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Content of patient education for chronic renal failure patients undergoing dialysis treatments

A literature review

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<p>The purpose of this thesis is to describe the content of patient education for chronic renal failure patients undergoing dialysis treatments. The goal was to find knowledge that can be utilized when developing patient education for dialysis patients. The study question was: what is the content of patient education among chronic renal failure patients undergoing dialysis treatments?</p> <p>Fifteen articles were obtained using CINAHL, MEDLINE, and Medic databases (n=15) and analyzed by applying to the principles of inductive content analysis. The findings are presented in a form of literature review.</p> <p>Education for patients undergoing dialysis predominantly focuses on the bio-physiological and functional aspects. A sweeping majority of the analyzed articles concentrate on content areas such as nutrition, fluid restrictions, care of the vascular access site, treatment options, and self-care objectives. A small portion of the articles mentioned physical activity and medication management, but not one of them studied the content of the education. Social aspects were also insufficiently covered in the reviewed articles. Two articles pointed out the benefits of peer support, and one discovered a need for information on peer support groups and patient organizations. Social aspects should be strongly emphasized in the future considering the broad impact of dialysis treatments on a patient's life. This literature review revealed that patients have inadequate knowledge on various aspects of dialysis treatments, indicating that further researched and developed of patient education is necessary.</p>	
Keywords	chronic renal failure, hemodialysis, peritoneal dialysis, patient education

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<p>Tämän opinnäytetyön tarkoituksena oli kuvailla nykyistä saatavilla olevaa kroonista munuaisten vajaatoimintaa sairastavien dialyysipotilaiden ohjauksen sisältöä. Tavoitteena oli kerätä tietoa, jota hyödyntämällä voitaisiin kehittää dialyysipotilaiden ohjauksen laatua. Tutkimuskysymykseksi muotoutui: "Millaista on kroonista munuaisten vajaatoimintaa sairastavien dialyysipotilaiden ohjauksen sisältö?"</p> <p>Analysoitavaksi valittiin yhteensä viisitoista tutkimusartikkelia CINAHL, MEDLINE ja Medic tietokannoista (n=15). Analyysi toteutettiin induktiivisen sisällönanalyysin periaatteita noudattaen. Opinnäytetyön tulokset on esitetty kirjallisuuskatsauksen muodossa.</p> <p>Kirjallisuuskatsauksen perusteella voidaan todeta dialyysipotilaan ohjauksen sisällön keskittyvän pääasiassa bio-fysiologiseen ja toiminnalliseen tietoon. Suurimmassa osassa tutkimusartikkeleista painotettiin aihealueita kuten ruokavalio, nesterajoitukset, hoitomuodot, veritien hoito ja itsehoito. Osassa artikkeleista mainittiin liikunta ja lääkehoito, mutta varsinaista potilasohjauksen sisältöä niihin liittyen ei tutkittu. Sosiaalinen ulottuvuus potilasohjauksessa oli myös rajallista. Kahdessa artikkelissa painotettiin vertaistuen merkitystä ja yhdessä artikkelissa todettiin potilaiden saavan liian vähän tietoa vertaistukiryhmistä ja potilasjärjestöistä. Potilasohjauksessa tulisi erityisesti korostaa sosiaalista ulottuvuutta. Ohjauksessa tulisi myös huomioida dialyysihoitojen laaja-alainen vaikutus potilaiden elämään. Tutkimusartikkeleiden analyysi osoitti, että potilasohjauksen sisältöä tulee edelleen tutkia ja kehittää, sillä potilaiden tietämys on puutteellista monilla eri dialyysihoitojen aihealueilla.</p>	
Keywords	krooninen munuaisten vajaatoiminta, hemodialyysi, peritoneaaldialyysi, potilasohjaus

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1 Introduction

End stage renal disease (ESRD) is a global health concern. In 2013, roughly 3.2 million people were being treated worldwide. The number of people developing ESRD is rising by an estimated 6% each year. (European Renal Care Providers Association 2017.) Chronic kidney failure is characterized by gradual and often permanent deterioration of kidney function. In end stage renal disease most of the regular kidney function has been lost. (Barnett, Yoong, Pinikahana & Si-Yen 2007.) Hemodialysis, peritoneal dialysis, and kidney transplant surgery are the only life sustaining renal replacement therapies (RRT) for patients with ESRD (Smeltzer, Bare, Hinkle & Cheever 2008: 1531). In 2013, an estimated 2.5 million people received dialysis therapies worldwide (European Renal Care Providers Association 2017).

Dialysis treatments are complex and immensely onerous on patients and their families. The treatment regimens require adhering to multiple lifestyle changes and restrictions. (Barnett et al 2007.) Furthermore, dialysis treatments greatly impact patients' health related quality of life (Yu & Petrini 2009). The most important aspect of nursing is preparing patients to independently manage their health (Bastable 2008: 10). In order to achieve the best possible outcomes of dialysis treatments, patients need to acquire adequate knowledge and a broad range of self-care abilities (Barnett et al. 2007). Educating patients can help them to prevent complications, adapt to new lifestyles, manage treatments, and help prevent crisis situations. Nurses play a vital role in providing patient education, as well as monitoring outcomes and treatment compliance. (Smeltzer et al. 2008: 49, 1531.)

