Experience of dialysis patients waiting for kidney transplantation

Literature Review

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Abstract

End stage renal disease diminishes the kidney functioning, therefor, patient’s survival is highly dependent on renal replacement therapy, dialysis. However, kidney transplant proves to be a long-term solution. Due to the increase in Kidney transplant demand, and a low availability of donors, it has significantly elongated the waiting period, impacting the experience of dialysis patients waiting for kidney transplant.

The research aimed at underlining the experiences of dialysis patients waiting for kidney transplant and the purpose was to examine the ways dialysis nurses could reinforce the experiences of patients waiting for transplantation. The method utilized was literature review analysis. A total of seven articles were chosen from three different databases; CINAHL, PubMed and google scholar. Content analysis of the original data was upheld to provide the understanding of dialysis patient´s experience during the waiting period.

The main categories identified are poor quality of life, support, hope, uncertainty and lack of trust, coping strategies, and preparation for the transplantation. The results have provided a comprehensive analysis of patient’s experiences, eliciting the requirement of more support towards dialysis patients predominantly those combating the psychological challenges, the necessity of patients ´ education and continuous provision of information concerning the transplant would ease the burden and uncertainty of the waiting period. The research recognizes the limitations of this study, hence recommending future research on patients experiences in individual countries and regions, which will provide effective solutions to regional specified problems.

Keywords/tags (subjects)

dialysis, waiting for kidney transplant, experiences, kidney failure, chronic kidney disease, end stage renal failure

Miscellaneous (Confidential information)

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1 Introduction

Chen, Knicely and Grams (2019) highlights the ferocity of chronic kidney disease as the 16th main cause of death worldwide. Renal or kidney failure occurs when the kidney loses its ability to function appropriately or an abnormality of the renal organ. This can be classified into acute and chronic kidney disease. Acute kidney failure occurs if a kidney loss its ability to function or a kidney damage within a period of three months, after three months without significant improvement despite necessary interventions, the diagnosis is termed as chronic kidney disease. (Chen et al. 2019.)

Usually, kidney failure patients undergo kidney dialysis, in which by the help of a dialysis machine, the body can filter waste products from the body, the accumulation of waste products in the body can be detrimental to the health of a person (Star 1998). Whereas renal transplant is a procedure done by transferring a healthy kidney from either a living or deceased donor to a patient with failed kidneys, enabling their kidneys to function without the need of dialysis. Nonetheless, in conservative management treatment, the patient does not undergo neither dialysis nor transplant, hence the patient receives treatment to manage the symptoms, therefore maintaining the normal kidney function. (Star 1998; Chen et al. 2019.)

Despite the different methods of treatment, kidney transplant proves to be the most effective intervention both medically, socially, and economically (Knihs, Sartoti, Zink, Roza & Schirmer 2013). Patients that qualify for a kidney transplant with an already available living donor undergo the procedure quickly, whereas patients with no living donors, are placed in a waiting list for a deceased donor kidney. However, there is more demand of kidney available for transplantation, due to an increase in dialysis patients (Sque, Frankland, Long-Sutehall, Addington-Hall & Mason 2010), hence the process of waiting normally takes a longer period ranging to approximately three years or longer.

During the waiting period, patients undergo numerous experiences that always affects their eligibility to undergo kidney transplantation, among other experiences which this study intends to uncover. Thus, the aim of this research study is to underline the experiences of dialysis patients waiting for a kidney transplant. Whilst the purpose is to examine ways in which dialysis nurses can reinforce patients experience while waiting for kidney transplantation.

2 Renal care

2.1 Chronic Kidney disease

Chronic kidney disease, CDK is referred to as the presence of kidney malfunction characterised by glomerular filtration rate, GEF or availability of kidney damage, known as albuminuria in a period more than three months (Levey & Coresh 2021). CDK is classified into five respective groups distinguished by the amount of GFR. The stages are classified in table 1: stages of chronic kidney disease as follows (Levey & Coresh 2021):

Table 1: Stages of Chronic Kidney Disease

Stages	**GFR in mL/min per 1.73 m^2**
Stage 1	Greater than 90
Stage 2	60-89
Stage 3	30-59
Stage 4	15-29
Stage 5	Less than 15

According to Hill, Fatoba, Oke, O´Callaghan, Lassserson and Hobbs (2016), chronic kidney disease is a current health problem that poses a burden to the health care system, due to its high economical cost, and its major impact on cardiovascular diseases. Moreover, from their data, it is estimated that about 13.4% of the world population suffer from CKD at stages between 1-5, whereas a prevalence of approximately 10.6% was recorded from patients with CDK at a stage between 3-5. Nonetheless, Chen et al. (2019) underlined that CDK is the world’s 16th leading cause of death, therefore, it elicits the impact of this disease as a global health problem.

Furthermore, it is estimated around 1.2 million people died from CDK in 2017. Currently, the number of people undergoing renal replacement therapy is estimated to exceed more than 2.5 million people, in which by 2030, the number is anticipated to double to approximately 5.4million people. On the other hand, due to inadequacy of renal replacement services, approximately 2.3 -7.1 million adults have prematurely succumbed to the disease before treatment. (Lancet 2017.)

2.2 End Stage Renal Disease

End Stage Renal Disease, ESRD refers to the final stage of Chronic kidney disease, in which the kidneys functionality is irreversible, therefore, impacting the lifespan of the affected person (Agarwal 2015). ESRD is characterized by the extremely diminished function of glomerular filtration lower than 15mL/min/ 1.73m^2 body surface area, which is insufficient for the natural kidney to function and maintain a healthy lifestyle without the need of renal replacement therapy such as dialysis or kidney transplant. (Khader, Snouber, Alkhatib, Nazzal & Dudin 2013.)

The incidence of ERSD continues to increase worldwide at a higher rate, in the United States of America, the prevalence of ESRD is 1500 per million compared to 800 per million in Europe. Whereas in other parts of the world, Jordan registers 300 patients per million, Iran, 360 cases per million, 600 per million in Saudi Arabia, and approximates 300 per million in Sub- Saharan Africa. (Mazdeh-Mahdava, Rouchi, Norouzi, Aghighi, Rajolani & Ahrabi 2007; Barsoum 2006.)

ESRD´s prevalence continuous to increase periodically, thus dialysis is offered as an intervention to patients with ESRD to improve their quality of life. The prevalence of ESRD is further exacerbated by the increase in life-style diseases such as diabetes mellitus and hypertension. (Mazdeh-Mahdava et al. 2007; Barsoum 2006.)

2.3 Roles and responisibilities of dialysis nurses´

Queeley and Campbell (2018), points out that renal replacement therapy is a necessity for survival for patients with ESRD. There are two types of renal replacement therapies: peritoneal dialysis, PD (Automated Peritoneal Dialysis, APD and Continuous Ambulatory Peritoneal dialysis, CAPD) and haemodialysis, HD. Nonetheless, both equally perform unison duties of maintaining the body´s homeostasis attained when toxins, solutes, and residue water are eliminated. (Queeley & Campbell 2018.)

Haemodialysis refers to the procedure in which an artificial machine takes up the functionality of a kidney, removing toxins and excess fluids from the body. Contrarily, peritoneal dialysis excretes predominately the unwanted metabolic substances. However, producing a similar result as HD of maintaining electrolyte and fluid balance, thus preventing metabolic acidosis. (Brunner 2010.)

The main differences of HD and PD is the mode in which the dialyzer fluid flows into the body acting as a semipermeable membrane. A HD patient use either an arteriovenous catheter/fistula or a graft, while peritoneal dialysis takes place on the peritoneal membrane in the abdomen (Brunner 2010). Moreover, haemodialysis proves to be more costly compared to peritoneal dialysis. In 2011, peritoneal dialysis cost 71,630 US dollars, compared to 87, 945 US dollars on haemodialysis. (Sachdeva, Zulfiqar & Aeddula 2020.)

