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EFFECTS OF CARDIOMYOPATHY AND HEART SARCOIDOSIS IN SEXUALITY AND THE NEED OF SEXUAL GUIDANCE

Karpatiat ry members´ experiences

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ABSTRACT

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The purpose of this study was to research the sexuality and changes in it on patients with heart muscle diseases. The study was aiming to find whether there was need to organize extensive guidance for the cardiomyopathy patients, concerning sexuality. The goal of this study was to recognize the need for sexuality guidance and find the most effective way to deliver it to the patients.

The study was performed by questionnaire with both quantitative and qualitative questions. The study was actualized in cooperation with Finnish patient organization for cardiomyopathy and heart sarcoidosis patients, Karpatiat ry. The target group was the adult members of Karpatiat ry.

The study showed that the changes in sexuality due cardiomyopathy/heart sarcoidosis and the need for sexual guidance varied remarkably. Additionally the study showed a lack of sexual guidance in caring of cardiomyopathy and heart sarcoidosis patients.

Further studies are needed to deepen the knowledge about the best location and time for sexual guidance.

Key words
cardiomyopathy, heart sarcoidosis, sexuality, sexual guidance

LIST OF ABBREVIATIONS

ARVC	Arrythmogenic Right Ventricular Cardiomyopathy
CMP	Cardiomyopathy
DCMP	Dilated Cardiomyopathy
HCMP	Hypertrophic Cardiomyopathy
HS	Heart Sarcoidosis
RCPM	Restrictive Cardiomyopathy
RN	Registered Nurse
STD	Sexually Transmitted Disease
WAS	World Association for Sexual Health
WHO	World Health Organization

CONTENTS

1 INTRODUCTION

Sexuality is a part of person´s life and often forgotten during an acute crisis of becoming ill. In chronical illnesses, the patient must learn to continue life in the terms of illness and sexuality should be one part of the life, in one form or another. Sexuality is not only the physical act of intercourse but an inborn and developing part of ourselves. Sexuality and sexual guidance are in a minor role in nursing education and it has not found its place in every day clinical nursing work.

Cardiomyopathy and heart sarcoidosis patients differ as a group from other heart disease groups in the age variation. There are older patients but also those who have started showing symptoms in teen age. Therefore, the sexual development is in different stages and the needs for sexual guidance may vary. The younger patients might need information about contraception and pregnancy with heart disease while the older might have more functional problems.

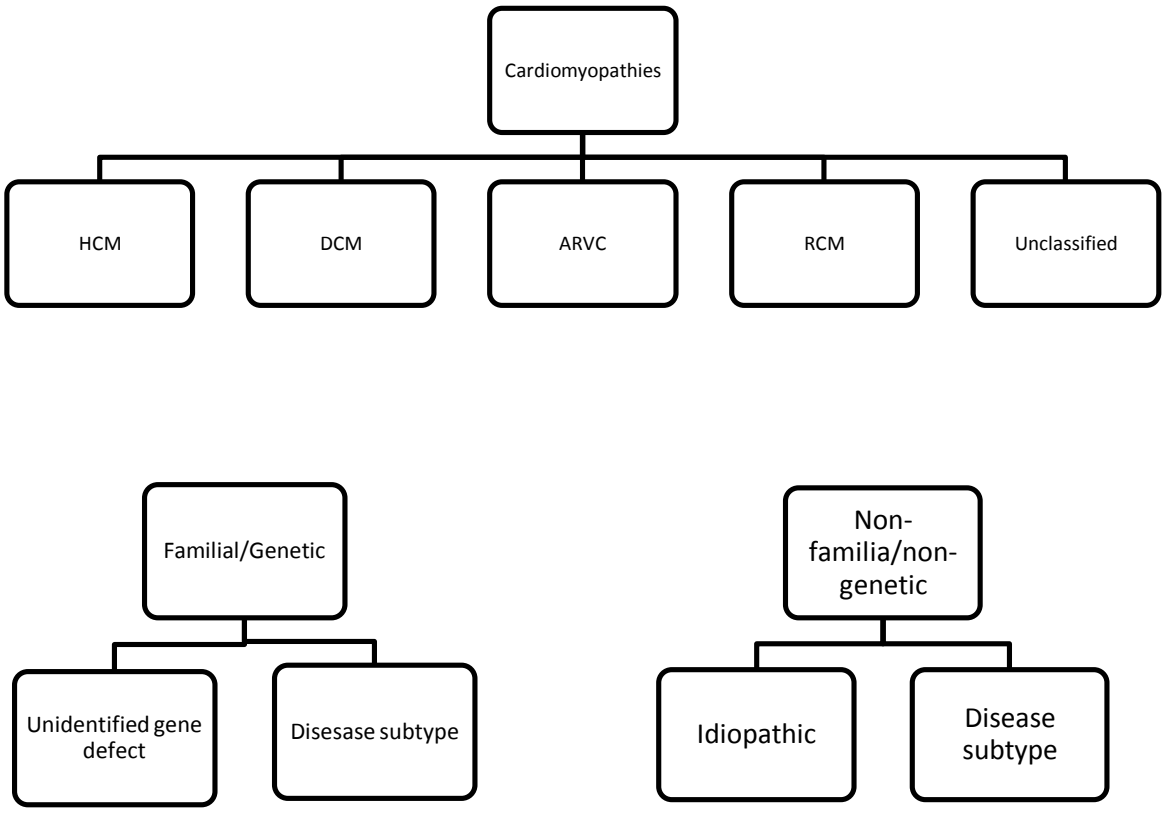
This study aims on finding the possible need for sexual guidance given by registered nurses in clinical settings. The goal of the study is to recognize the need of sexual guidance and find the most effective methods to deliver the information to the patient.

The researcher had the hypothesis of patients for not having enough sexual guidance from registered nurses. There are written material about heart diseases and sexuality, made by The Finnish Heart Association, Sydänliitto ry and the hospitals own materials. In researchers own practical experience, the leaflets are forgotten in clinical work and sexuality is left out of the discussion.

2 CARDIOMYOPATHY AND HEART SARCOIDOSIS

Cardiomyopathies (CMP) is a group of heart conditions changing the structure and function of the cardiac muscle. The classification of cardiomyopathies differs between sources. This study used the classification of WHO and International Society and Federation of Cardiology from 1995. The classification was chosen because of both sources are internationally recognized and the classification is widely used.

> Cardiomyopathies are defined as diseases of the myocardium associated with cardiac dysfunction. They are classified as dilated cardiomyopathy, hypertrophic cardiomyopathy, restrictive cardiomyopathy, and arrhythmogenic right ventricular cardiomyopathy." (Richardson, McKenna, Bristow, Maisch, Mautner, O´Connel, Olsen, Thiene, Goodwin, Gyarfas, Martin & Nordet 1996.)



GRAPH 1. Classification of cardiomyopathy (Adapted from Elliott et al. 2008)

More resent version of classification of cardiomyopathy is shown in the Graph 1. It was stated by the European Society of Cardiology in 2008 (Elliott, Andersson, Arbustini, Bilinska, Cecchi, Charron, Dubourg, Ku ¨hl, Maisch, McKenna, Monserrat, Pankuweit, Rapezzi, Seferovic, Tavazzi & Keren 2008). It is similar to the WHO classification by adding only to the unclassified cardiomyopathies as their own group. In this study the unclassified cardiomyopathies are not discussed as their individual group. Instead, the heart sarcoidosis is discussed separately because the study was actualized in cooperation with Karpatiat ry which is a patient organization for both cardiomyopathy and heart sarcoidosis patients. According to the Karpatiat ry, there is between 15 000 and 20 000 cardiomyopathy patients in Finland and approximately 200 heart sarcoidosis patients. The amount of cases is not registered in Finland (Karpatiat ry 2013).