According to previous research, the content of education for dialysis patients should include information about kidney function, the disease, and the different treatment options, e.g. nutrition, medications, different forms of dialysis, and kidney transplants (Alahuhta, Hyväri, Linnanvuori, Kylmäaho & Mukka 2008: 68-70). In addition, patients initiating hemodialysis treatments should receive further education and detailed instructions for the care of vascular access sites, sodium, phosphorus, potassium, and fluid restrictions, as well as medication management (Heiskanen 2013). The complexity of dialysis treatment and the continuous growth in the number of people developing end stage renal disease suggest that more emphasis should be put on patient education.

This literature review explores the content of patient education for renal failure patients undergoing dialysis treatments. The goal was to find information that can be utilized to further develop patient education for this patient population. This thesis is part of an ongoing project between Metropolia University of Applied Sciences and the Dialysis Teaching Center of the Hospital District of Helsinki and Uusimaa.

2 Renal failure and dialysis treatment

2.1 Renal failure

The kidneys are located against the dorsal body wall, in the superior lumbar region (Marieb 2014: 589). They are an essential organ for life and play a key role in the body's homeostasis: the stability and maintenance of the internal environment of the body. Kidneys reach homeostasis by filtering essential nutrients back into the bloodstream and excreting toxic substances and metabolic waste products as urine, thus maintaining the optimal acid-base balance, water and electrolyte balance, and normal blood pressure. Furthermore, kidneys produce renin that is a part of the blood pressure control mechanism, erythropoietin that stimulates red blood cell production, and an active form of vitamin D. (Naish, Revest & Syndercombe Court 2009: 729.)

There are a wide variety of conditions that can cause chronic renal failure, of which the most common causes are diabetes mellitus, hypertension, and glomerulonephritis. Diabetes alone accounts for 30-40% of cases needing dialysis. Other causes are calcification of blood vessels, long term exposure to environmental toxins, misuse of analgesics, and various hereditary diseases, such as polycystic kidney disease. (Munuais- ja maksaliitto ry 2016a; Naish et al. 2009: 766.)

Due to the kidney's ability to reserve in function, renal dysfunction is often asymptomatic until later stages of the condition. More than 75% of renal function can be lost before symptoms appear. Blood tests can give early warning signs of renal dysfunction in the form of a rise in plasma creatinine and a rise in urea. Kidney function can be measured and monitored with blood and urine samples. (Naish et al. 2009: 764.) Table 1 presents the five stages of CKD.

Table 1. CKD Stages (The Renal Association 2016)

Stage	GFR ml/min	Description
1	90+	Normal kidney function but urine findings or structural abnormalities or genetic trait point to kidney disease
2	60-89	Mildly reduced kidney function, and other findings (as for stage 1) point to kidney disease
3A 3B	45-59 30-44	Moderately reduced kidney function
4	15-29	Severely reduced kidney function
5	<15 or on dialysis	Very severe, or end stage kidney failure (sometimes called established renal failure)

As renal dysfunction affects essentially every organ system, potential clinical manifestations are extensive. Symptoms include cardiovascular manifestations, commonly hypertension and peripheral swelling, gastrointestinal manifestations such as nausea and vomiting, dermatologic symptoms like pruritus, and neurologic manifestations such as fatigue, muscle cramps, and agitation. (Smeltzer et al. 2008: 1527-1528.)

2.2 Dialysis treatment

Treatment for chronic renal failure patients aims to delay the progression of the disease and to minimize the complications involved (Kartinen 2016). Treatment options are dialysis or kidney transplant surgery (Munuais- ja maksaliitto ry 2016b). A kidney transplant is usually the most favorable option, although it is possible for only about 25% of patients due to underlying conditions (Saha 2012). Dialysis treatment replaces lost kidney function by removing fluid and waste products from the body, as well as maintaining normal electrolyte balance (Smeltzer et al. 2008: 1531).

Once Glomerular Filtration Rate (GFR) falls under 10 ml/min renal replacement therapy (RRT) should be initiated (Naish et al. 2009: 767). The methods of dialysis include hemodialysis (HD), continuous renal replacement therapy (CRRT), and peritoneal dialysis (PD) (Smeltzer et al. 2008: 1531). As CRRT is a highly specialized and complex method to treat acute kidney dysfunction (Langford, Slivar, Malone Tucker & Fothergill Bourbonnais 2008), this study will primarily focus on hemodialysis and peritoneal dialysis treatments.

2.2.1 Hemodialysis

Hemodialysis is achieved through vascular access, either via arteriovenous fistula, graft, or central venous catheter. Toxins and waste products are removed from the blood stream by connecting the vascular access site to a machine, a dialyzer, which works as a pump that circulates and filters the blood and returns it back into the patient. A single treatment takes 4 to 5 hours to complete and must usually be repeated three times a week. (Heiskanen 2013.)

2.2.2 Peritoneal dialysis

A soft catheter is positioned surgically through the abdominal lining into the peritoneal cavity behind the urinary bladder 2 to 4 weeks before initiating treatment. Dialysate fluid is infused into the peritoneal cavity through the catheter by gravity. (Kilpiö 2014.) The peritoneum then acts as a semi-permeable membrane that filters excessive fluid and metabolic waste products from capillaries into the dialysate fluid by osmosis (Naish et al. 2009: 767), after which the dialysate is drained and replaced (Kilpiö 2014). Peritoneal dialysis treatment must be repeated frequently to replace lost renal function (Smeltzer et al. 2008: 1545).

