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Quality of Life of people undergoing hemodialysis in Nepal and Norway

Master's Thesis in International Social Welfare and Health Policy

Faculty of Social Science

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<u>Abstract</u>

Introduction

Chronic kidney disease is increasing day by day in the world and it has become one of the leading reasons for mortality over the world. Currently, in the world, it is estimated that nearly 13.4% of people are suffering from chronic kidney disease. and the patient having ESRD and needs renal replacement therapy is estimated between 4.902 and 7.083 million. For survival from kidney disease, patients must undergo Renal Replacement Therapy (RRT), which includes Hemodialysis, Peritoneal Dialysis, and Renal Transplantation. Quality of life has become a worthwhile research tool in evaluating the results of treatment interventions in chronic diseases.

Methods

The purpose of this thesis is to explore the quality of life of people with chronic kidney disease in Nepal and Norway. The primary research question is 'What is the quality of life of people with CKD/ESRD?' and the secondary research question is 'What is the impact of hemodialysis on the Quality of life of people with CKD/ESRD?' The literature review method is used to do this assignment. To answer my first research question, I identified all studies that measured the QOL of patients at one point in time, using any questionnaire. To answer research question two, I first tried to find randomized controlled trials that compared hemodialysis with a control group, to estimate the impact of hemodialysis on the quality of life of people with CKD\ESRD. When this was not possible, I tried to find other study designs. I searched electronic databases to identify relevant studies. The data and statistics related to my assignments are taken from the studies provided by the authors as possible and available, and if the unavailable were narrated in words.

Findings

All together six studies met inclusion criteria and were analyzed; three studies were from Nepal and three from Norway. Studies from Nepal were used to answer research question 1 and studies from Norway were used to answer research question 2. The answer to the quality of



life of chronic kidney disease is undetermined. And for the second research question there did not appear to be any improvement in the quality of life for patients undergoing hemodialysis longer.

Conclusion

The study demonstrated that there are no differences in the quality of life of patients having chronic kidney disease in Nepalese\Norwegian patients and length of hemodialysis does not have any relationship with quality of life in both the countries. There can be various associated factors that have an impact on quality of life, that were not measured. Women, people with higher education, married people, or cohabiting reported a higher quality of life but people who are unemployed, geriatric patients, and have any disease or health problems have a lower quality of life.

Key words: Quality of life, hemodialysis, chronic kidney disease

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Oslo Metropolitan University, Faculty of Social Science

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Master's thesis: Quality of life of people undergoing Hemodialysis in Nepal and Norway

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1.5 List of abbreviations

Abbreviation

Term



| CKD | Chronic Kidney disease |
|-------------|---|
| ESRD | End-Stage Renal Disease |
| GFR | Glomerular Filtration Rate |
| KF | Kidney Failure |
| HD | Hemodialysis |
| PD | Peritoneal dialysis |
| RRT | Renal Replacement Therapy |
| QoL | Quality of Life |
| HRQOL | Health-Related Quality of Life |
| SF-36 | Short-Form Health Survey 36 |
| WHOQOL-BREF | World Health Organization Quality of Life |
| | Brief |
| BREF | Abbreviated Version |
| KDQOL-SF TM | Kidney Disease Quality of Life Short Form |
| SD | Standard deviation. |
| IQR | Interquartile range. |
| WHO | World Health Organization |
| CVD | Cardiovascular Disease |
| PCS | Physical Component Summary |
| MCS | Mental Component Summary |
| PF | Physical Functioning |
| RP | Role functioning Physical |
| RE | Role functioning Emotional |
| BP | Bodily pain |
| MH | Mental health |
| VT | Vitality |
| SF | Social functioning |
| LR | Literature Review |
| RCT | Randomized Control Trial |
| RQ | Research Question |
| | |



1.6 Definitions of key terms

Chronic Kidney disease

Chronic Kidney Disease is a rising public health problem that can be clearly described as kidney damage or diminished glomerular filtration rate by 60 mL\min per 1.73 m² for three or more months and elevated in the excretion of urinary albumin or both. (Jha et al., 2013)

Health

'Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity''(WHO, 1997

).

Quality of life

WHO defines Quality of life as "an individual's perception of their position in life in the context of culture and value systems in which they live and concerning their goals, expectations, standards, and concerns." (WHO, 1997

).

End-stage renal disease

End-stage renal disease can be described as an irretrievable decrease in the kidney function of a person which worsens life without dialysis treatment or kidney transplantation. This disease is affecting over 1500 people per million in the countries with a high incidence and it results in anemia, retention of fluid, risk of cardiovascular disease, bone, and mineral metabolism disease, and many others (Abbasi, Chertow, & Hall, 2010).

Hemodialysis

An outside filter named a dialyzer which has a semi-permeable membrane in it is applied to remove the extra water and wastes from the body. Wastes are separated from the body is done by producing a counter-current flow gradient, in which the blood passes across one direction and fluid passes through the opposite direction (Vadakedath & Kandi, 2017).



Peritoneal Dialysis

A peritoneum is applied as a natural semi-permeable membrane that eliminates the extra wastes and water in the dialysate (Fluid is passing by the semipermeable membrane of the dialysis) (Vadakedath & Kandi, 2017).

Renal Replacement Therapy

Renal replacement therapy combines forms of dialysis like hemodialysis and peritoneal dialysis, hemofiltration, and renal transplantation (Morris & Knechtle, 2008).

Kidney Transplantation

Transplantation is the surgical method of replacing a damaged kidney with the new one (Morris & Knechtle, 2008).

2 Introduction to this thesis

2.1 General background and problem statement

Chronic kidney disease is a leading cause of mortality and disability-adjusted life year (DALY) around the world. CKD is growing rapidly to a large extent in low- and middle-income countries. Even if screening and intervention help in the prevention of disease and management strategies reduces the incidence of chronic kidney disease but unfortunately it is not normally possible and available in the poorest countries (Jha et al., 2013). Furthermore, chronic kidney disease turns out to be a leading public health issue in the world and a key contributor to the whole non-communicable disease burden which relates to serious significance comprising increased risk of mortality, ESRD (end-stage renal disease) cardiovascular disease bone and mineral disease, adverse effects on metabolic and nutrition, infection, acute kidney injury and so on. In the world, it is estimated that the prevalence of chronic kidney disease is nearly 13.4% and the patient having ESRD and needs renal replacement therapy is estimated to be between 4.902 and 7.083 million (Lv & Zhang, 2019).

Globally, 10% of the population has suffered from chronic kidney diseases and due to a lack of inexpensive treatment, millions of people die every year (Foundation, 2015). Global burden of disease study 2010 points out that CKD was classed the ranking 27th in the list of reasons



for deaths in the world in 1990 which has risen to the rank 18th in 2010 as published in National Kidney Foundation. (Foundation, 2015).

More than one million people die each year due to the unavailability of treatment, as dialysis and kidney transplantation generates a huge economic problem in middle-income countries. As stated by WHO around 58 million people died in the world and among them, 35 million people died due to CKD. (Foundation, 2015).

Even though the meaning and categorization of chronic kidney disease have irradiated but in general terms, it can be explained as miscellaneous disorders that affect general functions and structure of the kidney and creates urine abnormalities. (Romagnani et al., 2017) Concerning all high income, middle income, and even in some low-income countries Diabetes and hypertension are the leading reasons for chronic kidney disease (Webster, Nagler, Morton, & Masson, 2017).

The Kidney has lots of functions such as cleaning the blood, removing extra fluids from the body in the form of urine, balancing the hormones crucial for the human body, and so on. But when these kidneys stop functioning, treatment is required to restore the essential jobs done by the kidneys and treatment includes Hemodialysis, Peritoneal dialysis, and kidney transplant. Both hemodialysis and peritoneal dialysis eliminate waste and extra fluids from the body and aid to control blood pressure. Hemodialysis can be performed at home, hospital, or dialysis center which lasts for about four hours generally three times a week (National Kidney Foundation).

Most of the time it is assumed that QOL is usually poorer among people with CKD than that of the general population due to the high burden of comorbidity and complications and depression makes social life poorer which risks decreased glomerular filtration rate. Peritoneal Dialysis (PD) can be accomplished all alone or with the help of a caregiver at home, at work, or in any other clean and well sterile area. This PD can be done several times a day every 4 to 5 hours with taking a long break during nighttime (using CAPD: continuous ambulatory peritoneal dialysis manual method) or throughout the night by the means of machines that make exchanges for 8 to 10 hours continuously with APD automated method (Zazzeroni, Pasquinelli, Nanni, Cremonini, & Rubbi, 2017). Some studies have shown that receiving dialysis at home such as PD leads to a better quality of life and an increase in effectiveness than in dialysis centers (Zazzeroni et al., 2017).



People who are suffering from kidney disease need treatment for survival and that is renal replacement therapy. Renal replacement therapy is the collective term for three types of treatment: hemodialysis, peritoneal dialysis, and renal transplantation which saves the life of people. Some studies explored that among other treatments majority of patients with kidney failure preferred renal transplantation as the most effective method of treatment which provides extreme ease, enhance overall health, and increases life expectancy and it has shown the best results in terms of morbidity, survival, and QOL contrasted with dialysis (both hemodialysis and peritoneal dialysis). Furthermore, renal transplantation is cheaper compared to dialysis throughout the average life span of the patient shown by some studies (Alvares, Cesar, de Assis Acurcio, Andrade, & Cherchiglia, 2012).

However, People's life won't change totally after dialysis but one must be careful about the diet and follow a diet plan developed by the dietician that meets your needs and maintains good health. Healthcare members will assist you and your family adapt to the alterations in your everyday life affected by your illness. When you become used to the treatment you may feel better and can carry out your activities like traveling or working but under the supervision of a doctor ("kidney disease," 2015 National Kidney Foundation).

As stated by World Health Organization (WHO) "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" It means that to be healthy one has to be not only free from diseases but also maintain and balance the social life which can be evaluated by determining the betterment in the quality of life associated to health care (WHO, 1997). WHO has also given a clear definition of quality of life as "individual's perception of their position in life in the context of the culture and value systems in which they live and concerning their goals, expectations, standards, and concerns". Quality of life is the term generally applied to represent health status, physical functioning, symptoms, psychological adjustment, well-being, life satisfaction, or happiness (WHO, 1997).

