy. It is necessary to organize excursions to dialysis centers for patients who are preparing for dialysis, so that they can clearly understand that dialysis in modern conditions is a simple and easy procedure and there is nothing to fear. **Continue moving:** it does not matter what condition the person is in, it is important to maintain an active lifestyle. Movement contributes to the adequate



functioning of all internal organs, which improves the overall well-being of dialysis patients at both the physical and psychological levels.

### ***Medical interventions***

**Early diagnosis:** early detection and registration with chronic renal failure is achieved by identifying at-risk groups for continuous monitoring of the condition of the kidneys. **Full examination:** in the event of the first signs of renal failure, a complete examination of the patients is necessary and the beginning of a gradual pre-dialysis preparation. **Upfront formation of fistula:** in identifying and developing already the third or fourth stage of chronic renal failure, it is necessary to pre-form vascular access in order to avoid emergency catheterization of the large vessels.

### ***Social help***

**Registration of disability group:** patients and their relatives should be informed about how and where they can apply for a disability group and what advantages it gives them. **Formalize social allowance:** what documents are needed and where to apply for social disability benefits. **Appointment of social worker:** where to go and what documents are needed to assign a social assistant to a dialysis patient.

**Medication provision:** dialysis patients are entitled to provision of dialysis therapy, as well as a number of medications in accordance with the legislation of the Republic of Kazakhstan on the guaranteed amount of free medical care.

### ***Changes in lifestyle***

**Keeping on a diet:** at the pre-dialysis stage, protein restriction is recommended. When conducting the dialysis period, patients are advised to consume a sufficient amount of protein foods in their diet. At the same time, nutrition of dialysis patients should be balanced and complete. You should not eat foods that contain large amounts of potassium (dried fruits, fresh vegetables, fruits). Restriction of foods containing large amounts of phosphorus (dairy products). The main condition for the diet for dialysis patients is that the diet should be balanced and complete. Provided there are no complications, the diet should not differ significantly from the nutrition of a healthy person. **Adhering to water-intake regime:** depending on the main

condition that led the patient to dialysis therapy, as well as the state of the excretory function of the kidneys, the recommendations on limiting the water-drinking regimen also change. So, strict adherence to the drinking regime is recommended in the complete absence of renal excretory function. At the same time, the task of the patients is to gain weight in the inter-dialysis period of no more than five per cent of the total body weight. **Adhering to treatment schedule:** compliance with the treatment regimen is important for maintaining the well-being of the dialysis patient. On average, sessions take four hours three times a week. In this case, it is necessary to take into account the individual approach to the management of each patient. Therefore, each patient has his/her own individual schedule for attending dialysis sessions. **Control of main illness:** often patients suffer from chronic renal failure for a long time, which develops as a result of various diseases affecting the kidneys. For example, diabetes and hypertension are the most common causes of chronic kidney disease. Therefore, constant monitoring of the underlying disease—blood sugar, blood pressure, etc.—is important.

Moreover, all proposed recommendations can be arranged in a specific order in accordance with Maslow's hierarchy of needs. According to this pyramid, it is important to start from the lowest level of needs. This way should be successful because without satisfying the needs of the lower level it is impossible to satisfy the upper level. So, firstly patients should be satisfied with diet and water-intake regime, the treatment that had made big changes in their lifestyle. Secondly, satisfaction with social help, medical interventions, and full information about dialysis issues should be considered. Thirdly, it is important for the emotional condition of the patient to be psychologically prepared for the dialysis. The fourth one can be achieved if all previous levels of the needs are completely satisfied—only in that case can patients think about issues of self-actualization.

As a result of the analysis and description of all the data obtained, the following main conclusion was made: improvement of the provision of dialysis care by reducing the risk of developing dialysis complications through joint pre-dialysis training for patients with chronic kidney disease and their family members.

## 7 Discussion

The purpose of this study was to improve the quality of nursing by creating recommendations for preparation of patients with end-stage of chronic renal failure and their family members at the beginning of dialysis to reduce the risk of complications and improve quality of life. This purpose was achieved by studying the experiences of dialysis patients, their relatives, dialysis nurses and nephrologists to prepare for dialysis and based on developing recommendations for nurses to prepare patients and their families for dialysis. Six areas of recommendations for nursing counseling of pre-dialysis education were identified: changes in lifestyle, social help, medical interventions, informing patients and their families, psychological preparation, and social life.

The main result of this study was that all respondents noted the importance of pre-dialysis preparation, as many have a difficult experience in adapting to the conditions of life with dialysis. Clarkson & Robinson (2010) confirm that late detection of CKD and, as a result, psychological unpreparedness is the main important problem for dialysis patients and their relatives, which significantly reduces the quality of life of this category of patients. All respondents surveyed noted that previously unprepared patients have more psychological problems on dialysis therapy, and they need a longer period of adaptation to new conditions than patients who have come to dialysis in a planned manner (Chen, Tsai, Hsu, Wu, Sun, Chou, Lee, Tsai, Wu, & Wang 2010). Continuation of communication, the so-called socialization of dialysis patients, was also noted. Unfortunately, many of them, after the start of dialysis therapy, began to communicate less with friends and relatives (Kazemi, Nasrabadi, Hasanpour, Hassankhani, & Mills 2011), due to a special treatment schedule. This, in turn, further aggravated the course of dialysis due to severe psychological state and deep depression (Chen et al. 2010). Thus, maintaining the ability to lead an active social life helps patients psychologically cope with the various problems that arise when dialysis occurs in their lives.

Another important issue is the complete lack of information on dialysis therapy and the need for lifestyle changes. This in turn also affects the standard of living of both

dialysis patients and their families. (Bonner & Lloyd 2012; Shnishil & Mansour 2017.) Full information and education of patients and their relatives is necessary to ensure compliance with the dialysis regime, aimed at improving the well-being of patients. It is for this purpose that three such important recommendations are highlighted as informing patients and their families, medical interventions, as well as changes in lifestyle.

In accordance with the dialysis patients' needs, it is necessary to consult the patients and their families at the pre-dialysis stage. Such a hierarchy (see Figure 5) of the recommendations makes it possible to correctly assess the level of human needs and provide the necessary information on meeting this level. Determining the needs of patients is carried out at the stage of nursing diagnosis. (Bayoumi 2012.) At the same time, it should be kept in mind that patient needs are constantly changing due to the initiation and conduct of dialysis therapy.