Dilated Cardiomyopathy (DCMP) causes the dilation of the ventricle, most often affecting the left ventricle. The aetiology has multiple factors including genetics, infections, toxins, metabolic factors and systematic diseases. The most common symptoms are similar to cardiac insufficiency, symptoms being fatigue, dyspnoea, arrhythmias and oedema. Diagnosis is conducted by echocardiogram and invasive investigations. The treatment consists of the basic treatment of cardiac insufficiency, beta-blockers, ACE-blockers, or angiotensin receptor blockers. Patients with severe cardiac insufficiency are treated with biventricular or arrhythmia pacemaker. Heart transplant is considered if the patient is otherwise healthy and would benefit from it. (Heliö & Peuhkurinen 2008.)

The etiological cause of DCMP is treated if known and treatable. In these cases, DCMP can be healed. The goals for treating patients with cardiac insufficiency with medical treatment are preventing further damage in kidneys, neuro-endocrinological and cytokine activation, fluid retention and arrhythmias. Patients need lifestyle counselling and support to cease smoking and drinking, losing weight and avoiding extra salt and liquids. Diabetes in DCMP patient should be well balanced and all patients with cardiac insufficiency should learn to control their weight and possible swellings regularly. (Heliö et al. 2008.) Pregnancy is not recommended for female patients with low cardiac function (Kaaja & Lehto 2008).

Hypertrophic Cardiomyopathy (HCMP) is the most common hereditary cardiac disease, estimation for adults is 2 cases in 1000 persons. In children the estimation is 3 in 100 000 and HCMP is the most common cause of sudden death in young persons and athletes. HCMP is often non-symptomatic or the only symptom is shortness of breath during exercise. Other symptoms, angina pectoris, arrhythmias and syncope can emerge as late as in fifties even though the hypertrophy develops during puberty or before age of 30.The hypertrophy is constant and there is no detectable increasing during years (Heliö, Kuusisto 2013; Kuusisto & Sinisalo 2008.)

The pathophysiological changes in HCMP are ventricular hypertrophy and altered diastolic function. Obstruction in the outflow channel of left ventricle, changes in the mitral valve, ischaemia without atherosclerosis, arrhythmias and sudden death are included to the findings in HCMP patients. The diagnosis of HCMP is conducted by echocardiogram. The prognosis differs between patients and the severity of the symptoms. Non-symptomatic patients have the same prognosis than the normal population while other patients can have high risk of sudden death. Therefore, it is important that the risk assessment is generated individually according symptoms, family background and exercise tests. HCMP is highly hereditary disease and therefore, the first line relatives should also be tested. (Kuusisto et al. 2008.)

The medical treatment, in case of obstructed outflow channel consists of beta-blockers, amiodarone and disopyramid. If the patient has chronic atrial fibrillation, anticoagulant treatment is needed. Endocarditis prevention is important in the patient with obstructed out-flow channel. Myotomy-myectomy is one of the possible treatments by opening the flow channel. In non-obstructive case the treatment is beta-blocker, verapamil and diuretics. HCMP can affect the life especially young persons. Patients with obstructive HCMP or symptoms are discharged from the military service and they need to consider their illness while choosing occupation because night work or irregular work is not recommended for them. They need to avoid extremely strong physical stress and have regular follow ups with medical personnel. Prevention of atherosclerosis is vital because HCM can cause ischaemia and atherosclerosis can worsen it. (Kuusisto et al. 2008).

Restrictive Cardiomyopathy (RCMP) is not one individual condition but rather a group diseases with different aetiologies. This group includes, for example idiopathic RCMP, heart amyloidosis and eosinophilic endomyocarditis. The common factor for all of them is that the cardiac muscle or endocardium is affected, leading to weakening of the passive elasticity and diastolic fulfilment of the chambers. The ventricles are normal in RCMP but the atriums are enlarged. The symptoms of the RCMP are diastolic insufficiency, chronic atrial fibrillation, conduction disturbances and thromboembolisms. The aetiology is complex and the diagnosis is conducted by echocardiogram and biopsy. Treatment of RCMP is mostly symptomatic care, diuretics and anticoagulant treatment. In case the aetiology behind RCMP is known cortisone, stem cell transplant or heart transplant can be considered. The prognosis differs according to the type of RCMP. (Kupari 2008).

Arrythmogenic Right Ventricular Cardiomyopathy (ARVC) is a genetic heart condition found in young adults. It causes left ventricular arrhythmias and right ventricle muscle replacement by connective and fat tissue. Estimated prevalence is 1/1000 to 1/5000. The diagnosis is conducted by electrocardiogram, biopsy and medical anamnesis. The patients must avoid hard physical stress because it can lead to deathly arrhythmias. The prognosis is individual and the treatment consist of beta-blockers, sotalol, amiodarone and pacemaker. (Heliö et al. 2013).

Heart Sarcoidosis (HS) is an infection based condition where sarcoid granulomas infiltrate the cardiac muscle causing fibrosis. The affected areas are commonly the free wall of the left chamber and basal septum. The symptoms are conduction disturbances, weaken contraction or diastolic restriction, mitral leakage, pericarditis, left chamber aneurysm, arrhythmias, syncope, pulmonal hypertension, cor pulmonale and cardiac insufficiency. HS can be localized to the heart or in 50% of cases it is affecting other parts of the body. The diagnosis is conducted by multiple investigations including electrocardiogram, echocardiogram, MRI, PET-scan and biopsy. The prognosis is bad and the treatment options are corticosteroids, cytostatic medication, pacemaker, implanted defibrillator and heart transplant. (Kupari & Kokkonen 2008; Kandolin, Lehtonen, Schildt, Granér, Salmenkivi, Ahonen, Karhumäki & Kupari 2009).

3 SEXUALITY

3.1 Definition of sexuality

Sexuality has numerous alternative descriptions. It is a complicated concept and different sciences have different view to sexuality. The biological and medical view is more physical than the view of psychological or sociological sciences that focus more on the psychology of the sexuality. Sexuality has existed in humans as long as the human cultural history. The scientific view to sexuality has however, existed considerably shorter time. Human sexuality is not completely physical phenomenon but affected by values and morals, religion, legislation and economic factors. (Virtanen 2002.) In this study, sexuality is viewed as it is defined in the Declaration on Sexual rights in 1999 by World Association for Sexual Health (WAS) and WHOs .

> Sexuality is an integral part of the personality of every human being. Its full development depends upon the satisfaction of basic human needs such as the desire for contact, intimacy, emotional expression, pleasure, tenderness and love. (WAS 1999.)

> …a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors. (WHO, 2006a)

The declaration of Sexual Rights states that “sexual rights are human rights pertaining to sexuality”. It defines that everyone has the right to equality and non-discrimination, life, liberty and security, autonomy and bodily integrity. People have right to be free of torture and cruel, inhuman treatment and all forms of violence. They have right to privacy and the highest attainable standard of health including sexual health and the possibility of satisfying and safe sexual experiences. Nevertheless, they have the right to benefit from science, get information and (sexuality) education and be free to form a relationship and family. (WAS 2014.)

Sexuality as a concept has been used since 1800s, first by biologist and later in more common use. The origin is in Latin word *sexus* that consider biological sex. Sexuality is a part of humanity and human wellbeing. Sexuality has as many forms as there are persons and there is no one clear definition but the features of full sexuality are person´s ability to be in contact with himself and others as unique, accept and like his body and enjoy sexuality while respecting others. (Ryttyläinen & Valkama 2010.)

Sexuality combines a large amount of different aspects in human life. It relates to our biological gender, sexual anatomy and physiology and psychological aspects, experienced gender, desire, motivation and early experiences (Nolen-Hoeksema, Fredrickson, Loftus & Wagenaar 2009). Sexuality is inborn ability that can be experienced and expressed in everything what the person is and does. (Apter, Väisälä & Kaimola 2006).

> Even though the survival of the species requires to sexes or two kinds of gametes, feeling pleasure requires only humanity. Sexuality is what we are, sex is what we do. (Translated from Apter et al. 2006.)