2.3 Patient education among renal failure patients undergoing dialysis treatments

Patient education aims to provide the patient with enough information about the disease and guidance regarding different treatment options (Alahuhta et al. 2008: 68). The Act on the Status and Rights of Patients obligates health care personnel to inform the patient about their health, importance of the treatment, alternative forms of treatment, their treatment's significance, and about other substantive factors involved in decision making (Act on the Status and Rights of Patients 785/1992 section 5). The patient has the right to be involved in the process of decision making as well as creation of the care plan (Act on the Status and Rights of Patients 857/2004 section 4 a). Safeguarding the patient's legally protected rights, patient education is of the utmost importance. It empowers patients and their families to make knowledgeable decisions regarding their treatment options (Murphy, Jenkins, McCann & Sedgewick 2008: 191-198).

The purpose of patient education is to promote, maintain, and restore health, including the "... prevention, treatment, and management of illness, and the preservation of mental and physical client well-being" (Miller & Stoeckel 2011: 5). Factors like the patient's age, developmental stage, life situation, and personality should all be considered when planning and implementing the education (Alahuhta et al. 2008: 68). There is no single best way to promote learning, but studies suggest that each learner's unique characteristics should be considered (Bastable 2008: 84).

The effectiveness of the education is largely dependent on the patient's motivation to learn; therefore, the goal is also to motivate the patient to care for themselves. (Alahuhta et al. 2008: 68.) Many studies have found that patient education has the potential to decrease anxiety, increase treatment compliance, reduce complications, and improve patients' quality of life (Bastable 2008: 10). Furthermore, it enhances independence and empowers patients by transitioning them from passive recipients to active participants in their care. It also has the potential to increase patient satisfaction as well as to protect the continuity of care. (Bastable 2006: 8-9.)

3 Purpose, goal, and research question

The purpose of this thesis is to describe the content of patient education for chronic renal failure patients undergoing dialysis treatments. The ultimate goal was to find knowledge that can be utilized when developing patient education for dialysis patients. The study question was, what is the content of patient education among chronic renal failure patients undergoing dialysis treatments?

4 Methods

4.1 Data collection method

This thesis was conducted as a qualitative research in the form of a descriptive literature review. The aim of a descriptive literature review is "... to identify, analyze, assess and interpret a body of knowledge on a topic." It can be commenced as an independent review that connects various aspects of the topic, or introduces new or contrasting interpretations of it. (Coughlan, Cronin & Ryan 2013: 15.) Research should primarily rely on original publications such as academic journals, textbooks, and research reports, to ensure the credibility of the data (Parahoo 2006: 122-126). Therefore, in this literature review, only original research articles published in academic journals were used.

4.2 Data collection

Nursing related studies should combine CINAHL and MEDLINE databases, in order to obtain the best results (Subirana et al. 2002). The searches were made using CINAHL, MEDLINE, and Medic databases. Search terms in CINAHL were: renal failure or kidney failure and dialysis and patient education. When using MEDLINE database, *nurs was added to the search terms. Search terms used in Medic database were dialyysi and *ohjaus, as Medic is a Finnish database. For inclusion, the research articles had to be relevant to the research question, and written in English or Finnish. The sources should be up-to-date (Parahoo 2006: 122-126), therefore only articles published between 2006 and 2017 were included. The search and selection process is presented in Table 2.

Table 2. Search terms and limitations

Database	CINAHL	MEDLINE	Medic
Search terms	Renal failure OR kidney failure AND dialysis AND patient education	Renal failure OR kidney failure AND dialysis AND patient education AND *nurs	Dialyysi AND *ohjaus
Years	2006-2017		
Limitations	English language Full text	English language Full text	Finnish language
Number of hits	104	33	3
Duplications removed	4		
Total number of fits	136		
Fit to selection criteria by title and abstract	68		
Fit to selection criteria by entire content	25		
Articles taken into analysis	15		

Initially the research articles were selected according to the relevance of the title and abstract, reflecting the purpose of this literature review. The content of the selected articles were then reviewed, and 15 articles relevant to the study question were chosen for further analysis. All articles were reviewed by both members of this thesis throughout the whole search and selection process.

4.3 Data analysis

The data was analyzed by applying to the principles of inductive content analysis according to the research question. The data was organized and coded into categories, using open coding in which notes and headings were created while reviewing the data. Content answering our research question was contracted and summarized from the chosen articles, after which the relation within the categories were identified. (Appendix Table 1.) Additional codes were developed as the analytical process progressed and the original coding schemes were revised and refined.

Content analysis aims to illustrate a phenomenon in a conceptual form. In inductive content analysis, the concepts are extracted from the data and it is useful when the data of the phenomena is scattered. This approach typically provides the researcher with a deeper understanding of the phenomena. (Elo & Kyngäs 2008: 107,109.) Considering the purpose and the aim of this study, inductive content analysis was an appropriate method for this thesis.

Some of the research articles answered our research question more broadly than others. For example, some of the articles included several aspects of the content of patient education, whereas others focused on one aspect. The articles containing multiple subjects of patient education were used in several categories to support the findings of the other articles or to give additional knowledge.

5 Results

5.1 Education on blood pressure control

A treatment group of hypertensive HD patients received education on blood pressure management. The content included explaining the pathophysiology and risks of hypertension in end-stage renal disease, as well as self-care objectives, interventions, and the importance of self-regulatory behavioral changes that could enhance blood pressure control. Each participant was provided with a home blood pressure device along with operating instructions on how to record their blood pressure correctly. They also received educational materials on sodium and fluid restrictions related to blood pressure management, and guidance in the upkeep of fluid balance and sodium intake logs. (Kauric-Klein 2012.)