The second result was that families play an important role in maintaining the psychological state of patients (Al Nazly et al. 2013). It is family support that is able to encourage patients and maintain a positive attitude throughout the entire period of renal replacement therapy (Aghakani, Sharif, Molazem, & Habibzadeh 2014). The family can provide patients with the necessary care at home. This is possible only with timely informing and proper training of family members. Therefore, medical personnel should work not only with patients, but also with their families. (Al Nazly et al. 2013.) Joint training of patients and their families is aimed at overcoming possible psychological problems that develop after the start of dialysis therapy. At the same time, relatives and patients will be able to help each other only if they are fully informed about the diagnosis, the whole process of dialysis and possible treatment options.

During the research, the experience and basic needs of patients in preparing for hemodialysis were studied. From this position, the nurses expressed that regular counseling of patients and their families at the pre-dialysis stage is effective and leads to the calm management of patients on dialysis. Nephrologists said that it was pre-dialysis preparation that helps reduce the development of possible dialysis problems. Dialysis patients shared their experiences and suggested that for the

further qualitative development of the dialysis service, it is necessary to actively conduct pre-dialysis training in conjunction with patients with chronic renal failure and their relatives. At the same time, relatives of dialysis patients themselves note the importance and necessity of psychological assistance and counseling to patients and their families, both before and after the start of dialysis therapy. To improve the quality of dialysis care, which is possible by reducing the risk of developing dialysis complications through joint pre-dialysis training for patients with chronic kidney disease and their family members, recommendations for nurses are made that meet the different levels of needs of patients with chronic kidney disease and their families. However, patients and their relatives prefer to communicate with the medical staff, rather than with nursing staff. The nurses themselves are not ready to provide counseling to patients and their families due to the lack of a thorough understanding of dialysis therapy and the lack of necessary communication skills for conducting comprehensive counseling.

## **8 Conclusion**

Dialysis is a complex, vital procedure that entails inevitable changes in the lives of each family member. The studied experience of dialysis patients and their relatives in preparing for dialysis showed that it was not always and not all had the opportunity to undergo pre-dialysis training in a timely manner due to the late detection of the terminal stage of chronic renal failure and the emergency start of dialysis therapy. Although psychological assistance and support is urgently needed both for patients and their relatives in order to cope with the difficult situation that has arisen in their family. Therefore, dialysis patients noted their need for timely and full information and pre-dialysis training.

The results of this study showed that improving the quality of dialysis care is possible by reducing the risk of developing dialysis complications through joint pre-dialysis training for patients with chronic kidney disease and their family members. Recommendations developed based on this study for nurses on the preparation of patients with end-stage chronic kidney disease and their family members for dialysis

are aimed at reducing the risk of developing complications and improving the quality of life of dialysis patients.

Results and recommendation of this study can serve as the beginning of further development in preparing patients for renal replacement therapy by introducing nursing recommendations at the primary health care level. These studies should be aimed first at identifying primary minor recommendations using the Delphi method, as well as further steps to implement the results obtained in practical public health.

### **Recommendations**

According to the results of the study, recommendations are made below.

#### **For healthcare managers:**

1. To organize pre-dialysis education for patients and their families. It is necessary to prepare qualified nursing staff. Organization of advanced training courses for nurses to develop communication skills and the ability to provide advice to patients and their families, as well as to study the characteristics of dialysis therapy and care for dialysis patients.
2. Training and education of specialists for working together in a multidisciplinary team for pre-dialysis training and patient management on dialysis

#### **For nurses:**

1. It is important for nurses to meet and fulfill their job descriptions and develop as a nursing professional. It will increase the professional level of dialysis nurses. So, by studying the issues of the dialysis nurses will be authoritative source of information for patients and their families in the era of universal accessibility of various kinds of information on the Internet.
2. Enhancing professionalism will allow dialysis nurses to become an authoritative source of information for patients and their families in an era of universal access to various types of information on the Internet.

**For relatives:**

1. Undergo pre-dialysis training with patients to get maximum information on home care.
2. Continue to provide full support to your loved ones chained to the dialysis machine.

**For patients:**

1. Learn to live with dialysis. You must understand and accept your condition and continue to live.
2. Follow recommendations for lifestyle changes and continue communication with your surroundings.

It is worth noting that in order to conduct high-quality pre-dialysis training for patients and their relatives, nurses need to use various kinds of demonstrative material and dialysis and all the necessary recommendations. Therefore, an important task is to develop and prepare training material and the conditions required by nurses for consultation. According to the interviews with dialysis patients and their relatives, dialysis nurses and nephrologists, the material could include: information leaflets with a list of permitted food, preparation of videos about life with dialysis, preparing a demonstration video about conducting dialysis sessions, organization of meetings with dialysis patients for live communication, and organizing excursions to dialysis centers to see everything with their own eyes.

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## Appendices

Appendix 1. Criteria for definition of CKD (by KDIGO 2012)