3.2 Changes is Sexuality due Cardiomyopathy/ Heart sarcoidosis and the Treatment

According Virtanen (2002), physical illnesses can affect the sexual interest in three ways, biologically, psychologically and socially. In CMP/HS patients, biological reasons can be direct effects of the illness, the effects of the treatment and physical exhaustion. Psychological reasons can be for example, non-sexual patient role, changed body-image, irritation, anxiety or fear caused by the illness, fear of being rejected by the partner and the need to set personal values again. In social level, it can be difficult to express feelings and sexuality, long pause in sexual activity or lack of partner (Virtanen 2002).

Serious illness has a large impact on the patient´s and relative´s lives. The seriousness of the situation, personalities of the persons involved and their resources affect the outcomes of the situation. In acute crisis, sexuality is not the first aspect of life to consider and the sexuality related questions are more practical or about losing the partner due the illness. Low self-esteem is one of the most typical problem concerning illness and sexuality. Self-image and sexual identity can be other significant parts of person to suffer from illness. Lack of sexual desire is common in both partners during crisis of illness. (Apter et al. 2006.)

Illnesses affecting the heart can have effect on the circulation of the erogenic areas, causing problems with arousal, erection problems and dry mucosas, these can be helped with medication or sex toys and other helping devises. The medical treatment of heart can cause erection problems or lack of desire but without the medication the heart might be too weak to survive the physical stress of having sex. The side-effects often reduce during the time. (Apter et al. 2006.)

The medication used to treat cardiomyopathy differ according the aetiology of the case but the most common medications are similar to other patients with cardiac insufficiency, ACE-blockers, diuretics, beta-blockers, digoxin, spironolactone, amiodarone and anticoagulants. These medications can have effects and side-effects that reduce the physical ability to have sex life. Beta-blockers can cause erection problems and exhaustion and ACE-blockers can cause also reduced libido. Digoxin has a rare side-effect, gynecomastia. Spironolactone is the more common reason for gynecomastia. It can cause impotency and irregularities in menstrual cycle. Anticoagulant warfarin can rarely cause priapism. The previously mentioned side-effects affecting the sexual organs directly are relatively rare but the medications have side-effects affecting the whole body and might affect the sexuality via other routes. Headaches, dizziness, stomach problems and hypotension are common especially in the early stages of medication use and can disturb the sex life. (Duodecim lääketietokanta 2015.)

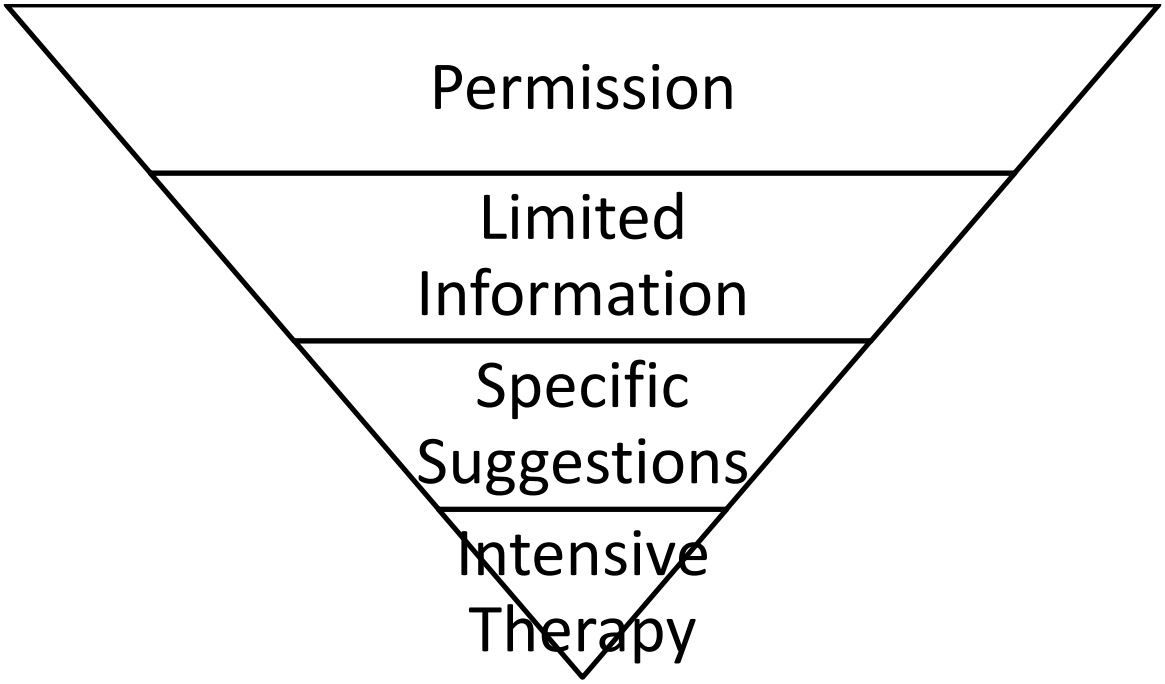
Other treatments of cardiomyopathy consist of pace makers and heart transplants and can cause visible scars and changes in self-image. Cardiomyopathy symptoms can reduce the quality of life if the patient is constantly tired, out of breath and feeling the arrhythmias. Weight loss and muscle atrophy can occur if the cardiac insufficiency. Oedema is a common symptom of cardiac dysfunction and can affect the self-image. Discussion with the partner is important to reduce the fears and misunderstandings. The basic rule is that sex is considered to be safe if the patient can climb to floor of stairs without problems. (Apter et al. 2006.)

4 SEXUAL GUIDANCE BY REGISTERED NURSE

Sexual guidance can be given by every health care professionals in every health care setting. It is situational and has a goal to reach. Sexual guidance focuses on giving information and accepting the patient and his sexuality. It differs from sexual counselling by not being process centred. (Ryttyläinen et al. 2010.) The two concepts are close and often used as synonyms in everyday language.

The sexual guidance offered by Registered Nurse (RN) is actualized according the same principles than any other nursing work. The principles are physical, social and psychological integrity, safety, continuation of the care, individuality, family centeredness, holistic care and autonomy. To provide integrity, the nurses should respect the patient´s body, provide privacy during sexual guidance and respect the patient´s family and sexual orientation. Safety in sexual guidance means trust, professionalism and respect. The patient should feel that he can speak openly. Continuity is actualized by proper documentation. In sexual matters, the documentation should be discussed with patient to avoid revealing too private discussions. Patient should always been met as an individual and the partner been included to sexual guidance if the patient wishes so. The patient has a right to decide whether he wants to talk about sexuality or not. The sexual guidance must be based on scientific facts. (Ryttyläinen et al. 2010). To be able to offer sufficient sexual guidance, the nurse should think about her sexuality, the feelings it might cause, values, norms and beliefes about sexuality. Nurses own attitudes cannot prevent the patient´s right to have sexual guidance. (Ryttyläinen & Virolainen 2009.)

Plissit-model by Jack Annon (1976), is commonly used to evaluate the level of sexual guidance, counselling and therapy needed. Plissit has four levels, Permission, Limited Information, Specific suggestions and Intensive Therapy. The needs of the patients in two first levels are met in basic health care or unspecialized health care professionals in special health care. Graph 2 shows the Plissit-model. The triangle is upside down to show the amount of patients in each level. Most of the patients need only guidance and counselling in Permission level and only small amount of patients need Intensive Therapy to win their sexual problems. (Ryttyläinen et al. 2010.)



GRAPH 2. Plissit-model, (Modified from Ryttyläinen et al. 2009)

Assigning permission is positive attitude to sexuality and its different ways of expression. In permission, the RN assigns a verbal or non-verbal sign that the patient's sexuality, his questions and feelings are accepted. In this level, the information offered is common sexual knowledge concerning contraception, prevention of Sexually Transmitted Diseases (STDs) and anatomy. Permission level supports patient that he is not alone with his questions. Assigning permission in Plissit-model means acceptance but acceptance has limits and the permission is only to socially and legally acceptable sexuality. In Limited Information level, the information offered concerns the patient´s illness and his sexuality. (Ryttyläinen et al. 2010).

