



**“YOU ARE ALLOWED TO BE
AFRAID!”**

Experiences from the Courses Arranged by
Finnish Diabetes Association

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Bachelor's thesis
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Nursing Programme
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TIIVISTELMÄ

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Degree Programme in Nursing
Medical - Surgical

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”Saa pelätä!”

Kokemuksia Suomen Diabetesliiton järjestämältä kurssilta

Bachelor's Thesis 57 sivua, joista liitteitä 10 sivua

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Diabeettinen nefropatia on vakava, etenevä sairaus. Etenemisprosessia voidaan hidastaa noudattamalla ravintoainerajoituksia, nesterajoitusta ja lääkehoitoa, sekä ylläpitämällä terveitä elämäntapoja. Potilaalle voi olla järkytys saada tietää sairastavansa munuaisten vajaatoimintaa – ei ole helppoa ymmärtää ja sisäistää sairauteen liittyviä rajoituksia ja hoito-ohjeita. Voidakseen oppia sairautensa hoitoa ja toteuttaa mahdollisia elämäntapamuutostarpeita potilas tarvitsee neuvontaa, toistuvaa ohjausta, asioiden perustelemista ja tukea. Siinä vaiheessa kun munuaissairaus etenee viimeiseen vaiheeseen, potilas tarvitsee dialyysihoitoa tai munuaissiirteen. Sairaudella, ja sen koko loppuelämän ajan kestäväällä hoidolla on mullistava vaikutus potilaan elämään.

Suomen Diabetesliitto järjestää Tampereella sijaitsevassa Diabeteskeskuksessa kursseja, joiden tarkoituksena on vastata diabeetikoiden tarpeisiin. Kurseja suunnitellaan näkövammaisille, mielenterveyskuntoutujille, maahanmuuttajille, kehitysvammaisille ja munuaissairaille diabeetikoille, sekä terveydenhuollon ammattilaisille. Tässä opinnäytetyössä keskitytään munuaisten vajaatoimintaa sairastaviin diabeetikoihin ja heidän kokemukseensa kurssilta, joka on räätälöity juuri heidän tarpeitaan ajatellen.

Tämän opinnäytetyön tarkoituksena oli selvittää diabeettista nefropatiaa sairastavien diabeetikoiden kokemuksia kurssista. Tietoa kerättiin haastattelemalla kurssilaisia. Haastattelutulokset osoittavat osallistujien olevan hyvin tyytyväisiä kurssin antimiin. He kaikki oppivat uusia taitoja, alkoivat paremmin ymmärtää sairauttaan ja sen hoitoa, hyötyivät vertaistuesta ja motivoituivat hoitamaan itseään paremmin. Kurssin merkittävyys ja tarpeellisuus tuli todistettua ilman epäilystä. Diabeetikoiden elämänlaatu voi merkittävästi kohentua Diabetesliiton järjestämien kurssien tarjoaman tuen ja koulutuksen kautta.

Asiasanat: diabetes, diabetic nephropathy, education, support, finnish diabetes association

ABSTRACT

Tampereen ammattikorkeakoulu
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PURANEN, ESSI:

You are allowed to be afraid!

Experiences from the Courses Arranged By Finnish Diabetes Association

Bachelor's Thesis 57 pages, appendices 10 pages

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Since diabetic nephropathy is a severe disease, which finally results in end stage renal disease (ESRD), it is a shock to find out having it. Progress can be slowed down by following strict restrictions on nutrition, keeping on mind fluid restriction, implementing medication and maintaining healthy habits. To internalize all these instructions the diseased needs teaching, repetition, reasoning and support. At the stage when kidney condition requires dialysis or organ transplantation, life changes again. Disease and its treatment, which continues rest of the life, has a huge influence on one's life.

Finnish Diabetes Association organizes courses in Diabetes Center to meet the needs of diabetics. This thesis focuses on diabetics with nephropathy and their experiences of the course tailored to them.

The purpose of the thesis was to explore the participants' experiences of the course. Description of the participants' views was obtained by interviews. According to results of the interviews the participants were very satisfied with the course. All of them learned new skills, obtained better understanding towards their disease and its treatment, benefited from peer support and became more motivated to take care of themselves. Some of them felt that the course was a salvation for them.

The importance of these courses was proven without doubt. Diabetics may achieve better quality of life due to substance of the courses arranged by Finnish Diabetes association.

Key words: diabetes, diabetic nephropathy, education, support, finnish diabetes association

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1 INTRODUCTION

Chronic diseases are the major cause of death in almost all countries. We have high level of vigilance towards the infectious diseases which are dreaded to mutate into pandemics, but we have failed to control enough “Silent Killers”, like Diabetes. (Mbaya, Gan, Algot, Bakker, Brown, Ramachandran, Roglic, Shaw, Silink, Siminerio, Soltész, Williams & Zimmet 2006, 3.)

In 2000 Finnish Diabetes Association initiated a large program to develop prevention and treatment of diabetes (DEHKO 2000-2010). When this program was designed, it was known that high costs of treatment of diabetes are not caused by increased blood glucose levels as much as due to several concomitant diseases caused by diabetes (Aarne, Koski, Huttunen, Bierganns & Telford 2011, 55).

Finnish Diabetes Association arranges educational and supportive courses for diabetics at Diabetes Center, which is located in Tampere. Multi-professional group of experts composed of specialized physicians, diabetes nurses, psychologists, dietitians, physiotherapists, pedicurist, social worker, renal nurse and other personnel is in charge of instructing the courses.

The purpose of the thesis was to explore how diabetics with diabetic nephropathy experience the education and support received in the course. The idea of this thesis arised from course activities of Finnish Diabetes Association. As a sponsor of courses for working-age diabetics, Social Insurance Institution is also interested in deeper evaluation of these service products.

The implementation was carried out by interviewing the diabetics that participated in second partition of their two-hold course. They all had diabetes and kidney disease due to diabetes. Since diabetes is origin for several consequences, the description of concomitant diseases in this thesis is limited to diabetes-specific diseases. Depending on the context the participants are called participants or informants.

2 PURPOSE, TASK AND OBJECTIVES

The purpose of this thesis was to explore how the participants coped before the course and what their experience of usefulness of the course arranged by Finnish Diabetes Association was.

Research questions of this thesis are:

1. How did the participants cope with their disease before the course?
2. What was their experience of the course?

By analyzing the information obtained the structures of the courses may be improved, and necessity of them can be shown to the Social Insurance Institution. In wider context the thesis may even help the policy-makers to see the importance of comprehensive education of diabetes, which may lead to decreased money consuming, prolonged working age, lessening in individuals' torment and improved job satisfaction among medical professional.

3 DIABETES AS A DISEASE

Incidence of diabetes in Finland is high. There are 40.000 type 1 diabetics and around 250.000 type 2 diabetics – undiagnosed type 2 diabetics are estimated to be around 200.000. Diabetes, and especially type 2 diabetes is nowadays the most common disease that eventuates in dialysis therapy. (What is Diabetes 2010.)

Proper basic care of diabetes is beneficial for both, individual and society. Severe complications are often connected to inadequately treated diabetes. The majority of the costs of treatment of diabetes are specifically due to complications. Occurrence of complications increases the costs on average more than 4,4-fold with type 1 diabetic, and more than 6-fold with type 2 diabetic. (Aarne et al. 2011, 55.)

3.1 Different types and risk factors

Diabetes is defined by the amount of glucose in blood plasma. The limit of normal percentage is 6,0mmol/l, and when the level stands in 7.0 or more after 12 hours fasting diabetes can be diagnosed. Since 2011 method HbA1c has been used to declare diabetes; when HbA1c value is 6,5 or more, there is a stage of diabetes. (Mustajoki 2012.)

Two main types of diabetes are type 1 and type 2. In type 1 the lacking excretion of insulin has to be replaced by life-long insulin therapy. The main goal in type 2 is to reduce the risk of arterial disease by taking care of blood glucose, blood pressure, blood fats and coagulation factors. (Mustajoki 2012.)

Type 1 diabetes is caused by slow destruction of pancreatic islets which leads to ending of insulin production. Because of insulin deficiency, the blood glucose level arises. Insulin injections are needed from the very beginning. Symptoms of type 1 diabetes occur in a few days or weeks. Common symptoms are weight loss, fatigue, polyuria (large amounts of urine) and excessed thirst. If there is a delay in diagnosing, the condition can process till acid poisoning. This condition is fatal and requires immediate hospital treatment. (Mustajoki 2012.)

Insulin resistance occurs in type 2 diabetes years before the diagnosis, as insulin transition from blood to cells is disordered. Pancreas need to produce excess amounts of insulin to obtain the needs of cells. By and by this extra effort leads to fatigue of insulin-producing cells and as a result blood glucose levels increase causing occurrence of diabetes. Usually insulin treatment is needed at later stage. Inherited tendency of prompting type 2 diabetes concerns approximately one third of citizens. Maintaining normal body weight and physical exercise has been found preventing towards type 2 diabetes. (Mustajoki 2012.)

Diabetes type 2 develops gradually during several years' time and without causing severe symptoms. Type 2 diabetes is often found by accident in routine check-ups, among treating an acute seizure or while unrevealing the reason behind an indefinable fatigue syndrome. Symptoms of type 2 diabetes can be fatigue especially after meals, irritation, visual blurring, leg pain and susceptibility to different inflammatory conditions. The higher the blood glucose level rises, the bigger amount of urine excretes and the thirst increases. (Diabeteksen oireet 2012.)

Gestational diabetes is diagnosed from increased blood glucose levels during pregnancy. Blood glucose levels return to normal after delivery, but the tendency to fall in diabetes later on is increased. Therefore it is important to monitor blood glucose levels and to take preventive actions. Diabetes resulting from pancreatic disease can be triggered by cholelithiasis or heavy alcohol consumption. Tumors and iron storage disease can also harm pancreas. Due to varying insulin deficiency both, tablets and insulin injections are needed. (Risk Factors for Diabetes 2012.)

Risk factors for diabetes depend on the type of diabetes. Although the exact cause of type 1 diabetes is unknown, genetic factors likely play a role. The risk of developing type 1 diabetes increases when one has a parent or sibling who has type 1 diabetes. Environmental factors, such as exposure to a viral illness, also likely play some role in developing type 1 diabetes. Other factors that may increase the risk include the presence of damaging immune system cells (autoantibodies). Sometimes family members of people with type 1 diabetes are tested for the presence of diabetes autoantibodies. Having these autoantibodies makes one in an increased risk of developing type 1 diabetes. But, not everyone who has these autoantibodies develops type 1. (Ilanne-Parikka et al. 2009, 329.)

Dietary factors have been linked to an increased risk of type 1 diabetes, such as low vitamin D consumption; early exposure to cows' milk or cow's milk formula; or exposure to cereals before 4 months of age or after 7 months of age. However, none of these factors has been shown to cause type 1 diabetes. Race causes variations in occurrence of type 1 diabetes; it is more common in whites than in other races. Certain countries, such as Finland and Sweden, have higher rates of type 1 diabetes. (Risk Factors for Diabetes 2012.)