Even though both systolic and diastolic blood pressures were significantly reduced in the treatment group, there was no improvement in blood pressure knowledge nor blood pressure self-efficacy, suggesting that blood pressure education alone does not produce behavioral change. Kauric-Klein proposed combining education with interventional methods such as monitoring, goal setting, and reinforcement for more favorable outcomes. The study found a strong connection between adhering to medicinal regimen, BP outcomes, and promoting patients' commitment to medication management. (Kauric-Klein 2012.)

5.2 Education on fluid restrictions

Patients undergoing HD and PD are often noncompliant with their treatment regime, especially with fluid and sodium restrictions (Barnett et al. 2007; Pessoa & Linhares 2014;

Su, Lu, Chen & Wang 2009). Maintaining a proficient fluid and sodium balance can be difficult to achieve and requires good self-management skills. This often leads to the patients neglecting fluid and sodium restrictions. (Su et al. 2009.) Failure to comply with these restrictions increases the risk of medical complications in dialysis patients. Nurses often have long-term relationships with their patients. Therefore, they are in an ideal role to provide ongoing education and encouragement about adhering to fluid restrictions, especially for those experiencing difficulties. (Barnett et al. 2007.)

An information needs survey revealed that patients undergoing HD had inadequate knowledge on fluid restrictions (Barnett et al. 2007). On the contrary, a study conducted in Finland discovered that patients receive adequate information regarding fluid balance and dry weight (Eloranta, Gröndahl, Engblom & Leino-Kilpi 2013). Pessoa and Linhares (2014) found that most of their patients were aware of fluid restrictions, yet they failed to associate interdialytic weight gain (IDWG) with excessive sodium intake. Therefore, adequate education on the importance of adherence, IDWG, and the potential risks of adverse outcomes is needed (Barnett et al. 2007).

Hemodialysis patients should be educated about fluid control, fluid balance, sodium intake, weight control, and complications of excess fluid. A study found that educating patients on these topics positively affects their adherence to fluid restrictions and their mean interdialytic weight gain. (Barnett et al. 2007.) Similar results were discovered in PD patients, showing increased knowledge, better clinical outcomes, and improved health-related quality of life as well as rehabilitation status (Su et al. 2009). Barnett et al. (2007) highlighted the importance of improving knowledge and self-management skills to maximize treatment efficacy, not only in patients new to dialysis programs, but also in patients already in dialysis treatments struggling with fluid compliance.

5.3 Education on nutrition

Dialysis patients expressed a considerable need for dietary counseling (Yu & Petrini 2009). Educating HD patients on nutritional subject matters — such as healthy diet, nutritional restrictions, and possible harmful consequences of non-adherence — can significantly improve their knowledge score and overall quality of life. Furthermore, dietary educational intervention can have a positive effect on different dimensions of health and reduce consequences of disease. (Ebrahimi, Sadeghi, Amanpour & Dadgari 2016.) Education provided to PD patients showed similar improvements as in HD patients, such

as adherence to dietary modifications and dialysis prescriptions, enhanced self-management and health status, and a perceived increase in the patient's quality of life (Su et al. 2009). Patients have a poor level of knowledge related to low protein diet, suggesting the topic should be focused on when educating patients on nutritional matters (Wells 2011).

Shi et al. (2012) educated the participants about hyperphosphatemia and associated risks, phosphorus in the diet including a list of foods high in phosphorus, and how to reduce phosphorus intake including nutritional information and recipes. Additionally, the participants received information about the normal range of serum biochemical tests and medicinal treatment of hyperphosphatemia. Oral phosphate binders and restricting phosphorus in the diet are the currently used methods for serum phosphorus control during dialysis. The educational program significantly improved the participants' serum phosphorus levels and their general knowledge of phosphate. The study found that an important factor in the reduction of serum phosphorus levels might be associated with the elaborate nutritional information, more specifically the instructions on how to avoid consuming additive-containing processed foods high in phosphorus. (Shi et al. 2012.)

5.4 Education on care of arterio-venous fistula

97.7% of patients with arterio-venous fistula (AVF) had inadequate knowledge regarding the care of it. The patients had a fairly good knowledge of avoiding traumas and excessive weight on the limb with the AVF, as well as exercising with a pliable object. However, there was a lack of knowledge related to the habitual verification of fremitus in the site of the AVF, keeping the dressing clean and dry after surgery, and keeping the bandage loose during the maturation period. (Pessoa & Linhares 2014.)

The best recalled practices during the curative phase were fluid restrictions, avoidance of excessive weight on the limb with the AVF and washing the limb with soap and water prior to HD. The importance of avoiding blood pressure measurements, blood sampling and administration of medicines on the limb with the AVF were also well remembered. Patients had inadequate knowledge on how to respond in case of hematoma formation in the site of the AVF. Furthermore, the patients reported not having access to information regarding appropriate AVF care. Patients did not adhere to certain practices despite having adequate knowledge. However, the study found that inadequate knowledge leads to inadequate self-care of the AVF. (Pessoa & Linhares 2014.)

5.5 Education on treatment options

Patients need to be able to make informed decisions about their treatment options. Self-care ability and an adequate level of knowledge regarding the dialysis modalities were found to be the leading factors contributing to the choice of dialysis modality. (Liang et al. 2011.) Sondrup, Copland, Black and Trask (2011) project that more patients would choose home dialysis if they were given additional support in the decision-making process. In fact, the study participants did express that peer support would encourage them to select independent dialysis.