5 RESEARCH QUESTIONS

The purpose of this study was to research the sexuality and changes in it among patients with heart muscle diseases. The study was aiming to find whether there was need to organize extensive guidance for the cardiomyopathy patients, concerning sexuality. The goal of this study was to recognize the need for sexuality guidance and find the most effective way to deliver it to the patients. The target group was the patients with cardiomyopathy or heart sarcoidosis. The target group was contacted via Karpatiat ry.

The interest in this subject was raised by after compliting practice and working with the heart patients both in acute ward and policlinic wards. In the researchers own experience in practical placements and work, patients and their families were receiving very basic guidance during their ward time or policlinic visits and the written information about heart diseases and their possible effect on sexuality and physical sexual problems was not shared to them.

In this research, the sexuality was seen as a part of person´s identity and the physical sex and intercourse are only part of sexuality. Sexuality is human right it is viewed as the WHO stated in 2006,

> a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. (WHO 2006.)

There were three research questions in this study.

1) How has the sexuality of the patients changed due the disease?

2) What kind of guidance related to sexuality and sex have the patients received from nurses during their process of illness?

3) What kind of sexuality guidance the patients and their partners need?

6 RESEARCH PROCESS

6.1 Semi-structured research

Semi-structured research combines both quantitative and qualitative research. In this study most of the questions were closed-ended questions using five point Likert-scale. Quantitative research collects data that can be statistically organized and it provides answers to questions such as how many or how often. Quantitative research describes the size of a phenomenon and provides data, how many or how often. Quantitative multiple choice questions provide data that can be mathematically analyzed and the comparison of the answers is easier. The quantitative approach was chosen because the study was first study to research cardiomyopathy patients and their need of sexual guidance and it was more useful in collecting data in a large population. The limitation in quantitative research is that it does not provide answers why something happens often or why many persons think or feel certain way. Therefore, the three qualitative, open questions were added to the questionnaire. Qualitative, open questions offer the participants a possibility to explain the situation in their own words. (Hirsjärvi, Remes & Sajavaara 2013)

6.2 Data collection and analysis

The data was collected via questionnaire (Appendix 1) that had both closed-ended and open-ended questions. The questionnaire was actualized only in Finnish. The questionnaire was self-modified according earlier thesis (Saksola 2009.) and the theoretical back ground. The closed-ended questions were measuring the changes in sexuality and the need and provided sexual guidance. The open-ended questions extended the information that the closed-ended questions were providing. The questionnaire was revised by the tutor teacher and a former professional researcher. According their advice, one option was added to the background information. The question about education level was changed to include kansakoulu, the old Finnish primary school system. One question was removed from the questionnaire because it was unclear and it did not have significance to the study. The clarity of the questionnaire was tested by sending it to a small, heterogenic group of seven persons from age of 20 to 79. The group included nursing students, heart patients and their relatives from different educational backgrounds. The persons chosen had a close contact with the researcher and therefore, the pre-test might have been affected by the relationship.

The questionnaire consisted of 14 questions; seven of those were about demographic factors and others were actual research questions that were either divided into statements or open questions. The quantitative questions used the Likert-scale with options agree-partly agree-cannot answer-partly disagree-disagree. The questionnaire was actualized with Webropol program and the questionnaire link was sent to Karpatiat ry via e-mail and the organization forwarded it to their members. Additionally, the link to the questionnaire was placed to the closed Facebook group of Karpatiat ry. Before the questionnaire was published, the researcher had written an open letter to Karpatiat ry magazine 3/13 (Appendix 3) and explained that the questionnaire is going to be sent to the members. The link to the questionnaire was sent with a cover letter (appendix 2) from the researcher and Karpatiat ry. The link was open for two weeks and 74 answers were received during that time. One answer was not used in this study because the instructions were not followed.

The open-ended questions were analysed with SPSS-programme and the closed-ended questions were analysed by reading them and grouping them. Multiple open answers were not accepted because the participants had not answered to the question. From the grouped answers the answers best presenting the group were chosen and translated to the thesis. The translations were done liberally to maintain the spirit of the answer. Both the Finnish answers, in their original form and the translations were taken to the thesis.

The target group was the members of Karpatiat ry. They have approximately 660 members, most of them patients and minority of them are patients 'relatives. The e-mail was sent to approximately 400 e-mail addresses from Karpatiat ry and in their closed Facebook- group of nearly 200 members.

Ethics was considered while conducting the research and the participants were informed about the aims of the research. The participants were informed that answering the questionnaire was voluntary and anonymous. The link to the questionnaire was sent via the Karpatiat ry and therefore the researcher did not receive any information about the participants outside the questionnaire. The participants received the contact information of the researcher in the cover letter, in case they had something to ask about the research.

Validity of the research was considered and the questionnaire was pre-tested. Validity means that the questionnaire measures the variables it is meant to measure. Validity is better in semi-structured questionnaire than in quantitative questionnaire because the different types of questions either support each other or reveal the mistake in understanding the questions. In this study the answers in open-ended questions correlated with closed-ended questions and therefore, the questionnaire has been valid. Reliability means that the results of the study would be same with different researchers. The reliability of the study was improved by using the most recent literature possible and pre-testing the questionnaire. The questionnaire was modified from previously used questionnaire rather than producing a completely new one.

7 RESULTS

Previous studies were found concerning myocardial infarction and other cardiovascular diseases and sexuality. Cardiomyopathy differs from other heard diseases in the patients age structure, the great ages of being diagnosed being younger than the average in other cardiological diseases. The previous studies were searched from Science Direct and Sage Premiere- databases. There were multiple researches concerning the heart patient, sexuality and nurse's role. Nevertheless, not recent Finnish researches and researches about cardiomyopathy was found.

A Dutch study from 2010 conducted in adult patients with congenital heart diseases and their partners. The results were that the patients were less likely to be involved in a relationship and they had more physical discomfort while having sex. The study found three central changes affecting the sex life, reduced physical stamina, mental changes and medication. The patients had lower self-esteem than average Dutch population. Scars and cyanosis were causing the the patients to be more self-conscious during sex. This study did not find connection between heart medication and erection problems or lubrication problems. (Winter, Reisma, Kedde, Bouma, Vis, Luijendijk, de Witte, Zwinderman, Vliegen, Pieper, van Dijk & Mulder 2010)

An American research has revealed that the cardiac nurses have progressed in providing sexual guidance between 1994 and 2009 but there is still concern about the sufficiency of of the provided amount of guidance. In this research, the patients had suffered from myocardial infarction. In this study, the researchers found that the nurses during 2009 experienced that they were more conservative than nurses during 1994 but they experienced that discussing sexuality with their patients was their responsibility. They thought that they can start the discussion about sexual concerns if the patient did not ask him- or herself. The most discussed concerns with patients in 1994 were the need to rest before sex, warning signals during the sex and the need of comfortable environment for sex. In 2009, the most discussed concerns were the same and additionally the time to start sex life again and with the medicines affecting sex. (Barnason, Mosack, Steinke & Wright 2011)

A Swedish national survey (2009) showed that the nurses working with cardiac patients felt like they were lacking with proper information about sex education to deliver to the patients. The researchers found out that the nurses were not providing information routinely. Oral information was seldom and written information was shared better. The partners did not receive the information and the patients were not asked about the situation when they came to check-up. In this research, the hospitals had groups for cardiac patients but there was very few including sexual information. (Fridlund, Ivarsson & Sjöberg 2009.)

In a study researching the impact of heart failure to men´s life, one quarter of the participants reported the effects on their sexuality and relationship. They would have hoped that they were offered information about the possible effects that the medication have to sex life. (Europe & Tyni-Lenne 2004). Another Swedish study showed that close relationship and sexuality can affect women´s well-being positively after myocardial infarction (Dahlberg, Ekenstam & Sundler 2009).