2.2 Purpose of this thesis

Chronic kidney disease is very high in developing countries of South Asia, eastern Europe, and Latin America and in South Asia, a few factors for rising CKD are Hypertension, low socioeconomic status, diabetes mellitus, environmental factors, and intrauterine growth retardation. (Abraham et al., 2015) more inclusive, cost-effective, and preventative interventions against



chronic kidney disease need to be carried out in developing countries. (Nugent, Fathima, Feigl, & Chyung, 2011)

Dialysis has a significant effect on people both mental and physical health. The inaudible agonies of dialysis patients contribute to psychological disorders (depression, anxiety, and stress) and therefore alter their overall quality of life (Bujang et al., 2015).

The burden of ESRD is expanding day by day and it creates economic troubles for patients, families, and the health system of developing countries like Nepal due to the high cost very few numbers of patients are receiving Renal Replacement Therapy each year. And some studies have found that QOL is better in transplant patients compared to dialysis in the case of physical, mental, and social relationships. However, the health system of Nepal has constrained and unstable access to transplant services, few nephrologists, the waiting time to get transplant service is lengthy, and not having enough money gives worry to people with ESRD. The lower QOL among dialysis patients in Nepal is due to physical pain, weakness, sleeplessness, difficulty in day-to-day activities, lack of support from family members, lack of awareness, and also due to increase frequency and duration of hemodialysis (Ranabhat et al., 2020).

However, in developed countries like Norway, people with kidney failure undergoing dialysis are mostly suffering from depression and symptoms related to it and suppressed in HRQOL (Østhus et al., 2010). Difficulties associated with health such as nutritional deficits, comorbidity, and reduction in physical capacity are mostly seen in older patients and younger patients have a quite better quality of life because of physical capacity and nutritional balance. Nutritional problems are common in older patients still they may not affect QOL (Lægreid, Aasarød, Bye, Leivestad, & Jordhøy, 2014).

2.2.1 Aims of the study

This assignment aims to explore the quality of life of people undergoing hemodialysis and to assess any changes or effects of dialysis on their quality of life.

2.2.2 Research question 1 (main objective)

What is the quality of life of people with CKD/ESRD?

2.2.3 Research question 2 (secondary objective)

What is the impact of hemodialysis on the Quality of life of people with CKD/ESRD?



3 Review of existing literature

The purpose of this chapter is to review some of the literatures and add the basic information about kidney disease and end stage renal disease, its complications and management with and with out renal replacement therapy. I also review the health care system of Norway and Nepal and related information.

3.1 End-stage renal disease (ESRD)

ESRD is colloquially known as kidney failure, which is the end stage of kidney/renal disease, and it affects over 1500 people per million people in countries with a high prevalence for example United State and Japan. Around two-thirds of people with ESRD receives hemodialysis, one quarter has kidney transplants and one-tenth receive peritoneal dialysis (Abbasi et al., 2010).

Numerous risk factors are included with ESRD such as old age, hypertension, diabetes, family history of renal disease, and many more which (ESRD) result in retention of fluid, anemia, bone and mineral disorders, and risk of cardiovascular disease. (Abbasi et al., 2010) This disease is irreversible because of reduced kidney function. Generally, the majority of patients eventually die from complications like cardiovascular disease, infection, progressive uremia, and other conditions if dialysis is not provided (Abbasi et al., 2010).

National Kidney Foundation has classified chronic kidney disease into five stages which means an individual's glomerular filtration rate lower than 15 mL per minute per 1.73m² surface area of the body or patients might require dialysis regardless of glomerular filtration rate (Abbasi et al., 2010).

The table below shows the stages of chronic kidney disease has been shown. The five stages explain how gradually the GFR rate decreased from more than 90 to less than 15. Stage 1 has the normal filtration rate, but protein is seen in the urine, second stage has a mild decrease in the GFR which is 60 to 90. Likewise, stage 3 has a moderate decrease in the filtration rate and reaches 30 to 59, the fourth stage has a severe decrease in the filtration rate and that is 15 to 29 and the last stage has less than 15 glomerular filtration rate and in this kidney, failure occurs, and a patient cannot survive without dialysis or transplantation.



Table 1Stages of chronic kidney disease

| Description | Glomerular Filtration Rate |
|--|---|
| Risk factors for kidney disease | (GFR) more than 90 |
| (e.g., diabetes, high blood pressure, family | |
| history, older age, etc.) | |
| Kidney damage (protein in the urine) and normal | More than 90 |
| filtration rate | |
| Kidney damage and mild decrease in filtration | 60 to 90 |
| rate | |
| Moderate decrease in filtration rate | 30 to 59 |
| | |
| Severe decrease in filtration rate | 15 to 29 |
| | |
| Kidney failure (dialysis or kidney transplantation | Less than 15 |
| needed) | |
| | |
| | Risk factors for kidney disease (e.g., diabetes, high blood pressure, family history, older age, etc.) Kidney damage (protein in the urine) and normal filtration rate Kidney damage and mild decrease in filtration rate Moderate decrease in filtration rate Severe decrease in filtration rate |

Source: (Manual) ESRD new patient education manual, NPE manual

3.2 Management of ESRD's complications

According to dialysis and transplant registries all over the world, researchers have reported that cardiovascular disease (which reports around 40%) and infection is still the leading causes of death and a high death rate endures after renal transplantation (Walker, 1997). The renal physician must monitor the CKD patient together with this, endocrine and cardiovascular specialist also helps in the management of a patient. Moreover, dietitians must assess nutritional status and suggest a diet plan for delaying the progression of kidney disease. Psychologists are also expected to take part in the management of patients because as kidney



disease develops, mental disorders might be associated with the physical condition (Yang & He, 2019).

<u>Cardiovascular management</u>: The major management in the case of CVD is to correct the pressure overload (hypertension) and volume overload (anemia along with the retention of extra salt and fluid retention) and dialysis should be adequate which means long and slow dialysis (8 hours per session) is required to sustain a proper dry weight (no fluid retention) and maintain the normal blood pressure level (Walker, 1997).

<u>Anemia management:</u> Human erythropoietin has been the most important and improved treatment for the last ten years and due to this quality of life has been enhanced by enhancing their energy level and exercise tolerance, reducing fatigue, decreasing the individual needs for blood transfusion, and risk hunger. Along with this, treatment using erythropoietin also reduces the risk of cardiovascular mortality with ESRD (Walker, 1997).

<u>Nutritional management</u>: Malnutrition is another associated reason for mortality and morbidity in ESRD. Patient dietary status should be regularly checked and a patient should have sufficient protein, calories, and energy intake where the changes if needed, should be recommended corresponding to the patient's cultural and socio-economic background (Walker, 1997).

Hyperparathyroidism and hyperphosphataemia management

Kidney has key function in metabolism of parathyroid hormone and vitamin D3 and reduced in production of vitamin D3 and phosphate retention develops hyperparathyroidism. Good dietary management with extra calcium and vitamins is necessary for kidney disease patient. So dietary management and control of hyperphosphatemia is crucial in early stage of disease (Walker, 1997).

It is well known that kidney disease cannot be cured but it can be managed to slow down damage or at least stop the progress of damage and to maintain kidney function by handling underlying conditions, lifestyle changes (following the diet chart, taking prescribed medicines, regular exercise, stop smoking or alcohol can lengthen kidney health) as well as by RRT (Kefale). Treatment of end-stage renal disease also depends on some factors and the doctors will recommend based on overall health, age, medical conditions, type of disease (acute or chronic), tolerance to medicines, procedures, or therapies, and others. And the treatment could include hospitalization, medications, and monitoring of electrolytes like potassium, sodium,



and calcium. In some cases, a patient may develop fluid overload, and dialysis and kidney transplantation is needed ("End Stage Renal Disease (ESRD)," 2021).

It is very important to measure the clinical outcomes and survival of people having end stage renal disease because quality of life is an indicator if the medical care and treatment patient are receiving is effective or not. Some of the factors are affecting quality of life of people while undergoing treatment modlaities are such as anemia, age, comorbidity and depression. This facors need to be assessed and treat accordingly. (Valderrábano, Jofre, & López-Gómez, 2001)



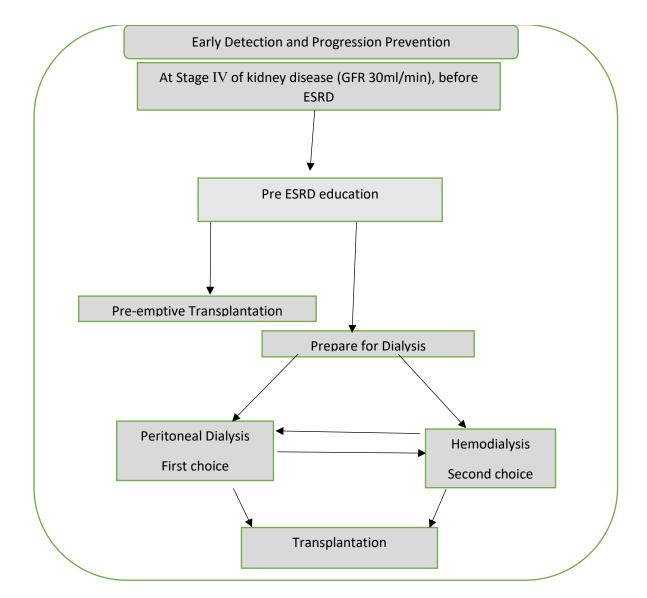


Figure modified from: (Davidson, Gallieni, Saxena, & Dolmatch, 2007).



In the figure above, the author has written that this figure is hardly reflected in reality, and it explained the treatment strategy of ESRD, and it emphasizes the benefits of peritoneal dialysis as the first choice (Davidson et al., 2007). ESRD early detection is important to reduce the progression of the disease when the kidney disease is at stage 4 (GFR 30ml\min). Pre-ESRD education is crucial to prevent the progression of the disease. And for the treatment modalities, peritoneal dialysis is considered the first modality of treatment, and peritoneal dialysis provides a survival benefit and better long-term and short-term outcomes in comparison with a patient undergoing hemodialysis before kidney transplantation. Hemodialysis is not considered a competitive therapy but instead complementary and the dialysis options are short-term treatment and transplantation is considered an option for the long-term treatment. Therefore this figure is rarely reflected in the reality (Davidson et al., 2007).