In selecting the appropriate renal replacement therapy (RRT), patients need educational materials that focus more on the lifestyle aspects, especially the benefits of home dialysis, instead of listing the positives and negatives of the different RRT options (Sondrup et al. 2011). In addition, patients have expressed a need to be educated on the side effects of dialysis, why it is important for them to adhere to the treatment, and what are the possible consequences of non-adherence (Clarkson & Robinson 2010). Patients have emphasized wanting more information on which treatment option best suits their lifestyle, especially their social and physical activities, and which one is the best for them medically. Another area of concern is how the disease affects their relatives. (Pagels, Wång & Wengström 2008.)

Comprehensive education about topics, such as dialysis options and related procedures, fluid balance and systemic infection management, can alleviate anxiety related to decision making, as well as improve patients' quality of life (Liang et al. 2011). Patients have suggested that the education should include practical information such as the space required for dialysis supplies, waste disposal management, swimming and bathing limitations (PD), travel restrictions (HHD), and infection prevention (Sondrup et al. 2011).

A study conducted in Finland found that patients receive sufficient information regarding treatment options (Eloranta et al. 2013). On the contrary, another study discovered that patients lack comprehensive education before the initiation of dialysis, especially about certain limitations of life on dialysis (Sondrup et al. 2011). Pre-dialysis education is crucial to patient empowerment, initiation of self-caring, and should aim to help patients in choosing a treatment option that best supports their lifestyle (Liang et al. 2011).

5.6 Education on social aspects

A study focusing on dialysis patients' perception on patient education, revealed that bio-physiological and functional aspects were adequately covered, whereas social aspects were not. Patients reported receiving a great deal of information on how to cope at home, but less than half reported being advised about patient organizations, peer support groups, and relatives possible participation in care. The study found lack of education also in areas such as kidney surgery, social services and financial matters. (Eloranta et al. 2013.) Dialysis treatments affect all aspects of health-related quality of life, including psycho-social and adverse financial effects. In order to optimize dialysis patients' quality of life, these aspects should be taken into consideration. Thorough education and individualized support would enhance patients' health-related quality of life. (Yu & Petrini 2009.)

Successful self-management requires productive communication and cooperation between healthcare professionals, patients and their families (Su et al. 2009). Family members' participation in educational sessions for dialysis patients should also be encouraged (Bayoumi & El-Fouly 2010). Implications of illness do not affect the individual patient alone, but can have immense impact on the lives of their family unit as a whole (Eloranta et al. 2013).

Patients quality of life is affected by socio-demographic factors such as age, duration of dialysis, marital status and educational level. This should be kept in mind when providing patient education, since ultimately, patients quality of life should be the nurse's primary concern. (Bayoumi & El-Fouly 2010.)

5.7 Education on physical exercise

Majority of patients with end stage renal disease do not get the recommended amount of physical activity - three 30-minute sessions per week. Surveyed patients reported having been talked to about exercise, but only half of them received actual guidance on possible programs they could attend. They proposed methods to promote greater participation in physical activities. These included recommendations from the doctor, encouragement from the whole care team along with friends and family, and routinely educating patients on issues related to physical activity. (Painter, Ward & Nelson 2011.)

Patients have voiced a great need for further informational support about exercise (Yu & Petrini 2009).

6 Discussion

6.1 Discussion of the results

Suffering from kidney disease and undergoing dialysis treatments greatly impact multiple dimensions of the patient's life; lifestyle, social life, and finances are all immensely affected. The patients are expected to follow and adhere to a range of complex treatment regimens and lifestyle restrictions. Providing dialysis patients with proficient education can alleviate anxiety, increase knowledge and self-management, and reduce consequences of the disease. (Barnett et al. 2007; Ebrahimi et al. 2016; Su et al. 2009.) Patient education can improve an individual's adherence to treatments and enhance their overall quality of life. Indeed, many of the studies found a connection between sufficient education and quality of life. (Ebrahimi et al. 2016; Liang et al. 2011; Su et al. 2009; Yu & Petrini 2009.)

Socio-demographic factors such as age, marital status, and educational level all impact the patient's quality of life and adherence to treatment and should be accounted for when providing education (Bayoumi & El-Fouly 2010; Yu & Petrini 2009). Implications of illness do not affect the individual patient alone, but can have an immense impact on the lives of their family unit as a whole (Eloranta et al. 2013). Several studies recommend including families and loved ones in the educational sessions as well as in the treatment process (Clarkson & Robinson 2010; Ebrahimi et al. 2016; Eloranta et al. 2013; Liang et al. 2011; Su et al. 2009). Two studies highlighted the importance of peer support (Eloranta et al. 2013; Sondrup et al. 2011), and one found that there is a demand for information regarding peer support groups and patient organizations (Eloranta et al. 2013). The social aspects were barely covered in the articles, highlighting the need to stress them to a greater extent in the future.

Most of the articles (e.g. Painter et al. 2011; Pessoa & Linhares 2014; Shi et al. 2012) on the content of patient education for dialysis patients emphasized the bio-physiological and functional aspects of managing the treatments. The content of education should

include information about kidney function, the disease, and the different treatment options as well as forms of dialysis (Alahuhta et al. 2008: 68-70). In addition, detailed instructions for the care of vascular access sites, education on fluid restrictions, and medication management guidance is required (Heiskanen 2013). Most of these topics were frequently mentioned in the majority of the articles. Multiple studies (Barnett et al. 2007; Clarkson & Robinson 2010; Pagels et al. 2008; Painter et al. 2011; Pessoa & Linhares 2014; Shi et al. 2012; Sondrup et al. 2011; Wells 2011; Yu & Petrini 2009) found that patients have gaps in knowledge in a broad range of content areas within the bio-physiological and functional aspects, suggesting that further patient education is required. Repetition and reinforcement of the education is advised to facilitate learning (Barnett et al. 2007).