It is not fully discovered why some people develop prediabetes and type 2 diabetes and others do not. Still there are certain factors increasing the risk. Weight and inactivity; the more fatty tissue one has, the more resistant the cells become to insulin. Inactivity increases the risk, because physical activity helps to control the weight, uses up glucose as energy and makes the cells more sensitive to insulin. (Risk Factors for Diabetes 2012.)

Family history; if a parent or sibling has type 2 diabetes, it increases one's risk to end up with diabetes. Getting older is also a risk factor. This may be because people tend to exercise less, lose muscle mass and gain weight as ageing. Then again, type 2 diabetes is increasing dramatically among children, adolescents and younger adults. Gestational diabetes during pregnancy increases the risk of developing prediabetes and type 2 diabetes later on. Delivering a baby weighing more than 9 pounds (4 kilograms) is also a risk of type 2 diabetes. (Risk Factors for Diabetes 2012.)

Polycystic ovary syndrome; women having polycystic ovary syndrome (a common condition characterized by irregular menstrual periods, excess hair growth and obesity) are at increased risk of developing diabetes. High blood pressure is one common risk factor. Having blood pressure over 140/90mmHg is linked to an increased risk of type 2 diabetes. (Risk Factors for Diabetes 2012.) Abnormal cholesterol levels increase the risk; low levels (<1) of high-density lipoprotein (HDL) increases risk of type 2 diabetes (HLA-laboratorio. 2012).

3.2 Diabetes-specific concomitant diseases

Diabetes is an origin of number of complications. Focus of this thesis was diabetics with diabetic nephropathy, and in addition to that only diabetes-specific diseases are discussed little more deeply in this thesis. Because the amount of data of all complications of diabetes is massive, it would be beneficial to investigate so large entirety in treatise on its own.

Prolonged high blood glucose level exposes patients suffering from diabetes to variety of concomitant diseases over the years. Concomitant diseases regarding to diabetes can be divided into diabetes-specific diseases and diseases most common in diabetics. Diabetes-specific concomitant diseases are microangiopathic diseases, e.g. diseases caused by capillary damage, such as retinopathy, nephropathy and neuropathy. Diseases most common in diabetics are different manifestations of arterial disease, such as lower limb ischemia, coronary artery disease and cerebrovascular disorders. The main reason for these diseases is atherosclerosis.

Significance of diabetes in public health is largely based on concomitant diseases. The most common concomitant diseases are arterial diseases; diabetes is predominant cause of heart infarctions, cerebral infarctions and lower limb amputations. Severe concomitant diseases of kidneys and eyes are also related to diabetes (Koski 2010, 55). According to Diabetes Barometer 2010 the costs due to diabetes treatment in Finland at 2007 was 833 000 000 Euros. The major component of costs was medications (29%). Specialist and primary care spent about same amount of money (33%). Devices to enable diabetics' self-care took only 5% of total costs. (Aarne et al. 2011, 55.)

Diabetes tends to cause nerve damages throughout the body. Symptoms such as numbness, pain and tingling can occur, or nerve damage can develop without any symptoms. Most susceptible areas to nerve damage are feet and legs, but nerve problems can occur in every organ system. In time the digestive tract, sex organs and heart can be damaged. Some form of neuropathy concerns about 60 to 70 percent of diabetics. Diabetic nerve damage can come into being at any time, but the risk increases with the duration of diabetes and also depends on quality of care. (Diabetic Neuropathies 2012.)

Diabetics with type 1 diabetes mellitus and age under 25 are the most prone to end up in condition called Diabetic Ketoacidosis (DKA), although it can happen to any diabetic person. This condition develops when there is lack of insulin in one's system. Insulin deficiency induces high blood glucose levels and leads into dehydration. The normal range for the body's pH is between 7,35 – 7,45. In DKA there is disturbance in pH, it drops lower than 7,35. The pH can fall even below 7, which is fatal. (Mustajoki 2013.)

In normal metabolism the body uses carbohydrates for fuel. When diabetic ketoacidosis occurs, the body uses fat for fuel instead of carbohydrates, a process called oxidation. This function results in blood sugar increasing. Extra sugar ends up into urine and finally into toilet, because the kidneys are not available to store extra sugar. As a result urination becomes increased and dehydration happens. In diabetic ketoacidosis about 10% of total body fluids are lost, and severe loss of potassium and other salts is common. (Stöppler 2013.)

The most common events that cause a person with diabetes to develop diabetic ketoacidosis are: Infection such as diarrhea, vomiting, and/or high fever (40%), missed or inadequate insulin (25%), and recently diagnosed or previously unknown diabetes (15%). Various other causes may include a heart attack, stroke, trauma, stress, alcohol abuse, drug abuse, and surgery. Approximately 5% to 10% of cases have no identifiable cause. (Stöppler, 2013.)

People with diabetes are at increased risk for eye complications. Most people with diabetes will get some form of retinopathy, a disorder of the retina. Diabetes can cause different eye complications, which develop in time by poor circulation and narrowed, weakened small blood vessels. Retina is the first part of the eye which is damaged; disorders of retina are generally called retinopathy. Cataracts results from blood glucose diffusing into the lens and causing swelling. This condition in which the pressure builds up in the eye mainly occurs in relation to repeated large, rapid changings of the blood glucose. (Eye complications, 2013.)

Gastroparesis is one result of the neuropathy in which food is delayed from leaving the stomach. Movement through the digestive tract is controlled by the vagus nerve. When the vagus nerve is damaged, peristalsis does not work normally. The stomach and intestines muscles function abnormally, or may not work at all.

By delayed chyme entering in small intestine –where the absorption takes place–gastroparesis causes difficulties in blood glucose balance. In this phase blood glucose levels rise. Estimation and anticipation of insulin doses related to meals is difficult. Disadvantages caused by gastroparesis are also bezoars and bacterial growth in chyme. As in relation to most of the long-term complications of diabetes, the organ of gastroparesis is high blood glucose level for long periods. (Gastroparesis and Diabetes, 2008.)

4 DIABETIC NEPHROPATHY AS A DISEASE

4.1 Renal functions and Renal Failure (RF)

Kidneys are located behind the abdominal cavity in front of the proximal ribs, on both sides of spine. They form a part of urine tract, together with pelvis renalis and the ureter. Bean-shaped kidneys are about the fist-size, and they weight about 150 grams each. Nephron is the functional unit of kidneys. It is a filter that removes waist products from the bloodstream and water and transfers them into the urine. There are approximately one billion nephrons in each kidney, and there will not develop new ones once they are destroyed. (Saha 2012a.)

Kidneys perform several vital functions, such as removing metabolic waste products and extra fluid from blood, regulating the body's water balance, and maintaining body's acid balance (pH). The kidneys also regulate the blood pressure and the balance of sodium and minerals. In addition to these functions, kidneys have some endocrinological tasks; they release a hormone called erythropoietin, which stimulates the bone marrow to produce red blood cells; a hormone called calcitriol, which is the active form of vitamin D; and a hormone called renin, which regulates blood pressure (Saha 2012a.)

Renal failure is a condition in which the kidneys are not working properly and fail to remove extra fluid and waste from the blood, leading also to imbalance in body chemicals. There is certain difference between an acute renal failure and a chronic renal failure, although both conditions are related to malfunction of the kidneys.

An acute renal failure happens suddenly and is usually caused by too low blood pressure - auto regulation cannot work when mean arterial pressure (MAP) drops below 60–80 mmHg. Calculation pattern for MAP: $(\text{diastolic} \times 2) + \text{systolic} / 3$. There is a bunch of origins that can cause blood pressure to drop; severe bleeding, dehydration, intoxications, contrast agents, trauma etc. This condition is usually curable, if accurately threatened. (Renal failure 2013.)

Each individual may experience the symptoms differently. Symptoms of acute RF may include following: fatigue, rash, poor appetite, swelling of the tissues, muscle cramps,

abdominal pain, back pain, pale skin, hemorrhage, weakness, diarrhea, bloody diarrhea, nosebleeds, severe vomiting, fever, no urine output or high urine output, history of recent infection, history of trauma, history of taking certain medications, inflammation of the eye and detectable abdominal mass. (End Stage Renal Disease, 2013)

Developing chronic renal failure happens slowly, usually over many years. This condition is irreversible. Finally in end-stage renal disease (ESRD) the patient needs dialysis or a kidney transplant. (Renal failure, 2013). The symptoms of chronic RF are mainly equal with those of acute RF, but there are some in addition: dry skin, bad breath, metallic taste in mouth, insomnia, malaise, headache, bone pain, itching, urinary incontinence, hearing loss, irritability, changes in mental alertness, poor muscle tone, and recurrent urinary tract infections. (End Stage Renal Disease, 2013.)

The diagnosis of RF is based on simple laboratory researches, such as measuring the amounts of substances that are secreted through the kidneys from the blood. If the secretion is impaired, the amount of the substance in bloodstream is increased. Creatinine is one efficient indicator, which is measured from urine and blood plasma. It is a waste product from energy-metabolism of the muscles, and the amount of it is approximately same every day. There is difference of normal amounts of creatinine between people – the more one has muscle tissue, the higher amounts of creatinine are secreted. Reference value is 60-100 μ mol/l for men, 50-90 μ mol/l for women.

While severe RF is considered, content of creatinine can be over 1000. Next recourse the physician performs is to determine a Glomerulus Filtration Rate (GFR). There is a certain pattern to calculate the GFR: patients's sex, weight and age are taken into consideration in relation to the amounts of creatinine. GFR is more accurate indicator to clarify the renal function. Reference value is $> 1,4$ ml/s. When RF is diagnosed by variations of amounts of creatinine and GFR, further researches to determine the cause of RF are needed. An increased amount of creatinine only reveals that there is a stage of renal insufficiency, not the cause of it. Therefore the ultrasound imagines or computer tomography (CT) is implemented, and often a biopsy is needed as well. (Mustajoki 2008.)

Most common causes of chronic nephropathy are diabetes, increased blood pressure, birth defects, immune disorders, infections, urine blockade and excessive use of pain

medication (NSAID). Therefore it is very important that the client manages diabetes continuously and maintains healthy lifestyle. If problems arise, it is important to promptly seek professional help. (Saha 2012b.)

4.2 Treatment and harm reduction of RF

Severe renal failure is treated with dialysis therapy or a kidney transplant. Dialysis therapy replaces part of kidney function. Dialysis can be done either as hemodialysis by circulating the blood through dialyzers, or as peritoneal dialysis, using the patient's own abdominal membrane as dialysis membrane. The type of treatment is selected individually. (Munuais- ja maksaliitto 2012.)

During hemodialysis artificial kidney circulates blood through dialyzer. The machine is divided in two separate containers that have semi-permeable membrane. Circulating blood is kept separate from external fluid and urea. Creatinine, Calcium, Potassium, Phosphorus and water soluble vitamins are transferred from blood to external fluid. This is called dialysis. During dialysis excess water is also removed and this is called ultra-filtration. Hemodialysis is implemented three times a week and usually lasts three to four hours. (Latja & Viitaniemi, 2004, 16-19).