3.3 Renal Replacement Therapy

Renal replacement therapy is done to remove extra waste and water from the blood used as an artificial replacement for lost kidney function in people with End-stage renal disease. Modern renal replacement therapy includes Hemodialysis, Peritoneal dialysis, and kidney transplantation. The patient may switch from one to another throughout the treatment therefore it is important to know that such modalities are not mutually exclusive.

Indications for RRT in end-stage renal disease are the overall disorders in extracellular volume and body fluid composition such aspects comprise volume overload, hyperkalemia, severe metabolic acidosis, and uremic signs and symptoms (like nausea, vomiting, anorexia) (Palevsky, 2005). But if the patient is critically ill renal replacement therapy should begin at an early stage before complications occur (Palevsky, 2005). The decision concerning detailed rules for RRT is dependent on not just the physical condition but also the psychological conditions and the lifestyle of the patient (Yang & He, 2019).

Hence peritoneal dialysis is the best choice for an initial treatment if the patient is going to have a renal transplant shortly, as well as for patients who want to be in more control of their dialysis or who plan to do dialysis at home (Yang & He, 2019).



3.3.1 Hemodialysis

Hemodialysis is performed usually three times a week for four hours each session or as per the need of the patient. This treatment is now safer than before and found rare cases of death and complications relating to dialysis and that is because of technical improvement (Ikizler & Himmelfarb, 2010).

Worldwide millions of patients die within weeks without hemodialysis. Diffusion, Convection, Adsorption, and Ultrafiltration are the principles of Hemodialysis. Diffusion represents the spontaneous passive circulation of solutes through the dialysis membrane and the rate of diffusion is dependent on the molecular weight, blood flow rate, dialysate temperature, etc. Convection represents the spontaneous transport of solutes around the dialysis membrane and it is reliable for scavenging macromolecules (Yang & He, 2019). Absorption is a process of eliminating molecules from the blood or plasma and it happens primarily for the hydrophobic properties of sorbents. Ultrafiltration represents the circulation of molecules through the semi-permeable membrane because of pressure differences (Yang & He, 2019). Dialysis does not fully cure the damaged kidney's function but somewhat executes the function of kidneys through diffusion (waste removal) and ultrafiltration (fluid removal) across a semi-permeable membrane (Vadakedath & Kandi, 2017).

3.3.2 Peritoneal dialysis

Life-time treatment is required in lifelong disease conditions such as chronic kidney disease and peritoneal dialysis is also one of the choices for lifetime treatment, together with other treatments like hemodialysis and transplantation (Burkart, 2020). It is another method of treatment for kidney failure like hemodialysis which does not cure the disease, but it does as many functions of the kidneys as possible. This procedure is performed at home by infusing dialysis fluid (dialysate) into the abdominal cavity (peritoneal cavity) through the catheter where the lining of the peritoneal membrane works as a membrane that allows fluid and waste products to go from the bloodstream into that dialysate (Burkart, 2020).

Peritoneal dialysis can be manually performed 4 to 5 times a day by infusing fluid into the abdomen and afterward letting it run out under gravity. Even though it is one of the good options for dialysis, it has some complications too. For example, infection (named peritonitis) if it is not treated on time it can be life-threatening (Burkart, 2020).



These days PD has become one of the choices of renal replacement therapy in which the survival rate of patients is the same as that of patients treated with hemodialysis and in the UK almost half of the patients with kidney failure are treated with this (Gokal & Mallick, 1999).

3.3.3 Renal Transplantation

Renal transplantation is the surgical replacement of a damaged kidney with the new one that helps to enhance the survivability of the patients and increases the quality of life of patients suffering from ESRD. Patients with CKD at stage 5 or stage 4 (GFR less than 15mL\min and 15-30mL\min respectively) with disease progression probably require renal replacement therapy within the six months are eligible for transplantation but a minority of patients are not suitable for transplantation. For example, patients having an infection, untreated HIV or AIDS, or conditions in which a life span is less than 2 years are not suitable for transplantation (Thiruchelvam, Willicombe, Hakim, Taube, & Papalois, 2011).

Patients who are unsuitable for transplantation should go for long-term dialysis. Brain or cardiac deaths are the sources of donors' kidneys for the past forty years but donations from living donors are also growing over the last decade (Thiruchelvam et al., 2011). Donors may be related genetically (father, mother, or family members) or emotionally (friend or spouse) to the recipient. The life expectancy of kidney donors has been found similar to a general population of similar age and does not raise the risk of acquiring ESRD and the average life expectancy of the recipient or after a kidney transplant is 8 to 15 years varying on the kind of graft (Thiruchelvam et al., 2011).

3.4 Healthcare systems in Nepal and Norway

Healthcare options are often dictated by environment and resources, and not simply patient indication and needs. Nepal and Norway are two contexts with quite different healthcare systems and resources.

Nepal is a small landlocked country in Southeast Asia with approx. 21.8 million. The average life span at birth is 57.52 years. Approximately 70% of health problems and deaths in Nepal are because of infectious diseases such as dysentery, hepatitis, meningitis, fevers, and various others (Rai, Rai, Hirai, Abe, & Ohno, 2001). Before 1950 there were very few doctors and



other health professionals treating around 8 million people. Following the introduction of the general health plan in 1956, notable progress was made in the health care sector to offer basic health care services to each people. In the recent health care delivery system, primary health care is provided by primary health care centers, health posts, and sub-health posts at the village development committee and electoral constituency level together with private institutions comprising hospitals, nursing homes, and medical college teaching hospitals (Rai et al., 2001).

In the context of non-communicable diseases like chronic kidney disease or end-stage renal disease in Nepal has increased from 10% to over 15.8% over the decade. Dialysis is an impossible choice for most patients because each month dialysis costs 20,000 Nepali rupees, while the average earnings per year of people are 26,000 rupees (Dahal & Kafle, 2016). Sometimes patients have no option and unwillingly they sell all their properties for treatment and transplantation and the results will not satisfy them due to the high cost and unavailability of kidney donors. Yearly patients more than 10,000 are suffering from kidney disease in Nepal and many people are unaware until the last stage (Dahal & Kafle, 2016). However, there are no clear statistics on the number of patients requiring renal replacement therapy or how many are undergoing dialysis because there is no renal registry available. The incidence of kidney disease are nearly 100 per million population as estimated by Dr. Rishi Kumar Kafle executive director of the national kidney center. And due to the lack of availability of healthcare facilities in rural areas, there are many undiagnosed cases (Mcgee, Pandey, Maskey, Frazer, & Mackinney, 2018).

The main feature of the Norwegian health care system is the prevalence of tax-enhanced public provision. A wide range of services is delivered by the Norwegian health care system not only in major urban areas but even in small areas besides socio-cultural and political factors therefore health service in Norway is traditionally in the hands of the public sector. Except for a few specialized private hospitals, health agencies, private doctors, or other health personnel work alongside the public system. After the 1969 Hospital act, Norway's 19 counties have assumed the planning and operating of the local hospital sector including general and psychiatric institutions and other medical services like laboratory, ambulance service, radiographic, and others (Van Den Noord, Hagen, & Iversen).

As already mentioned, the Norwegian health care system is publicly funded where the central government offers grants to the counties who, in turn, fund the bulk of the hospital sector, and



the municipalities fund the primary health care system. National Insurance Scheme (NIS) refunds all the expenses of individuals for childbirth, treatment of children, and treatment of industrial injury. The NIS is administered by the Ministry of health and social affairs which also manages the public pension system and other income transfer programs like sickness, disability, unemployment, and rehabilitation benefits (Van Den Noord et al.).

The average life span of Norwegians at birth is 74.2 years for men and 80.3 years for women levels among the highest in OECD countries and it is a growing trend. (Van Den Noord et al.) Overall CKD prevalence in Norway is 10.2% (Hallan et al., 2006) The number of patients undergoing dialysis in Norway has risen from 241 in 1990 and it was around 1240 in the year 2012 (Pike et al., 2013).

Nearly 84% of patients with kidney failure receive hemodialysis at hospitals, around 15 % of patients receive peritoneal dialysis at home and 11 patients (nearly 0.8%) receive hemodialysis at home by the end of 2012 (Pike et al., 2013).

The number of patients undergoing hemodialysis in Norway is nearly 18% which is few because of the availability of renal transplantation and the patient undergoing transplantation is nearly 82% (Fauchald et al., 1990). In Norway in 2017 a total of 274 kidney transplants were done which is equal to 51.9 per one million in the population. Sixteen percent were on re-transplantations (Leivestad, 2013). A total number of patients having CKD 424 died in 2017, among them 31 patients never started renal replacement therapy and 75 terminated the dialysis treatment, 109 were transplanted and 193 were on dialysis (Leivestad, 2013).

The burden of chronic kidney disease is increasing day by day in the world and the incidence is likely to be greater in developing countries due to poor socio-economic status, also the exact data are mostly not available. Expenditures are paid by the government in the developed world and only the small costs are paid by the patient self (Alebiosu & Ayodele, 2005). For instance, in the United State since 1972, the Medicare CKD program has carried approx. 80% of expenses of dialysis and transplantation for nearly 93% of patients. However, the case is different for most developing countries in that the patient self has to bear the costs of renal replacement therapy. That's why it's hard for most patients to continue with dialysis treatment. For example, in Nigeria approx. 70.8 % of the patient failed to keep up the dialysis for less than a month and only 1.9% stayed on dialysis for over 12 months (Alebiosu & Ayodele, 2005).



In the context of economic evaluation of Norway, haemodialysis at home was more effective and cost-effective contrasted with other haemodialysis modalities from both healthcare and societal perspectives. Peritoneal dialysis was the least expensive and thus, the most costeffective alternative in comparison to all haemodialysis modalities (Pike et al., 2013).