The nurses´ role in caring for dialysis patients ranges from many aspects such as care during the dialysis process, to patients´ education, transplant preparation and care after transplant. Nurses are essential as they are the only profession that encounters the dialysis patients more frequently than other health care professionals (The role of the Home Hemodialysis Nurse n.d.). Nurses’ roles include:

Formulating the patient´s care plan

Every dialysis patient is different, with different conditions and needs, thus nurses have role in assessing every patient individually, and creating a care plan that caters for their patient´s individual conditions and answers to their specific needs. It is important for a nurse to have effective communication skills, and cultivating a trusting relationship with the dialysis patient, and their family members. Moreover, nurses are expected to make a holistic assessment of a patient considering his/her personal life for their treatment plan. It is important for the nurse to be well familiar with the patient and create an environment in which the patient feels safe and secure. (Walker, Abel & Meyer 2010.)

Raising awareness of different treatment methods

The nurse ought to inform the patient on the different, available types of treatments that the patient can receive. The nurse informs on the advantages, disadvantages, and facilitating the decision-making process. In advertently aiding the patient in choosing the most suitable from of treatment. (Daugirdas, Blake & Ing 2012.)

Performing the dialysis treatment

The predominant role of a nurse is initiating and performing the dialysis process. As stated by the inventor of the dialysis machine, Malchesky (1993), on average, dialysis patients are expected to perform the procedure three times a week, in which the procedure lasts for a duration ranging from 3-4 hours per session. According to Murdeshwar and Anjum (2020), the paramount role of a nurse is overseeing the dialysis procedure and ensuring the correct medication administration.

Murphy (2019) elaborates the duties of a dialysis nurse before, during and after performing dialysis. Prior to dialysis, the patient´s fistula/ catheter is ensured safe and working before the process commences. Moreover, the nurse prepares the dialysis machine, preparing the dialyzer serum and performing the regular check-up before commencing. This includes monitoring of vital signs before, during and after. Generally, blood pressure and pulse rate are the most crucial. Whereas, depending on the situation, the patient´s temperature, blood sugar (diabetic patients), oxygen saturation and consciousness is monitored. Simultaneously, weighing the patients to monitor fluid consumption and regulation prior dialysis. This provides an opportunity to analyze patient´s fluid balance, providing the correct liquid consumption limitations. Conjointly, both during and after dialysis, the nurse monitors the patient well-being ensuring the process flows as anticipated. In terms of a reaction due to the side effects of dialysis, the nurse reacts correspondingly to the problem. (Murphy 2019.) On the other hand, dialysis nurses supervise the dialysis process at a home environment. This is true for patients under CAPD, which predominantly takes place at a home setting (Murdeshwar & Anjum 2020).

Educating dialysis patients

Nurses play a key role in educating patients. Patients’ education involves numerous factors such as fluid balance, independence at home monitoring such as measuring vital signs and weight, familiarizing with uremia complications, dialysis preparation, identifying immediate side effects of dialysis, infection control, proper medication use, physical activity, advice on sexual activity and other vigorous activities, among other factors affecting dialysis patients. (Murphy 2019.)

Apart from the detailed description of renal failure management, the nurse has a duty in enlightening the patient of the general prognosis of the disease. Offering education on deaccelerating the disease progression, and motivating patients to actively participate in decision making process and making beneficial choices on their health. (Murdeshwar & Anjum 2020.)

Furthermore, the nurse has a key role in educating the patients on nutrition. According to Ahmad (2009) renal failure patients are prone to malnutrition, Approximately, 30% oh hemodialysis patients, peritoneal dialysis patients 40%, and 44% of pre-dialysis patients are malnutritional. Thus, due to the malfunctioning of the kidney, it is essential that patients consume the recommended types of diet and fluids. In terms of fluids, patients have a limited number of fluids that they can consume usually approximately 500ml per day. Moreover, the diet for dialysis patients usually entails high protein, low in phosphorus and potassium, high sodium intake, with vitamin supplements and food high in carbohydrates and fat to avoid wasting. Nevertheless, nutritional education and guidelines ought to be extended to the family members as well as towards patient´s caregivers. (Cahyaningsih 2010; Brunner 2020; Murdeshwar & Anjum 2020.)

Prevention of dialysis complications

Apart from educating dialysis patients, nurses have a duty in preventing further worsening of the patients’ condition (Li & Chow 2011). For instance, nurses have a duty in educating the patient on proper use of medications such as hypertension drugs, and management of diabetes for diabetic patients, as this immensely affects the general health of a patient. Infection control is essential in dialysis patients since high infection rates has a negative impact on the cardiovascular activity (Li &Chow 2011).

Additionally, nurses have a duty in monitoring monthly blood results, and interpreting the results to the patients and advising them on the necessary intervention. Nonetheless, the nurse gives essential vaccinations such influenza vaccination and hepatitis when needed. To add, nurses plan and manage the administration of iron infusions that combats anemia that is common in dialysis patients and lastly, nurses take part in negotiating with the doctor on patients´ progression and whether there is need for medication changes. (Walker et al. 2010.)

Maintaining proper communication with other health professionals

Apart from the roles addressing to patients´ medical needs, nurses have a responsibility of maintain proper communication with different multi-professionals across the health care system (Chaharsoughi, Ahrari & ALikhah 2014). This is essential as dialysis nurses encounter numerous health professionals such as dentists, diabetic nurses, doctors, nutritionists, home care nurses, social workers, physiotherapists, transplant coordinators, psychologists, occupational therapists, and palliative care unit whenever needed among other professionals. (Walker et al. 2010.)

Supporting the patients

Nevertheless, nurses have a vital duty of encouraging the patients, supporting them as they undergo dialysis and experiencing an intensive period before kidney transplant. It is essential that patients are empowered and well informed during the waiting period of dialysis. This goes hand in hand with the family members, it is the nurse’s role to keep them updated on their family member´s condition and prognosis. (Daugirdas, Blake & Ing 2012.) A nurse is required to have the skills to relay information to patients and recognizing when the appropriate time is to educate and guide both the family members and the patient. (Walker et al. 2010.)

Patient preparation for kidney transplantation

According to Thomas, Wulf, Blosser, Dick, Murray and Naghavi (2014), the prevalence of kidney transplantation has risen in the world by approximately 120%. In 2010, around 82 people received transplantation in a population of 1 million people. The criteria of patient selection for kidney transplant, is both patient related, and hospital/ transplant center related. The factors influencing the patient include patient´s age, individual´s patient blood group, patient´s waiting period, similarity in the human leukocyte antigens, the cause of ESRD, previous transplants, race, and ethnicity. Whereas the hospital centered factors consist of the size of the hospital, the rate of kidney allocation in the specific hospital/center and the availability of living donors. (Dudley, Johnson, Thomas, Ravanah, Ansel 2009.)

Walker et al. (2010), underlines the role of nurses in educating and raising awareness to dialysis patients on the possibility of kidney transplantation. The nurse educates on the advantages and possible disadvantages of transplantation to the patient and the family members, ensuring that they are aware of the possibility of kidney transplantation as a solution to ESRD. Additionally, apart from raising awareness on possible transplantation, the nurse educates patients and family members on the process of attaining kidney transplant and ensure patients are registered on the transplant list whenever, they achieve the criterion required for transplantation. (Walker et al. 2010; Murphy 2019.)

3 Aim and Purpose

The aim of this research is to underline the experiences of dialysis patients waiting for a kidney transplant from available research articles. Whereas the purpose of this research is to analyse ways in which dialysis nurses can reinforce dialysis patients experience while waiting for kidney transplantation. The research question is: What are the experiences of dialysis patients while waiting for kidney transplantation?

4 Research methodology

4.1 Literature review

In accordance with Cronin, Ryan, and Coughlan (2008) literature review offers a critical analysis that is objective to the topic under investigation. Utilizing the already available research and creating a conclusion from the various sources (Ward-Smith 2016). This is further elaborated by Knopf (2006) as a summary of existing knowledge on a specific topic under investigation.