Criteria	Comment
Duration 43 months, based on documentation or inference	<p>Duration is necessary to distinguish chronic from acute kidney diseases</p> <ul style="list-style-type: none"> <li>-Clinical evaluation will often enable documentation or inference of duration</li> <li>-Documentation of duration is usually not declared in epidemiologic studies</li> </ul>
GFR $\leq 60$ ml/min/1.73 m <sup>2</sup> (GFR categories G3a-G5)	<p>GFR is the best overall index of kidney function in health and disease</p> <ul style="list-style-type: none"> <li>-The normal GFR in young adults is approximately 125 ml/min/1.73 m<sup>2</sup>. GFR <math>&lt; 15</math> ml/min/1.73 m<sup>2</sup> (GFR category G5) is defined as kidney failure</li> <li>-Decreased GFR can be detected by current estimating equations for GFR based on SCr or cystatin C but not by SCr or cystatin C alone</li> <li>-Decreased eGFR can be confirmed by measured GFR, if required</li> </ul>
Kidney damage as defined by structural abnormalities or functional abnormalities other than decreased GFR	<p>Albuminuria as a marker of kidney damage [increased glomerular permeability],</p> <p>urine AER <math>\geq 30</math> mg/24 hours, approximately equivalent to urine ACR <math>\geq 30</math> mg/g (<math>\geq 3</math> mg/mmol)</p> <ul style="list-style-type: none"> <li>-The normal urine ACR in young adults is <math>&lt; 10</math> mg/g (<math>&lt; 1</math> mg/mmol)</li> <li>-Urine ACR 30-300 mg/g (3–30 mg/mmol; category A2) generally corresponds to “microalbuminuria,” now referred to as “moderately increased”</li> <li>-Urine ACR <math>&gt; 300</math> mg/g (<math>&gt; 30</math> mg/mmol; category A3) generally corresponds to “macroalbuminuria,” now termed “severely increased”</li> <li>-Urine ACR <math>&gt; 2200</math> mg/g (220 mg/mmol) may be accompanied by signs and symptoms of nephrotic syndrome (e.g., low serum albumin, edema, and high serum cholesterol)</li> <li>-Threshold value corresponds approximately to urine reagent strip values of trace or +, depending on urine concentration.</li> <li>-High urine ACR can be confirmed by urine albumin excretion in a timed urine collection expressed as AER</li> </ul> <p>Urinary sediment abnormalities as markers of kidney damage</p> <ul style="list-style-type: none"> <li>-Isolated non-visible (microscopic) hematuria with abnormal RBC morphology (anisocytosis) in GBM disorders</li> <li>-RBC casts in proliferative glomerulonephritis</li> <li>-WBC casts in pyelonephritis or interstitial nephritis</li> <li>-Oval fat bodies or fatty casts in diseases with proteinuria</li> </ul>

	<p>-Granular casts and renal tubular epithelial cells in many parenchymal diseases (non-specific)</p> <p>Renal tubular disorders</p> <ul style="list-style-type: none"> <li>-Renal tubular acidosis</li> <li>-Nephrogenic diabetes insipidus</li> <li>-Renal potassium wasting</li> <li>-Renal magnesium wasting</li> <li>-Fanconi syndrome</li> <li>-Non-albumin proteinuria</li> <li>-Cystinuria</li> </ul> <p>Pathologic abnormalities detected by histology or inferred (examples of causes)</p> <ul style="list-style-type: none"> <li>-Glomerular diseases (diabetes, autoimmune diseases, systemic infections, drugs, neoplasia)</li> <li>-Vascular diseases (atherosclerosis, hypertension, ischemia, vasculitis, thrombotic microangiopathy)</li> <li>-Tubulointerstitial diseases (urinary tract infections, stones, obstruction, drug toxicity)</li> <li>-Cystic and congenital diseases</li> </ul> <p>Structural abnormalities as markers of kidney damage detected by imaging (ultrasound, computed tomography and magnetic resonance with or without contrast, isotope scans, angiography)</p> <ul style="list-style-type: none"> <li>-Polycystic kidneys</li> <li>-Dysplastic kidneys</li> <li>-Hydronephrosis due to obstruction</li> <li>-Cortical scarring due to infarcts, pyelonephritis or associated with vesicoureteral reflux</li> <li>-Renal masses or enlarged kidneys due to infiltrative diseases</li> <li>-Renal artery stenosis</li> <li>-Small and hyperechoic kidneys (common in more severe CKD due to many parenchymal diseases)</li> </ul> <p>History of kidney transplantation</p> <ul style="list-style-type: none"> <li>-Kidney biopsies in most kidney transplant recipients have histopathologic abnormalities even if GFR is <math>&gt;60</math> ml/min/1.73 m<sup>2</sup> (GFR categories G1-G2) and ACR is <math>&lt;30</math> mg/g (<math>&lt;3</math> mg/mmol)</li> <li>-Kidney transplant recipients have an increased risk for mortality and kidney failure compared to populations without kidney disease</li> <li>-Kidney transplant recipients routinely receive subspecialty care</li> </ul>
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Abbreviations: ACR, albumin-to-creatinine ratio; AER, albumin excretion rate; CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; GBM, glomerular basement membrane; GFR, glomerular filtration rate; RBC, red blood cell; SCr, serum creatinine; WBC, white blood cell.

## Appendix 2. Memo of a dialysis patient\*

## Памятка диализного пациента

Заместительная почечная терапия (далее – ЗПТ) включает в себя: гемодиализ (далее – ГД), перитонеальный диализ (далее – ПД), трансплантацию почки. ГД – это способ продления Вашей жизни, методом пропускания крови через аппарат «Искусственная почка», когда сами почки не выполняют функцию очистки крови. Проведение процедуры ГД несет риск развития различных осложнений, о которых Вас проинформирует врач.

Для улучшения качества Вашей жизни, должны соблюдаться следующие условия:

1. до начала процедур ГД Вы должны предоставить справку об отсутствии у Вас вирусного гепатита В и С и проведенной вакцинации против гепатитов;
  2. необходимо формирование сосудистого доступа (артериовенозной фистулы, установка постоянного катетера);
  3. ГД должен проводиться стандартно 3 раза в неделю по 4 часа, т.е. 12 часов в неделю, нельзя пропускать процедуры гемодиализа;
  4. должны соблюдаться правила асептики и антисептики: смена перчаток медперсоналом после каждой процедуры (4 - 5 перчаток за одну процедуру), кварцевание диализного зала и промывка гемодиализного аппарата между сменами, применение одноразовых расходных материалов, обработка рук и поверхностей антисептиками в случае попадания крови;
  5. регулярное обследование Вас на вирусный гепатит и раздельное лечение (на специально выделенных аппаратах) больных с гепатитом;
  6. обследование и лечение проводится согласно КП;
  7. в междиализный период Вам надо строго соблюдать питьевой режим (ограничение жидкости до 500-700 мл/сут, если у Вас нет мочи) и ограничить соль, острое, продукты, содержащие калий (бананы, картофель, фрукты, овощи, соки.), фосфор (рыба, яйцо, сыры, молоко, творог);
  8. для профилактики и лечения анемии Вам регулярно должны вводиться эритропоэтины (3 раза в неделю, 1 раз в неделю или 1-2 раза в месяц) и препараты железа внутривенно, до достижения целевого уровня гемоглобина не ниже 110 г/л;
  9. для лечения нарушений фосфорно-кальциевого обмена в зависимости от результатов исследований должны назначаться препараты, до достижения целевых уровней паратгормона 150 - 300 пг/мл, кальция 2,10 - 2,37 ммоль/л, фосфора не выше 1,78 ммоль/л;
  10. ежемесячно лечащий врач должен оценивать эффективность процедур гемодиализа по индексу адекватности, который должен быть  $\geq 1,2$ ;
  11. Вы должны всегда иметь при себе паспорт диализного пациента.
- По всем вопросам Вы можете обратиться к лечащему врачу и главному внештатному нефрологу Управления здравоохранения Вашего региона.