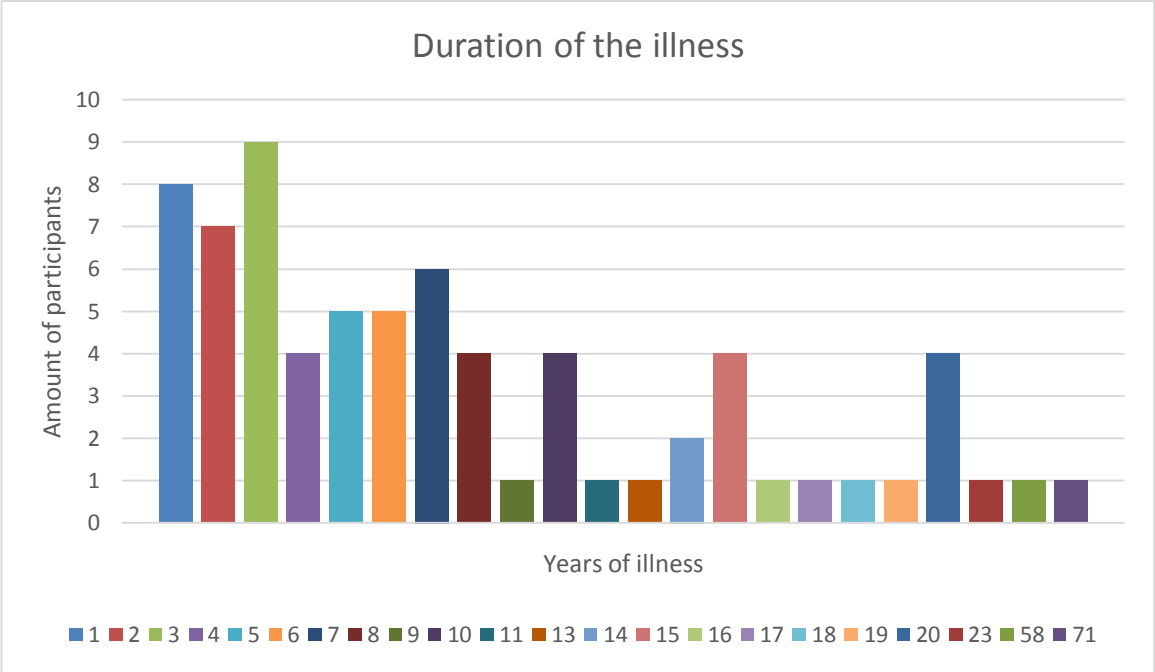
7.1 Demographic factors

The questionnaire was answered by 74 persons and one of the answers was decided to leave out from the research because the participant had not understood the instructions. One participant had not answered to two demographic factors questions concerning the diagnosis and the duration of illness. This participant was accepted to the research because these two questions were classified as non-compulsory demographic factors. The gender division in the participants was nearly even, the amount of female participants being 54, 8 % (N= 40) and male participants 45, 2 % (N=33). The largest age group in this research was over 60 years old 39, 7 % (N= 29) and the groups 51 to 60 (N= 20) and 41 to 50 (N= 17) had been active in taking part to the research. The low numbers of participants in groups under 30 years (N=1) and 31-40 years (N=6) can be due the age profile of diagnosed patients in Karpatiat ry or due lack of interest to participate.

As seen in Table 1, nearly half of the responders (47, 9%) had second grade education and 37 % had a higher education. In this population, there were 11 persons who had achieved only grade school education. The largest amount of participants were 39 persons from Southern Finland, 7 % (N= 29) and 32 from Western Finland , 9 % (N= 24). Over 60 % of the participants were married but there were participants in every categories. Dilated cardiomyopathy was diagnosed in 75, 3 % (N= 55) of the participants, Hypertrophic cardiomyopathy in 15, 1 % (N=11) and heart sarcoidosis in 8, 2 % (N=6). One participant had not answered this question and there was no participants diagnosed with restrictive cardiomyopathy.

TABLE 1. Sociodemographic data

Characteristics of the participants	**Percentage**	**N (Sample size)**
Gender		73
Female	54,8	
Male	45,2	
Age		73
Under 30 years	1,4	
31-40	8,2	
41-50	23,3	
51-60	27,4	
over 60	39,7	
Education		73
Grade School	15,1	
Second Grade school	47,9	
University Education	37,0	
Living area		73
Province of Southern Finland	39,7	
Province of Eastern Finland	15,1	
Province of Western Finland	32,9	
Province of Oulu	9,6	
Lapland	2,7	
Marital status		73
Single	2,7	
In a relationship	15,1	
Co-habit	8,2	
Married	64,4	
Divorced	6,8	
Widow	2,7	
Diagnosis		72
Dilated Cardiomyopathy	75,3	
Hypertrophic Cardiomyopathy	15,1	
Heart sarcoidosis	8,2	



GRAPH 3. The duration of illness.

The duration of the illness varied remarkably from 1 year to 71 years, the mean being 9, 13 years (Graph 3). The largest singular groups was three years (N=9). Majority of the participants had received their diagnosis in the last decade. There was notable increase in every 5 years after the first five years. This could be a result of participants estimating the duration instead of giving an accurate time from diagnosis.

7.2 Research results

The participants answered widely in this question. Some participants felt that the illness had changed nothing in their sexuality while others were having problems. On average those who completely agreed with the statements in the questionnaire were minority. The changes that most common were in self-image (45, 2% partly or completely agreed), lowered self-esteem (43, 9%), changes in body-image (39, 7%), lack of sexual interest (53, 4%) and fears concerning sexual activity (46, 5%).

TABLE 2. The changes in sexuality.

Cardiomyopathy/Heart sarcoidosis has caused the following changes in my sexuality	Completely disagree N (%)	Partly disagree N (%)	Cannot answer N (%)	Partly agree N (%)	Completely agree N (%)
Changes in self-image	20 (27, 4%)	9 (12, 3%)	11 (15, 1%)	24 (32, 9%)	9 (12, 3%)
Lowered my self-esteem	19 (26%)	16 (21, 9%)	6 (8, 2%)	24 (32,9)	8 (11, 0%)
Changes in body image	14 (19, 2%)	14 (19, 2%)	16 (21, 9%)	23 (31,5)	6 (8, 2%)
Changes in sexual identity	24 (32, 9%)	11 (15, 1%)	10 (13, 7%)	19 (26, 0%)	9 (12, 3%)
Thoughts of sexuality not belonging into the life of ill	42 (57, 5%)	12 (16, 4%)	8 (11, 0%)	4 (5, 5%)	7 (9, 6%)
Feelings of unworthiness or shame	40 (54, 8%)	9 (12, 3%)	4 (5, 5%)	14 (19, 2%)	6 (8, 2%)
Change of roles in relationship	26 (35,6	14 (19, 2%)	13 (17, 8%)	15 (20, 5%)	5 (6, 8%)
Difficulties to attend new relationships	19 (26, 0%)	4 (5, 5%)	34 (46, 6%)	5 (6, 8%)	11 (15, 1%)
Social withdrawal	27 (37, 0%)	13 (17, 8%)	11 (15, 1%)	15 (20, 5%)	7 (9, 6%)
Arousal problems in women	20 (27, 4%)	5 (6, 8%)	31 (42, 5%)	9 (12, 3%)	8 (11, 0%)
Erection problems in men	8 (11, 0%)	8 (11, 0%)	30 (41, 1%)	13 (17, 8%)	14 (19, 2%)
Lack of sexual interest	12 (16, 4%)	16 (21, 9%)	6 (8, 2%)	23 (31, 5%)	16 (21, 9%)
Partner lacking sexual interest	24 (32, 9%)	9 (12, 3%)	16 (21, 9%)	17 (23, 3%)	7 (9, 6%)
Fears concerning sexual activity	19 (26, 0%)	14 (19, 2%)	6 (8, 2%)	25 (34, 2%)	9 (12, 3%)
Pain restraining sexual intimacy	36 (49, 3%)	10 (13, 7%)	8 (11, 0%)	12 (16, 4%)	7 (9, 6%)
Danger related to sexual activity	34 (46, 6%)	12 (16, 4%)	15 (20, 5%)	7 (9, 6%)	5 (6, 8%)
Problems with masturbation	26 (35, 6%)	13 (17, 8%)	24 (32, 9%)	7 (9, 6%)	3 (4, 1%)

Open question about other changes in sexuality was answered by 32 participants and there were answers from no changes to both positive and negative changes. The illness had affected the physical appearance and psychological aspects of sexuality.