Like other countries, dialysis is expensive compared to the per capita income of Nepal and it is about US dollar 205 per month which becomes US dollar 2460 per year. Even though it sounds cheap relative to the western price but it becomes expensive in Nepal and around 45% of people stop their treatment because of the high price (Hirachan, Kharel, Shah, & Ball, 2010).

| | Nepal | Norway | | |
|---------------------------|---------------------------|--------------------------------|--|--|
| Average lifespan at birth | 58 | 74.2 Male | | |
| | | 80.3 Female | | |
| Prevalence of CKD/ESRD | 15.8% | 10.2% | | |
| Deaths due to CKD/ESRD | unknown | 424 (in 2017) | | |
| per year | | | | |
| Amount of kidney disease | unknown | 1240 (in 2012) | | |
| patients per year | | | | |
| The financial burden of | Prohibitively expensive. | National Insurance Scheme and | | |
| hemodialysis | One month costs 20,000 | the Norwegian healthcare | | |
| | Nepali rupees, and the | system support financially, se | | |
| | average earnings per year | treatment is free. | | |
| | of people are 26,000 | | | |
| | rupees. | | | |
| | 45% of patients stop | | | |
| | within one year. | | | |

Table 2 Compariosn of relevant CKD facts

3.5 Overall Quality of Life

Quality of life is the term generally applied to represent health status, physical functioning, symptoms, psychological adjustment, well-being, life satisfaction, or happiness. Confusion between the terms "quality of life" and "health-related quality of life" and variations in their



definitions can hamper making progress in research and interpreting the literature (Ferrans, 2005). As the objective of this assignment is to explore the quality of life of people undergoing hemodialysis and compare the quality of life of people of Norway and Nepal (those who have chronic kidney disease and are undertaking hemodialysis), I will briefly differentiate HRQOL as my focus is on overall QoL.

Health-Related Quality of life (HRQOL) focuses on health-related factors features of quality of life that produce an effect on physical or mental health. It is affected by both individuallevel and community-level factors. On an individual level, perception (energy level, mood) of physical and mental health is assessed, as well as their connection: comprising health hazards, social support, and financial condition. At the community level, HRQOL factors include community-level resources, conditions, strategies, and practices, that impact the health perceptions and functional status of people (Control & Prevention, 2005).

The overall quality of life (QOL) is not limited to health-related factors or QoL as related to physical or mental health. For the remainder of this thesis, I will use "QOL" to refer to the overall quality of life. QOL goes beyond health and ill-health as relevant factors and tries to measure aspects of culture, values, and traditions, social and environmental aspects of life, and their relations with quality of life. QOL evaluates an individual's happiness, a feeling of wellness, and life satisfaction, and at the community level, the capacities of an individual to take part in activities and impact decisions that might affect their quality of life (Singh & Dixit, 2010). In this understanding, disfunction, illness, injury, medical treatment, and health care policy are not exclusively measured as factors that impact QOL.

The WHO QOL Group has also developed a commonly used description concerning the quality of life as the "opinion of people pertains to their status in life in circumstances of the culture and value systems in which they are residing and in connection to their goals, expectations, standards, and concerns" (WHO, 1997). 'Quality of life is a wide-ranging concept which has an impact on the composite way by individuals' physical health, mental condition, the height of freedom, connection to the society, personal beliefs and association to the prominent aspects of their environment' (WHO, 1997.)



| WHOQOL Domains of | Facets incorporated within domains | |
|-------------------------|---|--|
| quality of life | | |
| 1. Physical health | Activities of daily living | |
| | Dependence on medicinal substances and medical aids | |
| | Energy and fatigue | |
| | Pain and discomfort | |
| | Sleep and rest | |
| | Mobility | |
| | Work capacity | |
| 2. Psychological | Bodily image and appearance | |
| | Negative feelings | |
| | Positive feelings | |
| | Self-esteem | |
| | Spirituality\Religion\Personal beliefs | |
| | Thinking, learning, memory, and concentration | |
| 3. Social relationships | Personal relationships | |
| | Social support | |
| | Sexual activity | |
| 4. Environment | Financial resources | |
| | Freedom, physical safety, and security | |
| | Health and social care: accessibility and quality | |
| | Home environment | |
| | Opportunities for acquiring new information and skills | |
| | Participation in and opportunities for recreation/leisure | |
| | Physical environment (pollution/noise/traffic/climate) | |
| | Transport | |

Table 3 WHOQOL domains and facets of quality of life

Source: (WHO, 1997

)



3.5.1 Measuring quality of life

Medical treatment has shifted from a focus on curing a patient to a focus on rehabilitation and management of chronic diseases. Quality of life has become a worthwhile research tool in evaluating the results of treatment interventions in chronic diseases and chronic kidney disease or ESRD is one of them (Sathvik, Parthasarathi, Narahari, & Gurudev, 2008).

QoL instruments can be classified as generic or disease-specific. Generic instruments are intended to measure the QoL of a non-specified group of people or patients. Results from generic instruments can be compared across groups. Disease-specific instruments emphasize a specific disease or population. They are usually more sensitive in determining a wide range of dysfunction, flexible, and help clinicians to deal with a certain disease. Instruments can be administered in a questionnaire, structured interview, or even a single item (Danquah, Wasserman, Meininger, & Bergstrom, 2010).

The WHO Group's definition of QOL and their QOL instruments are commonly used, such as 24-question WHOQOL-BREF and the longer version, the 100-question WHOQOL (Bonomi, Patrick, Bushnell, & Martin, 2000). The WHOQOL-BREF measures four domains of quality of life and its "facets", or items measured by each question. QOL is essential in evaluating people's health and it centers on the psychological and physical health and performance of individuals (Van Esch, Den Oudsten, & De Vries, 2011).

3.5.2 Factors related to the quality of life

The physical and psychological domains of people's QOL are negatively impacted by air pollutants, toxins, noise, and dirtiness. People's QOL is also reduced due to building environmental factors such as pollution-related diseases such as respiratory infections, asthma, and noise exposure in the long term can cause hearing impairment, hypertension, sleep disturbance, anxiety, and depression. Social-economic factors like income, education, and employment might affect the daily living and QOL of an individual (Wong, Yang, Yuen, Chang, & Wong, 2018).

At the same time, QOL can be positively impacted by features of the environment such as green space, clean environment, safe parks, and along with these health-related behaviors (participating in physical activities, walking in leisure time, refraining from smoking, following a healthy diet can reduce the stress level and are related with better quality of life in all the four domains (Wong et al., 2018).



There are also disease-specific factors of QOL. One important factor for ESRD patients may be dialysis. Time, frequency. dose and adequacy of dialysis are strongly associated with patients' outcomes. This could be said to higher the dose of dialysis and higher the survival rate and quality of life as well. Nephrologists are trying to treat the patient with kidney failure as sufficiently as possible to improve the survival rate and quality of life of the patient (Stankuvienė, Žiginskienė, Kuzminskis, & Bumblytė, 2010).

Some of the studies have noted that patients' quality of life has improved from pre-dialysis to dialysis. Even if the patient has a risk of comorbidity diseases such as infection, cardiovascular disease, and other symptoms, people experience a substantial improvement in overall quality of life from pre-dialysis to the dialysis period (Moore, Carter, Mitra, Skevington, & Wearden, 2020b).

Moreover, patients treated with haemodialysis experience changes in their daily life and the continuation of work, studies, and life plans. But some patients undergoing hemodialysis often experienced worse quality of sleep, pain, fatigue, vomiting, and reduced physical activities. To improve quality of life, patients' needs and expectations as well as other renal replacement therapy options might need to be considered (Dąbrowska-Bender, Dykowska, Żuk, Milewska, & Staniszewska, 2018).

3.5.3 The relationship of co-morbidities to quality of life

Co-morbidity is an important determinant of outcome in patients with ESRD and it includes medical conditions or illness but not complications of CKD (e.g., renal anemia). Yet in many cases, it remains unclear. For instance, Diabetes is commonly regarded as a co-morbid condition but mainly if Diabetes and CKD co-exist, diabetes (i.e., diabetes nephropathy) is the underlying condition of CKD. Chronic medical conditions (like depression, sleep disorder, etc.) are related to chronic kidney disease (Mucsi, Kovacs, Molnar, & Novak, 2008).

Patients with less severe impairment of kidney function and who are not on dialysis have high mortality compared to those who have maintained kidney function (Tonelli et al., 2015). In the United State at the time of the COVID-19 pandemic seven months period (February-August 2020), an estimated death rate was 6,953-10,316 and that was the excess deaths that occurred



among ESRD patients the reason for excess deaths among ESRD patients might include the unmet need for health service or due to pandemic. The estimated mortality rate among dialysis patients is two to three times higher than among kidney transplant patients (Ziemba et al., 2021).

4 Methodology

The purpose of this chapter is to describe and discuss the method and methodology that has been applied to this research.

4.1 Methodological approach: literature review

Epistemology: " epistemology is the theory of knowledge embedded in the theoretical perspective and thereby in the methodology" (Al-Ababneh, 2020). The first element in epistemology comprises three major types: objectivism, constructionism, and subjectivism (Al-Ababneh, 2020). and the second element is Theoretical perspectives (entails the main assumptions of selecting methodology) which comprises: positivism and post-positivism, interpretivism, etc. the third element is Methodology (a plan of action or strategy that shapes the research method) and comprises: survey, theory, analysis, etc. and the fourth one is Method and it's a technique that collects and analyses the data, and the data are collected as per the research questions and which comprises: questionnaire, observation, interview, etc. (Al-Ababneh, 2020).

The approach used in this assignment is positivist/post-positivist and this assignment. For example, I am assuming that quality of life is something that can be measured by a questionnaire. 'Positivist utilizes the scientific methods and their language to investigate and write about human experiences' (Habib). and it says to establish the truth and objective reality scientific method is only the way and a 'Post-positivist approach is based on the assumption that the method to be applied in a study should be selected based on the research question being addressed' (Habib).



I have decided to answer my research questions using a literature review. A literature review is defined as an analysis of articles, books, and other sources related to a specific problem, area of research, or theory, and thereafter providing a description, summary, and critical evaluation of this work and are they are enterprise to provide an outline of sources which have been discovered while studying a particular topic and to demonstrate to the readers how this research fits into the larger field of study (Ramdhani, Ramdhani, & Amin, 2014).

Literature reviews within health and medicine are a way to systematically collect the impact of a treatment, instead of relying on experts' opinions to decide on optimal treatments. One of my research questions is "How does hemodialysis affect the quality of life of patients with CKD?" there are some studies where we can find the answers given by a lot of experts that simply presented narratively in the studies what they thought and some of them have been listed quantitatively too. In contrast, it would be better to attempt systematic literature reviews to find scientific evidence that answers the research questions rather than rely on experts' opinions.

Literature reviews are important because it helps to find all the relevant evidence to answer the research question that has been formulated and it also helps to support identifying the relevant articles (Sajeevanie, 2021). If there are one or more research questions also Literature Review is the best methodological tool to give answers and it is to assess the state of knowledge on a specific topic. Literature Review is also used to build research plans, recognize research gaps, and discuss the issue associated with research (Snyder, 2019).