Two of the articles mentioned covering physical activity in patient education (Bayoumi & El-Fouly 2010; Su et al. 2009), but only one article researched the topic. Painter et al. (2011) discovered that most patients with ESRD do not exercise enough, nor receive an adequate amount of education or encouragement from health care providers on the topic, suggesting that this content area should be emphasized when providing patient education in the future. Healthcare providers should incorporate strategies to increase physical activity in this patient population.

Medication management is an essential part of ESRD treatments. Research conducted by Eloranta et al. (2013) stated that the participating patients received enough information about medication management. This is inconsistent with other research that found that patients lack information on the topic and expressed a strong need to receive further guidance (Yu & Petrini 2009; Pagels et al 2008; Clarkson & Robinson 2010). Additionally, patients expressed inadequate knowledge on side effects of prescribed medications (Clarkson & Robinson 2010). The content of patient education should include information regarding medication management (Alahuhta et al. 2008: 68-70; Heiskanen 2013). In the search conducted by the authors, not one article actually covered the content of patient education regarding medication management, suggesting that more nursing research should be done on the topic.

Nurses often have more interaction with patients than any other healthcare professional. Therefore, they are in an optimal position to provide ongoing patient education, support and encouragement, and thus promote self-care efficacy, and overall quality of life. (Barnett et al. 2007; Ebrahimi et al. 2016; Kauric-Klein 2012; Smeltzer et al. 2008: 1531;

Su et al. 2009; Wells 2011.) Continuous education of nurses is vital in supporting the nurses' unique role as both a patient educator and a patient advocate.

Although patient education has a positive effect on knowledge as well as adherence to treatment, it is meager on its own. Combining education with goal setting and reinforcement, and providing patients with additional support can have more desirable outcomes. (Kauric-Klein 2012; Pessoa & Linhares 2014.) The effectiveness of the education is also largely dependent on the patient's motivation to learn (Alahuhta et al. 2008: 68). Indeed, two studies found that having adequate knowledge does not always correlate with treatment adherence (Kauric-Klein 2012; Pessoa & Linhares 2014). Therefore, nurses should not only educate their patients but find ways to motivate them to commit to their care.

The articles present different aspects of the educational content to be considered, as well as the elements nurses should emphasize when providing education. Ideally, the education should be personalized and supportive of the patient's lifestyle. All of the articles showed that there is a shortage of knowledge in a wide range of topics related to the complex treatment regimens, indicating that patient education as well as the content of the education, requires ongoing research and further development.

This literature review is limited by a general lack of research conducted in Finland on the content of patient education for dialysis patients; only one Finnish research article met the inclusion criteria. Considering the differences in health care systems worldwide, these results are generalizable, but not directly applicable to the Finnish health care system.

6.2 Discussion of ethics

Ethical aspects must be considered throughout the entire research process; in determination of the topic and the method, along with the publication of the data (Parahoo 2006: 111). Researchers conducting a literature review should "... ensure that contributors are properly acknowledged" and "... that the review does not contain plagiarized material" (Wager & Wiffen 2011). In this thesis, all authors of the original publications were rightfully acknowledged. Ethical responsibilities of the researcher also entail that the study is conducted in an unbiased manner and results reported truthfully (Gillis & Jackson 2002: 346,347). All literature is sufficiently represented in the final review.

The authors of this literature review did not have any personal or financial interests in relation to the research partner nor the research process. The research partner was not involved in any part of the research process. Safeguarding the ethical principle of do no harm (National Advisory Board on Research Ethics 2009), all reporting is done in a respectful and non-judgmental manner.

6.3 Discussion of validity

The searches were done using reliable databases, solely with search terms presented in Table 2. The data search was conducted systematically, and only peer reviewed research articles were selected. Parahoo defines validity as the accuracy of the findings compared to the study subject (2006: 80). The findings were critically evaluated throughout the whole process of this literature review, and only articles that reflected the research question were used in the final analysis. Only relevant literature was selected while ensuring that pivotal material was not excluded. In order to assess the validity and reliability of the research, the study question should be elementary and the conduction of the study transparent, as well as the manner in which the data is assessed and how the outcomes are reached (Parahoo 2006: 80, 145).

In order to avoid misinterpretation, the researcher must remain objective to the findings (Gillis & Jackson 2002: 346,347). Therefore, all findings in this thesis are directly derived from the research articles taken into analysis. Avoiding misinterpretation and the potential bias, both members of this literature review participated in all phases of the process. The whole literature review was carried out in a truthful and transparent manner.

7 Conclusion

Dialysis treatments are complex, strenuous, and affect almost every aspect of the patient's life. In order to achieve the desired treatment outcomes, patients are required to obtain an extensive amount of knowledge and manage complicated self-care programs. Patient education aims to motivate and empower patients, as well as promote their independence and adherence to treatment regimens. This literature review revealed a broad range of content areas related to patient education for dialysis patients. A nursing-specific aspect was prominent throughout, as most authors of the reviewed articles emphasized the unique role nurses possess as patient educators. The themes on the content of the education predominantly focused on the bio-physiological and functional aspects; dietary and nutritional information, treatment options, and self-care objectives were all thoroughly covered. The content areas not covered in the viewed articles related to the bio-physiological and functional aspects were information regarding physical activity and pharmacological treatment.