There are two different forms of peritoneal dialysis. Continuous Ambulatory Peritoneal Dialysis (CAPD) is the most common of them. 1,5 to 3 liters of dialysate (dialysis fluid) is drained into the abdomen, where peritoneal membrane cleans the wastes from the blood stream. This procedure is carried out four to five times daily. The fluid stays 4 to 8 hours in the abdomen, then it is drained out and immediately new dialysis fluid is inserted. CAPD allows the patient to be active more than other forms of dialysis – simple exchange of the fluid is easy to perform and can be done in any clean spot. (Dialysis therapy, 2011.)

Automated Peritoneal Dialysis (APD) is a procedure in which the dialysis is performed at home using the machine. Most patients spend 8 to 10 hours at night time attached to the machine; while they are asleep the machine exchanges the fluid 3 to 5 times. Some patients may need an extra procedure during daytime (What is the difference between CAPD and APD, 2011.)

When a person with diabetes and RF undergoes dialysis therapy, there are some restrictions in intake of minerals and some vitamin deficits that have to be replaced. Phosphorus and Potassium intake from food has to be restricted. Both are important nutrients but with RF they cumulate in organs. Vitamin supplements contain lots of additives like Zinc, Magnesium, vitamin A, etc. and these can cumulate in organs as well. (Latja & Viitaniemi 2004, 15.)

A client who undergoes hemodialysis needs vitamin B and C supplement, because foods that naturally contain these vitamins have high levels of potassium. Also vitamin D concentration in blood is lower and has to be replaced with supplement. Calcium supplement is needed to balance phosphorus absorption. RF causes deterioration in secretion of erythropoietin (EPO) that is needed in production of red cells. EPO supplements can be injected 1-3 times a week. During these injections iron supplement is also needed, because iron is needed in red cell production. Iron can be given either in injection form or orally. Restriction with fluid intake correlates with urine output, daily intake is calculated by adding 800mls to daily urine output. Too much fluid can cause edema/swelling, respiratory distress, elevated blood pressure and cardiac ischemia. (Latja & Viitaniemi. 2004, 16-19.)

Nowadays kidney transplant is considered as the best option in treating End Stage Renal Disease (ESRD). A transplant enables the patient live exempted of the dialysis machine. Unfortunately transplantation is not suitable for every patient; there are certain factors that may preclude transplantation; _____

Kommentti [WU1]: Koska kyseessä kuvio, siinä pitäisi olla otsikko. Jos se on otettu jostain lähteestä, lähde on mainittava. Lisäksi taulukot, kuvat on numeroitava

Table 1: Issues that may preclude transplantation

Psychological factors	Obesity	General health issues
Cardiovascular disease	Active cancer	Peripheral vascular disease
Certain knowledge of a patient's reluctance towards required medical treatment		

When none of these barriers shown in the table 1 above exist, the patient will go through several tests and if not unsuitable, will be put on a transplant waiting list. It is impossible to determine the waiting period, the schedule depends on the number of kidneys available and existence of a compatible organ to insert. Adequacy of the transplant is determined by cross match test, which shows if the recipient's blood cells damage or kill cells in transplant. Also HLA genes are used to determine tissue compatibility. (Transplantation, 2013).

If the cross match test shows recipients' cells attacking towards donors white blood cells, these cytotoxic antibodies likely cause rejection towards the donor's transplant in recipients system. When this is the case, transplantation cannot be performed. Concerning tissue compatibility the match does not have to be complete, rejection may not occur if tissues of the recipient and the donor are sufficiently similar. (HLA-laboratorio, 2013.)

A healthy person normally has two kidneys, but can continue normal living with just one. If the cross match test is negative between the recipient and the donor, the donor can decide to cede one of his/her kidneys to the patient. Often the donors are family members of the recipient. Living donation may save the recipient from dialysis treatment, if a relative donates a kidney before that stage. Among all transplant procedures this is most successful – living transplant is usually healthier, starts to work immediately after transplantation and lasts 15 to 20 years. (Transplantation, 2013.)

Finnish legislation regarding organ donating reformed in 2010. There is a lack of organs that are suitable to use in transplantation and this reformation aims at enhancing the number of transplantations. Before this reformed act existed, permission from relatives was required, unless the donor had an organ donor card. Within current legislation it is assumed that a deceased person agrees to provide his/her organs unless there is evidence of opposite. Before performing the transplantation, the doctor has to try to find out what was the deceased's will. In unclear incidents transplantation can be performed, even though if there is no certainty of deceased's will in adequate time. (Elinluovutus, 2010.)

Transplantation requires immunosuppressive therapy for the rest of the recipients' life. Immunosuppressive drugs depresses the body's own defense system so that white blood cells do not react towards invaders, which they consider the transplant is as well. The

most common drug combination forms of three different immunosuppresses, which are chosen of these; Syklosporiini to inhibit T-lymphocytes function, Atsatriopiini to inhibit T- and B-lymphocytes function and Corticosteroid to depress function mentioned above and to resist inflammations, Takrolinuusi to replace Syklosporin and Mykofenolaattimofetiili to replace Atsatriopiini when needed. Immunosuppressive drugs may induce severe adverse reactions, as alterations on blood values, hypertonia, hyperglycemia, myopatia, osteoporosis etc. They also are nephrotoxic and neurotoxic agents and have plenty of interactions. (Koskinen 2013.)

Kidney and Liver Association (MUSILI) sustains statistics of organ transplants in Finland. In 2010 the first pancreas-kidney transplantations were performed and the number is increasing. The most common transplanted organ is kidney.

Table 2: Statistics of Organ Transplants in Finland

Siirretty elin (Transplants)	2008	2009	2010	2011	2012
Munuainen (Kidney)	150	180	175	177	199
Maksa (Liver)	47	48	50	56	52
Sydän (Heart)	21	13	22	18	22
Keuhko (Lung)	12	13	15	23	26
Sydän-keuhko (Heart-lung)	-	-	-	-	1
Haima (haima-munuainen) (Pancreas-Kidney)			2	1	8
Ohutsuoli (Small intestine)			1	-	2
Yhteensä	230	254	265	275	310

(Munuais- ja maksaliitto 2013.)

5 SELF-MANAGEMENT COURSES FOR DIABETICS WITH RF

5.1 Diabetes Center

Diabetes Center is located in Tampere, next to Lake Näsijärvi in a scenic location. The Center is owned by Finnish Diabetes Association and 60 employees are working in this nationwide Course Center. Course participants are diabetics, their significant others and health care professionals. Annually around 1700 people participate in the courses.



Photo 1: Diabetes Center. (Photo: Essi Puranen 2010)

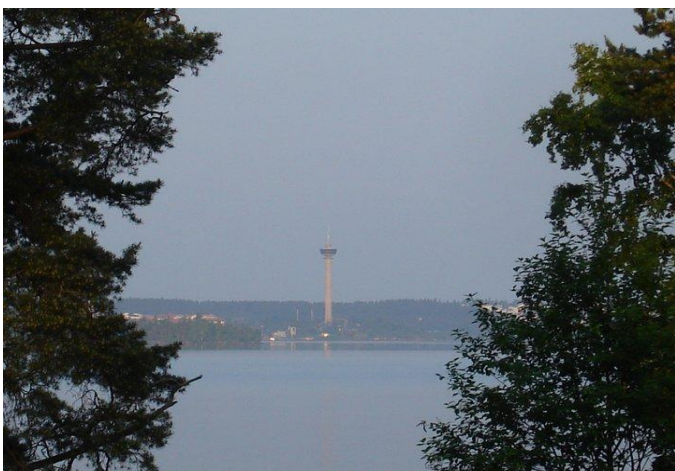


Photo 2: At 2am from the wharf of Diabetes Center. (Photo: Essi Puranen 2010)

The complex includes 25 twin rooms, 56-seat auditorium, well equipped sports hall, gym, sauna and lounge with fireplace, swimming pool, teaching kitchen, D-store, group-rooms and 100-seat dining room.



Photo 3: Dining Room. (Photo: Essi Puranen 2011)



Photo 4: Corridor. (Photo: Essi Puranen 2011)

Different outdoor activities are possible in courtyard; there is a tennis field, large grass area for games, children's playground, a pavilion, camp fire place, swimming beach, row boats, fishing poles, bicycles, walking poles etc. From the shore the stairs lead straight into the lake.



Photo 5: Sauna. (Photo: Essi Puranen 2011)



Photo 6: Leisure. (Photo: Essi Puranen 2011)

5.2 Description of Course contents

The participants are divided in two groups based on the phase of their kidney disease, The third group is formed from significant others of them. The groups take turns in alternative discussions conducted by a diabetes nurse, a psychologist, a dietitian, a podiatrist or a renal nurse. There are also lectures for all together, for example given by a specialist in internal medicine, nephrologist, social worker and physical therapist.

One object of the course is to create an atmosphere in which the clients experience peer support. The first day starts with lunch and then the clients participate in course opening event. This event form of introductions and the clients nominate their expectations and wishes towards the course. These proposals are written down and the personnel inform the clients about the assemblage in which their proposals will be considered.

After rounding the house and showing all parts of it to the clients, personal, informal interviews take place. A questionnaire has been filled in in advance by the participant and information given will be checked over. Discussion determines the participant's status of life at the moment, coping at home with the diseases and care. Lab values will be considered as well. After the dinner the clients join together at the sports hall. A diabetes nurse and physical therapist conduct some activities aiming to grouping and clients getting to know each other.

Before stretching guided by a physical therapist and having breakfast, the clients measure their blood glucose, blood pressure and weight. Assistance is offered if they have any difficulties with measuring. Forenoon continues with group sessions, spouses of the participants participate in these sessions. At a group conducted by doctor and dietician the contents are type 1 and type 2 diabetes as a disease, self-care and individuals' possibility to influence their own condition. The intention is that the participants achieve understanding of importance of blood glucose monitoring in reconciliation of nutrition and insulin therapy. The doctor also explains a target of blood glucose balance, basics of the care and basics of hypo- and hyperglycemia. One of the groups has discussion with the psychologist.

At diabetes nurses' group normal pancreas function is sifted through, as well as an imitation of that function established by multi-injection therapy. The duration of an insulin action is demonstrated in a group by drawing a picture and related to this, a recommended blood glucose level measuring is discussed. Injecting insulin and the goals of care are also concerned.

After lunch and outdoor activities, groups 1 and 2 gather together to their own spots. This is the place to share parts of their life story with the group. The aim is to attach ones' own life stories to the stories of diabetes and kidney. Grouping is also part of the goals. Between dinner and supper the leisure instructor guides grafting to those who want to participate in manual skills action.

The first action of the day number three begins in the sports hall with stretching guided by a physical therapist. Then the program continues with the group meetings; one group has discussion with their diabetes nurse, the second with a dietician and the group of spouses discusses with a renal nurse. Their subject is the spouses' alternative roles in supporting diabetes care. They draw their own role map and through that review their own time consumption and resources.