The main aim of the literature review is to help the readers to understand the whole assignment and understand the strengths and weaknesses of the assignment. The process of the literature review is done with carefully formulated steps and steps are a. Outlining the research topic and creating the research questions, b. Identifying appropriate study with inclusion and exclusion of articles and keywords used, c Extraction of data, and d Summarize and concluding the literature reviews (Ramdhani et al., 2014).

4.1.1 Research question 1:

To answer my first research question, I identified all studies that measured the QOL of patients at one point in time, using any questionnaire. I included all cross-sectional studies.



4.1.2 Research question 2:

To answer my second research question, I first attempted to find randomized controlled trials that compared hemodialysis with a control group, to estimate the impact of hemodialysis on the quality of life of people with CKD\ESRD. When this was not possible, I proceeded to other study designs. Below I describe the types of appropriate designs.

Randomized controlled trials of hemodialysis

When we want to conduct and do the interpretation of the research better knowledge of the study design is especially important. To measure the effect of hemodialysis (intervention) on quality of life (on an outcome) the gold standard is a randomized control trial. in medical research. Patients are randomly assigned to receive the treatment or the comparison, and the outcome of interest is measured before and after the treatment and comparison are received. In this way, any differences in the outcome between the two groups are assumed to be due to the effect of the treatment, as the groups should not differ in any other way.

However, randomized controlled trials are no longer conducted that compare patients undergoing hemodialysis versus patients without treatment, because untreated ESRD will lead to death. Blinding is also not possible for interventions such as surgery, dialysis, etc. Randomization, allocation concealment, etc. are some of the unique benefits of RCT however the studies are not realistic, and sometimes the studies cannot be performed in certain situations (Kumar, Khan, & Chatterjee, 2014).

Therefore, if RCTs are impractical and unethical like in this case the next appropriate study design can be a non-randomized design that compares patients receiving hemodialysis to patients receiving a control treatment. However, the same issue exists: no studies will not provide patients with no treatment for ESRD.

The next relevant study design is observational. The observational study includes crosssectional studies, case-control, prospective and retrospective cohort studies and the key characteristic of the observational study is that intervention was not planned for (it was not controlled) but defined through clinical practice, therefore the researcher is "observing" effects (Mariani & Pego-Fernandes, 2014).



Longitudinal studies following patients before and after hemodialysis

This section aims to compare the quality of life of patients before and after hemodialysis with my studies. Four of my studies (except Gyawali et al.,) were done to know the QoL of the patient at one point in time. A longitudinal study was done at ten Renal units in England by using questionnaires before and after dialysis (Moore, Carter, Mitra, Skevington, & Wearden, 2020a). and found out that the general quality of life of patients has improved from pre-dialysis to dialysis. The study has added that before starting dialysis patients have poor QOL and it has improved from moderate to good in all domains (physical, social, psychological, and environmental), especially in physical domains because of good quality of sleep (Moore et al., 2020a).

Even though the studies compare the hemodialysis patient before and after and the studies find out that the QOL improved after dialysis, we cannot accurately say that the changes are due to hemodialysis only because several factors affect QOL. Maybe the improved QOL is due to time, age, health insurance, financial support, quality care received from family members and health personnel, and sometimes due to the mode of dialysis (Zhou et al., 2017).

Cross-sectional studies

Another relevant study design is a cross-sectional study design, in which patients self-report changes in QOL during dialysis. However, self-reports of change cannot be certainly due to dialysis. Even if we ask patients undergoing hemodialysis to assess their changes in quality of life just for one point of time either using quantitative or qualitative methods, we cannot get the changes in QoL to a treatment for the reason that there are some weaknesses in both methods and one time is not enough to measure the perception of the patient, their feelings and some patient could disremember something.

4.1.3 Study identification

a. Outlining the research topic and creating the research questions

And this is of course the initial step, and before doing any research we define the research topic, aims, or objectives and formulate the research question. It is the guide for the whole assignment (Rhoades, September 2011). In my assignment, I have described it clearly in the introduction



chapter as well. The topic I have selected to do my research is 'what is the quality of life of people undergoing hemodialysis in Nepal and Norway' together with this I thought to collect information and see among Nepal and Norway. I also formulated two research questions to make my work easily complete. The two research questions are simultaneously RQ.1 'what is the quality of life of patient with CKD/ESRD?' And RQ.2 'what is the impact of hemodialysis on quality of life of people with CK/ESRD?'

b. Identifying appropriate study with inclusion and exclusion of articles and keywords used

I searched the following electronic databases: ORIA (Oslo met), Google Scholar, and PubMed, as well as the website ResearchGate. The websites of relevant organizations such as WHO, the National Kidney Foundation, and John Hopkins University were searched for articles and information. Reference lists of some articles were also checked out for related articles. My supervisor helped me to find the articles and some articles were provided by her. The main words used in the search of electronic databases were quality of life, chronic kidney disease, end-stage renal disease, hemodialysis, patient's perception, economic burden, and the healthcare system. The published data was generally not focused because it was not so easy to find the published data as needed. Articles were selected if they were able to describe the quality of life, chronic kidney disease, and impacts of hemodialysis.

My supervisor and I together assessed the articles I found for eligibility, that is, whether they met inclusion criteria. I also took additional help such as searching the articles, how to search in Oria, and keywords used in searching from librarians from Oslo Metropolitan University (Oslo met) specified in social science and health science, and their knowledge and experiences benefited me a lot in gathering the needed articles and journals. This also includes the inclusion and exclusion of articles; relevant articles are added and irrelevant are excluded. I have explained very clearly about inclusion, exclusion, and keywords used in section 5.1. (Rhoades, September 2011). I also read the references in these articles and "chased" citations to find additional publications from the same authors.

4.1.4 Data extraction

From each article, the following data were extracted: bibliographic information (author, year, country), research questions, study design, patient characteristics, quality of life instrument used, and mean or median quality of life scores (and standard deviation or interquartile range,



respectively). The data and statistics related to my assignments are taken from the studies provided by the authors as possible and available, and if the unavailable were narrated in words.

4.1.5 Synthesis

The final step of a literature review is to summarize the data and make a conclusion. It was not appropriate to combine results across studies in a meta-analysis, as studies were so heterogenous and many did not provide the necessary information (such as standard deviations) while others did not provide mean scores, which are necessary for meta-analyses. Instead of statistically summarizing results, I presented quality of life scores in a figure side-by-side, to help readers see similarities and differences across studies. This provided a narrative answer to RQ1. To answer RQ2, I would have meta-analyzed QOL scores after dialysis, but I identified no relevant studies to answer RQ2. Therefore, I instead narratively summarized any conclusions the authors drew about changes to QOL during hemodialysis.

5 Findings

5.1 Description of included studies

The table below describes the included studies with research questions and the studies added in these assignments with information on authors and their research's aims and which studies are giving answers to the research questions that I have formulated. I included studies that partially answered my research questions.

| Authors and country | Research questions I have | | |
|---|---------------------------------------|--|--|
| | formulated for my study | | |
| Gyawali (2013) Nepal | What is the quality of life of people | | |
| 'Study on the quality of life of chronic kidney disease | with CKD/ESRD? | | |
| stage 5 patients on hemodialysis' | What is the impact of hemodialysis | | |
| | on the Quality of life of people with | | |
| | CKD/ESRD? | | |
| | | | |
| Anu (2013) Nepal | What is the quality of life of people | | |
| 'Quality of life of patients undergoing hemodialysis at | with CKD/ESRD? | | |
| B.P Koirala institute of health science`' | | | |



| | What is the impact of hemodialysis |
|---|---------------------------------------|
| | on the Quality of life of people with |
| | CKD/ESRD? |
| | |
| Joshi (2017) Nepal | What is the quality of life of |
| 'Assessment of quality of life of patients undergoing | people with CKD/ESRD? |
| hemodialysis using WHOQOL BREF questionnaire: | What is the impact of hemodialysis |
| a multicentre study' | on the Quality of life of people with |
| | CKD/ESRD? |
| | |
| Vangen KG (2014) Norway | What is the impact of hemodialysis |
| 'A survey of physical activity in dialysis patients in | on the Quality of life of people with |
| Northern Norway' | CKD/ESRD? |
| | |
| Lægrid (2012) Norway | What is the impact of hemodialysis |
| 'Nutritional problems, overhydration and the | on the Quality of life of people with |
| association with quality of life in elderly dialysis | CKD/ESRD? |
| patient' | |
| Lægrid (2014) Norway | |
| 'The impact of nutritional status, physical function, | What is the impact of hemodialysis |
| comorbidity, and early versus late start in dialysis on | on the Quality of life of people with |
| quality of life in older dialysis patients | CKD/ESRD? |
| | |
| | <u> </u> |

Table 5 Description of included studies

Table below describes the authors and countries they did the studies with target groups that include the number of patients, gender, age, and disease stage, what type of study design, and quality of life measurement tools. There are altogether six studies (three are from Nepal and two are from Norway) and three measurement tools are used by the authors.



Table 5 Description of included studies

| Authors, | Target groups | Study | QoL |
|----------|--|-----------|-------------|
| country | | design | measurement |
| | | | Tools |
| Gyawali | 50 chronic kidney disease patients were on | cross- | SF-36 |
| 2013 | hemodialysis and among them, 32 were male | sectional | |
| Nepal | (64%) and 18 were female (36%) with a mean | | |
| | and median age of patients of 47.14 \pm 16.65 | | |
| | and 48.50 years, respectively. | | |
| | | | |
| Anu | The sample comprises 50 patients among them | cross- | SF-36 |
| (2013) | 36 were male and 14 were female and most of | sectional | |
| Nepal | them were above 40 years. | | |
| Joshi | A total of 142 patients were there and among | Cross- | WHOQOL- |
| (2017) | them ninety-one were male and fifty-one were | sectional | BREF |
| Nepal | female. Data were collected for 5 months | | |
| | duration in two major centers in Kathmandu. | | |
| Lægrid | Patients over 75 years were asked to participate | Cross- | SF-36 |
| (2012) | by January 2008 at 3 dialysis units. | sectional | |
| Norway | | study | |
| Lægrid | Older dialysis patients over 75 years of age | Cross- | SF-36 |
| (2014) | who were receiving dialysis from January 2009 | sectional | |
| Norway | and alive till September 2009 were included. | study | |
| | Total patients were 320 and among them, 233 | | |
| | (73%) were ready for participation, 67% were | | |
| | men and 33% were women. | | |
| Vangen | 30 patients on chronic dialysis participated in | Cross- | KDQOL- |
| (2014) | the study among them 22 were on HD. | sectional | SF1.3 |
| Norway | | study | |



5.2 Research question 1: What is the quality of life of people having CKD\ESRD?

Before summarizing QoL scores across studies, it is necessary to first explore the different instruments used.