The extent to which the articles covered the social elements of patient education was fairly restricted. Very few articles even mentioned the importance of incorporating these elements into the patient's education, and only one examined the actual content. Considering the broad impact of dialysis treatments on the patient's life, social aspects should be strongly emphasized in the future. Patient education, the planning and implementation of the care plan, as well as the way in which health care providers support their patients, should always stem from the individual's needs. Open communication and collaboration between the multidisciplinary healthcare team, the patient, and their family is vital in order to achieve ideal treatment outcomes.

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Framework for data analysis

Table 1. The content of patient education for renal failure patients undergoing dialysis treatments

Author(s), year and country where the study was conducted	Purpose	Participants (sample size)	Data collection and analysis	Main results
Barnett et al., 2007, Malaysia	To examine the effectiveness of a patient education program on fluid compliance as assessed by interdialytic weight gain, mean predialysis blood pressure and rate of fluid adherence.	n= 26 HD patients with an interdialytic weight gain of greater than 2,5 kg.	An exploratory study conducted using a quasi-experimental, one-group design. Statistical analysis.	Patients undergoing HD and PD are often noncompliant with their treatment regime, especially with fluid and sodium restrictions. Failure to comply with fluid and dietary restrictions increases the risk of medical complications. Therefore, adequate education on the importance of adherence, IDWG, and the potential risks of adverse outcomes is needed. An educational program containing information about fluid control, fluid balance, and sodium intake, weight control and complications of excess fluid had a positive effect on the participants. Following the program their adherence to fluid restriction increased and their mean interdialytic weight gain decreased.
Bayoumi & El-Fouly, 2010, Saudi-Arabia	To improve self-care and quality of life of HD patients through teaching and evaluating their quality of life.	n= 50 patients receiving maintenance HD.	A structured interview questionnaire. Data was analyzed using statistical methods.	Educational program provided for HD patients, was found to greatly improve multiple aspects of their quality of life. Patients quality of life is affected by socio-demographic factors such as age, duration of dialysis, marital status and educational level. This should be kept in mind when providing patient education, since ultimately, patients quality of life should be the nurse's primary concern. The study concluded that the patient's family should also attend the education.

Clarkson & Robinson, 2010, USA	To explore the lived experience of patients with end-stage renal disease to determine if they are adequately educated about their illness to avoid the possible complications associated with the disease.	n=10. 4 participants on PD and 6 on HD.	Interview. Data was analyzed using inductive content analysis.	The study found a lack of patient education concerning medications and their side effects. The patients also desired education about the side effects of dialysis treatments. Another theme that arose was the importance of adherence to their treatment, as well as the possible consequences of non-adherence. Patients also wanted more emphasis put on early detection and treatment. The education should be clear and elementary to avoid confusion, and it should be divided to multiple appointments.
Ebrahimi et.al., 2016, Iran	To determine the effects of educational instructions on HD patients' knowledge and quality of life.	99 patients randomly assigned to control and experimental groups.	A questionnaire. Data was analyzed using statistical methods.	The study found that educating HD patients on nutritional subject matters — such as healthy diet, nutritional restrictions, and possible harmful consequences of non-adherence — significantly improved their knowledge score and overall quality of life. The study concluded that dietary educational intervention can have a positive effect on different dimensions of health and reduce consequences of disease.
Eloranta et al., 2013, Finland	To analyze the dialysis patients' perceptions of empowering patient education and the factors connected to it.	n=138 patients cared for in four dialysis units in one hospital district.	The data was collected using the Knowledge Expectations of hospital patients' scale (KEhp). The data was analysed using statistical methods.	Patients perception on patient education revealed that bio-physiological and functional aspects were adequately covered, whereas social aspects weren't. Less than half of the participants reported being advised about patient organizations, peer support and possible participation of the relatives. The dialysis patients need bio-physiological and functional knowledge on how to live a full life with the disease and the dialysis treatment. In the future, more attention should be paid to the social knowledge in the education of dialysis patients.

Kauric-Klein, 2012, USA	To determine if a supportive educative nursing intervention incorporating blood pressure education, monitoring, goal setting and reinforcement would improve BP control in a chronic HD population.	n=118 participants recruited from six HD units in the Detroit metro area.	A randomized experimental design.	Even though both systolic and diastolic blood pressures were significantly reduced in the treatment group, there was no improvement in blood pressure knowledge nor blood pressure self-efficacy, suggesting that blood pressure education alone does not produce behavioral change in HD patients. The research proposed combining education with interventional methods such as monitoring, goal setting and reinforcement for more favorable outcomes. The study found a strong connection between adhering to medicinal regimen, BP outcomes, and promoting patient's commitment to medicines management.
Liang et al., 2011, Taiwan	To identify the factors affecting Taiwanese patient's selection of PD in preference to HD for chronic kidney disease.	n= 130 chronic renal failure outpatients from nephrology clinics at four separate Taiwanese hospitals.	A questionnaire. Data was analyzed using statistical methods.	Self-care ability and adequate level of knowledge regarding the dialysis modalities were found to be the leading factors contributing to the choice of dialysis modality. Comprehensive education about topics, such as dialysis options and related procedures, fluid balance and systemic infection management, can alleviate anxiety related to decision making, as well as improve patients' quality of life. Pre-dialysis education is crucial in empowering patients to become self-caring and should aim to help patients in choosing a treatment option that best supports their lifestyle.
Pagels et al., 2008, Sweden	To enhance patients' disease-related knowledge, involvement, and self-care ability.	n=70 participants were recruited to the nurse-led clinic. n= 153 patients in a comparison group receiving conventional care.	A questionnaire. Data was analyzed using statistical methods.	A nurse-led clinic was found to have a positive effect on patients. There was an increase in the number of patients choosing independent dialysis, positive changes in their health-behaviors, and in self-care ability. Self-care ability and treatment options effect on daily living as well as on their family, was rated as most important disease-related areas of knowledge.