Several subjects are sifted through during the course; components of diabetes, diabetic nephropathy and their treatment are reviewed from many perspectives. All the experts in charge of the course have their own specialty, but such as different sections of living interact with one another, so the experts also have knowledge tangential on each other's related to this whole entity of content of the course. The frame of the course is constant, but the variations for instance in contents of discussions naturally varies regarding to participants' needs. Table 3 below shows some of the subjects the experts of Finnish Diabetes Association share with the participants at the course tailored for diabetics with nephropathy.

Table 2: The Frame of the Course Contents

DIABETES NURSE	PSYCHOLOGIST	RENAL NURSE	DOCTOR	NEPHROLOGIST	DIETITIAN	PEDIATRIST	LEISURE INSTRUCTOR	PHYSICAL THERAPIST	SOCIAL WORKER
Diabetes care in exceptional occasions	Diabetes as a partner	Phases of kidney disease	Type 1 and type 2	Diabetic kidney disease	Assistance in calculating carbohydrates	Foot self-care	Crafts	Sports	Discussions
Hypoglycaemia, Interpreting readings	Resources and managing	MUSILI-organization	Self-care	Transplantations and medication related to it	Connections between nutrition and kidney disease	Monitoring, hygiene, risks	Music panel	Stretching	Responses to questions draft in advance
Pancreas, insulin therapies, injecting	Intimate relationship and sex	Peer support	Comorbid diseases and treatment		Guidance towards healthy nutrition	Regular check-ups	Color relaxation	Games	
Measurements, Equipment			Sexual functions		Demonstration of cooking		Karaoke	Relaxation	
Life stories, Feelings			Medication to treat impotence				Quizzes	Individual guidance	
Interviews and discussions			How to continue from now on						

5.3 Previous Studies

Some studies relating to this thesis have been reviewed. The studies concern diabetics' courses, a nurse's experiences on appointments in her office, philosophy of empowerment, adaptation to chronic illness and peer support.

British Diabetes Association has implemented kindred courses for adult diabetics. The courses lasted for a weekend and are called "Diabetes self-management training and psychological support weekends". Smeesters, Skinner and Martin conducted a study considering the effect of the course on participants' lives (Smeesters, Skinner & Martin 2007).

Nurse consultant Debbie Hicks has pondered about shortened durations of nurse-diabetic appointments. 30 minutes' appointment time was shortened to 20 minutes, and then to ten minutes. Hicks states that it is impossible to shift through every aspect required in patient encounter in this time (Hicks 2007).

Martha M. Funnell, CDE (Certified Diabetes Educator) and Robert M. Anderson, EdD (Doctor of Education) have studied the philosophy of empowerment as a part of diabetics' care. The approach is based on informed, proactive health care teams working with actively involved patients (Funnell & Anderson, 2003).

Livneh and Antonak have written a Primer for Counselors about psychosocial adaptation to chronic illness and disability. They discuss of comprehensive affect of chronic illness or disability in deceased's life (Livneh & Antonak, 2005).

Doctoral Dissertation of Mikkonen explores peer support. In this wide study she approaches the model from different angles, shifting through silence knowledge, alterations caused by disease, inferiority, benefits of peer support etc. (Mikkonen 2009).

(Appendix 1)

6 METHODOLOGY

6.1 Qualitative Research

Qualitative research aims to reach people's motivations, attitudes, concerns, behaviors, value systems, life styles etc. Instead of seeking answers to questions like "what", this method concentrates on achieving answers to questions like "how" and "why". Nowadays qualitative research is becoming accepted in medicine as well, in nursing practice it has been an important tool for some time. (Qualitative Research in Nursing 2012.)

Qualitative method is useful in inquiring people's experiences, and this kind of approach can lead into discovering new perspectives to phenomenon that is partially known already. In qualitative research the data is collected from those who are most aware of the phenomenon, in this research they are diabetics with nephropathy (Hirsjärvi & Hurme 2004, 25-28).

There is an assumption that the knowledge obtained by interviews is more accurate than those given on "tick the box"- forms. By interviewing there is a possibility to clarify the answers or to deepen data obtained, for example by asking reasoning. By interviews more individuals are reached, because denial is less than in researches implemented in terms of form. (Tuomi & Sarajärvi 2009, 75.)

Qualitative method was a natural choice for this thesis, since the purpose was to obtain information of the courses tailored to diabetics with nephropathy. The participants were the most aware of the impression of the course towards their lives. They also were the only ones who could narrate their past and describe their feelings.

6.2 Data gathering

Semi-structured theme-interview was used to gain the material. Semi-structured interview is a method to use, when the researcher has limited themes from which s/he wants to gain information (Tuomi & Sarajärvi 2009, 75).

There were twelve participants on the second part of two-hold course and five of them were informants of the thesis. Distribution of age of the informants was 26 to 65, a mean age was 44 years. Three of the informants were women, two were men. One of them was undergoing hemodialysis, one had a kidney transplant and one had severe other complications due to diabetes. Rests of them were on different phases of irreversible kidney disease and did not have other severe complications at this phase.

The personnel of Diabetes Center informed the participants about the thesis and interviews related to that in advance and they were all willing to participate. Because of the number of researchers – only one – the number of informants was limited. The informants were beforehand also informed about the written consent form.

6.3 Data Analysis

Traditional method in qualitative research is content analysis. When there is a phenomenon or an issue that needs to be described, the results are not processed as numbers, but classified and described verbally. The analysis method is deductive analysis of the content because the case is semi-structured theme interview (Tuomi & Sarajärvi 2009, 103-113).

Analysis process was initiated by listening the interview tape-recordings and transcribing them. Data obtained by interviews was reduced, original expressions related to chosen themes were raised up and data irrelevant to this research was omitted. Original expressions with the same meaning were grouped into categories. Literature was analyzed using deductive content analysis. (Tuomi & Sarajärvi 2009, 110-115.)

7 RESULTS

7.1 Thoughts about Kidney Disease before the Course

Since the informants were in different phases on their diabetic nephropathy, their understanding of kidney disease was varying before they participated in the course. Some did not have any idea of the disease before the course; some concerned it as no scary issue far in the future, some had been afraid of it.

It just needed to be accepted and lived with day by day. It would just come along, for example I wasn't going through dialysis or other treatment, and they were not relevant to me at this time. Like I don't have problem with it... I'll just be realistic – I have it, but it is not like a threat.

Not any kind of thoughts about that.

It was scary. Very scary.

7.2 Thoughts about Diabetes before the Course

Before participating in a course for diabetics with diabetic nephropathy thoughts of the informants regarding diabetes as a disease and its treatment were varying. Two informants had been on diabetes course before and these two brought up acceptance as a beneficial piece of knowledge gained from the course.

I had been here before... I was encouraged to accept my disease to some extent. It is much easier to live with it when you accept it.

I have participated in several courses and everything has changed... insulin treatment regimen have developed and atmosphere is not as judgmental as it used to be. If you had something sweet it was as if you took a bite from a forbidden fruit... With a change in atmosphere came acceptance as a human being, instead of feeling like outcast.

Other informants, who did not have experience of the course before, seemed to be more insecure and green regarding their diseases and treatment. Comparing the situation before and after the course, there was a significant change in attitudes towards the disease.

I was pissed at times... then I felt indifferent... and other times it was fine.

I was on tablet therapy for a while and then switched into two injection therapy and my blood glucose levels were poorly controlled... Then I received a leaflet on this course... thought, that I might participate in this course.

7.3 Benefits from first course section

The informants experienced a number of benefits the course brought into their lives. Motivation to implement self-monitoring was improved due to reasoning of issues and received knowledge of how different aspects interact with each other. Duration of diabetes was more than ten years among the informants, but they had some uncertainty regarding basic care of diabetes.

I gained all sorts of useful info during the course... and some basics that I have incorporated in my life. Like changing needles.

I was in a situation... First of all my blood glucose levels were on roller-coaster, going up and down, up and down, up and down, which burdens your system of course, and will be seen in lab results, and in everyday life as exhaustion. Well, during the course my main goal among others was to get my "roller-coaster" under control. We managed to get it under control, using knowledge what was learned there.

Before the course life was in total imbalance hanging a thread and living exhausted, unable to do or think anything... And like... I didn't know what made sense with all demands and rules on my diet, since I had to manage

it myself... But then on the course I received a good package of information on skills and knowledge that I needed and I learned a lot.

Anxiety has diminished, I could get rid of the thought of my life being over... I would have to quit my job and everything else.

7.4 Alterations on Future Views

Attitude towards future was quite positive during a second part of the course. The impression was that during the first part of the course the informants gained vital information and became motivated to take better care of themselves. Improved laboratory values, increased wellbeing and enthusiasm for example to exercise and participate in daily routines show the impact of information and support given.

Hmmm... yes, yes! More positive towards kidneys... changed to more positive. I used to be insecure and more scared without knowledge on disease.

Well, I haven't had any horror scenarios on future... I have anticipated no deterioration in near future. That is how I try to think.

This first part of the course helped me to see that I'm not in a desperate situation. It encourages me to see other people in similar situation, still continuing to live and laugh... I'm not destined to live without joy, but instead can have a positive outlook on life. I didn't have to be afraid of challenges like dialysis, that wasn't a current problem, but still I see it as a tool of survival when needed.

Quite positive. I like my job and I am willing to continue it as long as possible.

7.5 Improved self-esteem

The informants' opinion was that their self-uniqueness and self-dignity improved due to the course offerings. Learning new skills, gaining information, meeting peers with same issues and having succeeded experiences was healing occasion to them. Improved readings in laboratory tests after following the instructions and information gained in the course were concrete evidence of one's possibility to affect their own condition.

I'm proud of what I gained myself due to course! I won myself and compete with myself instead of competing with others. Those lab values are indicative, but I've managed to get them down, considering both, diabetes and kidneys. So, the direction is better! I myself did it! With instructions of others, though.

Sure, it increased my self-esteem in a way that I didn't have to be ashamed of my disease or my weakness.

It has caused me to realize that other people care about me and I don't have to be alone with my problem. I want to work on my disease and not disappoint the people who work on the same goal with me.

7.6 License to fear, release from guilt

Reassurance regarding self-confidence, fears, life control and feelings of guilt seems to be significant. Positive feedback plays an important role in people's lives, as well as release from wrong assumptions and guilt.

You are allowed to be afraid! I've got a permission to be afraid, and not quilt myself.

The fact that I'm able to care for myself. I know what I'm doing... I have more certainty.

I have got support on many levels and been able to ponder things, realizing what I can do, and what not to do. I have experienced strong support system and positive feedback. I wasn't left by myself with my thoughts.

7.7 Rationalizing the backgrounds

The informants learned practical skills in treating their diabetes and were able to transfer those skills to their everyday life. Reasoning and understanding how different sections of life affect each other, such as blood glucose level, nutrition, exercise, medication etc. supports them in self-care.

Well, those needles and everything else... dosing of insulin...

They explained everything very well, including all the details on causes and consequences. They didn't just tell us what to do, but taught reasoning behind it. My blood glucose level at the time was 8.2 and now it is 7.1. First of all I'm much more active since my blood glucose level is not that high. And what a surprise! My couch is alone in the corner, wondering where the couch potato went! I don't feel all exhausted anymore.