С памяткой ознакомлен \_\_\_\_\_ ФИО пациента

\* Memo of a dialysis patient is borrowed from the Order of the Ministry of Health of the Republic of Kazakhstan dated 30 December 2013 №765 "On approval of the standard for the provision of nephrological assistance to the population in the Republic of Kazakhstan" Annex 6.

Appendix 3. Statement to the Local Ethics Committee

To the chairman of the Local Ethics  
Committee

JSC "KazMUCE"

Ospanova D.A.

by a master student of the first year of  
training in the specialty "Nursing"

Makhigul Maxudova

**STATEMENT**

I ask you to conduct an ethical review of the research papers on the topic:  
**Development of recommendations for nurses to prepare patients and their families  
for dialysis.**

On the basis of the Medical Center "Zhasandy buirek"

To the address: Almaty, 102A Pyatnitsky street.

The main researcher: Makhigul Maxudova - Master of Kazakh-Finnish Magistracy in  
the specialty "Nursing".

The main researcher

Makhigul Maxudova

## Appendix 4. Study protocol

### Study protocol

**Theme:** Development of recommendations for nurses to prepare patients and their families for dialysis

**Purpose:** to improve the quality of nursing by creating recommendations for preparation of patients with end-stage of chronic renal failure and their family members at the beginning of dialysis to reduce the risk of complications and improve quality of life.

**Objectives:**

1. Study experience and basic needs of patients in preparation for hemodialysis.
2. Develop and justify nursing recommendations for counseling patients and their families at the beginning of hemodialysis.

**Research questions:**

1. What are patients' and their relatives' views on the experiences, basic needs of patients with end-stage of chronic renal failure to create recommendations for nurses to prepare patients and their families for dialysis?
2. What are nurses' and nephrologists' views on the experiences and basic needs of patients with end-stage chronic renal failure to create recommendations for nurses to prepare patients and their families for dialysis?

**Methodology:**

Qualitative research.

Data collection method—semi-structured interview.

Data-analysis method—content analysis, inductive approach.

**Annotation**

Annually more than 2.5 million people with chronic renal failure around the world receive renal replacement therapy – dialysis (Al Ismaili, Al Salmi, Al Maimani, Metry, Al Marhoobi, Hola, & Pisoni 2017). Dialysis is a vital procedure, since it helps to purify

the blood from toxins and remove fluid from the body, i.e. it performs the physiological work of the kidneys when they themselves are unable to cope with this (Medical encyclopedia, 2016; MedlinePlus, 2019). Diabetes mellitus and hypertension are the most common causes of chronic kidney disease - a gradual, progressive, and permanent loss of kidney function (Ghaderian & Beladi-Mousavi 2014). Against the background of chronic diseases, it is important to have a timely examination of the kidneys and, if necessary, gradual preparation of patients for the beginning of renal replacement therapy (Clinical protocol of the Ministry of Health of the Republic of Kazakhstan "Chronic kidney disease in adults" 2016).

An important fact is the preparation of patients and their family members for dialysis. Chronic renal failure and dialysis is quite a serious hardship, both for the patient himself and for all members of his family (Walker, Abel, & Meyer 2010). This is due, first of all, to the lack of information, the need to change the family lifestyle, the adaptation of the new regime of the day and nutrition, etc. In this difficult period, patients and their families need moral support, obtaining reliable information necessary to adapt to new conditions of life, which contributes to the effectiveness of replacement renal therapy. (Life on dialysis 2018; Neyhart, McCoy, Rodegast, Gilet, Roberts, & Downes 2010.)

The nurse plays an important role in preparing patients for dialysis (Walker et al. 2010). Important aspects in this case are patient care and compliance with basic vital rules for hemodialysis patients - diet, care for vascular access, etc. (Life on dialysis 2018). A trained nurse who is not only involved in the procedure of hemodialysis and patient care in a hospital environment, but also conducts outreach of the main aspects and rules of life with hemodialysis, helps to gain knowledge and necessary skills. (ibid.; Clinical protocol of the Ministry of Health of the Republic of Kazakhstan "Chronic kidney disease in adults" 2016; Al Nazly, Ahmad, Musil, & Nabolsi 2013.) The nurse acts as a mentor, educator, and guide, who helps the patients and members of his family to adapt to new conditions of life (Walker et al. 2010). Recommendations received by patients and their relatives should help to reduce the level of stress, and also to prepare for the beginning of hemodialysis, giving explanations of what needs to be done, to observe, the importance of the procedure, care of vascular access, possible complications and consequences, etc. In a word,

prepare patients mentally and psychologically for the vital procedure of hemodialysis. (Life on dialysis 2018.)

## Appendix 5. Questions for interview

### For patients and their relatives

1. Study of personal data:  
sex  
age
2. Diagnosis:  
which pathology led to program hemodialysis,  
how long  
your preparation for hemodialysis
3. Hemodialysis:  
what time do you get the program?  
Control methods  
Your expectations
4. Counseling:  
types of renal replacement therapies,  
who prepared you and how  
diet  
dry weight
5. Relatives:  
Lifestyle, changes  
Relationships

### For nurses

1. What time do you work in the dialysis department?
2. What are the main challenges faced by dialysis patients?
3. What recommendations are needed by patients and their relatives in preparation for dialysis therapy?



## Appendix 6. Presentation of the study to the participants

### **Dear Usmanov Anvar Ravshanovich!**

The purpose of this study is to improve the quality of nursing by developing recommendations for the preparation of patients with the final stage of chronic renal failure and their families at the beginning of dialysis to reduce the risk of complications and improve the quality of life. The aim of the study is to create recommendations for the doctors and nurses on patients and their families' needs in preparation for hemodialysis.

I ask for your consent to conduct interviews with patients, their relatives, and also employees of your department. Participation in the study is completely voluntary, and withdrawal from participation does not entail any consequences.