Literature review in nursing profession is essential as it is key in creating the most effective evidence-based practises that is vital in policy making/changing, planning of interventions, and identifying the need of further research in a certain field (Ward-smith 2016; Whittermore & knalf 2005)**.** Therefore, as emphasized by Cronin et.al (2008), literature review is key in the nursing education as it is the core principle in research process, paramount in steering forward the entire health care profession. Literature review proves the most effective research methodology to answer this study´s research question. This is because the topic at hand is not widely investigated, yet vital. Thus, it seemed more logical to analyse the available research.

4.2 Literature search

The article selection process aimed at selecting the most suitable studies to address the research question. The research is specified, detailed to the research question and to a specific time frame. The analysis involved an inclusion and exclusion criteria to acquire well reliable and trustable data.

The research articles were retrieved from three databases including, Cumulative Index of Nursing and Allied Health plus full text (CINAHL), PubMed and google scholar. However, google scholar predominantly provided full text which was either unavailable or required payment in both PubMed and CINAHL, therefore, google scholar proved economical. Moreover, to obtain the attained research articles, the articles available in the databases were filtered by a precise criterion which is condensed into the Population, Intervention, Comparison, Outcome and Study (PICOS) criteria, this is represented in table 2: PICOS criterion.

The research question ´´ What are the experiences of dialysis patients while waiting for kidney transplantation? ´´ is disassembled to address the specific requirements of PICOS. The population of the research are dialysis patients, intervention being the kidney transplantation, comparison as experiences. Whereas the outcome is not applicable to this research. The selected studies must be published from the year 2010-2021, in English language, abstract available, peer reviewed, free text for Jyväskylä university of applied sciences, JAMK students and must be an original research. These is summarised in the table below.

Table 2: PICOS criterion

PICOS	**Criterion**
Population	Dialysis patients or haemodialysis or hemodialysis or peritoneal dialysis patients.
Intervention	kidney transplantation or kidney transplant or renal transplant or renal transplantation.
Comparison	patients’ experiences or perceptions or attitudes or views or feelings.
Outcome	Not Applicable.
Studies	Articles published from 2010-2021, original studies, English Language, abstract available, free text for JAMK students, Peer reviewed articles.

Moreover, the search parameters implemented included both ´´AND´´ and ´´OR´´. The ´´ OR ´´ parameter is displayed in table 2: PICOS criterion. However, in this manner the research question is expressed whilst searching for the articles: Dialysis patients (OR haemodialysis OR hemodialysis OR peritoneal dialysis patients) AND Kidney transplantation (OR Kidney transplant OR renal transplant OR renal transplantation) AND patient´s experiences (OR attitudes OR perceptions OR views OR feelings).

From the different databases, 71 articles were obtained from PubMed, and 283 from CINAHL database. Additional 10 articles were obtained from google scholar database. Three same articles were identified as duplicates in the databases leading to a total of 361 articles. After screening the articles, scrutinizing the relevance of the article to the research question, non-original articles excluded and the availability of full text reviewed, a total of 344 articles were eliminated. The remaining 17 articles were further reviewed, 10 articles are eliminated, hence 7 different articles selected to address the research question. This is presented in figure 1: Article selection process (PRISMA chart).

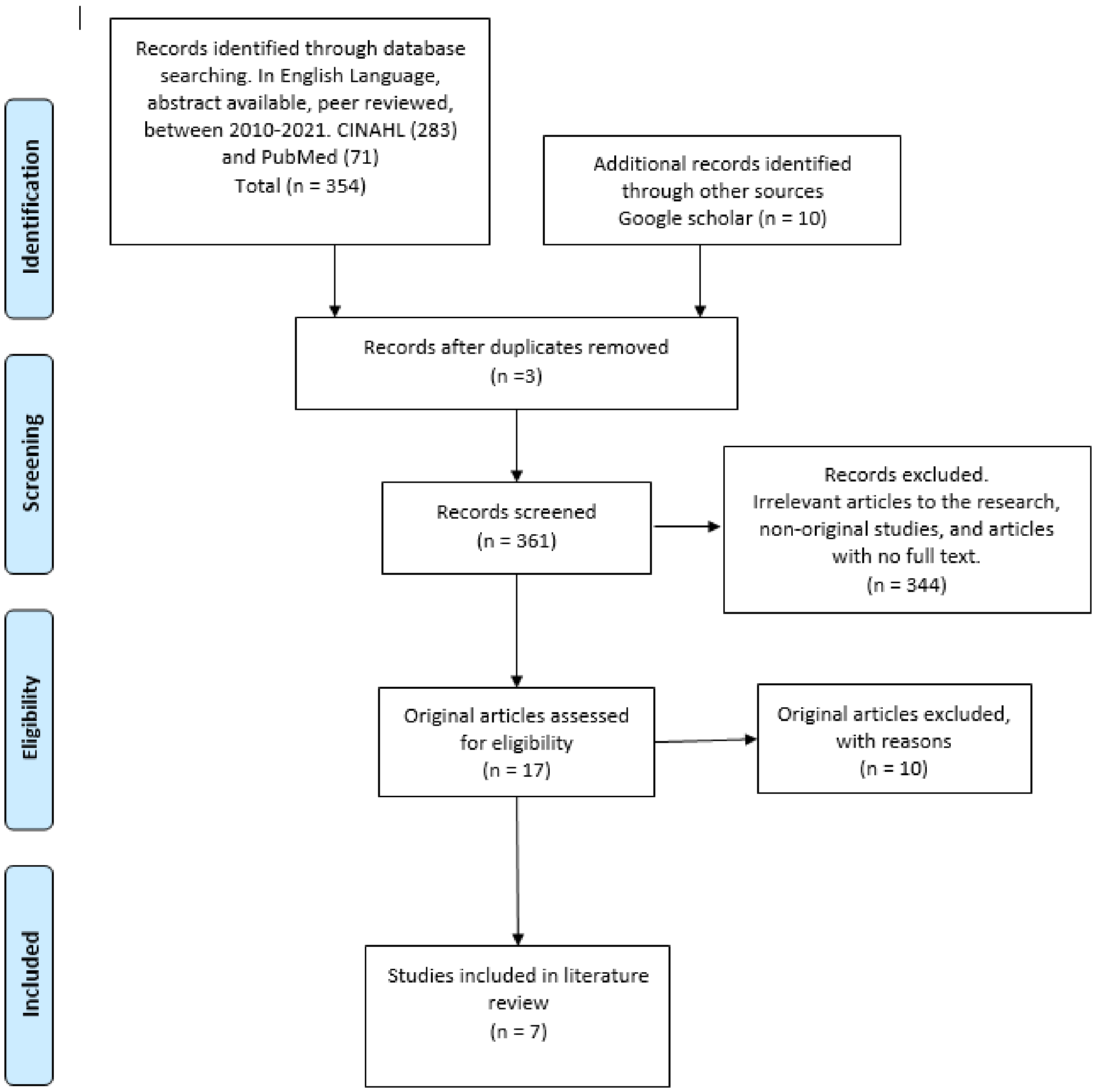

Figure 1: Article selection process (PRISMA chart)

4.3 Data analysis

Content analysis of data is upheld, an objective method used in describing the content obtained from the articles. This method enables the researcher to easily understand the data by categorizing similar ideas, connotation, and interpretations. (Elo & kyngäs 2008.) The information is collected from every article and grouped into similar categories, hence, the analysis done by dividing the contents into different categories and subcategories. The articles predominantly provided similar results thus, data saturation was obtained already at article number five. Despite data saturation, the remaining two articles were analysed to further reinforce the understanding of dialysis patient´s experiences.

Table 3: content analysis example represents the process of data analysis. The example provided is from the main category ´´support´´, with three distinct sub-categories, ´´support from family, the dialysis community and from the health care professionals´´. The figure does provide the original interpretations, classified as the theme identified from the research articles.