> Olen sairastumisen vuoksi laihtunut useita kymmeniä kiloja ja entisestä minästäni on vain jäljellä luuranko ilman mitään muotoja. Arpi ja tahdistin vain pullottavat rintakehällä, siinä missä ennen omasin pyöreät rinnat. Nainen, 31-40

> I have lost tens of kilos because of the illness and there is only a skeleton without any shapes left of what I used to be. Just he scar and the pacemaker bulging on the chest where used to be round breasts. Female 31-40.

Tiredness and the effects of medication was one of the reasons for the changes in sexuality.

> Sosiaalinen vetäytyminen liittyy siihen, etten enää jaksa yhtä paljon kuin aiemmin. Tarvitsen lepo- ja palautusmisaikaa. Nainen, 41-50

> Social withdrawal is connected to the fact that I´m not able to do as much anymore. I need time to rest and recover. Female, 41-50.

> Cardace ja Bisoprolol -lääkitys yhdistettynä normaaliin verenpaineeseen aiheuttaa erektio-ongelmia ja varsinkin ongelmia riittävän erektion ylläpitämisen kanssa. Mies, 41-50.

> Cardace (ramipril) and Bisoprolol medications together with normal blood pressure are causing erection problems and espesially problems with keeping up the erection. Male 41-50.

There were also positive changes due the illness.

> Avoimuus ja aktiivisuus lisääntynyt. Nainen yli 61.

> Openess and activity has increased. Female over 61.

TABLE 3. The current situation of the sexual guidance

I feel that	Completely disagree N (%)	Partly disagree N (%)	Cannot answer N (%)	Partly agree N (%)	Completely agree N (%)
I have received sufficient oral sexual guidance from RN	47 (64,4%)	9 (12,3%)	10 (13,7%)	6 (8,2%)	1 (1,4%)
I have received sufficient written material about sexuality from RN	46 (63,0%)	9 (12,3%)	10 (13,7%)	7 (9,6%)	1 (1,4%)
I have received sufficient information from RN how to find information concerning sexuality	50 (68,5%)	11 (15,1%)	7 (9,6%)	4 (5,5%)	1 (1,4%)
I have received sufficient sexual guidance in basic health care	57 (78,1%)	7 (9,6%)	8 (11,00%)	1 (1,4%)	0 (0%)
I have received sufficient sexual guidance in central hospital care	55 (75 ,3%)	8 (11,0%)	6 (8,2%)	3 (4,1%)	1 (1,4%)
I have received sufficient sexual guidance in university hospital care	56 (76,7%)	5 (6,8%)	10 (13,7%)	1 (1,4%)	1 (1,4%)
RN have brought up sexuality in discussion	59 (80,8%)	5 (6,8%)	5 (6,8%)	3 (4,1%)	1 (1,4%)
I have brought up sexuality in discussion	45 (61,6%)	8 (11,0%)	6 (8,2%)	8 (11,0%)	6 (8,2%)
RN are prepared to discuss about sexuality	33 (45,2%)	6 (8,2%)	26 (35,6%)	5 (6,8%)	3 (4,1%)
The sexual guidance has considered prevention of pregnancy (STDs	49 (67,1%)	2 (2,7%)	17 (23,3%)	4 (5,5%)	1 (1,4%)
The sexual guidance has considered physical sexual problems	45 (61,6%)	6 (8,2%)	14 (19,2%)	8 (11,0%)	0 (0%)
The sexual guidance has considered feelings about sexuality	49 (67,1%)	6 (8,2%)	12 (16,4%)	5 (6,8%)	1 (1,4%)

Table 3 shows clearly that the participants had not had sufficient sexual guidance. In the population of 73 patients, one completely agreed that he/she had had sufficient sexual guidance. Majority of the 43 participants who answered to open question about good or bad in the sexual guidance revealed that there was none. Some participants had guidance in orientation course but thought that it was stereotypic and childish. Some of the women talked about the issues with their gynecologist and a few men wrote that the subject was raised only when erection medication was needed. Strong relationship was seen as an asset in difficulties.

> en muista, että sekskuaalisuutta olisi käsitelty missään vaiheessa, paitsi ehkä kuntoutuskurssilla tai sitten jossain välissä on sanottu, että tauti saattaa aiheuttaa erektio-ongelmia. Otin erektio-ongelman itse puheeksi vuosikontrollissa ja sain Viagran reseptin Mies, 51-60.
>
> I don´t remember that sexuality would have been discussed in any point, maybe except in a rehabilitation course or said at some poin that the illness might cause erection problems. I brought up the erection problem in the annual control and i got a prescription for Viagra. Male, 51-60

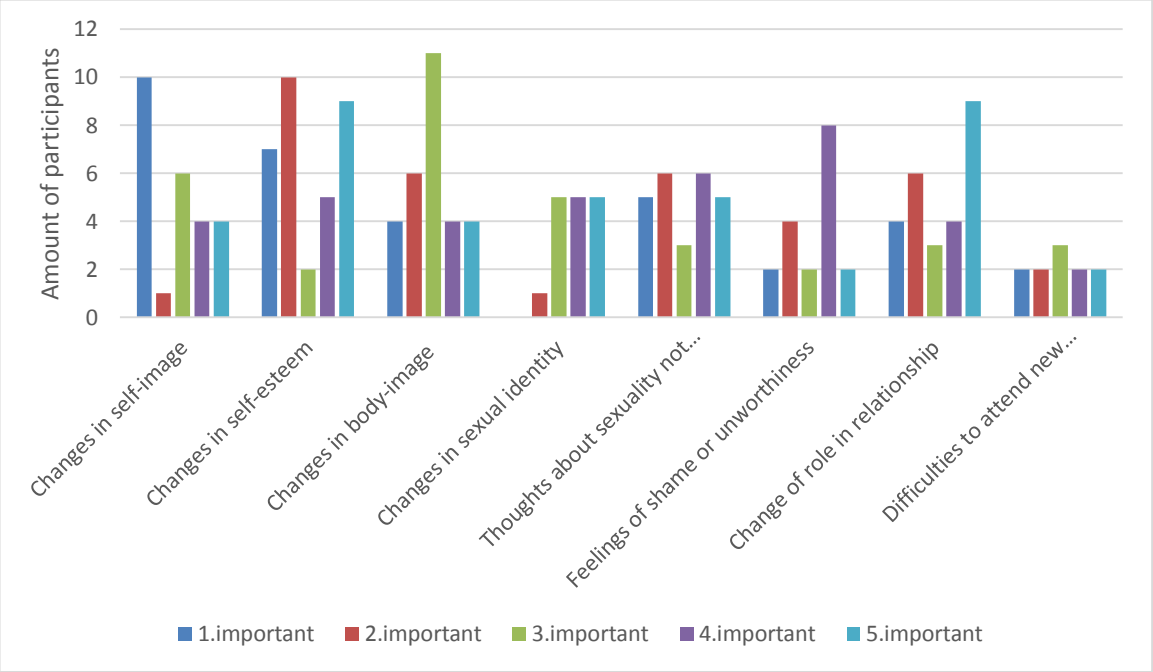
> Suoraa sanottu että se kuuluu parisuhteeseen. ehkäisystä puhuttiin sairastumisen alkuvaiheessa, ja tästä johtuen minulla päädyttiin sterilisaatioon, joka hyvä vaihtoehto ollut. Nainen, alle 30.
>
> I´ve been directly told that it (sexuality) belongs in to the relationship. Birth control was talked in the early stages of the illness and therefore sterilization was chosen for me, it has been a good choice. Female, under 30.

> Ohjausta ei ole ollut, ilmeisesti ajatellaan, että näin vahoilla ei ole seksielämää. Pitkässä parisuhteessa on selvitty hyvin vankan luottamuksen turvin. Nainen, yli 61.
>
> There has not been guidance, apparently it is thought that this old don´t have sex life. In a long relationship we have survived well with strong confidence. Female, over 61.