I learned a lot on lessons and being interviewed by a dietitian and diabetes nurse and meeting a doctor. My treatment regimen was changed into multi-injection therapy, which proved it to be a right choice in my case.

7.8 Issues in receiving information

At time of interviews only one of the informants was undergoing dialysis. This treatment was initiated in between two course sections, so it had continued a short duration. There was lack of some basic knowledge regarding kidney failure, although in dialysis unit the personnel must know about connection between nutrition, laboratory values, medication etc. and repeatedly inform the patient about these subjects. Issue can be a person's ability to receive information.

Yes, it is important to take care of the one you have, or both, the best you can. My situation has gotten to a point where I have to go through dialysis, which was started in between these course sections.

For example the calcium tablet. I had been instructed to take it every day. Well, I just took it once a day at random times and didn't even remember it every day. Here they provided a reason why it needs to be taken just before the meal, because of phosphorus. I hadn't known why I was taking it.

This nutrition... the fact how much it matters and the results have proved it. It is not that complicated at all, if you gain information and be able to adapt it.

7.9 Improved general wellbeing

In addition to disease treating skills the course has influenced other aspects of life, such as on general inertia, lack of energy and pleasure.

Well... wellbeing and energy level... now it means everything to me. And before nothing was exiting unlike now.

It is – wellbeing.

I sure got me moving and going outdoors. I've gained self assurance.

7.10 Peer support

The importance of peer support seems to partially depend on an individual's psychosocial surroundings. Duration of the illness may also affect one's attitude; if the disease is comparatively new, a significance of peers could be more important.

It is really good.

It is not a lifeline to me. Maybe if I have a question I just call and ask what someone else does in the same situation.

Well, here peer support has been amazing! Like during small group conversations we have been able to discuss intimately very personal matters. It has become an important asset.

It has been extraordinary the way how we talk on free time and in small groups. You learn to listen to the opinions of others and we have talked through different things. And after all, we are all in the same boat.

It feels like it brings us closer together as a group. There are so many types of diabetes, like this disease as well, but this is kind of extra... extra quality we all have.

7.11 Supporting aspects

Amid all stressful and unfamiliar issues the informants have found support in several aspects. Family and friends play a significant role, positive attitude and succeed in achieving desired laboratory readings are subjects that empower them. Focusing on present instead of grieving the past, or worrying the future is perceived as good doctrine.

Good friends... That you go outside even when you are not in the mood. And making sure not to worry too far ahead. If you have issues, as the ones we discussed about here, just live one day at the time and don't worry about the past or future, but this day.

Strong motivation and family. I find strength in my children and family, my husband... for instance cooking for them and keeping positive attitude. It gets you damn far!

My family sure is the first lifeline on supporting system and then it is professionals. Those two are the tools I use on this journey with my disease.

Some of the informants considered the course as a turning point of their life. They felt themselves exempted of the fear, became empowered and got back faith in tomorrow.

It was like a saver to get on this course! My life has changed... totally changed. Now that I have more information, I'm not so scared anymore. I understand that there are other people in similar situations and I'm not the only defective here.

To begin with it has been important to notice how much I can do to improve my lab results and then regulate my mood. My spirits have lifted compared to initial state of shock after hearing about my disease. It was so important to participate in this course that has empowered me to continue my life.

8 CONCLUSIONS

8.1 Discussion of the Results

The purpose of this Bachelors' thesis was to find out how the course organized by Finnish Diabetes Association was experienced by people with diabetes and diabetic nephropathy. The results obtained by the interviews proved vital importance, some of the informants reported of total alteration in their outlook of life. The course appears to meet expectations and needs of participants.

The object was to produce information about the participants' experiences of the courses to Finnish Diabetes Association and to The Social Insurance Institution. Information obtained can be used in developing quality of course activities. Results also ensure the need of the courses in sponsors' point of view. The results did not bring up needs of improvements for course contents, although there is always opportunity to do things even better. The demand for these courses was undeniable – the only negative point in a whole entity the participants expressed was their assumption that this was the last course they can participate.

The courses implemented in Diabetes Center are conducted in accordance with the philosophy of empowerment (Funnell & Anderson, 2003). The idea of this concept is patient-centered, and professionals are seen as partners or coaches, not as the authority. Funnell and Anderson have conducted Empowerment and self-care courses for diabetics and they have found certain improvement in results in comparison to previous, ineffective intervention strategies. "With empowerment diabetes care is collaboration between equals; professionals bring knowledge and expertise about diabetes and its' treatment, and patients bring expertise on their lives and what will work for them." (Funnell & Anderson 2003.) The objective in the course is to set individual, suitable goals for each individual participant in their care, and to find realistic recourses to achieve them.

The informants had different individual experiences in managing with their diseases before the course. Those who had participated in course for diabetics before brought up acceptance. Accepting one's disease makes life easier was intramural experience. Acceptance from outside was a relief, for example in attitudes towards nutritional re-

restrictions regarding diabetics. Kindred courses have been implemented in the UK. They have lasted for a weekend and were called “Diabetes self-management training and psychological support weekends”. The authors Smeesters, Skinner and Martin conducted a study considering these “camps”, as they call them, and the study evaluated the effects of a support the adult diabetics received. They state that being diagnosed with chronic illness can cause emotional reactions, such as anxiety, anger and denial. These negative feelings can affect the adjustment process. Still accepting the condition is necessary owing to lifestyle changes required for successful management of the disease. (Smeesters, Skinner & Martin 2007, 256.)

At the results of Doctoral Dissertation of Mikkonen almost all of the informants had been shocked when they got to know having an irreversible disease. They felt that their and their family members’ lives were in chaos. They felt like everything was stalled and nothing was like before. Depression appears to be an essential emotion of Mikkonen’s informants’ life in time after having diagnosis. (Mikkonen 2009, 101.)

The informants of this Thesis also described time before this course as a roller coaster. This metaphor suits for both, “fishtails” in blood glucose balance and uncertainty about the right choices and wrong ones. Stories created an impression of chaotic situation, which included anxiety, fear, shame, insecurity, exhaustion and grief. High percentage of adults with diabetes has been identified having lack of knowledge in self-management skills of diabetes, such as insulin administration, glucose testing and diet ever since insulin treatment was first introduced. “Adult support weekends that offer diabetes information and emotional support in an informal workshop setting may help enable better self-management for people with diabetes by addressing these issues”. (Smeesters et al. 2007, 256.)

Mutual experience of offerings of the course was impressive. After the first course section in January, changes in many aspects of life occurred in the participant’s lives. These improvements motivated them to implement better self-care: they had learned how they can affect their own well-being. Better coping in everyday life, increased amount of energy, succeeds and decreased feeling of being excluded was the alteration occurred in their life between two course sections. The informants managed to transfer a lot of subjects learned in the first course section into their everyday life. Psychologist Jukka Marttila states that development in self-care of diabetes and improvement in results is

always a positive issue, which is a reason to be proud of. “I learn, I can, I get along!” Improvement in self-care and experience of one’s effect on one’s own situation through that may be an important “end of the threat” even in opening knots of depression. (Ilanne-Parikka et al. 2009, 56.)

Information about diabetes and diabetic nephropathy was a basic to orientate towards the best possible choices. Reasoning had an important role in understanding the purpose of measurements, nutrition, medication, regular check-ups, as well as motivation to implement this complicated design of care. Strong impression of peer support was to notice that there are people suffering of same issues, and they still do smile and desire to live – projection of others helps to embrace wider perspective. Instructed practical training, such as injecting and cooking was an important aspect, people tend to remember better things they have actually done themselves. The results from the study of Smeester et al also show that self-management education had positive outcomes, which included self-care behaviors, improvements in skills, psychological outcomes and metabolic control. (Smeesters et al. 2007, 257.)

An unusual benefit during the courses was the ability to meet a psychologist and learn from her. According to Diabetesbarometri 2010, it is rare that mental health professional is part of diabetics’ care. 63% of public health care centers do not use psychologists’ services at all. Psychologist Jukka Marttila discusses about connection between diabetes and mood; diabetes may affect one’s feelings and moods as blood glucose values change. On the other hand, stress may affect blood glucose levels. So, severity of diabetes together with demanding self-care affect the mood, and the mood certainly affects implementing self-care. (Ilanne-Parikka et al. 2009, 55.)

Digestion of new information is difficult, especially if there is too much of it at one time. Individual, who just became aware of having a severe disease, hardly is in a position to embrace a punch of instructions. Neither are those with longer duration of disease. Nowadays a lot of patient information is available in leaflets, but even if the instructions are given verbally and literally, the anguished person rarely is able to digest much. Long-term, repetitive, visual and auditory learning conducts subjects into long-term memory. Nurse consultant Debbie Hicks (2007, 363) discusses about troubles caused by limited time in appointments with diabetics; practice nurses usually have only ten minutes for new patients and same time for follow-ups. She wonders how it is pos-

sible to encompass required investigations, such as education, weight, blood pressure and foot examination in that time. "It takes time to understand from the point of the person with diabetes why the problem exists in the first place, and then we have to set an agreed care plan in addition to providing information and support" (Hicks 2007, 363). Funnell and Anderson (2003) have also discussed about limited time the professionals have to spend with the patients with diabetes. They state that addressing psychological and emotional needs does not necessarily increase visit time; they have experienced that using empowerment approach actually increases the efficiency of visits, and thus may decrease the length of the visit. Offering recommendations that will not be implemented or are irrelevant for patient is wasting time. They have found beneficial to initiate every appointment by addressing the patients' issues and concerns. (Funnell & Anderson 2003.)

There are many factors that interact creating a profound effects on life of individuals with disabilities and chronic illnesses; functional limitations, uncertain prognosis, psychological distress, alterations in managing daily routines and life roles, the impact on significant others and sustained financial losses. Stress exists due to different threats the diseased may experience, such as those towards one's well-being; independence; body integrity; future plans and goals. Onset of medical impairment and disability or loss of body functions is traumatic and can lead to crisis. The crisis can trigger a mourning process which is comparable to loss of loved one, and the diseased expresses feeling of despair, grief and bereavement as s/he has forfeited significant next of kin. (Livneh & Antonak 2005, 12-13.)

Definition of body image as unconscious design of one's body reflects interpersonal, temporal, environmental factors. As chronic disease impacts physical appearance, it causes alterations in one's body image and self-concept. Stigmatizing by stereotypes and prejudging causes increased distress to diseased ones, resulting in reduced self-esteem, withdrawal from social situations and even from rehabilitation and treatment environments. (Livneh & Antonak 2005, 14.)

Diabetes Center is an ideal state in implementing comprehensive teaching when diabetes and concomitant diseases caused by diabetes are concerned. Course activities create an atmosphere in which learning is easy, support available and multi-professional team provides answers. Freedom of everyday duties, such as taking care of home and work,

provides space to focus on one's condition and improving it. Comfortable environment in a beautiful spot, possibility to sit on campfire near by the waterside or inside by the fireplace, take a sauna bath above the lake or at the indoor sauna, swim in the lake or in the pool inside, exploit all sport options in a well-equipped sports hall or outside and enjoying delicious food are good recourses to get rid of everyday life. There is also a good selection of karaoke discs in the lounge with fireplace.