5.2.1 QoL measurement tools in use to compare the studies have to use the same tools.

In this thesis, three different quality of life measurement tools are used, and they are SF-36, KDQOL SFTM 1.3, and WHOQOL-BREF. Instruments to measure QOL are divided into two types: Generic and disease-specific which may be in the form of a single question or a questionnaire format.

Generic instruments incorporate single indicators (in the form of a single question like 'how is the quality of life'), health profiles (often used measures in the assessment of QOL), and patient preferences (patient choice for treatment and outcomes). The medical outcomes study short form (SF-36) used in this thesis is a widely used generic instrument in patients with end-stage renal failure. And another study of generic instrument used in this study is WHOQOL-BREF. The world health organization quality of life-Bref is comprised of a 26-item questionnaire with four domains (physical, psychological, social, and environmental) and overall QOL with general health scores (Danquah et al., 2010).

The third instrument used in this study is the Kidney Disease Quality of Life Short Form (KDQOL-SF) which is a disease-specific instrument that focuses on a specific disease or population. These are more appropriate in determining impairment, and more flexible and helpful for physicians or health personnel working with a specific disease (Danquah et al., 2010).

Domain scores in all the instruments range from 0 to100 where a higher score signifies a better quality of life, and a lower score signifies the worst quality of life.

This table (table no. 6) is articulated to compare the measurement tools of quality of life that are included in my studies. There are three tools used overall in five studies. And it is also mentioned that available scores in each measurement tool like physical, mental, social, environmental, and overall health and all the associated domains are mentioned.



| | QoL measurement tools in the included studies | | | |
|--------------------------------|---|--------------------|-----------------|--|
| Scores available in each | SF-36 | WHOQOL-BREF | KDQOL SF TM 1.3 | |
| measurement tool | | | | |
| Overall Quality of Life | No | Overall Quality of | | |
| | | Life | | |
| Overall health | General health | Overall health | | |
| | Perceptions | | | |
| Physical domain | Physical component | Physical domains | Physical | |
| | summary | | functioning | |
| | PCS: | | Physical role - | |
| | Physical | | functioning | |
| | functioning | | Energy\fatigue | |
| | Role – functioning | | | |
| | physical, | | | |
| | Vitality, | | | |
| | Pain | | | |
| Mental domain | Mental component | Psychological | Emotional well- | |
| | summary MCS: | domains | being, | |
| | Role-functioning | | Emotional role- | |
| | emotional, | | functioning | |
| | Mental health | | | |
| Social domain | Social functioning | Social- | | |
| | | relationships | | |
| | | domains | | |
| Environment domain | | Environment | | |
| | | domains | | |

Table 6 Comparison of the QoL measurement tools identified in included studies

5.2.1.1 SF 36- Medical Outcome Study Short Form

SF-36, the Medical Outcome Study Short-form Health Survey (also abbreviated as MOS SF-36), is a generic, self-administered questionnaire, but is well recorded and certified in nearly



all ages of CKD patients. The questionnaire comprises 36 items, which are evaluated into 8 scales, and 8 scales are condensed into 2 combined scales: physical composite summary (PCS) and which consists of physical functioning, role-functioning physical, role-functioning emotional, general health perception, and mental composite summary (MCS) consists of social functioning, vitality, bodily pain, and mental health (Danquah et al., 2010). All the domains were ranges from 0 to 100 where higher scores indicate better QOL and 0 indicates worst QOL (Danquah et al., 2010).

5.2.1.2 WHOQOL-BREF- World Health Organization Quality of Life-BREF

The world health organization quality of life (WHOQOL-BREF) questionnaire is comprised of 26 items, among them, items 1 and 2 evaluate individuals' overall understanding of QOL and health and the remaining elements are classified under physical, psychological, social, and environmental domains (WHO, 1997

). A 5-point Likert scale is used to rate every item. Responses are rated in a positive direction. Raw scores can be transformed to a 0-100 scale utilizing a transformation formula, in which a higher value signifies better QOL (WHO, 1997

).

5.2.1.3 KDQOL SF TM 1.3- Kidney Disease Quality of Life Short Form

This is the self-reporting method to evaluate the specific concern of individuals with kidney disease and dialysis. The questionnaire has been interpreted from the Norwegian version and has thirty-three questions that are associated with kidney disease, level of work, sleeping pattern, cognitive and sexual function, social support, help, support from dialysis staff, and patient satisfaction. "The KDQOL SF- questionnaires range from 0-100, with higher scores reflecting better QOL in the following areas: physical functioning, role limitations due to physical functioning, physical health problems, role limitation due to emotional health problems, emotional well-being, and energy\fatigue" (Hays et al., 1997).

5.2.2 Quality of life scores across studies



Below is the error bar which shows quality of life of scores across included studies is shown where people undergoing hemodialysis measured on 0 to 100 sales. In the measurement of 0 to 100 scales 0 represents the worst quality of life and 100 represents the best quality of life. The figure displays results from three studies. The bar heights represent the mean or median value of each study's QOL domain. The black error bars show the distribution of scores, per study. And two studies are not shown because data provided from the studies were not valid or numerical values were not normally distributed.

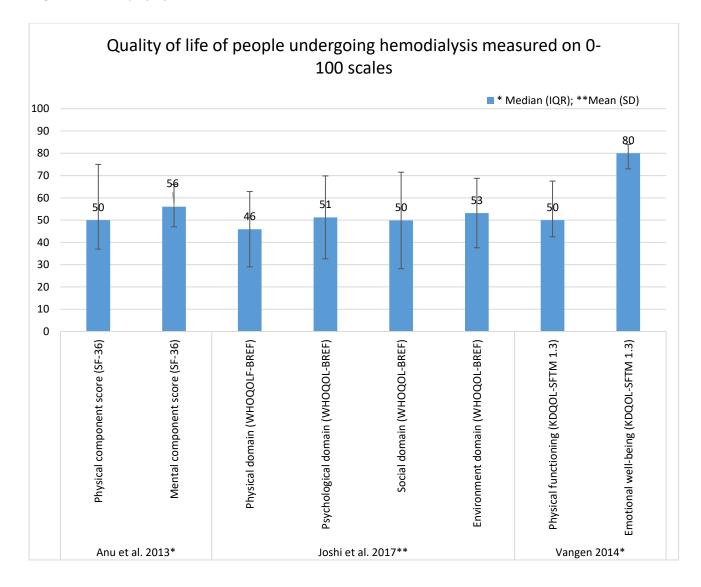


Figure 2 Quality of life score across the included studies



In the studies where the mean value is shown (Joshi et al.,) the error bars show the 95% of confidence interval or the range of scores in which the mean value would be measured in 95 of 100 random samples taken from the larger population. In this study (Joshi et al.,). the scores obtained in the four domains of WHOQOL BREF are physical domain 45.93 \pm 16.90, psychological domain 51.23 \pm 18.61, social domain 49.86 \pm 21.64, and the environmental domain 53.17 \pm 15.59 (data are shown in mean SD).

For the studies where the median value is shown, the error bars displayed the interquartile range or the range representing 50% of the observations. Both Anu et al. and Vangen KGl. report medians. In Anu, the physical component score (PCS-SF 36) median value is 50 (IQR 37-75). The value of the Mental Component Score (MCS -SF 36) the median value is 56 and the value of the interquartile range is from 46.5 to 65.5. And the study (Vangen et al.). the score obtained in physical functioning and emotional wellbeing of KDQOL SF 1.3 are 50 and 80 respectively and the data are shown in the median (IQR) range (Vangen, 2019).

The results from two studies – Lægrid (2012) and Lægrid (2014) – are not shown in the figure above. In both studies, the authors reported the means and standard deviations of each subcomponent of the SF-36. However, many scores were not normally distributed, and the reported scores did not make sense (such as a standard deviation larger than the mean), so they have not been added to the figure. These results are presented in tabular form.

| SF-36 domain scores | Lægrid 2012 | Lægrid 2014 |
|----------------------------|-------------|-------------|
| | Mean (SD) | Mean (SD) |
| Physical Functioning | 38 (26) | 40.9 (27.4) |
| Role functioning physical | 31 (42) | 17.9 (32.8) |
| Bodily pain | 52 (30) | 57.3 (30.2) |
| General health | 51 (22) | 45.7 (23.3) |
| Vitality | 34 (21) | 39.3 (22.2) |
| Social Function | 62 (26) | 63.0 (29.2) |
| Role functioning emotional | 62 (44) | 42.7 (43.7) |
| Mental health | 71 (21) | 73.6 (20.2) |

Table 7 SF-36 domain scores of two studies Lægrid (2012 and 2014)



The difference found by the authors were clinically significant in five scales out of eight scales (BP, GH, SF, RE, MH) but none of them were statistically significant (Lægreid, Bye, Aasarød, & Jordhøy, 2012). However, it is not clear that the appropriate statistical tests were significant, as some scales were non-normally distributed. This author compared the SF-36 scores between patients, with their physical capacity in the subjective global assessment (SGA) questionnaire and found statistically significant, the greater score for SF-36 relates to physical capacity except for role function emotional. Due to the unequal distribution of scores, the results were not reported by the authors (Lægreid, Aasarød, Bye, Leivestad, & Jordhøy, 2014).

The results from the study by Gyawali (2013) are not presented in the graph above. As this study has not given data about the quality of life at one point in time but it has done the study at the beginning and end of two months period.

As per my research question, one quality of life is an important tool in the case of people having chronic kidney disease and people undergoing hemodialysis. Even if all the studies reported that scores range from 0 to 100 scales, it is not reasonable to statistically combine the scores because studies have reported both mean and median values where mean values are not normally distributed. The mean score of physical domains is 46, the psychological domain is 51, the social domain is 50, and the environmental domain is 53 from a study done by Joshi et al. The median score from Anu et al in PCS is 50 and MCS is 56 and the third one is Vangen KG where a median of physical functioning is 50 and mental wellbeing is 80. And all the scores range around 46 to 56 on a scale of 0 to 100 where a higher score indicates better quality of life and a lower one indicated the worst quality of life. There is one exception that emotional wellbeing from the study Vangen KG score is 80. It is difficult to identify the patterns of domains specific scores (as there is no certain domain that has particularly higher or lower scores than others). Because of the difference in the scores, the results cannot be generalized, and we cannot answer if the quality of life of hemodialysis patients is worst or better in any particular domain.