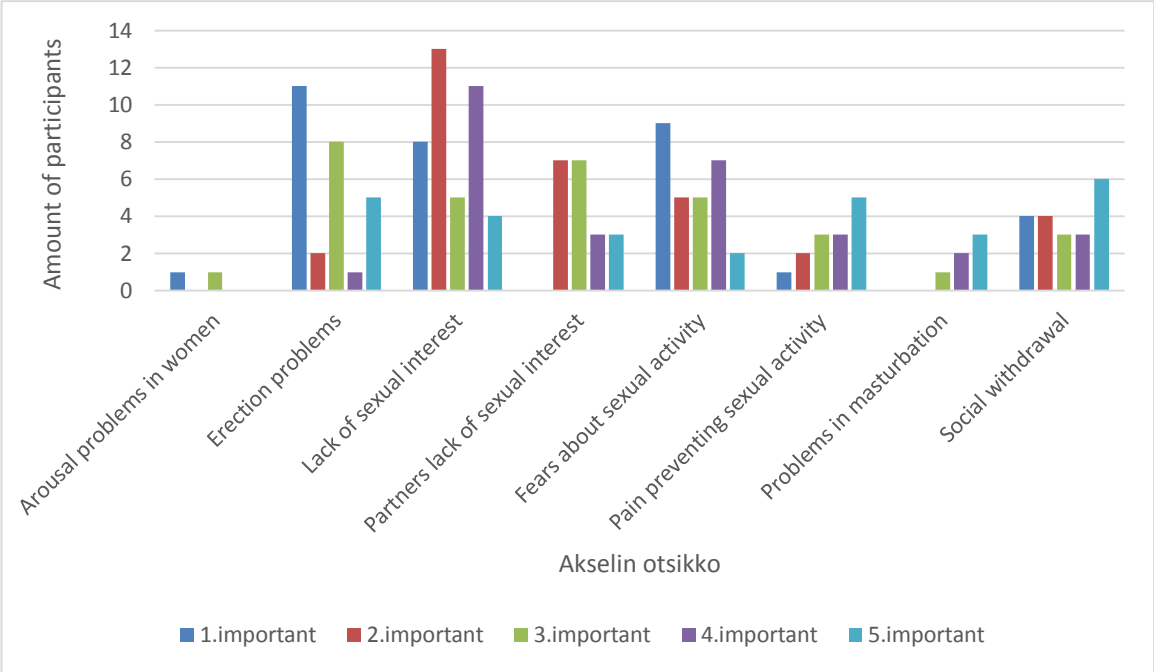
TABLE 4. The important factors in sexual guidance.

I find it important that	Completely disagree N (%)	Partly disagree N (%)	Cannot answer N (%)	Partly agree N (%)	Completely agree N (%)
Registered nurses give oral sexual guidance	7 (9,6%)	6 (8,2%)	20 (27,4%)	19 (26,0%)	21 (15,3%)
Registered nurses give written material about sexuality	7 (9,6%)	7 (9,6%)	15 (20,5%)	13 (17,8%)	31 (42,5%)
Registered nurses tell where to find information about sexuality if I have questions	8 (11,0%)	4 (5,5%)	12 (16,4%)	16 (21,9%)	33 (45,2%)
I receive sexual guidance in basic health care	14 (19,2%)	7 (9,6%)	18 (24,7%)	22 (30,1%)	12 (16,4%)
I receive sexual guidance in central hospitals	12 (16,4%)	5 (6,8%)	19 (26,0%)	18 (24,7%)	19 (26,0%)
I receive sexual guidance in university hospital	8 (11,0%)	6(8,2%)	23 (31,5%)	16 (21,9%)	20 (27,4%)
Registered nurse brings up sexuality in reception or nursing situation	9 (12,3%)	8 (11,0%)	15 (20,5%)	16 (21,9%)	25 (34,2%)
I can ask registered nurse about sexual issues I have in mind	6 (8,2%)	1 (1,4%)	13 (17,8%)	16 (21,9%)	37 (50,7%)
Registered nurses have good skills to talk about sexuality with me	6 (8,2%)	2 (2,7%)	11 (15,1%)	16 (21,9%)	38 (52,1%)
Sexual guidance consideres prevention of pregnancy/STD´s	12 (16,4%)	9 (12,3%)	19 (26,0%)	14 (19,2%)	19 (26,0%)

Table 4 shows that the participants think that sexual guidance offered by RN is important. The most important aspects in the sexual guidance were written material (60, 3% partly or completely agreed) and explaining where to find more information (67, 1%). The widest variation in this question was in the statements concerning the place the sexual guidance is provided and there is no clear answer where the sexual guidance should be actualized. The least important factor in the guidance was the prevention of pregnancy and STDs. This might have been affected by the age of the participants. Majority of the participants (56, 1%) felt that it is important that the nurse begins the conversation about sexuality. The possibility to ask questions from the nurse was found even more important (72, 6 % partly or completely agree)



GRAPH 4. The most important issues to discuss in sexual guidance, part 1.



GRAPH 5. The most important issues to discuss in sexual guidance, part 2.

Graphs 4 and 5 show that the answers to the question about priority of issues to be discussed in sexual guidance. They were asked to choose five most important topics and number them from one to five. The most often mentioned topic was lack of sexual interest (41 participants chose it into their top 5), lowered self-esteem (33), changes in body-image (29), fears about sexual activity (28) and men's erection problems (27).

In the open question about wishes on ways to improve sexual guidance (37 answers) the major wish was that the issue would be talked about instead of a silence. The participants wished that they would have a change to talk about sexuality if they had the need.

> Tämä keskustelu pitäisi kuulua jokaisen potilaan vakioohjelmaan. Vaikka ongelmia ei olisikaan niin valtaosaa potilaista asiat avarmaankin askarruttavat. Mies, 51-60.
>
> This discussion should be part of every patient´s normal programme. Even if you wouldn´t have problems, most of the patients are thinking about the things. Male, 51-60.

Nurses should have the skills to bring up the sexual issues and see when the patient is ready to talk about it.

Rohkeus tarttua asiaan asiakkaan ehdoilla kuunnellen herkin tuntosarvin, mitä asiakas kehollaan viestii, koska asia saattaa olla hyvinkin arka ja siitä saattaa olla todella vaikea puhua. Nainen, yli 61.

Courage to bring up the issue on patient´s condition, listening with sensitive ears what the patient is messaging with her body, because the subject might be very sensitive and difficult to talk about. Female, over 61.

8 DISCUSSION AND CONCLUSION

8.1 Discussion of the research methods and limitations

Semi-structured questionnaire was chosen because the study was a basic study where the most important information is quantitative information. The answers to the qualitative questions offered additional information about why the participants felt the way they did. Internet based questionnaire was chosen because sexuality is a sensitive subject and it might have been more difficult for participants to answer if there was a chance of being seen while answering. The research revealed practical information about the lack of sexual guidance. The questionnaire was sent to approximately 400 persons and 73 answers were accepted. The answering percentage in this study was between 15 and 20 %. The actual number of the persons who received the questionnaire is not known because the questionnaire was sent via Karpatiat ry. and some of the e-mail addresses might have not been updated.

Finding literature for the base of the questionnaire was challenging but the bachelor thesis actualized by Jonna Saksola in 2009 was very helpful while forming the actual questionnaire. SPSS-programme was used while analysing the data but the researcher found it difficult due lack of proper skills to using this programme.

Ethics was considered while implementing the research. The participants were offered information what they were answering for and they did it voluntarily. The anonymity of the participants was secured. Validity and reliability of the thesis were maintained by using previously used questionnaire as a mold for the questionnaire used and pre-testing the guestionnaire. The literature used was the most resent found. Having both Finnish answers in the open-ended questions and the translations visible in the thesis is supporting the reliability.

8.2 Discussion of the research findings

The researcher´s original hypothesis that the patients would have changes in their sexuality due the illness and their need for sexual guidance was partly confirmed. The lack of sexual guidance offered by nurses at the moment was confirmed completely.