In the interview, we want to get information about the experience of patients and their families. The choice of the interviewed participants is done on volunteers who gave their consent and contact details. They will be contacted personally in the summer of 2018. The interview is presented in the form of an individual interview with each participant, during which a digital audio recording of the conversation is made without mentioning the names and other possible identifiers of the person. At the same time, if there is a reluctance to continue the conversation, the interview stops and can be resumed only if the respondent agrees. On average, the interview takes about one hour. During the conversation, the participants will be asked to answer a number of open questions concerning the research topic.

The material collected from interviews with patients, their relatives, as well as department employees, will be fully encoded, so that all information will be depersonalized, and study participants cannot be identified. The research material is stored in a closed cabinet, only the researcher has a key. The researcher undertakes to comply with the existing guidelines for the preservation of legislation in the field of research and data protection. The results of the research will be a master's thesis, and the articles will be published in international scientific journals. The research material will be eliminated as appropriate after the study is completed.

Sincerely,

#### **Researcher:**

Makhigul Maxudova  
Tel.: +7 702 567 62 01  
e-mail: [mahi@list.ru](mailto:mahi@list.ru)

#### **Supervisors:**

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[Johanna.Heikkila@jamk.fi](mailto:Johanna.Heikkila@jamk.fi)

**Dear Patient!**

The purpose of this study is to find out what recommendations the patients and their families need in preparation for hemodialysis. The aim of the study is to create recommendations for the doctors and nurses on patients and their families' needs in preparation for hemodialysis

I ask for your consent to conduct an interview with you and your relatives. Participation in the study is completely voluntary, and refusal to participate in the survey does not affect the treatment that you receive. In the interview, we want to get information about the experience of patients and their families. The choice of interviewed patients is done on volunteers who gave their consent and contact details, they will be contacted personally in the summer of 2018. The interview is presented in the form of an individual interview with each participant, during which a digital audio recording of the conversation is made without mentioning the names and other possible identifiers of the person. At the same time, if there is a reluctance to continue the conversation, the interview stops and can be resumed only if the respondent agrees. On average, the interview takes about one hour. During the conversation, the participants will be asked to answer a number of open questions concerning the research topic.

The material collected from interviews with patients will be fully encoded, so that all information will be depersonalized, and patients cannot be identified. The research material is stored in a closed cabinet, only the researcher has a key. The researcher undertakes to comply with the existing guidelines for the preservation of legislation in the field of research and data protection. The results of the research will be a master's thesis, and the articles will be published in international scientific journals. The research material will be eliminated as appropriate after the study is completed.

Sincerely,

**Researcher:**

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**Dear Relative!**

The purpose of this study is to find out what recommendations the patients and their families need in preparation for hemodialysis. The aim of the study is to create recommendations for the doctors and nurses on patients and their families' needs in preparation for hemodialysis.

I ask your permission to conduct an interview with you. Participation in the study is completely voluntary, and refusal to participate in the survey does not affect the treatment that a member of your family receives. In the interview, we want to get information about the experience of patients and their families. The choice of interviewed relatives of patients is made on volunteers who gave their consent and contact details, they will be contacted personally in the summer of 2018. The interview is presented in the form of an individual interview with each participant, during which a digital audio recording of the conversation is made without mentioning the names and other possible identifiers of the person. At the same time, if there is a reluctance to continue the conversation, the interview stops and can be resumed only if the respondent agrees. On average, the interview takes about one hour. During the conversation, the participants will be asked to answer a number of open questions concerning the research topic.

The material collected from interviews with the patient's relatives will be fully encoded, so that all information will be depersonalized and the participants in the study cannot be identified. The research material is stored in a closed cabinet, only the researcher has a key. The researcher undertakes to comply with the existing guidelines for the preservation of legislation in the field of research and data protection. The results of the research will be a master's thesis, and the articles will be published in international scientific journals. The research material will be eliminated as appropriate after the study is completed.

Sincerely,

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**Dear Nurse!**

The purpose of this study is to find out what recommendations the patients and their families need in preparation for hemodialysis. The aim of the study is to create recommendations for the doctors and nurses on patients and their families' needs in preparation for hemodialysis.

I ask your permission to conduct an interview with you. Participation in the study is completely voluntary, and refusal to participate in the survey does not affect your work. In the interview, we want to get information about the experience of patients and their families. The choice of interviewed patients is done on volunteers who gave their consent and contact details, they will be contacted personally in the summer of 2018. The interview is presented in the form of an individual interview with each participant, during which a digital audio recording of the conversation is made without mentioning the names and other possible identifiers of the person. At the same time, if there is a reluctance to continue the conversation, the interview stops and can be resumed only if the respondent agrees. On average, the interview takes about one hour. During the conversation, the participants will be asked to answer a number of open questions concerning the research topic.

The material collected from the interview with the nurses will be fully encoded, so that all information will be depersonalized, and the study participants cannot be identified. The research material is stored in a closed cabinet, only the researcher has a key. The researcher undertakes to comply with the existing guidelines for the preservation of legislation in the field of research and data protection. The results of the research will be a master's thesis, and the articles will be published in international scientific journals. The research material will be eliminated as appropriate after the completion of the research.

Sincerely,

**Researcher:**

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## Appendix 7. Informed consent to participate in the study

### **Informed consent to participate in the study (for patients)**

I was asked to give my consent for an interview for research purposes. The aim of the study is to create recommendations for the doctors and nurses on patients and their families' needs in preparation for hemodialysis.

With this informed consent, I confirm that I am given full and comprehensive explanations of the nature of the research, its objectives, and the confidentiality of the study. I confirm that the information given by me during interviewing reflects the reality.

I understand that my participation in the study is voluntary, in case of any discomfort; I have every right to refuse to participate in this study and to withdraw my data. Denial of participation or withdrawal of consent does not affect the process of my treatment.

By signing this consent letter, I voluntarily grant my consent for interviewing and using the findings for research purposes.

Date \_\_\_\_\_

Signature \_\_\_\_\_

Clarification of the name \_\_\_\_\_

I agree to the interview.

Phone number

**Informed consent to participate in the study (for relatives)**

I was asked to give my consent for an interview for research purposes. The aim of the study is to create recommendations for the doctors and nurses on patients and their families' needs in preparation for hemodialysis.

With this informed consent, I confirm that I am given full and comprehensive explanations of the nature of the research, its objectives, and the confidentiality of the study. I confirm that the information given by me during interviewing reflects the reality.