Photo 7: Karaoke. (Photo: Essi Puranen 2010)

8.2 Credibility of the Thesis

The researcher is not allowed to break confidence or obligation to maintain the identity of the informants' secret. While implementing the research the researcher must do exactly what s/he has declared. Into the research the researcher may only apply those issues that have been agreed with the informant (Kuula 2006, 91).

Informants' consent is essential in all human sciences. The primary and most important relevance is to get people to understand the subjects in which they agree to participate. Carefully written or verbal promises are relevant, because they are basis on access to collected data and further processing of it. The researcher must try to ensure that everyone participating in the study has understood contents of all parts of information given;

why and for what purpose the research material is collected for; how it is edited and maintained; who will have access to the material. (Kuula 2006, 104.)

The informants received verbal information of the research prior to their participation from the personnel of Diabetes Center. Before interviews the author repeated the purpose of the study. The informants were informed about tape recording of the interviews and transcription of them. Usage of the results in thesis was told to informants, as well as about providing information to Finnish Diabetes Association and The Social Insurance Institution to gain deeper data of participants' experiences. Kuula states that to motivate the candidates it is beneficial to let them know what kind of new information the research is reaching and how the results can benefit in the future (Kuula 2006, 106). According to law, anonymisation is correct, when single candidates cannot be identified from the material easily and without unreasonable costs. The essential rule is that outsider cannot unambiguously determine individuals of the material. (Kuula 2006, 112.)

The informants were informed about a possibility to cancel their participation at any phase. The identity of the informants was not published and all details of their interviews that could easily reveal the identity were omitted. Then again, since the interviews took place at Diabetes Center during the course, the personnel and peers were aware of their participation. Tape-recorded interviews were demolished after transcribing them.

Literary consent for interview (Appendix 2) and its usage in Bachelor's thesis was asked for all informants. The questions were semi-structured, and the author had consulted TUTKA (the Research Group of Course Activities of Diabetes Association) in tailoring them.

Tape recorded interviews were listened several times before transcribing. While producing the thesis the interviews were translated in English, positioned according to themes and read over and over again. Due to the translation the quotes are not exactly original, but all effort was used to preserve the content and relevance of them. Assistance from Maria DeMarco (RN), who is equipped with equal skills in both languages, English and Finnish, was received in transcribing the interviews. A Finnish version of interviews can be found in appendices of the thesis (Appendices 3 and 4).

Some previous studies which are produced on kindred subjects were reviewed. The references are trustworthy, and the authors are experienced scientists. Results of their studies are similar with this thesis, which ensures the credibility of the thesis. Since the method is qualitative and research questions considered people's experiences and attitudes, the similarity of the results is significant.

Timing of the interviews may have an effect on the results; the informants had had the first section of their course in January and the interviews were implemented during the second course section in May. The informants were motivated to achieve desired lab results during the time before the second course section, and were eager to implement the alterations needed in their life to succeed in this accomplishment. One of the informants expressed this feeling saying: *I want to work on my disease and not disappoint the people who work on the same goal with me.* This positive form of competition likely considers the peers as well. There is a possibility that their motivation would not have been so high if there had not been the reunion with familiar professionals and peers to look forward. All in all the outcomes of their self-care, and as a consequence, the results of the interviews could have been less positive in case of different timing of interviews.

8.3 Recommendations for further research

Approximately one in ten citizens in Finland has diabetes. Likely everyone has a relative, friend or colleague having this disease. Diabetes is a national disease in Finland, and the amount of both, type 1 and type 2 diabetics is increasing. (Suomen Diabetesliitto, 2012.)

Considering some positive facts related to diabetes awareness and care, there are actions to take to turn this deterioration towards right direction. Diabetes treatment has developed in strides; there is large amount of better knowledge and different therapies available in diabetes type 1 treatment in contrast to time a few decades ago. Due to these improvements diabetes type 1 is easier to treat and to take care of than earlier.

A study completed in 2001, "Finnish Diabetes Prevention Study" was the first study in the world to show the fact that type 2 diabetes can be prevented, or onset of it can be delayed. In 2002 published American study confirmed these results that Finnish researchers had found (Hytönen & Joutsivuo 2005, 62).

These facts raise the question; what is it about? Knowhow is better, but incidence of the disease increases. Reasons behind this dilemma might be several. There is still lack of knowledge in diabetics, but also in nursing personnel. This may be covered by education. There is lack of time, which goes for both, the nurse encountering the diabetic and the nurse educating him/herself about diabetes care. This may be covered by increasing the number of nurses and investing in diabetes education.

Another cause might be the exhaustion the diabetic experiences. One may feel being outsider and left alone without proper information of the disease and its treatment. Situation likely leads into depression, which may become an obstacle in inspiring about self-care. In addition to the possible solution models above, this may be resolved by investing in psychological skills of nurses, as well as easier access in psychologists' appointments. One definitely beneficial improvement would be if there was a possibility for every diabetic to join these courses of Finnish Diabetes Association.

Interesting and beneficial research subjects for further researches would be to investigate nurses' knowledge of diabetes in different medical care settings, as well as nursing homes. Comparison of time used in nurses' appointments with diabetics at the clinic in Finland and other countries would be clarifying; since we have a high knowledge of diabetes in Finland, why there is not relevant correlation with results? Can the reason be poor flow of information and support from professionals to diabetics?

In addition to these proposals it would be interesting to implement some follow-up to the informants of this thesis. Finding out their situation during longer time period may produce beneficial ideas to develop the care of diabetics in general, and of those who have diabetic concomitant diseases.

A comparison of skills and knowledge between diabetics who have been participated in these courses, and those who does not have this experience, might also bring up an appropriate data to determine the quality and need of the courses.

REFERENCES

- Aarne, M., Koski, S., Huttunen, J., Bierganns, E. & Telford, K. 2011. Diabeteksen ehkäisyn ja hoidon kehittämisohjelma (DEHKO 2000–2010) Loppuraportti. Kirjapaino: Kehitys Oy.
- Funnell, M. & Anderson, R. 2003. Patient Empowerment: A Look Back, A Look Ahead. American Association of Diabetes Educators.
- Hicks, D. 2007. Are we losing the art of nursing? *Journal of Diabetes Nursing* Vol 11 No 10. London: Enterprise House.
- Hirsjärvi, S. & Hurme, H. 2001. Tutkimushaastattelu, teemahaastattelun teoria ja käytäntö. Helsinki: Yliopistopaino.
- Hytönen, Y. & Joutsivuori, T. 2005. Arjen asiantuntijat – Diabetesliiton viisi vuosikymmentä. Tampere: Kirjapaino Hermes Oy.
- Ilanne-Parikka, P., Rönnemaa, T., Saha, M., Sane, T. 2009. Diabetes. 6. uudistettu painos. Hämeenlinna: Kariston Kirjapaino Oy.
- Koski, J. 2010. Diabetesbarometri 2010. Suomen Diabetesliitto.
- Koskinen, P. 2011. *Therapia Fennica*. Munuaisensiirto.
- Kuula, A. 2006. Tutkimusetiikka. Aineistojen hankinta, käyttö ja säilytys. Jyväskylä: Gummerus kirjapaino Oy.
- Latja, M. & Viitaniemi, K. 2004. Hemodialyysi osana elämääsi. Pirkanmaan Munuais- ja Siirtopotilaat ry.
- Livneh, H. & Antonak, R. 2005. Psychosocial Adaptation to Chronic Illness and Disability: A Primer for Counselors. *Journal of Counseling & Development*. Vol 83.
- Mbaya, J., Gan, D., Algot, B., Bakker, K., Brown, J., Ramachandran, A., Roglic, G., Shaw, J., Silink, M., Siminerio, L., Soltész, G., Williams, R. & Zimmet, P. 2006. *Diabetes Atlas*. 3th edition. Belgium: Hoorens Printing NV
- Mikkonen, I. 2009. Peer Support in Different Illness Groups. Akateeminen väitöskirja. Sosiaalipolitiikan ja sosiaalipsykologian laitos. Kuopion yliopisto.
- Mustajoki, P. 2013. Lääkärikirja Duodecim. Asidoosi.
- Mustajoki, P. 2008. Lääkärikirja Duodecim. Senkka ja sata muuta tutkimusta.
- Saha, H. 2012a. Lääkärikirja Duodecim. Krooninen munuaisten vajaatoiminta.
- Saha, H. 2012b. Lääkärikirja Duodecim. Munuaisten vajaatoiminnan syyt.

Seemsters, H., Skinner, C. & Martin, J. 2007. Diabetes self-management training and psychological support weekends. *Journal of Diabetes Nursing*. Vol 11. No 7. London: Enterprise House.

Tuomi, J. & Sarajärvi, A. 2009. Laadullinen tutkimus ja sisällön analyysi. Jyväskylä: Gummerus Kirjapaino Oy.

Mikä on diabetes? 2012. Diabetesliitto. Read 4.2.2013. http://www.diabetestutkimus.fi/files/36/Mika_on_diabetes_esite.pdf

Collazo-Clavell, M., Davidson, N. & Moreland, P. 2012. Diabetes. Risk Factors. Read 29.12.2012. <http://www.mayoclinic.com/health/diabetes>

Eriksson, J., Lahdenperä, S. & Olkinuora, J. 2011. Diabeteksen oireet. Read 10.8.2012. <http://www.dextra.fi/lääkärikeskus/munkkivuori/diabetesklinikka>

Dyck, P., Feldman, E., Arbor, A. & Vinik, A. 2009. Diabetic Neuropathies. NIDDK. Read 20.8.2012 <http://diabetes.niddk.nih.gov/dm/pubs/neuropathies/>

Eye complications. 2012. American Diabetes Association. Read 5.1.2013. <http://www.diabetes.org/living-with-diabetes/complications/eye-complications/>

Stöppler, M. 2012. Diabetic Ketoacidosis. Read 5.1.2013. <http://www.emedicinehealth.com>

Gastroparesis and Diabetes. 2008. NIDDK. Read 4.9.2012. <http://diabetes.biosino.org>

The Kidney. 2009. Fresenius Medical Care. Read 8.1.2013 http://www.fmc-renalpharma.com/the_kidneys.htm

Insuficiencia Renal. 2012. Instituto Nacional de Cancer de los Institutos Nacionales de la Salud de EE.UU. Read 18.1.2013. <http://www.cancer.gov/diccionario?CdrID=462925>

End Stage Renal Disease (ESRD). 2011. Health Library of John Hopkins Medicine. Read 18.1.2012. <http://www.hopkinsmedicine.org/healthlibrary>

The Kidneys and how they work. 2012. NIDDK. National Institutes of Health (NIH). Read 7.1.2013. <http://kidney.niddk.nih.gov/kudiseases/pubs/yourkidneys/>

What is the difference between CAPD and APD? 2011. The National Kidney Federation. Read 12.1.2013. <http://www.kidney.org.uk/Medical-Info/pd/pdchoice.html>