5.3 Research question 2: What is the impact of hemodialysis on the quality of life of people with CKD\ESRD?

According to my second question 'what the impact is of hemodialysis on the quality of life of people with CKD\ESRD or change over time. And in this research question, there is no randomized trial or other controlled trials, therefore I summarized with the answers that none of the studies have reported the impact of hemodialysis on quality of life or there is no relationship between quality of life and length of treatment with hemodialysis. or in other words, I can explain like

all the studies examined the duration of hemodialysis with quality of life domains. No study reported that higher or lower quality of life scores was associated with a shorter or longer period of hemodialysis. There did not appear to be any improvement in quality of life for patients undergoing hemodialysis longer.

| Authors | Hemodialysis and association with quality of life | | |
|---------------|--|--|--|
| Anu (2013) | In the physical component summary and mental component summary, the length | | |
| | time on hemodialysis is not associated with quality of life | | |
| Joshi (2017) | In physical, psychological, social, and environmental domains, length of time of | | |
| | hemodialysis is not associated (at one point in time) with quality of life, divided into | | |
| | "3 months – 1 year", "1-5 years", or "5+ years". And the impact of hemodialysis or | | |
| | the quality of life of a patient with CKD is not associated with time measured in "3 | | |
| | months – 1 year", "1-5 years", or "5+ years". | | |
| | | | |
| Vangen (2014) | In all the domains Physical functioning, physical component summary, Role | | |
| | functioning physical, role functioning emotional, general health perceptions, mental | | |
| | component summary, social functioning, vitality, pain, and mental health, length of | | |
| | time on hemodialysis is not associated. | | |
| Lægrid (2012) | There is no significant associations between quality of life and hemodialysis over | | |
| | time, but the exact date has not been reported by the author. | | |
| Lægrid (2014) | In all the domains of physical functioning, physical component summary, Role | | |
| | functioning physical, role functioning emotional, general health perceptions, mental | | |

Table 8 Hemodialysis and association with quality of life



| | component summary, social functioning, vitality, pain, and mental health there is r | |
|----------------|--|--|
| | association between early versus the late start of hemodialysis. | |
| Gyawali (2013) | The authors report that there are "some noticeable changes seen in the quality of life | |
| | but do not report the relationship between the beginning and end of two months of | |
| | dialysis with quality of life in all the domains because there is a lack of data. | |

Anu (2013)

This study was done by measurement tool SF36 domains and dimension by Anu (2013) Nepal: Median (IQR), and the study result showed that in the Physical component summary duration of hemodialysis is not associated (at one point in time) and in the Mental Component Summary duration of hemodialysis is not associated (at one point of time). And the other dimensions are respectively Physical functioning, Role functioning physical, role functioning emotional, general health perceptions, mental component summary, social functioning, vitality, pain, and mental health (Anu, Pushpa, & Kumar, 2013).

Joshi (2017)

A study was done to find out the effect of hemodialysis over time using the World Health Organization Quality of Life (WHOQOL-BREF). Chronic kidney disease has an impact on the quality-of-life patient and the effects are perceived predominantly in the physical, psychological, social, and environmental domains.

None of the domains or overall domains (physical, psychological, social, and environmental) were associated with the length of hemodialysis measured in 3 months -1 year, 1-5 years, or 5+ years, and likewise, the duration of chronic kidney disease is not associated with the time which was measured 3 months -1 year, 1-5 years, or 5+ years in all the domains.

The table shows the mean score, the standard deviation of WHOQOL-BREF domains from Joshi 2017.

Table 9 Mean score and standard deviation of WHOQOL-BREF From Joshi (2017)

| Duration of | Physical | Psychological | Social domain | Environmental |
|--------------|----------|---------------|---------------|---------------|
| hemodialysis | domain | domain | | domain |
| Joshi (2017) | | | | |



| 3 months-1 | 46.6±14.7 | 53.4±15.5 | 51.9±19.0 | 50.1±15.1 |
|-----------------|-----------|-----------|-----------|-----------|
| year | | | | |
| 1-5 years | 45.5±18.0 | 49.7±19.3 | 52.7±21.5 | 53.9±16.1 |
| ≥5 years | 46.3±17.1 | 52.8±20.9 | 38.8±23.2 | 55.4±14.5 |
| <i>p</i> -value | 0.938 | 0.540 | 0.022 | 0.337 |
| comparing | | | | |
| scores across | | | | |
| duration | | | | |

Vangen (2014)

KDQOL-SFTM1.3 (0-100) method is used by the author to find out the results in all the domains and is simultaneous. In the context of Physical functioning, it is not associated with hemodialysis over time. There is no association between emotional well-being, emotional role functioning, and energy/fatigue level with hemodialysis over time (Vangen, 2019).

Lægrid (2012): Results were imprecisely reported. The authors report that physical functioning, physical component summary, Role functioning physical, role functioning emotional, general health perceptions, mental component summary, social functioning, vitality, pain, and mental health, had no significant associations with quality of life within hemodialysis, over time, but the exact date has not been reported by the author (Lægreid et al., 2012).

Lægrid (2014): From the study (linear regression analysis and scatter plots) done by the author there is no significant association between QOL scores and early versus late start in dialysis. And the results in the domains like Physical functioning, Role functioning physical, role functioning emotional, general health perceptions, physical component summary, mental component summary, social functioning, vitality, pain, and mental health is not reported by the author (Lægreid et al., 2014).

Gyawali (2013)

This study is done by the authors by using SF-36 in Nepal with around 50 patients undergoing hemodialysis. According to the authors, there are enhancements in almost all aspects of general



functioning and mental well-being and a diminished quality of life in the case of physical functioning and it is noted that decline in physical function, role limitation in physical and mental condition, and overall health. Still, the results cannot generalizable (according to the authors) (Gyawali, Paudel, Chhetri, Shankar, & Yadav, 2013). However, the authors provided no data or numbers, therefore we can't confirm these changes.

6 Discussion

In this thesis, I have conducted a literature review to synthesize the quality of life of people who have chronic kidney disease, kidney failure, or end-stage renal disease in Nepal and Norway. The first research question was 'what is the quality of life of people with CKD\ESRD?' and the second research question was 'What is the impact of hemodialysis on the quality of life of people with CKD\ESRD?' I have gone through all the related articles and collected six articles from Norway and Nepal. I compared overall and domain scores of quality of life across studies to answer research question 1, and I compared studies' analyses of the length of time on hemodialysis with quality of life to answer research question 2.

6.1 Research Question 1: What is the quality of life of people with CKD\ESRD?

All the studies I have gone through for my thesis and all the studies reported that scores range from 0 to 100 scales, but it is not reasonable to statistically combine the scores because studies have reported both mean and median values where mean values are not normally distributed. It is difficult to identify the patterns of domains specific scores (as there is no certain domain that has higher \lower scores than others). Except for one emotional well-being from Vangen. Because of the difference in the scores, the results cannot be generalized, and we cannot say if the quality of life of hemodialysis patients is better or worst in a particular domain.

I also have gathered six studies from Nepal and Norway to know the quality of life of hemodialysis patients and impacts of hemodialysis on quality of life and if there is any difference between Nepalese patients and Norwegian patients, but I did not perceive any difference in the results but I had expected I could find some difference. It might be because I have done literature reviews with very few studies, and I did not get answers as expected. So,



I cannot say if the quality of life of Norwegian patients is better than Nepalese patients and vice-versa.

If I had chosen a different method, such as interviews with patients, maybe I would have got the exact results that were expected. If a patient is inactive or has any coexisting disease like diabetes mellitus or any other severe conditions patients might not be able to cooperate. Older and too younger patients might not show interest and reject the proposal of study (Lægreid et al., 2012). Chronic kidney disease is related to the health-related quality of life, its effect on HRQOL and glomerular filtration so might be other methods are useful (Gyawali et al., 2013). To get a good result it's very important to take sample sizes that are large enough or the research should be conducted in the whole country, and it is not even possible to take an interview with all the patients. In my view there are a few other problems with interviewing in Nepal is impossible. For example, searching for the patient in different hospitals overall Nepal is tough and taking interviews. In Norway, language becomes the first barrier to conducting an interview. So, I preferred to review the literature so that I can find the answers to my question.

6.2 Research Question 2: What is the impact of hemodialysis on the quality of life of people with CKD/ESRD?

Related to the second research question, no randomized trial or other controlled trial has been used. Therefore, the answer to the question can be summarized as that none of the studies have reported impacts or causes of hemodialysis on quality of life. In other words, I can report that we do not know the actual effect of hemodialysis on quality of life. Overall, there appears to be no relationship between hemodialysis and quality of life, because no study reported that length of hemodialysis is linked with high or low quality of life. (However, an exact conclusion cannot be drawn from my analysis, so I cannot be sure that hemodialysis does or does not improve quality of life.)

This is surprising that more time on hemodialysis was not associated with a higher quality of life, as hemodialysis and other chronic disease treatments are supposed to improve quality of life. Some studies have noted there are changes in quality of life, but we cannot be sure if the changes are because of hemodialysis or other factors. Other factors may be responsible for changing the quality of life for patients. So, I have gone through the studies done by H Barzegar et al., in Iran, we found there is no relationship between quality of life and duration of



hemodialysis but the poor quality of life can be associated with old age (Barzegar, Jafari, Charati, & Esmaeili, 2017). And another study done by K Gerasimoula et al. reported that sociodemographic and clinical variables are related to the quality of life of hemodialysis patients (Gerasimoula et al., 2015). From the studies, we can conclude that quality of life can be associated with other factors than the length of hemodialyses such as age, gender, education, and clinical factors such as associated disease conditions.

To make the quality of life better for people having chronic kidney disease other alternatives to the treatment can be applied. Other alternatives like peritoneal dialysis and renal transplantation might improve quality of life. Being a health care professional and with experience working in a dialysis department, I can recommend changing the treatment modalities. If possible, transplantation is always a better option and long-term treatment option because once transplantation is done dialysis is not needed. Another treatment is peritoneal dialysis and home hemodialysis can improve quality of life and medications and supplements can be helpful.