I understand that my participation in the study is voluntary, in case of any discomfort; I have every right to refuse to participate in this study and to withdraw my data. Denial of participation or withdrawal of consent does not affect the treatment of a member of my family.

By signing this consent letter, I voluntarily grant my consent for interviewing and using the findings for research purposes.

Date \_\_\_\_\_

Signature \_\_\_\_\_

Clarification of the name \_\_\_\_\_

I agree to the interview.

Phone number

**Informed consent to participate in the study (for nurses)**

I was asked to give my consent for an interview for research purposes. The aim of the study is to create recommendations for the doctors and nurses on patients and their families' needs in preparation for hemodialysis.

With this informed consent, I confirm that I am given full and comprehensive explanations of the nature of the research, its objectives, and the confidentiality of the study. I confirm that the information given by me during interviewing reflects the reality.

I understand that my participation in the study is voluntary, in case of any discomfort; I have every right to refuse to participate in this study and to withdraw my data. Denial of participation or withdrawal of consent does not affect the process of my work.

By signing this consent letter, I voluntarily grant my consent for interviewing and using the findings for research purposes.

Date \_\_\_\_\_

Signature \_\_\_\_\_

Clarification of the name \_\_\_\_\_

I agree to the interview.

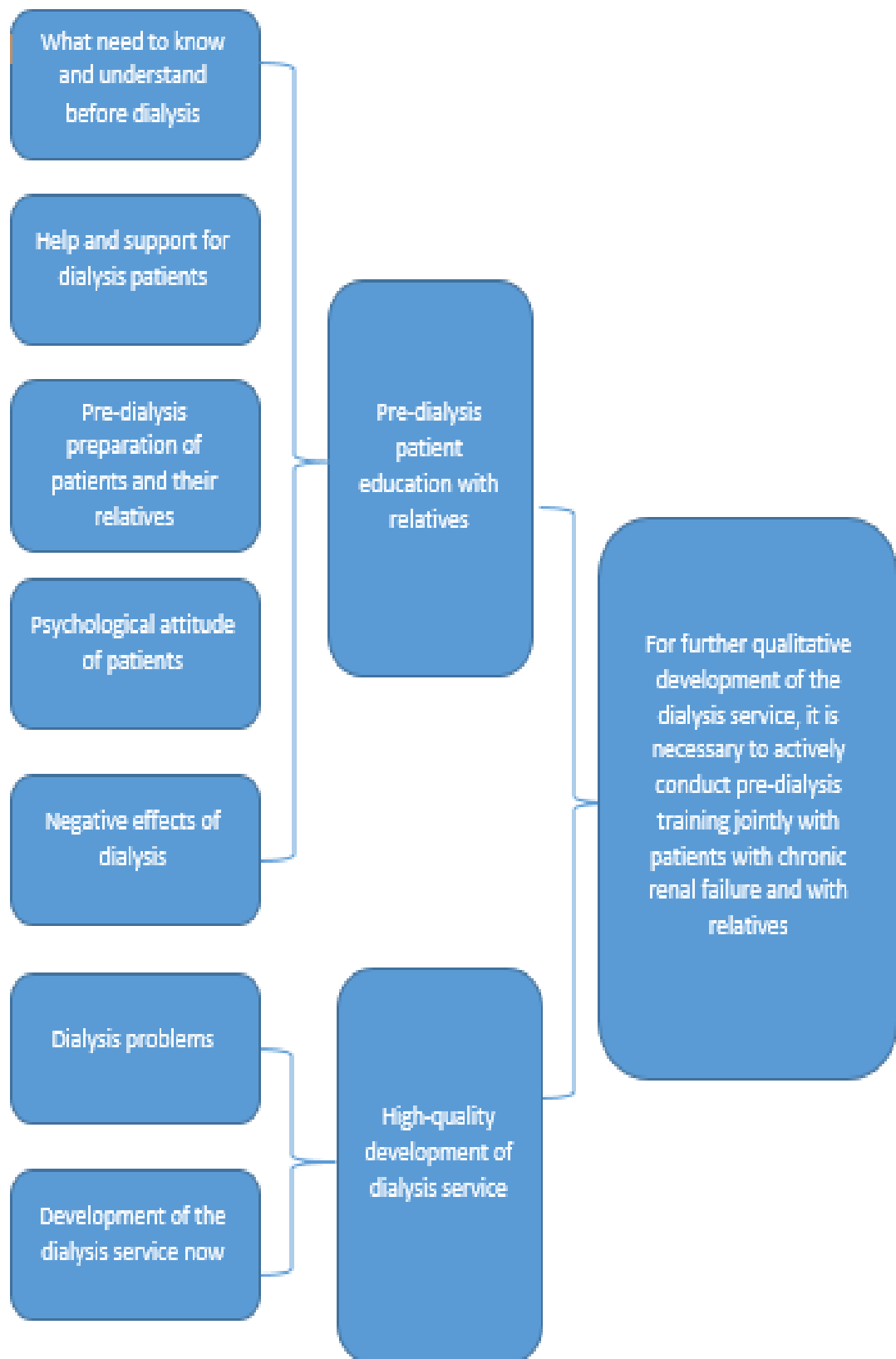
Phone number

## Appendix 8. The process of inductive content analysis

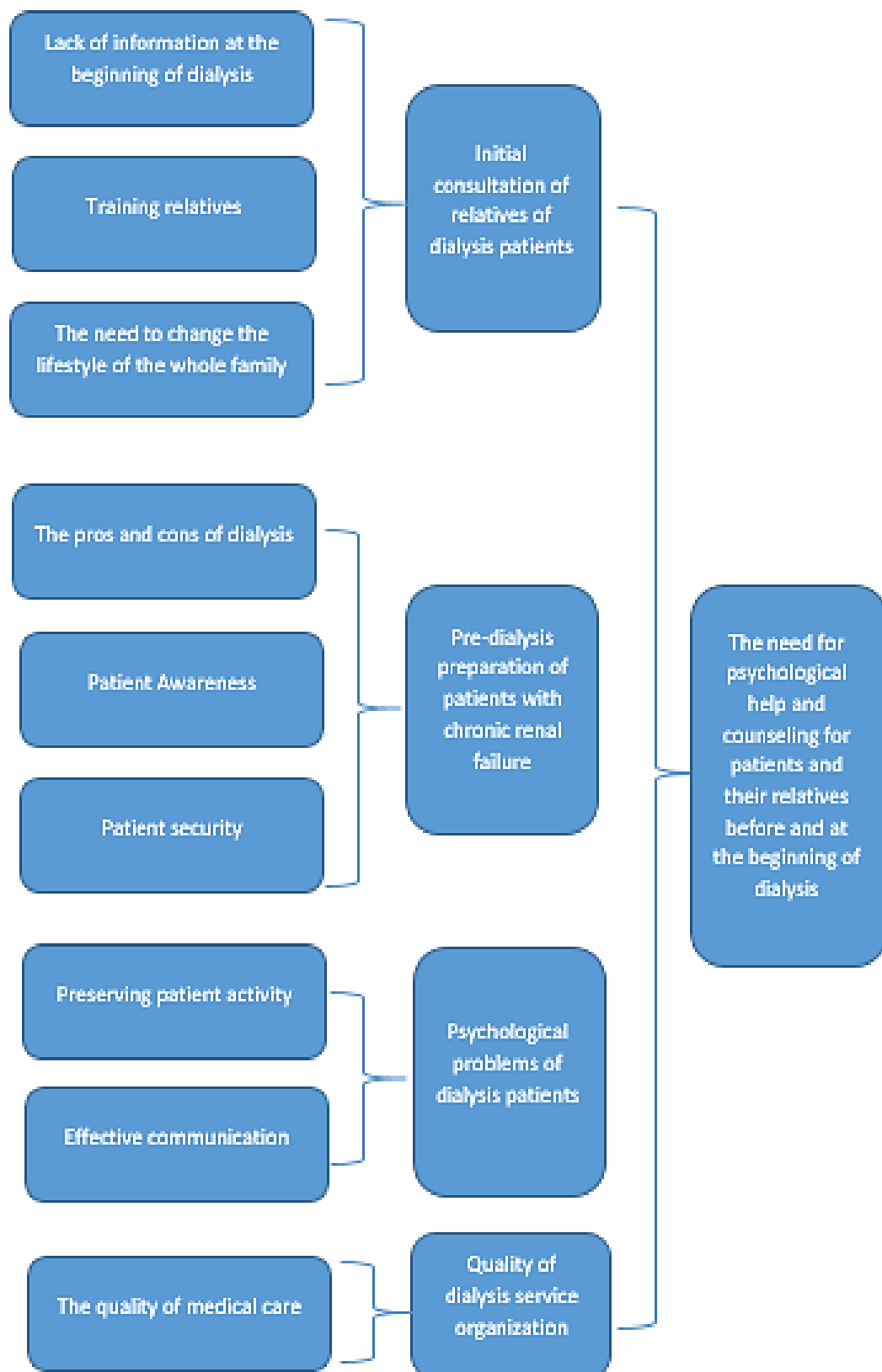
<b>Original expressions</b>	<b>Coding</b>	<b>Sub Categorization</b>	<b>Categorization</b>	<b>Abstraction</b>
nor do you know how to help	inability to help, helplessness	Perception of dialysis by relatives	Initial consultation of relatives of dialysis patients	The need for psychological help and counseling for patients and their relatives both at the stage of pre-dialysis preparation and in the first days of the start of dialysis therapy
What attitude can there be if there is nothing more to help?				
don't even want to remember that month in the hospital	relation of relatives to dialysis			
my attitude is sad				



## Appendix 9. Scheme of the abstraction process for group of patients



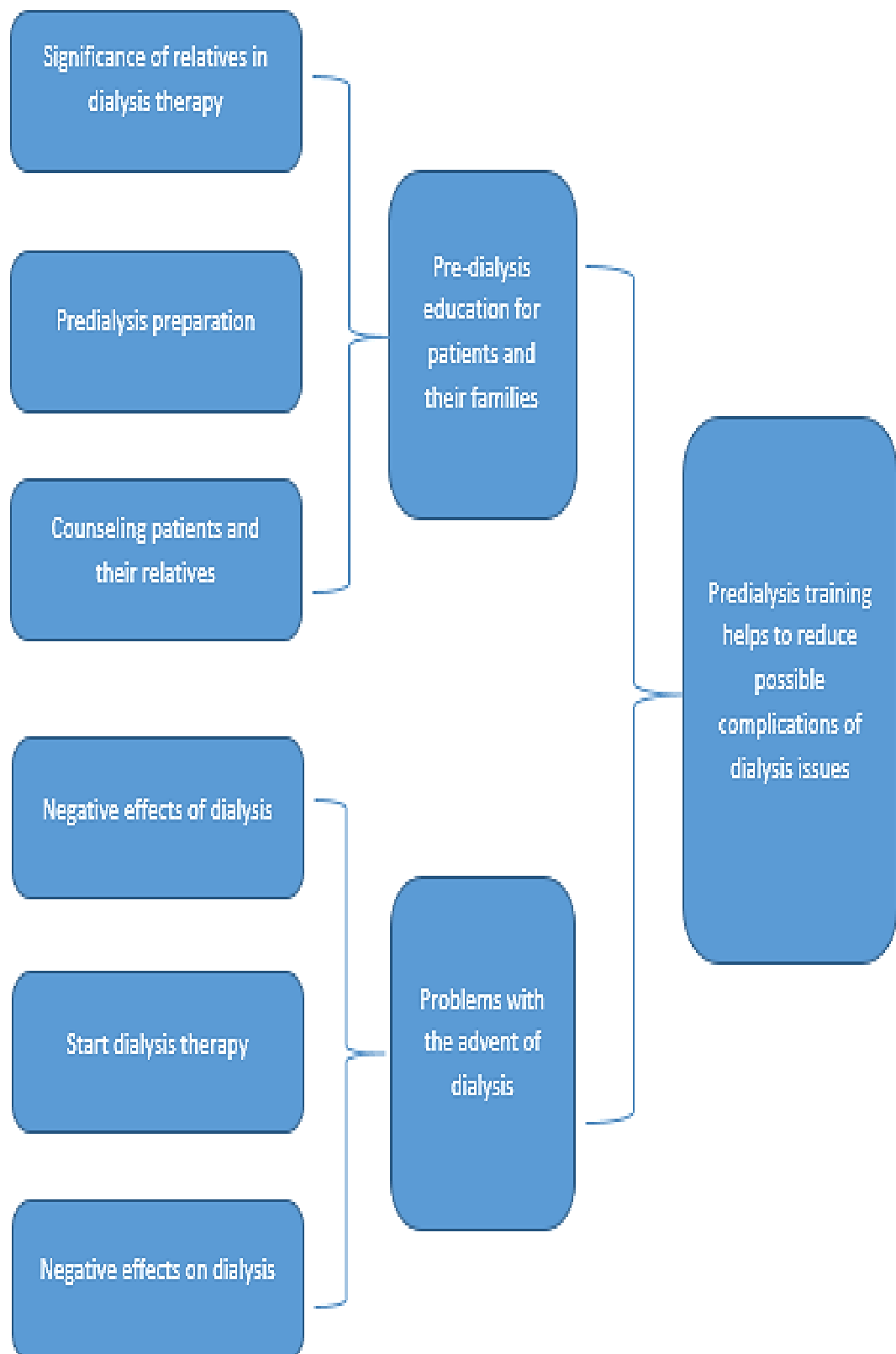
Appendix 10. Scheme of the abstraction process for group of patients' relatives