Table 3: Content analysis example

Source	**Themes identified from the research articles**	**Subcategory**	**Category**
Jin Chong, *et.al* (2016)	Support from the health care workers who constantly encourage them to continue waiting.	Health care professionals.	**Support**
Jin Chong, *et.al* (2016)	Constant support from family members, as they are equally affected by ESRD. Family proved as a source of strength.	Family.	
Burns, *et.al* (2017)	Despite family members promising to donate, patients expressed fear of the effect of surgery on their loved ones.		
Burns, *et.al* (2017)	In Australia, the dialysis community provided an environment in which patients share their experiences and support each other.	Dialysis community.	
Burns, *et.al* (2017) Knihs, *et.al* (2013)	Peer support among dialysis patients		

5 Results and findings

Analysis of data is concluded, and various categories are obtained. These categories include poor quality of life, support, hope, uncertainty and lack of trust, coping strategies and preparation for the transplantation. This is represented in the table 4: categories and subcategories below.

Table 4 : Categories and sub-categories

What are the experiences of dialysis patients while waiting for kidney transplantation?	
Categories	**Subcategories**
Poor quality of life	• Psychological effects • Physical effects • Economic challenges
Support	• Health care professionals • Family • Dialysis community
Hope	• Freedom and normality • Shattered hopes • Temporary treatment
Uncertainty and lack of trust	• Constantly waiting • Anxiety and fear around kidney transplant • Limited education and missing information. • Suspicion of inequality
Coping strategies	• Acceptance • Shift of focus • Trusting higher being
Preparation for the transplantation	• Maintaining health • Financial preparation • Ready to go. • Perception towards the donor

5.1 Poor quality of life

Dialysis patients have identified numerous challenges during the waiting period. These challenges ranges from the psychological, physical, and economic impacts. Beginning with the psychological effects, majority of the patients elicited that dialysis greatly impacted their mental health (Jin

Chong, Kyung Kim, Reul Kim &Lee 2016). Many expressed that they are battling both anxiety and depression. Anxiety due to contemplating on the long waiting periods, among fear of dialysis complications, and fear of death prior to the transplant. Majority of the articles highlighted the profound impact of the long waiting periods on the patients, expressing their lives as dependant on a machine (Yurttas & Nar 2018). (Knihs et al. 2013; Yngman-Uhlin, Fogelberg & Uhlin 2015.)

Nevertheless, negative impacts of dialysis are considerably highlighted in their experiences. According to Burns, Fernandez, and Stephens (2017), Jin Chong et al. (2016), Moran, Scott, and Darbyshire (2010); Yngman-Uhlin et al. (2015) and Yurttas & Nar (2018), dialysis poses a major restriction in the patient´s personal lives. For instance, these restrictions include working, travelling, some daily activities, hobbies, among others. Nonetheless, life restriction is enlarged by the dialysis procedure. Patients testified to dialysis being energy draining, thus majority are forced to dedicate the residual time after dialysis to succumb the exhaustion by resting.

In addition, due to the elongated waiting period, dialysis patients are exposed to numerous health risks such as infection, and cardiovascular diseases, as well as an overall weaken immunity that inadvertently impacts their ability to undergo kidney transplant, producing negative health prognosis after transplantation, and decreasing the chances of attaining the transplant by an early death. Moreover, physical pain is underlined as a negative impact of dialysis by a research done by Yngman-Uhlin et al. (2015). (Burns et al. 2017; Jin Chong et al. 2016; Moran et al. 2010; Yurttas & Nar 2018.)

On the other hand, the financial burden of receiving the renal replacement therapy proves to be a challenge to the patients, especially patients from low middleclass countries, compared to the upper western countries. Sque et al. (2010) address the need of financial support towards the dialysis patients, as they need regular health check-ups, medications coupled with the dialysis therapy. (Yngman-Uhlin et al. 2015.)

5.2 Support

Despite the negative experiences whilst waiting for transplantation, dialysis patients expressed that they have received immense support from their family members, especially the immediate family, the spouse, and the children. Jin Chong et al. (2016) pointed out that the family members are equitably impacted by the disease and the extended waiting period. However, they provide strength to the sick family member. Nevertheless, some family members provided support by volunteering to donate a kidney, but the patients refused due to the possible negative impacts of the surgery to the family member (Burns et al. 2017).

Another source of support came from the hospital. Both from the health care professionals and the dialysis patients´ community. Patients in South Korea testified to continuous support from the health professionals to be vigilant and persistent in waiting. Whereas, both in Australia and Brazil, patients expressed the importance of the support received from their fellow patients. Patients shared amongst each other their experiences and encouraged one another to continue waiting. (Jin Chong et al. 2016; Burns et al. 2017; Knihs et al. 2013.)

5.3 Hope

Hope is a factor highlighted in every article analysed. A major aspect recognised is the hope in patients waiting to gain once again freedom and normality in their lives. As mentioned earlier, dialysis proves to be exhausting and demanding, however amid the challenges, the anticipation of obtaining kidney transplantation offers the energy to continue waiting and hoping for a better life post-transplant. Therefore, the weight of dialysis is diminished by the idea of kidney transplantation. Additionally, in line with Moran et al. (2010) many patients perceive dialysis treatment as a temporary solution while waiting for a permanent solution that is kidney transplantation. Contrary to being hopeful of the future, patients who have waited for a long time, predominantly, more than the estimated waiting duration, exhibited loss of hope in the future (Yngman-Uhlin et al. 2015).

5.4 Uncertainty and lack of trust

Previously, hope is highlighted in dialysis patients waiting for transplantation, however, the continuous waiting with no specific date of transplantation is frustrating to the patients. Patients communicated doubts on whether they will undergo kidney transplant. Additionally, due to the lack of control on the kidney transplant allocation, many find themselves frustrated (Sque et al. 2010).

This is further exacerbated by the requirement of patients to be alert for 24 hours daily, waiting to be contacted by the transplant unit. (Jin Chong et al. 2016; Burns et al. 2017.)

Furthermore, fear and anxiety are demonstrated as one of the experiences. As explained by Moran et al. (2010), patients are constantly waiting for transplantation, thus anxiety in being offline when called for transplantation. Even so, the hardships are worsened when one is called for transplantation but fails to be chosen among the different candidates. Likewise, dialysis patients articulates different emotions experienced from being called yet not attaining the criteria. This is labelled as a ´´roller coaster of emotions´´ that is taxing to their wellbeing (Jin Chong et al. 2016).

Moreover, in conjunction with the physical impacts of dialysis, there is fear in dialysis patients that their wellbeing and immunity will aggravate, thus minimizing the chances to obtain the transplantation. Along with fear concerning the transplant, there is numerous apprehensiveness concerning the effectiveness of the kidney transplant. Worries on the results of the transplant, complications after the transplant, fear of the transplant failing and questions on their long-term survival. (Moran et al. 2010.)

It is underlined by Yngman-Uhlin et al. (2015), dialysis patients conveyed the disappointment in limited information provided by the health care workers and the transplant unit. Patients mentioned there is lack of information on the waiting list, and doubts on whether they are still on the list after being sick. Moreover, patients expressed the absence of regular meetings with the transplant team (Sque et al. 2010), absence of adequate information on both the advantages and disadvantages of receiving kidney transplantation (Yngman-Uhlin et al. 2015) and misunderstanding on the waiting time (Moran et al. 2010).

As a result of lack of information and education, suspicion on inequality has developed among the patients. Particularly when one patient waits for a longer time compared to a newcomer who waits for a shorter duration. Just as Sque et al. (2010) illustrates, absences of a detailed explanation on the kidney allocation process raises questions against the transplant team. At large, various complications on the allocation process, elongated waiting phase and disappointments develops immense lack of trust towards the kidney transplant team. (Jin Chong et al. 2016; Burns et al. 2017; Moran et al. 2010.)