Regarding low- and middle-income countries, I can simply note the quality of life might be affected by hemodialysis or other factors. Hemodialysis is an unaffordable treatment for the most patient in the context of Nepal. Many patients cannot continue the treatment or take the alternatives and it might affect their quality of life. There can be other associated factors as well while patients were receiving hemodialysis both in Nepal and Norway such as age, gender, education, and other comorbid disease condition. There seem to be no differences between the impacts of hemodialysis on the quality of life of patients having chronic kidney disease as the length of hemodialysis does not have any relationship with the quality of life in both the countries.

The results of this study can also be compared with other studies done in Ghana by Tannor et al. The results reported that the overall mental component summary is lower than the physical component summary and this may be due to the burden of disease. So, a focus on mental health is necessary to improve quality of life (Tannor et al., 2019). Another study from Brazil (Cruz et al., 2011) reported mean value and SD where the scores of the physical and mental component summaries were in middle values between 40 to 50 where scales range from 0 to 100 in which 0 is worse and 100 is a better quality of life. The result of this study indicates there appear to be no differences among patients regarding physical component summary and



mental component summary with the patient undergoing hemodialysis but patients having CKD stages 1 and 2 have lower emotional role functioning and general health, in stage 3 physical role functioning and vitality and stage 4 and 5 and hemodialysis physical role functioning and general health (Cruz et al., 2011).

The results of this study is also comparable with the the studies conducted in other countries such as Ghana and in those study they mentioned that patient's emotional health also should be focused to improve QoL but when compared with Brazilian patients there is no difference found in the results.

A comparison has been done with the general Norwegian and Nepalese populations' quality of life. According to the Norwegian population's quality of life, the results noted that the mean value of quality of life was 84.1 (SD 12.5). Women, people with higher education, married people, or cohabiting reported a higher quality of life whereas unemployed people, people having disease or health problems reported lower quality of life (Wahl, Rustøen, Hanestad, Lerdal, & Moum, 2004). The study done in Nepal with WHOQOL-8 question scale which is a short and practical scale where each item of the scale is rated on 5 point scale and score from 1 is worst and 5 is best and the sum range from 5 to 40 scale and according to Nepalese aging people from rural and urban areas with quality of life and the mean value was 25.7 (SD 4.2) where 49.2% reported good quality of life. People living in urban areas, employed people, people without other physical health problems, and adequate time spent with family reported good quality of life whereas geriatric patients with depression reported poor quality of life (Risal et al., 2020).

Recently there are almost thousands of instruments to measure the quality of life, generic and disease-specific. Generic can be measured in the general population, and it can be enforced to several conditions as well as disease-specific is enforced for particular diseases like chronic kidney disease. But the impacts of hemodialysis and quality of life are different in different people, experiences can be varied due to culture, norms, country and family, and social relationships so the ideal way to measure the effect of hemodialysis on quality of life is should be done carefully (Theofilou, 2013).

The vast majority of the instruments use self-administered questionnaires, as well as some use an interview format. Usually, the perfect way to measure the quality of life does not exist, therefore researchers use different measures and some of the research uses both generic and



disease-specific methods to get a good result on the quality of life of patients. But other researchers disagreed that using both tools might create a problem for the patients and results might get affected. However, some research agreed that a combination of both tools (generic and disease-specific) on one hand helps in comparison of the results and on other hand will identify susceptibility to changes in disease progress or treatment response (Danquah et al., 2010). So, both measurement tools can be used to do the research and compare the result.

6.3 Reference to the literature review

Reference is an indication of where the information or work is taken. There are several ways for writing references like APA style, MLA style, etc. Good referencing is important to get rid of plagiarism (cheating) and that should include detail such as page number, author's name, chapter, URL, language, and other details if possible. Copying or abusing other ideas, words, or concepts is prohibited. (Santini, 2018)

In this assignment, I have gone through the articles with some keywords used in searching the articles quality of life, chronic kidney disease, hemodialysis, and effect of hemodialysis. I have done the proper citations/references as possible and use APA 6^{th} style and references are properly mentioned below in the bibliography section.

6.4 Implications of academic study

Here I will highlight the importance of my thesis on clinical policies and practices and further research. And I will discuss how hemodialysis changes the quality of life of people and further what can be done to improve the QOL of the patient. Some of the implications are:

Implications 1: Effective and quality treatment is needed to improve the quality of life

This is true that good health treatment is important to improve quality of life. Not only this family support, social interaction, care, and support from health personnel and advice help to improve health conditions and the quality of life. When I went through the articles I found out that many people are not able to afford the hemodialyis and many of them discontinue the treat



because of high cost. So, in my opinion Government should support or provide quality treatment as possible in Nepal.

Implications 2: Valid measurement tools are required to adequately measure the quality of life

An effective measurement tool is needed to find out exactly the perception of the patient towards their health, healthcare invention, and quality of life. But sometimes it becomes tough because patient won't cooperate or gives wrong answers and for those who won't respond it becomes difficult to generalize the results. Therefore, measurement tools according to the patients, socio-cultural background, educational level, and health condition should be applied to get effective results.

Implications 3: Education and awareness

Low- and middle-income countries like Nepal need more awareness and education regarding chronic kidney disease, regular health checkups, and early treatment of the disease. People won't go to hospitals for minor signs and symptoms which creates bigger issues in the future. Education regarding kidney diseases is most important not only in low- and middle-income countries but also in high-income countries which aids in reducing morbidity and mortality.

6.5 Limitations of the theory or method of research

This thesis has aim to find out the quality of life of people undergoing hemodialysis in Nepal and Norway with the formulation of two research questions. The first research question was 'What is the quality of life of people with CKD/ESRD?' And the second question was 'What is the impact of hemodialysis on the Quality of life of people with CKD/ESRD?' Although this study has managed to obtain all the purposes/goals some limitations to the study were displayed when writing this thesis.

I may not have identified every single published study that could have been relevant. One of the limitations was restricted keywords. Of course, it is helpful if there are more keywords in searching and selecting the articles. But there were very few keywords, and it was tough to get the exact data and articles as wanted. Searching articles were very tough in the context of Nepal. Published articles were not available online and available articles were not able to give the correct information. Some articles were found in the Norwegian language and it was difficult to translate the whole article and therefore there was limited access. Nevertheless, it was



challenging to work on the topic with less evidence and supportive knowledge, but intense support from my supervisor and my interest motivated me to work ahead.

Similarly, another limitation was this study focused mainly on hemodialysis and therefore did not consider the effect of peritoneal dialysis and transplantation. Articles were more available with peritoneal dialysis and transplantation.

I did not conduct interviews for this assignment as it was not possible to conduct in Norway due to the language barrier and impossibilities in Nepal. If I had conducted interviews maybe I could have gotten in-depth and clear information that could help me with the analysis. Interviews would have required qualitative analysis rather than coming means and medians on questionnaire scores.

Many articles were excluded because they did not give enough information on the quality of life and hemodialysis and focused more on other treatment modalities. Also, sufficient supportive and relevant articles were not found due to the narrow focus.

In this study, I was not able to quantitatively combine results from all the studies because all the studies have not provided valid data, all were not in the same domains and there were no certain domains which have a higher or lower score which creates problem in finding answers to the research question 1 and because of no use of randomized control trial I was not able to access if there are any changes in quality of life due to dialysis or other reasons are associated for the change and answer the research question 2.

Furthermore, While going through the study I found it difficult to conclude as some authors have not provided the data and some authors have given unclear data. For example, some authors did not report numbers, while others may have used incorrect statistical tests. These types of limitations made the analysis difficult. Which makes me difficult to find a conclusion and read the results. This is a limitation of the literature review as a method – I am dependent upon high-quality studies to conclude.

6.6 Recommendations for future research

Referring to the limitations mentioned above and giving some suggestions to fix the limitations some of the suggestions and recommendations in this section are noted down. For example, the above discussion has disclosed the unavailability of valid data from Nepal and not from



Norway as well which makes it difficult to conclude. Constructing valid data and information in this area is vital which helps in future research.

This assignment is done by reviewing the articles related to kidney disease, treatment, quality of life, and hemodialysis. This study focused on the quality of life of people with chronic disease and the impact of hemodialysis on quality of life but did not focus on other treatments such as peritoneal dialysis and kidney transplantation. Similarly, this study was limited to the quality of life with limited studies. Therefore, it is recommended for future research that to find out the information on the research questions, the topic should be broadened, more possible methods should be applied, and more studies should be taken if possible.

6.7 Conclusion

Chronic kidney disease is emerging rapidly in the world, and it has become one of the leading causes of mortality. In this literature review, I formulated research questions and went through relevant articles from both Nepal and Norway on patients' quality of life. Quality of life has become a worthwhile research tool in evaluating the results of treatment interventions in chronic diseases. Before jumping to the conclusion let me remind the research questions that I have formulated to do this assignment. The primary research question is 'What is the quality of life of people with CKD/ESRD?' and the secondary research question is 'What is the impact of hemodialysis on the Quality of life of people with CKD/ESRD?'

To answer the first result question gathered studies got a score around 46 to 56 except for one and that is emotional well-being and scales range from 0 to 100 where 0 is the worst quality of life and 100 is the best. None of the studies reported a score of 0 or 100 to consider the exact result. Because of the difference in the scores, the results cannot be generalized, and we do not know if the quality of life of hemodialysis patients is worst or better in any particular domain.

To know the impact of hemodialysis on the quality of life of people with CKD or ESRD in the gathered studies there is no randomized trial or other controlled trials, therefore I finalized with the answer that no studies have reported impacts of hemodialysis on the quality of life or there is no relationship between quality of life and hemodialysis. And none of the studies reported that higher or lower quality of life is associated with the length of hemodialysis done.



When the comparison was done with other studies, we perceived that quality of life can be associated with other factors than the length of hemodialyses such as age, gender, education, and clinical factors such as associated disease conditions. And I did not find any surprising results when I compare the studies from Nepal and Norway. But when comparing the findings with the general population in Norway and Nepal I found that Women, people with higher education, married people, or cohabiting reported a higher quality of life but unemployed people, geriatric patients, and any disease or health problems have a lower quality of life.

In ending, I hope this thesis will help future researchers who are interested in a patient who has kidney disease and how the quality of life is affected by hemodialysis, guide them in collecting information and they will know how the condition of Nepal is and how it is in Norway.

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