Senkka ja sata muuta tutkimusta. 2008. Mustajoki, P. & Kaukua, J. Read 16.1.2013 <http://www.terveyskirjasto/tk.koti>

HLA-laboratorio. 2012. Helsingin Yliopisto. Kliinisteoreettinen laitos Haartman-Instituutti. Read 2.2.2013. <http://www.hi.helsinki.fi/tietoa/hla.html>

Transplantation. 2013. The Kidney Foundation, Canada. Read 17.2.2013 <http://www.kidney.ca/page.aspx?pid=340>

Elinluovutus. 2010. Sosiaali- ja terveysministeriö. Read 19.1.2013. http://www.stm.fi/sosiaali_ja_terveyspalvelut/terveyspalvelut/elinluovutus

Munuaisensiirto. 2011. Therapia Fennica. Kandidaattikustannus Oy. Read 5.2.2013.
<http://www.therapiafennica.fi/wiki/index.php?title=Munuaisensiirto>

Elinsiirrot Suomessa. 2012. Munuais- ja maksaliitto ry. Read 5.2.2013.
http://www.musili.fi/sairaudet_ja_elinsiirrot/elinsiirrot/elinsiirrot_suomessa

Qualitative Research in Nursing. 2012. Nursing Research. Read 10.2.2013.
http://nursingplanet.com/research/qualitative_research.html

Diabetestutkimussäätiön esite. 2012. Suomen Diabetesliitto. Read 17.2.2013.
http://www.diabetes.fi/files/533/Diabetestutkimussaation_esite.pdf

APPENDICES

Appendix 1. Table of Researchers of previous Studies

Funnel, M. & Anderson, R. 2003.	Patient Empowerment: A look back, a look ahead.	The Diabetes Educator 2003	American Association of Diabetes Educators
Hicks, D. 2007.	Are we losing the Art of Nursing?	Journal of Diabetes Nursing. Vol 11 No 10	London: Enterprise House
Mikkonen, I. 2009.	Peer Support in Different Illness Groups	Akateeminen väitöskirja. Sosiaalipolitiikan ja sosiaalipsykologian laitos.	Kuopio: Kuopion Yliopisto
Smeesters, H., Skinner C., Martin, J. 2007.	Diabetes Self-management Training and Psychological Support Weekends	Journal of Diabetes Nursing. Vol 11 No 7	London: Enterprise House
Livneh, H. & Antonak, R. 2005	Psychosocial Adaptation to Chronic Illness and Disability	A Primer for Counselors. Journal of Counseling & Development. Vol 83	American Counseling Association

Appendix 2. Literary Consent

SUOSTUMUS HAASTATTELUUN JA LUPA HAASTATTELUN KÄYTTÖÖN OSANA TUTKIMUSTA

Suostun sairaanhoitajaopiskelija Essi Purasen haastateltavaksi hänen opinnäytetyöhönsä liittyen. Opinnäytetyön aihe on ”Munuaistautia sairastavan diabeetikon kokemus Diabetesliiton järjestämän kurssin kokonaisvaltaisesta vaikutuksesta omaan elämään”.

Haastattelulla kartoitetaan kurssilaisten kuntoutusprosessin kulkua, kurssin antamia työkaluja ja uusia näkökulmia sekä pyritään löytämään prosessin jatkumisen kannalta tärkeitä muita mahdollisia tuen tarpeita.

Haastattelu nauhoitetaan sanelukoneelle, jonka jälkeen haastattelija purkaa sen sanatar-
kasti kirjalliseen muotoon. Haastateltavan henkilöllisyys ei missään vaiheessa tule pal-
jastetuksi. Haastattelua ei käytetä sellaisenaan mihinkään muuhun tarkoitukseen eikä
muussa yhteydessä kuin osana haastattelijan opinnäytetyötä, sekä dokumenttina selvitet-
täessä Kelalle Diabetesliiton järjestämien kurssien tuloksellisuutta.

Valmistuttuaan opinnäytetyö esitetään haastattelijan oppilaitoksessa TAMK:ssa ryhmäl-
le ja opettajille, yhteensä noin kolmelletoista hengelle. Lisäksi Diabetesliitto saa opin-
näytetyön käyttöönsä.

Tampereella __ __ _____

Appendix 3. Interview replies in Finnish language

1 (7)

8.1 Thoughts about kidney disease

Since the informants were in different phases on their diabetic nephropathy, their understanding of kidney disease was varying before they participated in the course. Some did not have any idea of the disease before the course; some concerned it as no scary issue far in the future, some had been afraid of it.

“Se on vähän sama juttu et se on hyväksyty, että se on ja sen kans mennään päivä kerrallaan. Et se vaan tulee siäl mukana. Et ku mä en tee sitä... esimerkiks dialyysiä ja tämmösiä, ne ei oo mulle ajankohtasia nytte. Että... ei mull’ oo sen kans mitään... kai se mennään sillai realistisesti. Että se on, muttei se oo mikään peikko.”

”Ei minkäänlaisia ajatuksia.”

”Se tuntu pelottavalta. Pelottavalta.”

8.2 Thoughts about diabetes

Before participating in course for diabetics with diabetic nephropathy thoughts of the informants regarding diabetes as a disease and its treatment were varying. Two informants had been on diabetes course before and these two brought up acceptance as a beneficial piece of knowledge gained from the course.

“Mä olin ollu aikasemmin täällä... mulle jäi semmonen, että yrittäkää nyt jollain tasolla se hyväksyä, se asia. Se on paljon helpompi sen kanssa elää. Sellainen hyväksyntä.”

”Mä olen ollu aika monella kurssilla ja kaikki on muuttunut... insuliinit kehittyneet ja tota niin sillä tavalla tullut semmosta ei-niin-tuomitsevaa mitä joskus aikasemmin ollu... Aikaisemmin oli niinku kiellettyä hedelmää, olit syönyt jotakin makiaa ja... ja tota se on samalla tehnyt semmosen olon, että on niin kun ihminen ihmisten joukossa, ettei oo mikään hylkiö.”

Other informants, who had not experience of the course before, seemed to be more insecure and green regarding their diseases and treatment. Comparing the situation before and after the course, there was a significant change in attitudes towards the disease.

“No välillä potutti... välillä ei ollut mitään... välillä oli ihan ok.”

2 (7)

"No mä olin aikani tablettihoidolla ja sitten siirryin kaksipistoshoitoon... hoitoon ja tota... ne arvot oli aika pahat... sain sitten esitteen näistä kurssista... tuli isäni kanssa juteltua ja juttelimme esitteestä... että kai sinne kurssille vois mennäkki."

8.3 Benefits from first course section

The informants experienced a number of benefits the course brought into their lives. Motivation to implement self-monitoring was improved due to reasoning of issues and received knowledge of how different aspects interact with each other. Duration of diabetes was more than ten years among the informants, but they had some uncertainty regarding basic care of diabetes.

"Kaikkei tosi hyödyllistä infoo sain kurssilta ja... joitakin perusjuttuja, joita sitten on toteuttanu. Niin kuin muun muassa neulanvaihto."

"Mull' oli niin ku semmoinen... se sokeritilanne ensinnäkin, että mä menin vuoristorataa ylös-alas, ylös-alas, ylös-alas ja totta kai se rassaa kroppaa, ja sitten totta kai se näkyy siellä labra-arvoissa ja totta kai se näkyy kotona siinä, et mä en jaksa mitään. Noh, nyt sitten kun me oltiin siel kurssilla, tavoite oli mulla, et se oli mun se oikeestaan –tottakai täältä tuli muitakin- mut ainoo oli se, et saadaan se vuoristorata niin ku pienemmälle marginaalille. Saatiin se pienemmälle marginaalille, niillä opeilla ja ohjauksilla mitä täällä oli."

"Ennen kurssia elämä oli semmosta katotaan nyt kuinka tässä pärjätään ja pärjätäänkö tässä ollenkaan ja ei jaksanu mitään tehdä, eikä jaksanut mitään aatella. Ja tota... ei niinku tienny mikä olis viisasta, et ku pitäis tehdä sitä ja pitäis tehdä tätä ja sitten toikaan ei sovi ja ruokavalio oli oma asiansa hoitaa ja ... Mut sitte tota noin ni kurssilla ollessa mä sain niin kun todellisen, tuhdin tietopaketin missä oli just semmosia tietoja ja taitoja, joita mä kaipasin ja sain yleisiltä luennoilta paljon."

"Semmonen ahdistuneisuus on vähentynyt. Se kuitenkin pyöri mielessä ja oli alitajunnassa, että tuntu siltä, että tää nyt on tässä... joutuu työn jättämään ja kaikki..."

8.4 Alterations on future views

Attitude towards future was quite positive during the second part of the course. The impression was that during the first part of the course the informants gained vital information and became motivated to take better care of themselves. Improved laboratory values, increased wellbeing and enthusiasm for example to exercise and participate in daily routines show the impact of information and support given.

"Mmmm... no on, on, on! Et munuaisten kannalta niinku myönteisemmin... myönteisemmin muuttunu että. Ennen oli vähän silleen epätietonen ja ... pelot- pelottavampaa oli, et ku ei tienny."

"No ku ei mull' oo sen tulevaisuuden kans ollu semmosta... mustia peikkoja... Mullon olettamus, ettei tuu mitään pahempia ainakaan ihan heti tuolla, että... yritän olla sillee."

"Kyllä tää ensimmäinen kurssi niin ku valotti sitä et sitä ei ollutkaan niin epätoivonen ja sit ku mieltii, että on toisiakin, jotka on samanlaisessa tilanteessa ja silti ne jaksaa elää ja hymyillä, ni se rokkas muakin niinku... ettei tässä olekaan tuomittu mihinkään kurjuuteen, vaan pystyin katsomaan elämää niinkun myönteisesti. Ja uusia haasteita, tai siis niin ku dialyysihoidosta sillon puhuttiin... sekään ei ollu sillon vielä ajankohtasta, ni ei tarvinnu sitä ajatella minään mörkönä, vaan hyvänä selviytymismahdollisuutena."

"Aika positiivinen on. Minä tykkään työstäni ja haluan jatkaa sitä niin pitkään kuin mahdollista."

8.5 Improved self esteem

The informants' opinion was that their self-uniqueness and self-dignity improved due to the course offerings. Learning new skills, gaining information, meeting peers with same issues and having succeeded experiences was healing occasion to them. Improved readings in laboratory tests after following the instructions and information obtained in the course were concrete evidence of one's possibility to influence their own condition.

"Mä voin olla ylpee kurssin ansiosta siihen mitä mä oon saanu ittelleni. Mä oon voittanu niinko itteni – mä en kilpaile muita vastaan vaan itteeni. Siinä, että mä oon saanu sitä sokrujuttua ja siin samassa munuaiset, ninku jo vähäsen – nehän on viitteellisiä ne arvot- mutta se, että vähän niin ku laskemaan sielläki. Että suunta on parempi, ni mä oon siitä ihan hiton niinku ylpee ittestäni! Minähän sen oon tehny! Toisten neuvoilla."

"Kyllä joo, se vahvisti itsetuntoo kummasti ettei mun enää tarvinu hävetä omaa sairauttani eikä voimattomuuttani."