5.5 Coping strategies

Because of numerous experiences whilst waiting for transplantation, many patients have devised various ways to endure the challenging phase. Acceptance proves to be the most common strategy for many patients, as highlighted by both Jin Chong et al. (2016) and Burns et al. (2017). Dialysis patients affirmed that accepting the situation the way it is has supplemented their experience by helping them to cope. Understanding that they cannot control when they will receive the transplantation and intentionally deciding to wait for that day, lessens the worry of ever receiving kidney transplantation.

Furthermore, majority confirmed that shifting their focus from waiting for the transplantation to partaking in hobbies, working from anything else pertaining dialysis, has immensely helped during the waiting season. Nonetheless, many patients stated that trusting in higher power, relieves the tribulation of waiting. Some patients draw their strength from their religion and having trust and faith in their God. (Jin Chong et al. 2016; Burns et al. 2017; Yngman-Uhlin et al. 2015; Knihs et al. 2013.)

5.6 Preparation for the transplantation

In preparation for the kidney transplant, patients highlighted the need of maintaining a healthy lifestyle to undergo the transplantation. According to Jin Chong et al. (2016), patients mentioned the importance of being healthy during the dialysis season since one can be called anytime for transplantation. Nevertheless, patients are expected to regularly undergo medical check-ups assessing their fitness for transplantation.

Moreover, in preparation for transplantation, patients highlighted the significance of saving money for the transplant beforehand. Nonetheless, dialysis patients expressed their readiness to have the transplantation by always having their phone online waiting for the call and having their luggage ready for the day. (Yngman-Uhlin et al. 2015; Jin Chong et al. 2016.)

Lastly, patients demonstrated concerns about the source of the kidney for the transplantation. Numerous concerns on the deceased person providing the kidney and concerns towards the donor’s family. Burns et al. (2017) states that patients conveyed sadness and sorrow towards the deceased donor, whereas Yngman-Uhlin et al. (2015) and Knihs et al. (2013) emphasized the emotional conflicts of wanting a kidney transplant that translates to hoping for the death of another person. On the contrary, patients admitted that deceased donor is a better substitute to living donors (Burns et al. 2017).

6 Discussion

6.1 Discussion of the main findings

Numerous experiences are identified from the research articles, both negative and positive experiences of dialysis patients whilst waiting for kidney transplantation. Beginning with the challenges identified, patients have immensely expressed the emotional burden, anxiety, depression, and fear weighing on them on account of the waiting process. Emotional burden is evident due to the various emotions experienced throughout the process, anxiety caused by the different life restrictions of dialysis and depression because of the numerous frustrations one endures during the waiting and lose of hope after waiting for a lengthen period. Accompanying emotional distress, patients have expressed conflicts in thought concerning deceased donors. They have communicated feelings of sadness and guiltiness for waiting for someone to die to receive a kidney. However, majority have testified a deceased donor as a better alternative to living donors. (Jin Chong et al. 2016; Yurttas & Nar 2018; Yngman-Uhlin et al. 2015.)

Fear is expressed on account of several reasons. These include the fear of dialysis complications and general health deterioration owing to the long waiting period. Moreover, there is minimal actions patients can take towards the situation as their lives is dependent on dialysis (Yurttas & Nar 2018). Nevertheless, there are numerous concerns relating to kidney transplantation such as fear of kidney transplant complication, failed kidney transplant, and as well as fear owing to the survival rate after transplantation. (Knihs et al. 2013; Yngman-Uhlin et al. 2015.)

Furthermore, apart from the psychological challenges, physical challenges are underlined in the experiences of dialysis patients. Many patients have highlighted that dialysis is indeed exhausting and energy consuming (Burns et al. 2017; Yurttas & Nar 2018). Moreover, being on dialysis has generally lowered their quality of health. Whereas other patients revealed that they experience pain due to dialysis (Yngman-Uhlin et al. 2015).

A paramount aspect distinguished from the dialysis patients is the disappointment on the services received from the health care professionals and the transplant team. Matters causing apprehension include the limited information on the waiting list, lack of regular information or meetings with the transplant team, limited information on the negative impacts of kidney transplantation compared to the benefits of kidney transplant, and unrealistic expression of the waiting period. These concerns have deeply impacted the patients thus developing doubt and lack of trust towards the health care professionals. (Jin Chong et al. 2016; Yngman-Uhlin et al. 2015; Burns et al. 2017; Sque et al. 2010; Moran et al. 2017.)

Patients recognize the need of education on the positive and negative impacts of transplantation. It is common for the health care workers to emphasizes greatly on the positive effect of the transplant; however, patients request the need of a balanced evaluation of transplantation. Despite transplantation, lessening the hardships of dialysis, patients are expected to constantly consume immunosuppressant medications to prevent organ rejection which intern has side effects to the patients. An example of the side effect includes an extremely weaken immunity, that one is exposed to numerous diseases and infections, inadvertently impacting the quality of life of the patients. (Yngman-Uhlin et al. 2015; Legendre, Canaud & Martinez 2013.)

Nevertheless, concerning patients´ education, patients demonstrated frustration, distress, and doubt after the average waiting period comes to an end. Many patients translated the average waiting period as the culminated waiting period. Hence, after the average waiting time has ended, patients are extremely distressed. Therefore, nurses and health care workers working with dialysis patients ought to explain further that the waiting period can be longer or shorter than the average duration. Besides, further education on the factors influencing the transplantation, is required to be thoroughly elaborated. Factors such as the age of the patient, years spent on dialysis, human Leukocyte antigen compatibility, cardiovascular health among others influencing kidney transplantation is to be explained hence creating understanding on the patients, and in turn mitigating the uncertainty, lack of trust and difficulties in the waiting period (Legendre et al. 2013). (Ynhman-Uhlin et al. 2015; Moran et al. 2010; Sque et al. 2010.)

In addition, patients expressed the financial burden of being under dialysis, this was evident in middle class countries in which the government does not cover for the health insurance. Patients felt the burden of saving finances for kidney transplant as well as receiving dialysis therapy, majority forced to live below their means to save money. (Yngman-Uhlin et al. 2015; Sque et al. 2015.) On the other hand, despite the numerous challenges, patients have devised numerous coping strategies. For instances, paying attention towards their hobbies, and careers. Together with acceptance to the situation and putting their trust in a higher power (Khins et al. 2013; Jin Chong 2016). These strategies have been influential to the waiting season, it has reinforced the experience by redirecting their attention away from the waiting.

Regardless of the numerous challenges, support exhibited by the health care professionals, fellow patients and family members has been a major source of support towards the dialysis patients (Jin Chong et al. 2016; Burns et al. 2017; Khins et al. 2013). Support ranges from emotional support, support in daily activities and in addition to the financial support. Moreover, during the waiting period hope is seen as a driving force, an integral ingredient to stay persistent while waiting. Many patients expressed the joy in gaining normality in their lives after transplantation. Eliciting their excitement to embark once again in daily activities such as hobbies, travelling and generally living a normal life from spending several hours in the dialysis centre. This is exhibited by patients always preparing themselves for the transplantation. Ensuring they are healthy, always online to receive the call, packing their luggage and being financially ready as dialysis is only a temporary treatment (Moran et al. 2010). (Jin Chong et al. 2016; Ynhman-Uhlin et al. 2015.)

From the analysis derived, there are three implications towards the renal patients care. First and foremost, dialysis patients need additional support especially due to the negative psychological impacts. Therapy sessions will prove supportive and aiding to anxiety, depression, and enduring the roller coaster of emotions. Sessions together with a psychologist, social workers as well as dialysis patients´ community meetings will tremendously supplement their experiences.

Simultaneously, patients expressed the need of more education and information from the health care professionals. Therefore, the transplant team especially nurses should offer more precise, continuous information to the patients, eliminating traces of doubts towards the transplant team. Thirdly, since dialysis nurses keep the most contact with the dialysis patients, they ought to monitor not only the physical progression of the disease, but also other aspects of life including the psychological health, home environments among different spheres of life and referring patients to further help whenever required.