Painter et al., 2011, USA	To provide an overview of the importance of exercise and physical activity to individuals with end-stage renal disease undergoing dialysis.	n=1323	A questionnaire. Data was analyzed using statistical methods.	Majority of patients with ESRD do not get the recommended amount of physical activity - three 30-minute sessions per week. They reported having been talked to about exercise, but only half of the respondents received actual guidance on possible programs they could attend. Patients proposed ways to promote participation in physical activities. These included recommendations from the doctor, encouragement from the whole care team along with friends and family, and routinely educating patients on issues related to physical activity.
Pessoa & Linhares, 2014, Brazil	To identify the knowledge, attitude and practice in self-care patients receiving dialysis with arteriovenous fistula.	n=30 patients using the AV fistula.	A questionnaire. Data was analyzed using statistical methods.	97.7 % of patients with arterio-venous fistula (AVF) had inadequate knowledge regarding the care of it. There was a lack of knowledge related to the habitual verification of fremitus in the site of AVF, keeping the dressing clean and dry after surgery, and keeping the bandage loose. Patients also had inadequate knowledge on how excessive sodium intake affects interdialytic fluid retention, and how to act in case of hematoma formation in the site of the AVF. Furthermore, the patients reported not having access to information regarding appropriate AVF care. Patients did not adhere to certain practices despite of having adequate knowledge. However, the study found that inadequate knowledge leads to inadequate self-care of the AVF.
Shi et al., 2012, China	To prospectively evaluate the effects of a nurse-led educational intervention on the management of hyperphosphatemia as well as knowledge of phosphate among patients with end-stage renal disease.	80 participants randomly assigned to experimental group (n = 40) and control group (n = 40).	A questionnaire. Data was analyzed using statistical methods.	The educational program significantly improved the participants' serum phosphorus levels and their general knowledge of phosphate. The study found that an important factor in the reduction of serum phosphorus levels might be associated with the elaborate nutritional information, specifically the instructions on how to avoid consuming additive-containing processed foods high in phosphorus.

Sondrup et al., 2011, Canada	To better understand independent dialysis patient perceptions and possible barriers related to choosing therapies.	n= 6 3 patients on PD and 3 patients on HHD.	The data analysis method involved use of an interpretive descriptive approach.	Patients lack comprehensive education before the initiation of dialysis, especially about certain limitations of life on dialysis. In selecting the appropriate RRT, patients need educational materials that focus more on the lifestyle aspects, especially the benefits of home dialysis, instead of listing the positives and negatives of the different RRT options. Patients would choose home dialysis more likely if they were given additional support in the decision-making process. The study participants expressed that peer support would encourage them to select independent dialysis treatment.
Su et al., 2009, China	To explore the effects of promoting self-management on the well-being of patients having PD.	n= 30 patients on PD for at least 6 months.	Quantitative study. Data was analyzed using statistical methods.	After the intervention, there was great improvements in HD patients, such as adherence to dietary modifications and dialysis prescriptions, enhanced self-management and health status, and a perceived increase in the patient's quality of life. It increased the participants' knowledge, clinical outcome and health related quality of life. There was a statistically significant improvement in self-care ability as well as self-efficacy.
Wells, 2011, USA	To describe the relationship between HD knowledge and perceived medical adherence to a prescribed treatment regimen in African Americans diagnosed with end stage renal disease and to determine if an educational intervention improved HD knowledge and medical adherence.	n= 85	A questionnaire. Data was analyzed using statistical methods.	The education intervention resulted in increased knowledge in hemodialysis, but did not affect adherence to treatment. The study found that the greatest lack in knowledge before and after the educational intervention was related to anemia. The question most often missed was related to low protein diet.

Yu & Petrini, 2009, China	To explore health-related quality of life of end-stage renal disease patients undergoing HD.	n=16 HD patients.	An interview. Data was analyzed using Colaizzi's phenomenological method to transcribe and analyze the data.	Dialysis treatments affect all aspects of health-related quality of life, including psycho-social and financial ones. In order to optimize dialysis patients' quality of life, these aspects should be taken into consideration. Thorough education and individualized support would enhance these patients' health-related quality of life. Teaching HD patients on subjects such as treatment options, renal disease, diet and fluid management, exercise, and care of vascular access, potentially improves their self-care ability as well as quality of life.
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Content of patient education for chronic renal failure patients undergoing dialysis treatments – A literature review

Salli Lunka and Heini Luukkanen

Background

This literature review is a part of an ongoing project between Metropolia University of Applied Sciences and the Dialysis Teaching Center of the Hospital District of Helsinki and Uusimaa.

Purpose and aim

The purpose of this thesis is to describe the content of patient education for chronic renal failure patients undergoing dialysis treatments. The ultimate goal was to find knowledge that can be utilized when developing patient education for dialysis patients. The study question was, what is the content of patient education among chronic renal failure patients undergoing dialysis treatments?

Results

This literature review revealed that the content of patient education predominantly focuses on the bio-physical and functional aspects, such as blood pressure control, fluid restrictions and nutrition, care of the vascular access site, and different treatment options. Patient education regarding physical exercise, pharmacological management, and social aspects of dialysis should be better incorporated into future education. The analyzed articles showed that patients have inadequate knowledge on various aspects of dialysis treatments, indicating the need for further research and ongoing development of patient education.