"On vaikuttanut, sillä tavalla, että tuntee että muutkin pitää... ööö... tai välittää minusta sillä tavalla että... etten mä joudu yksin olemaan sen ongelmani kans... Haluan niinkun tehdä... ponnistella paljon ittekin sen eteen ja olla semmonen, että ei halua tuottaa pettymystä niille ihmisille, jotka näkee vaivaa mun puolestani..."

8.6 License to fear, release from guilt

Reassurance regarding self-confidence, fears, life control and feelings of guilt seems to be significant. Positive feedback plays an important role in people's lives as well as release from wrong assumptions and guilt.

"Et niinku saa pelätä! Tuli niinku... lupa. Eikä... eikä saa syyllistää itseensä."

"Se tietysti, että osaa hoitaa ja se että semmonen niinku että varmempi tietysti niistä."

"Olen saanu hyvin paljon semmosella tavalla, että tota... moni asia niin on tullut tota niin... aika perusteellisesti, mitä tää aika on antanu myöden niin pohtia ja... ja... saanu sillä tavalla vähän niinku synninpäästöjä, että... että kyllä nyt niin voi tehdä, että... saanut tämmöistä, tämmöistä hyvin voimakasta kannustusta ja semmosta. Pieniä kehuja, että on se ollu ihan oikeen, että tee niin vaan. Ettei oo jääny ihan omaan pieneen pollaan toi asia pohdittavaks."

8.7 Rationalizing the backgrounds

The informants learned practical skills in treating their diabetes and were able to transfer those skills to their everyday life. Reasoning and understanding how different sections of life affect towards each other, such as blood glucose level, nutrition, exercise, medication etc. supports them in self-care.

"No ne neulat, ja sitten kaikkee... insuliiniannostusta ja..."

"Kun täälä selitettiin niin hyvin mikä... mitä mikäkin tarkoittaa ja mitä... mikäkin johtaa mihinkin ja näin. Että se tausta, eikä vaan sanottu, että tee näin, vaan se selitettiin ja perusteltiin. Niin tota mull' oli sillon 8.2 sokrut -pitkä-, nyt on 7.1. Eli lähetään siitä; mä oon paljon virkeempi, kun ne sokerit ei oo ollu korkeella, ja... ihan kauhee katastrofi! Sohva on ihan yksinään siä olkkarin nurkassa, että missä paras kaveri o?! Et ei oo semmosta nuutuneisuutta."

"Sain yleisiltä luennoilta paljon ja sitten myös niissä ravitsemusterapeutin ja diabeteshoitajan henkilökohtaisissa haastatteluissa ja lääkärin tapausmisessä. Siellä muun muassa siirryttiin sitten mulle käyttämään tätä monipistoshoittoa, mikä osoittautui ihan oikeaks ja hyväks ratkasuks mun kohdalla."

8.8 Issues in receiving information

At time of interviews only one of the informants was undergoing dialysis. This treatment was initiated in between two course sections, so it had continued a short time. There was lack of some basic knowledge regarding kidney failure, although in the dialysis unit the personnel must know about connection between nutrition, laboratory values, medication etc. and repeatedly inform the patient about these subjects. Issue can be a person's ability to receive information.

"Joo, kyllä se on tärkeää hoitaa sitä ainokaista, taikka niitä ainokaisia mitä on, sen minkä pystyy. Mutta mullakin on tilanne se, että ehti mennä tähän... toi dialyysihoito tässä vaiheessa, mikä sitten tässä kurssien välissä aloitettiin."

"Esimerkiksi toi kalkkitabletti, mulle oli vaan sanottu... että se pitää ottaa joka päivä. No, mä oon ottanu sen vaan johonkin aikaan päivästä, enkä... aina ei oo muistanu ottaa. Nyt täällä vasta perusteltiin sitä... että otetaan just ennen ruokailua. Sen fosforin takia. En minä tienny mitä varten sitä pitää ottaa."

"Tää ravitseminen... ravitseminen... siihen, että kuinka paljon sillä voidaan vaikuttaa ja tulokset on jo näytetty, että... et tota... ne ei kovin monimutkaisia asioita sillä tavalla loppujen lopuksi oo, kun on ko niihin tota... pikku hiljaa tässä syventynyt."

8.9 Improved general wellbeing

In addition to disease treating skills the course has influenced other aspects of life, such as general inertia, lack of energy and pleasure.

"No se jaksaminen ja energisyys... se on niinko koko elämässä nytte. Ja sitte ku ennen ei oikein mikään huvittanu, niin siellä huvittaa paljon enemmän."

"Sellanen... jaksaminen!"

"Kyllähän se innosti alkuun varsinkin tota liikkumaan ja ulkoileen. Ja justiin toi sitä semmosta toimintavarmuutta."

8.10 Peer Support

6 (7)

Importance of peer support seems to partially depend on an individuals psychosocial surroundings. The duration of the illness may also affect one's attitude; if the disease is comparative new, significance of peers could be more important.

"Siis se on tosi hyvä."

"Ei mulle se mikään... elämän kohokohta oo. Että, mut jos tulee ehkä jollekin jotain asiaa, niin todennäköisesti vaan soittaa ja sanoo et hei, mites toimit, tai mitä nyt tehään tai näin, että."

"No täällä nimenomaan se vertaistuki on ollut ihan vallaton! Et tota, kun on keskusteltu, oltu pienissä ryhmissä ja pystyty keskusteleen henkilökohtaisesti asioista ja intiimisti, ni se on ollu sellanen... siitä on kyllä tullu erinomaisen hyvä voimavara."

"Se on ollut tota niin erinomainen, sillä tavalla, että kyllä ne jutut on erilaisia tuolla iltakeskusteluissa ja tuolla ryhmissä. On oppinut kuuntelemaan toistenkin mielipiteitä... ja saanut tota niin... yhdessä on käyty niitä asioita paljon lävitse. Ja tota niin... kaikkihan tässä jollakin tavalla samassa veneessä ollaan..."

"Tota tuntuu, et se lähentää enemmän niin ku taas tätä ryhmää, porukkaa. Diabetestahan on niin montaa lajia, niin kun on tätäkin, mutta tää on yks semmonen lisä... lisäominaisuus, muillakin."

8.11 Supporting aspects

Amid all stressful and unfamiliar issues the informants have found support in several aspects. Family and friends play a significant role, positive attitude and succeed in achieving desired laboratory readings are subjects that empower them. Focusing on present instead of grieving the past, or worrying the future is perceived as good doctrine.

"Hyvät ystävät... Sitte varmaan se, että vaikei huvita niin menee ulos, välillä. Ja se ettei murehdi sitä tulevaisuutta niin ku kauheen pitkälle. Että jos jotain on, niin ku täälläkin on tullu puhetta, että eletään sitä tätä päivää. Ja ei murehita kauheesti menneitä eikä tulevia, vaa yritetään tässä."

"Iso motivaatio, ja se perhe. Mä jaksan sen lapsen ja perheen, miähen kanssa siälä, niin ku... tehä niille välillä ruokaa, esimerkiks. Ja positiivinen asenne! Se on se, että sillä pääsee niin jumalattoman pitkälle!"

"Kyllä se perhe on niin ku semmonen ensisijainen, ja sitten ne... nää tota jatkuvat hoitosuhteet... ne on niinku semmosia... semmosia virallisia apukeinoja, joita mä oon hyödyntäny tässä matkan varrella."

7 (7)

Some of the informants considered the course as a turning point of their life. They felt themselves exempted of the fear, became empowered and got back faith in tomorrow.

"Täähän oli ihan mun elämän pelastus että pääsin tänne kurssille! Se on muuttunu... muuttunu ihan kokonaan, nyt kun tietää asioita, niin ei enää pelota. Ja se että toisillakin on tätä samaa... minä en oo ainoo... ainoo viallinen."

"No, alusta kun lähdetään, niin kun on huomannut, että kuinka paljon on itse voinut vaikuttaa näihin laboratoriotuloksiin, ja sit tää oma mieli... mieliala on parantunut siitä, että oli se aika tyrmistyttävä tieto silloin alkuun kuulla, että nyt on... näin on asiat ja... ja tota... oli kyllä hyvin tärkeä asia, että mä pääsin tälle kurssille ja... ja saan tosi paljon tästä hyvästä elämää eteenpäin."

Appendix 4

HAASTATTELUKYSYMYKSET OPINNÄYTETYÖHÖN

1. Kuinka pitkään olet sairastanut diabetesta?
2. Minkälaisia ajatuksia Sinulla oli diabeteksestä ja sen hoidosta ennen ensimmäistä kurssia?
3. Miten olet kokenut kurssin vaikuttaneen omaan elämääsi, jos ajattelet tilannetta ennen ensimmäistä kurssia, kurssin aikana ja sen jälkeen?
4. Minkälaisia ajatuksia Sinulla oli munuaissairaudesta ja sen hoidosta ennen kurssia?
5. Onko suhtautumisesi tulevaisuuteen muuttunut?
6. Vaikuttiko kurssi kokemukseesi omasta ainutlaatuisuudestasi ja arvokkuudestasi?
7. Minkälaisiin asioihin sait kurssilta vahvistusta/lievitystä; itsetunto, elämän hallinta, pelot, syällisyys?
8. Mitä olet oppinut kurssilla diabeteksen hoidosta? Jos opit, oletko kyennyt hyödyntämään oppimasi arkielämässä?
9. Mitä olet oppinut munuaissairauden hoidosta?
10. Mihin muihin asioihin kuin diabeteksen hoitoon kurssi on omassa elämässäsi vaikuttanut?
11. Miten koit vertaistuen merkityksen kurssilla ja sen jälkeen?
12. Minkälaiset asiat ovat tukeneet Sinua?
13. Minkälaista tukea koet tarvitsevasi nyt?
14. Minkälaisia odotuksia Sinulla on tämän toisen kurssin suhteen?

CATEGORIES**Appendix 5**

Subcategories	Main categories	Unifying categories
<p>Accepting the disease makes it much easier to live with it</p> <p>With a change in atmosphere came acceptance as a human being</p>	Acceptance	Improved life quality
<p>Noticing how much one can do to improve own well-being</p>	Motivation in self-care	
<p>Before nothing was exiting unlike now.</p> <p>Couch is alone in the corner, wondering where the couch potato went!</p>	Increased energy levels	
<p>Moving and going outdoors</p> <p>Cooking</p> <p>Spending time with family</p> <p>Positive attitude gets one damn far!</p>	Coping in everyday life	
<p>Concrete evidence of interactions between different aspects of living</p>	Better lab values	
<p>Other people do care, no need to be alone with the problem</p> <p>Not feeling like outcast</p>	Decreased feeling of being excluded	
<p>Diminished anxiety. Getting rid of thought life being over</p> <p>Positive outlook of life, instead of being destined to live without joy</p> <p>Not being in a desperate situation</p>	Hope	
<p>Receiving information diminishes fear</p> <p>Not being the only defective individual</p> <p>No need to be ashamed of ones' disease or weakness</p>	Decreased shame and fear	