6.2 Validity and reliability

To determine the validity of the analysed research articles, the selected articles were subjected to further analysis to examine the quality of the research articles. This was completed by Hawker, Payne, Kerr, Hardey and Powell (2002) critical appraisal analysis format. Each section of the research article was graded from 0-4, 0 representing poor quality, whereas 4 symbolizing high quality. The specific article analysis can be viewed in Appendix 1: Table of articles.

Several questions where generated specific to each section, providing guidance on the grading system. The questions were as follows:

1. Abstract- Does the abstract precisely elaborate the study?
2. Introduction and aims- Is the background of the study consistent to the research, and is the aim of the research highlighted?
3. Method and data- Does the research utilise appropriate method which is explained?
4. Sampling- Is the sampling criteria adequate to supplement the aims?
5. Data analysis- is there adequate information on the data analysis process?
6. Ethics and bias- Are the ethical concerns and biases addressed?
7. Results- Are the findings from the research well elaborated?
8. Transferability or generalizability- Can the research findings be generalized to the wider global?
9. Implications and usefulness- What is the usefulness of the research findings to the transplant policies and practices?

Out of the seven articles, the highest score attained was 36, whereas the minimal score of 31. The highest attainable score is 36. The average score of the articles is 34 underlining the high quality of the articles adopted to address the research question. A detailed analysis of every article is found in appendix 2: quality of articles. (Hawkers et al. 2002.)

Therefore, it is evident the study implements excellent sources of information. The rigorous data selection process that was implemented, immensely aided the process of selecting the most suitable sources to address the research question at hand. The results and findings provided an analysis and summary from the seven research sources, thus generating high-yielding, significant and educative information on dialysis patient´s experience while waiting for renal transplantation. Nevertheless, providing coherent suggestions to promote the quality of care provided by nurses and other health care professionals towards dialysis patients. (Knopf 2006.)

There are limitations on the findings of this study. This research offers a worldwide evaluation on the experiences of dialysis patients, therefore providing a general implication on improving the quality of life during the waiting phase. However, to enforce effective solutions, additional qualitative research must be conducted that is regional and country specific. This proves more advantageous, because different countries have different organization structure as well as economic stability.

6.3 Ethical considerations

The research conducted is a literature review, therefore, no patients were involved during the data collection process. However, the researchers considered in the literature review have attained permission from their respective organisations/ hospitals to conduct the study. Four out of seven researchers did provide written consent to the individuals participating, offering the ability to withdraw from participating at any time and patient´s confidentiality preserved (Appendix 2: Quality of articles). Nonetheless, the research is written in congruence with the report writing format of JAMK and preventing plagiarism. Furthermore, this research is forwarded to Turnitin, a plagiarism detection software. (Govil 2013.)

Nevertheless, the aspect of social injustices and differences in health care services is widely highlighted in this research. The findings of this study are limited due to the dissimilarities among the countries. Its is evident that patients living in the low-income countries, are extensively negatively impacted compared to patients under a well-developed health care system and services provision. Moreover, the ferocity of health injustices impacts the implications of this study. Patients living in developed countries with health security are privileged to access psychological support, whereas, dialysis patients in low middle class countries, receiving further support and services translates to further economic burden. (Ruger 2006.)

6.4 Conclusion

The research aimed at identifying the experiences of dialysis patients waiting for kidney transplant. In which the research question is extensively covered. Dialysis patients experiences psychological burden due to dialysis and the long waiting period. (Jin Chong et al. 2016; Yurttas & Nar 2018; Knihs et al. 2013; Yngman-Uhlin et al. 2015.) Negative physical impacts are identified due to dialysis as well as the complications of dialysis (Burns et al. 2017; Jin Chong et al. 2016; Moran et al. 2010; Yngman-Uhlin et al. 2015; Yurttas & Nar 2018). Additionally, economical burdens of dialysis are expressed as a challenge experienced by patients (Yngman-Uhlin et al. 2015; Sque et al. 2010.)

Due to the long waiting periods, a stagnant life, fear, anxiety, and uncertainty are highlighted among the patients (Jin Chong et al. 2016; Sque et al. 2010; Moran et al. 2010; Burns et al. 2017). Nevertheless, lack of information concerning the kidney transplantation process and allocation, in addition to limited education has developed suspicion towards the transplant team (Jin Chong et al. 2016; Burns et al. 2017; Sque et al. 2010; Moran et al. 2010; Yngman-Uhlin et al. 2015). Despite the challenges, many patients have devised ways to cope with the situation (Yngman-Uhlin et al. 2015; Jin Chong et al. 2016; Burns et al. 2017; Knihs et al. 2013).

Nonetheless, dialysis patients revealed concerns towards the deceased donor, however preferring deceased donor compared to living donors (Burns et al. 2017; Yngman-Uhlin et al. 2015; Knihs et al. 2013). Moreover, patients highlighted the importance of preparing for transplantation (Yngman-Uhlin et al. 2015; Jin Chong et al. 2016). Despite the negative experiences, dialysis patients underlined that kidney transplant provides hope for a normal life after transplantation (Burns et al. 2017; Jin Chong et al. 2016; Yngman-Uhlin et al. 2015; Moran et al. 2010). Additionally, support from the dialysis unit health care personnel, family members, and dialysis community reinforced the overall experience during the waiting period (Burns et al. 2017; Knihs et al. 2013; Jin Chong et al. 2016).

There are numerous useful suggestions made to improve the patients experiences whilst waiting for kidney transplant. Nurse should pay further attention towards the psychological health of dialysis patients, providing continuous information and education concerning the transplant, identifying their challenges, and offering the possible interventions. However, further research suggestions are stated to enhance the quality of life of dialysis patients during the waiting phase. It is essential to perform further research on the experiences of dialysis patients during the waiting season in specific countries/regions to implement efficient interventions compared to the world-wide analysis.

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Appendices

Appendix 1. Table of articles

Authors, (Year), Country	**Purpose and Aims of the Study**	**Research Methods or Instrument**	**Sample (*n*)**	**Validity / reliability**	**Main results**	**Critical appraisal (Hawker et. al 2002)**
Jin Chong, H., Kyung Kim, H., Reul Kim, S. and Lee, S. 2016 South Korea	Exploration of Korean dialysis patients´ experiences waiting for transplantation.	Qualitative research. Via individual long interviews that were transcribed.	8 participants waiting for transplantation, each diagnosed with ESRD, above 19 years old, waited for more than 1 year.	The research is reliable, and its findings are useful to the nature of the research question and to the renal unit.	Research findings are enlightening on the experiences of dialysis patients on the waiting list.	**35**
Burns, T., Fernandez, R. and Stephens, M. 2017 Australia	Highlighting the experiences of dialysis patients waiting for kidney transplant from a deceased donor.	Qualitative research method. Interviews conducted.	The sample were conducted in metropolitan hospital, two foster groups with six participants were attained. The participants ranged from 29-63 years-old,	The research is valid and can be generalised. The sample is random in a metropolitan hospital; hence the data is not biased, but general.	The results findings narrate the experience of a waiting dialysis patient waiting for a deceased donor.	**35**

			on dialysis for a period of 10-72 months.			
Yngman-Uhlin, P., Fogelberg, A. and Uhlin, F. 2015 Sweden	Investigating the experience of dialysis patients waiting for transplantation.	A qualitative research. Information collected via Interviews, in which the content was descriptively analysed.	8 patients under dialysis for a period of 6 months at minimal were selected. Patients waiting for kidney transplant. Aged 33-53 years. 7 men, 1 woman.	Reliable data that can be generalised. The sample is random and includes a wider age group.	This study shades light on the importance of needed support to be given to the patients prior to kidney transplant. Additionally, it suggests the need of more patient´s education of post transplantation.	**34**
Moran, A., Scott, A., and Darbyshire, P. 2010 Republic of Ireland	Exploring the experiences of haemodialysis patients whilst waiting for kidney transplant.	Utilised the Hermeneutical phenomenological methodology. Qualitative research through Interviews.	16 patients with ESRD undergoing haemodialysis therapy between 1month to 5 years. 7 women and n9 men. Above 18 years old. 30-65-years-old.	Valid results finding that is easily generalized to the wider population since the participants were chosen around the country.	Three main themes were identified from the research. ´´Uncertainty, living in hope and being on hold´´. Nonetheless the need of nurses frequently communicating with patients was underlined.	**34**