Appendix 11. Scheme of the abstraction process for group of nurses



Appendix 12. Scheme of the abstraction process for group of nephrologists



Appendix 13. Recommendations for nurses on how to prepare patients and their families for dialysis according to dialysis patients' and their families' opinions

**Mutual psychological preparation of patients and their families for beginning of dialysis therapy.** Intended to help patients and their families to understand and accept CKD, put up with invalidization and also be ready for inevitable changes in life. It is important that patients do not get obsessed with their diagnosis and wait for death. It is necessary to look in future and continue living with dialysis.

Psychologically prepared and tuned up patient will not fear dialysis, this is a great help in management of such patients. Families are required to be ready that one of their family members will require more attention and care to get adapted to new conditions of life with dialysis. In most cases family members had to take difficult and important burden of supporting stable emotional condition of the dialysis patients. Psychological consultations are needed not only at pre-dialysis stage but also at the beginning of the dialysis therapy as well as periodically to support psychological condition of these patients and their families.

**Informing patients and their families.** Comprehensive informing of patients and their families about causes leading to dialysis, about dialysis itself, frequency of dialysis procedures, renal replacement therapy options, opportunities for donorship, possible complications without dialysis, difference between urgent and planned beginning of dialysis, necessity for upfront formation of access to blood vessels, inevitability of changes in lifestyle for the whole family. It is preferable to reveal CKD in advance and start early preparation for renal replacement therapy. Consultancy must also include rules for care in home conditions. It was proposed to organize special course for patients and their families on preparation for the dialysis therapy.

**Recommendations about nutrition for the whole family.** Adherence to basic nutrition rules, restriction of salt and fluids. Patients must strictly keep to the diet in order to avoid additional stress-induced tension. How to cook meal for the whole family considering needs of dialysis patients.

**Timely seeking for medical assistance.** Timely seeking for medical help, full medical examination and treatment allows early discovery of kidneys pathology and timely preparation for renal replacement therapy.

**Distraction from personal condition.** It is important that patients stay involved in activities that are interesting for them, distract themselves from thoughts about their illness, continue socializing with their surrounding and continue full social life.

**Choosing dialysis center.** Patients are needed to familiarize with organization of dialysis service and work of dialysis centers, choose the most suitable center for them and their attending doctor whom they will fully trust.

**Social help.** Patients and their families must know what kind of social assistance they are legitimate to receive and where and how to register all the required documents, what range of medical care is provided by the government, issues of medication provision.

**Working with families separately.** Psychological preparation, training. Special training must be provided for patients' relatives who are providing daily care and ultimate support to dialysis patients. This is especially important when dialysis therapy was started urgently. Family members must clearly understand how to perceive new condition of their close relative, how to support them, how to treat fistula, what lifestyle is acceptable with the new conditions – day regimen, water-intake regime, how to take care about the dialysis patients, what to do in case of critical or emergency situations, how to create safe and comfortable conditions at home.

**Continuing moving.** Patients and their families must clearly understand that continuing moving activity promotes better health state of any human that is why it is not allowed to stop dozed physical exercises in order to maintain weight and keep trim.

Appendix 14. Recommendations for nurses on how to prepare patients and their families for dialysis according to nurse and medical staff

**Psychological preparation of patients and their families for beginning of dialysis**

**therapy.** Aimed at cognition of the patient's condition, deep understanding of necessity for dialysis therapy, importance of support from family members. It is important to accept the diagnosis and not be afraid of the dialysis, recognize that life is not over and continues with the dialysis, invalidization is not a conviction. Correct psychological aid and support helps to form positive attitude of patients and their families to dialysis.

**Informing patients and their families about dialysis.** Keeping patients with CKD and their relatives informed about the illness process, possible outcomes and complications, various options of renal replacement therapy, rules of the dialysis procedure (discipline and frequency of the procedures), difficulties that may arise during and after dialysis, advantages of smooth introduction to dialysis and disadvantages of urgent beginning of the dialysis therapy. It is necessary to not only talk and hand in bulletins but also show video and photos, arrange visits to dialysis center for the patients to see the reality of dialysis therapy and have opportunity to talk to dialysis patients.

**Forming access to blood vessels.** At the stage of pre-dialysis therapy patients are recommended to form arteriovenous fistula so that in future with the start of dialysis therapy they don't have to undergo through traumatizing catherization of central vessels.

**Recommendations about changing lifestyle.** Keeping to a diet (reduction of kitchen salt – correct way of cooking), restriction of water intake regime (saving from summer heat), changing of day regime for smooth attendance to dialysis procedures, rules of conduct during dialysis and between, constant control of primary illness (hypertonia, diabetes and etc.). These principles are necessary to maximize life duration without renal dialyzer and ensure there are no complications associated with the dialysis therapy.

**Social help and support.** Patients and their families must clearly understand what kind of help they can get from the government. For this purpose, they should be familiarized with necessary actions to take to register disability group of dialysis patient and what documents to gather and where to submit for registration of the social assistant status.

**Socializing.** Patients must continue active way of life, communicate, be interested in activities around them. Family has an important and major task to maximally help patients to save their social network and even expand by means of modern telecommunication technologies.