Yurttas, A. and Nar, N. 2018 Turkey	Identifying the challenges of kidney transplant patients and underlining the social, physical, and psychological problems after transplantation.	Qualitative research via interviews. data transcribed verbatim.	15 patients who have undergone kidney transplant in the last six months. 21-58 years.	Despite the document exploring the challenges of patients post transplantation, the participants review on their experiences whilst waiting for transplantation.	Kidney transplant has lessened their numerous challenges compared to the waiting period while undergoing dialysis.	**31**
Knihs, N., Sartori, D., Zink, V., Roza, B., and Schirmer, J 2013 Brazil	The aim of the research is to underline the experiences of renal failure patients in the list of kidney transplant.	Descriptive, explanatory qualitative research.	A sample of 20 patients undergoing the renal replacement therapy.	The results of this articles are valid and can be utilised to the wider community. The sample size is sufficient to be generalized.	The results are organized into different theme on the patient´s experiences, adding the research´s implications.	**36**
Sque, M., Frankland, J., Long-Sutehall, T. and Mason, J. 2010 United Kingdom	The purpose of this research is to understand the experience of adult dialysis patients waiting for transplantation.	A qualitative research. Data collected through single interviews. Themes identified when data was analysed.	A sample of 30 people. 16 men and 14 women. Three different races, with waiting time ranging from 4 months to 9 years.	The research is authorized by the National Health System in Britain, proving reliable. The sample size is sufficient to be generalized to a wider population.	Numerous themes are identified from the research. These include seeking normality, hope and many more.	**35**

Appendix 2. Quality of articles

Author	Abstract and title.	Introduction and aims	Method and data	Sampling	Data analysis	Ethics and bias	Results	Transferability and generalizability	Implication and usefulness	Total points
Jin Chong, H., Kyung Kim, H., Reul Kim, S. and Lee, S.	4 Explicit description of the study.	4 The background is clear, and the aim is precise.	4 The method used is consistent to the research.	3 The sampling is appropriate and clear. However specific to one kidney centre in Korea.	4 Rigorous information on the data analysis.	4 The ethical matters are addressed in the research. The participants privacy is maintained.	4 The results identified are well analysed and logically represented in different categories.	4 The data can be generalized to a wider population both in South Korea and abroad.	4 The information attained is highly useful to the kidney transplant organization calling for rectification in the policies and practices.	35
Burns, T., Fernandez, R. and Stephens, M.	4 The abstract provides the necessary information	3 The background briefly explained, and the aim of the	4 Valid methodology utilised compared to the	4 Sufficient information on the sampling process provided.	4 Well described data analysis process. Detailed	4 Ethical matters addressed. Patient´s	4. Useful results obtained that is well presented in a logical manner.	4 The results can be transferred to any country, as it	4 The results and finding offers a new perspective especially on deceased donor as a	35

	about the article.	research mentioned.	research question.	Detailed information. Justified the small sample.	step to guidance.	privacy highly respected.	Findings are supported by the participant´s responses.	Is generalisable.	source of kidney.	
Yngman-Uhlin, P., Fogelberg, A. and Uhlin, F.	4 Adequate information is provided on the abstract, Providing a clear picture of the research.	3 The article provides limited background information and a brief introduction. Nevertheless, the aim is mentioned.	4 The method is consistent to the research, that is clearly described in the article.	4 Adequate information on the sample is provided, offering a detailed description of the patient.	3 Data analysis fairly described. Limited information provided on the process.	4 Ethical issues well addressed. Written consent provided, and the consent to perform the research given by a trusted authority.	4 The results are well presented in differed themes making it easy to follow and understand. Enough analysis of the finding provided.	4 The findings of this research can be generalized to a wider population. However, only one woman participated, perhaps offering less perception of the opposite gender.	4 The findings are useful to the renal unit. Numerous issues have been raised from this article from the role of the nurse to the doctors, and the environment of the renal unit setting.	34
Moran, A., Scott, A., and Darbyshire, P.	4 The research provides a clear abstract	3 Some background provided, aim of the research outlined.	4 Appropriate method utilised. Adequate information	4 Good sample size. Full responses from	4 Organized manner of data analysis. Themes identified.	3 Ethical issues addressed. However, no	4 Findings are clear. Tables well explained. Findings	4 The results are useful and can be generalized to a	4 The implications identified from the research should highly	34

	detailing the research.	Background information not sufficiently supplementing the research.	provided on data collection and collection.	the interviewers.	Data analysis described.	documents signed by the participants to promote their confidentiality and interests.	supported by interviewer´s comments. Well explained, easy to follow.	wider population.	be implemented in in the renal unit.	
Yurttas, A. and Nar, N.	4 The abstract is clear, providing a good overview of the whole research.	4 The introduction is significant to the research and the aim of the research is directly mentioned.	4 The method is appropriate for this research. Well explained.	4 A big sample size that eventually supplements the research.	2 Information provided on data analysis, however, poorly organized, themes not identified. Lack of proper organization.	4 Ethical issues handled well. Written consent provided to the participants. Permission for the research obtained.	2 Findings are mentioned in a disorganized manner. Difficult to follow.	3 Large sample size, hence, can be generalized to a wider population.	4 In spite of poor organization of the finding, the results echo's the need of changes in the nursing care of renal patient.	31
Knihs, N., Sartori, D., Zink, V., Roza, B., and	4 The article provides a structured abstract with full	4 The article offers a concise introduction with recent information.	4 The method utilized is coherent to the	4 The sample is explained in detail, up to their level of education.	4 Data analysis is described well. The	4 Ethical issues identified and justified. Written	4 The results are easy to understand and follow. Well	4 The results and findings can be generalized to a	4 The research implications and clear. It does suggest the need of	36

Schirmer, J	information and tittle.	The research question is clearly stated.	research question.	Response rates well identified.	themes are identified. Numbers do add up.	consent given to participants and permission of the research attained.	described and organized. Results do answer the aims.	wider population.	nurses to improve the care offered toward renal patient.	
Sque, M., Frankland, J., Long-Sutehall, T. and Mason, J.	4 The abstract is clear, detailed, and offers key information of the article.	4 A long introduction is provided entailing the research question.	4 A descriptive analysis of the data is provided. Clear details provided of the data.	4 A huge sample of participants, detailed information of the participants provided.	4 Data well analysed into differed themes. Easy to follow and understand, very descriptive. Findings supported by the participant´s statements.	4 Ethical concern address. The research is approved by the national health system in Britain, participants provided with signed consent.	4 The results and finding address the aim of the research. Sufficient data from the research support the finding.	3 Despite the big sample size, majority of the participants were white, only a few where black and one Asian. The findings can be generalized, however more research need to be done covering different races.	4 The researchers offer through suggestion on the improvement on the renal health care system. Indeed, neuron changes are requiring to improve the experiences of dialysis patient waiting for transplantation.	35

Appendix 3. Research articles

Author	**Title**	**Journal**	**Year**	**Quality Approved** **Total score allocation Maximum score = 36**
Jin Chong, H., Kyung Kim, H., Reul Kim, S. and Lee, S.	Waiting for a kidney transplant: the experience of patients with end-stage renal disease in South Korea	Journal of Clinical Nursing.	2016	35
Burns, T., Fernandez, R. and Stephens, M.	The experience of waiting for a kidney transplant; a qualitative study.	Journal of renal care.	2017	35
Yngman-Uhlin, P., Fogelberg, A. and Uhlin, F.	Life in standby: haemodialysis patients´ experience of waiting for kidney transplantation.	Journal of Clinical Nursing.	2015	34
Moran, A., Scott, A., and Darbyshire, P.	Waiting for a kidney transplant: patient´s experiences of haemodialysis therapy.	Journal of advanced Nursing.	2010	34
Yurttas, A. and Nar, N.	The feelings and concerns of patients with kidney transplant in Turkey: A qualitative study.	International Journal of caring Sciences.	2018	31
Knihs, N., Sartori, D., Zink, V., Roza, B., and Schirmer, J.	The experience of patients who need renal transplantation while waiting for a compatible organ.	Text context Nursing.	2013	36

Sque, M., Frankland, J., Long-Sutehall, T. and Mason, J.	Life on a list: an exploratory study of the life world of individuals waiting for a kidney transplant.	-	2010.	35

Appendix 4. Categorization table.

Source	**Themes identified from the research**	**Subcategory**	**Category**
Jin Chong et.al (2016)	Prolonged waiting periods for transplantation has a negative impact on the patient´s psychological and physical health.	Psychological effects.	**Poor quality of life.**
Yurttas and Nar (2018)	Life dependant on a machine.		
Jin Chong et al. (2016)	Depression.		
Knihs et al. (2013)	Fear of dialysis complications		
Knihs et al. (2013)	Fear of death before kidney transplant.		
Jin Chong et al. (2016)	Patients are affected with depression, anxiety and a poor quality of life while waiting.		

Yngman-Uhlin et al. (2015)	Anxiety on whether kidney transplant will work and the side effects of kidney transplant.		
Yngman-Uhlin et al. (2015)	Fear of falling back on dialysis after transplantation		
Burns et al. (2017) Jin Chong et al. (2016) Moran et al. (2010) Yngman-Uhlin et al. (2015) Yurttas and Nar (2018)	A limited life, restrictions in personal life such as travelling, working and general daily activities, that is further enhanced while being on the waiting list for kidney transplant.	Physical effects.	
Burns et al. (2017)	Dialysis is physically and mentally draining.		
Yurttas and Nar (2018)	After four hours of dialysis, the rest of the day was spent to recover from the exhaustion.		
Yngman-Uhlin et al. (2015)	Pain		
Jin Chong et al. (2016)	The waiting period poses numerous challenges for dialysis patients, as they are prone to cardiovascular disease, infection and a general weaken immunity that further deteriorates their prognosis after		

Yngman-Uhlin et al. (2015) Yurttas and Nar (2018)	kidney transplant. Nevertheless, raising the mortality rates while waiting for kidney transplant. Stressful.		
Yngman-Uhlin et al. (2015)	Economic challenges.	Economic challenges.	
Sque et al. (2010)	Need of disease related benefits.		
Jin Chong et al. (2016)	Support from the health care workers who constantly encourages them to continue wait.	Health care professionals.	**Support**
Jin Chong et al. (2016)	Constant support from family members, as they are equally affected by ESRD. Family proved as a source of strength.	Family.	
Burns et al. (2017)	Despite family members promising to donate, patients expressed fear of the effect of surgery on their loved ones.		
Burns et al. (2017)	In Australia, the dialysis community provided an environment in which patients share their experiences and support each other.	Dialysis community.	
Burns et al. (2017)	Peer support among dialysis patients.		

Knihs et al. (2013)			
Burns et al. (2017) Jin Chong et al. (2016)	Despite dialysis being tiresome, kidney transplant is a source of hope for a better future. Burden of dialysis is lifted by the thought of kidney transplant.	Freedom And normality	**Hope**
Jin Chong et al. (2016)	Hopeful for normality after kidney transplant.		
Yngman-Uhlin et al. (2015)	Less hope for those who have waited for a long time.	Shattered hopes	
Moran et al. (2010)	Viewing dialysis therapy as a temporary treatment before transplantation.	Temporary treatment	
Jin Chong et al. (2016) Burs et al. (2017)	An uncertain life, as no one knows when the transplantation will occur.	Constantly waiting.	**Uncertainty and lack of trust.**
Jin Chong et al. (2016)	Continuous wait for transplantation 24 hours waiting for a call.		
Jin Chong et al. (2016)	Long waiting periods brings numerous doubts on whether kidney transplant will ever take place.		

Jin Chong et al. (2016)	Frustration of waiting for a long period of time.		
Sque et al. (2010)	Lack of control and doubt if they will ever a transplantation.		
Moran et al. (2010)	After a failed kidney transplant, lack of hope. A stagnant life.		
Jin Chong et al. (2016)	Fears as their condition continues deteriorating while waiting for transplant, thus reducing the possibility of undergoing transplantation.	Anxiety and fear.	
Jin Chong et al. (2016)	Patients experiences a rollercoaster of emotions after failing to reach the criteria for transplantation or being omitted from the waiting list.		
Moran et al. (2010)	Distress after being chosen as a candidate and not receiving the transplant.		
Moran et al. (2010)	Anxiety on missing the transplantation call.		

Burn et al. (2017)	Concerns on the outcome of the transplant. Concerns of long-term survival. Fears of complications of the surgery. Fear of no change after the transplantation. Fear of losing all hope in life after transplantation fails.	Fear around kidney transplantation.	
Jin Chong et al. (2016)	Limited information on the waiting list.	Missing information.	
Yngman-Uhlin et al. (2015)	Limited information of what is happening in the waiting list, after missing transplantation.		
Burns et al. (2017) Moran et al. (2010)	Suspicion on equality of kidney distribution. Especially after waiting for transplantation, yet others wait for a shorter time.	Suspicion of inequality.	
Sque et al. (2010)	Lack of detailed information of kidney allocation, the criteria make it suspicious.		
Jin Chong et al. (2016)	The complication of the waiting process.		

	Due to long waiting periods, and numerous frustrations, majority fail to trust the allocation process.		
Sque et al. (2010)	Lack of regular meetings with the transplant co-ordination team.	Limited education.	
Yngman-Uhlin et al. (2015)	Lack of adequate information on the negative impacts of transplantation. Need of balance between positive and negative impacts.		
Moran et al. (2010)	Misunderstanding average waiting time as the accurate waiting time. Negative impacts after the average time have passed.		
Jin Chong et al. (2016)	Ensuring they are healthy and ready for transplantation.	Maintaining health.	**Preparation for the transplantation**
Jin Chong et al. (2016)	Taking the necessary tests in preparation for the transplant.		
Jin Chong et al. (2016)	Saving money for the operation.	Financial preparation.	
Yngman-Uhlin et al. (2015)	Having their luggage ready, all the time.	Ready to go.	

Yngman-Uhlin et al. (2015) Jin Chong et al. (2016)	Being alert always waiting for a call.		
Burns et al. (2017)	Better alternative than living donors.	Perception towards the donor	
Burns et al. (2017)	Sense of sadness towards the deceased donor.		
Yngman-Uhlin et al. (2015) Knihs et al. (2013)	Conflicted emotions hope after accident deaths.		
Jin Chong et al. (2016) Burns et al. (2017)	Letting go of worry. Avoiding worrying on things that they cannot control. ´´If the call comes it comes if it doesn´t if it doesn´t´´. Different ways to cope with the disappointments and frustrations. Finding numerous ways to cope with dialysis and waiting.	Acceptance.	**Coping strategies.**
Yngman-Uhlin et al. (2015)	´´stop´´ waiting.		

Jin Chong et al. (2016)	Investing time in their hobbies.	Shift of focus.	
Jin Chong et al. (2016)	Getting a job and working.		
Jin Chong et al. (2016)	Trusting God to care for them	Trusting higher being.	
Knihs et al. (2013)	Faith, strength from the religion.		