The sexuality of the patients´ had changed both mentally and physically and the lack of sexual interest was the most common change. Other common changes were changes in self-image, self-esteem and body-image. The situation of sexual guidance was poor and only 1, 4 % of the participants completely agreed to have had sufficient sexual guidance from a registered nurse. The nurses 'preparedness to discuss about sexuality was observed low.

The patients found the sexual guidance important and especially the written material and the location of more information were seen significant. There was no clear answer whether the patients would like to have their guidance in basic health care or in special health care settings. The participants found important both the nurse beginning the discussion about sexuality and the possibility to ask themselves about their questions. The need for guidance about contraception and STD prevention was divided into two. This might be because the elderly in long relationships do not need contraception and the risk for STDs is lower. In all questions the amount of cannot answer- answers were relatively high. This might be due either unwilliness to answer or because the question was not clearly presented.

8.3 Conclusion

Some of the patients were having changes and problems in sexuality due cardiomyopathy/heart sarcoidosis, others did not. The need of sexual guidance varied but the lack of it was seen nationally. In conclusion, nurses should have the readiness to discuss sexual matters with the patients if they have problems or questions but not to force the information to them. Nurses´ education of sexual guidance should be improved to in order to create an open atmosphere where a patient can ask about sexuality without fear.

8.4 Implications for nursing practice and further studies

Sexual guidance and especially offering written material should be a part of the nursing care of the patients with cardiomyopathy or heart sarcoidosis. The nursing care should be planned by including sexuality and relationship issues. Additional sexuality education nursing education would be beneficial. Further studies are needed to find out what would be the most beneficial venue and time for sexuality guidance in the nursing care of cardiomyopathy and heart sarcoidosis patients.

REFERENCES

Apter, D., Väisälä, L. & Kaimola, K. Seksuaalisuus. 2006. Jyväskylä, Duodecim.

Barnason, S., Mosack, V., Steinke, E. & Wright, D. 2011. Progress in Sexual Counseling by Cardiac Nurses 1994 to 2009. Heart & Lung: The journal of acute and critical care. May-June 2011, e15-e24. Available: http://sciencedirect.com/science/article/pii/S014795631000364X Accessed 7 January 2015.

Dahlberg, K., Ekenstam, C. & Sundler, A. 2009. The Meaning of Close Relationships and Sexuality: Women´s Well-Being Following a Myocardial Infarction. Qualitative Heatlh Research. March 2009, 375-387. Available: http://ghr.sagepub.com/content/19/3/375.long Accessed 7 January 2015.

Duodecim Lääketietokanta. 2014. Available: http://www.terveysportti.fi/terveysportti/laake.dlr_laake.koti Accessed 7 January 2015.

Elliott, P., Andersson, B., Arbustini, E., Bilinska, Z., Cecchi, F., Charron, P., Dubourg, O., Kühl, U., Maisch, B., McKenna, W., Monserrat, L., Pankuweit, S., Rapezzi, C., Seferovic, P., Tavazzi L. & Keren, A. 2008. Classification of the cardiomyopathies: a position statement from the european society of cardiology working group on myocardial and pericardial diseases. European Heart Journal, January 2008. Available: http://eurheartj.oxfordjournals.org/content/29/2/270.article-info Accessed 5 January 2015.

Europe, E. & Tyni-Lenne, R. 2004. Qualitative Analysis of the Male Experience of Heart Failure. Heart & Lung: The journal of acute and critical care. July-August 2004, 227-234. Available: http://www.sciencedirect.com./science/article/pii/S014795630400069X Accessed 7 January 2015.

Fridlund, B., Ivarsson, B. & Sjöberg, T. 2009. Information from Health Care Professionals about Sexual Function and Coexistence After Myocardial Infarction: A Swedish national Survey. Heart & Lung: The journal of acute and critical care. July-August 2009, 330-335. Available: http://www.sciencedirect.com/science/article/pii/S0147956309000028 Accessed 7 January 2015.

Heliö, T. & Kuusisto, J. 2013. Kardiomyopatiat ja myokardiitti, in a book Nuorten sydänsairaudet. Sydänlapset ja –aikuiset ry, Keuruu; Otavan kirjapaino Oy.

Heliö, T. & Peuhkurinen, K. 2008. Laajentava kardiomyopatia, in a book Kardiologia, Second edition. Duodecim, Jyväskylä; Gummerus Kirjapaino Oy.

Hirsjärvi, S., Remes, P. & Sajavaara, P. 2013. Tutki ja kirjoita, 15-17th edition. Helsinki, Kustannusosakeyhtiö Tammi.

Kaaja, R & Lehto, P. 2008. Sydän ja Raskaus, in a book Kardiologia, Second edition. Duodecim, Jyväskylä; Gummerus Kirjapaino Oy.

Kandolin, R., Lehtonen, J., Schildt, J., Granér M., Salmenkivi, K., Ahonen, A., Karhumäki, L. & Kupari, M. 2009. Sydänsarkoidoosi. Lääketieteellinen Aikakauskirja Duodecim, 2009;125(21):2344-50. Available: http://www.duodecimlehti.fi/web/guest/arkisto?p_p_id=Article_WAR_DL6_Articleportlet&p_p_action=1&p_p_state=maximized&viewType=viewArticle&tunnus=duo98400 Accessed 5 January 2015.

Karpatiat ry. 2013. Available: http://www.sydanliitto.fi/web/karpatiat/etusivu Accessed 5.1.2015.

Kupari, M. 2008. Restriktiivinen kardiomyopatia, , in a book Kardiologia, Second edition. Duodecim, Jyväskylä; Gummerus Kirjapaino Oy.

Kupari, M. & Kokkonen, J. 2008. Sydän munuaisten vajaatoiminnassa, systeemisissä sairauksissa ja hermo-lihastaudeissa, , in a book Kardiologia, Second edition. Duodecim, Jyväskylä; Gummerus Kirjapaino Oy.

Kuusisto, J. & Sinisalo, J. 2008. Hypertrofinen kardiomyopatia, in a book Kardiologia, Second edition. Duodecim, Jyväskylä; Gummerus Kirjapaino Oy.

Nolen-Hoeksema, S., Fredrickson, B., Loftus, G. & Wagenaar, W. 2009. Atkinson & Hildegard´s Introduction to Psychology, 15th edition. Wadsworht.

Richardson, P., McKenna, W., Bristow, M., Maisch, B., Mautner, B., O´Connel, J., Olsen, E., Thiene, G. Goodwin, J., Gyarfas,I., Martin, I. & Nordet P. 1996. Report of the 1995 World Health Organization/International Society and Federation of Cardiology Task Force on the Definition and Classification of Cardiomyopathies. Circulation 1996; 93:841-842 Available: http://circ.ahajournals.org/content/93/5/841.long Accessed 5.1.2015.

Ryttyläinen, K. & Valkama, S. 2010. Seksuaalisuus hoitotyössä. Helsinki, Edita.

Ryttyläinen, K. & Virolainen I. 2009. Lupa puhua – Asiakkaan ja potilaan seksuaaliohjaus hoitotyössä. Jyväskylän ammattikorkeakoulu, Keski-Suomen sairaanhoitopiiri. Available: http://www.seksologinenseura.fi/tiedostot/LupaPuhua.pdf Accessed 5 January 2015

Saksola, J. 2009. ”Tärkeä, mutta vähän puhuttu asua!” Seksuaaliterveyden huomioiminen erikoissairaanhoidon kuntoutusohjauksessa. Opinnäytetyö. Jyväskylän ammattikorkeakoulu. Availble: http://www.theseus.fi/bitstream/handle/10024/17594/jamk_1239872728_2.pdf?sequence=2 Accessed 5 January 2015

Virtanen, J. 2002. Kliininen seksologia. Helsinki: Werner Söderström Osakeyhtiö.

Winter M., Reisma, C., Kedde, H., Bouma, B., Vis, J., Luijendijk,P., de Witte, P., Zwinderman, A., Vliegen,H., Pieper, P., van Dijk A. & Mulder, B. 2010. Sexuality in Adult Patients With Congenital Heart Disease and their Partners. The American Journal of Cardiology. October 2010, 1163-1168. Available:

http://www.sciencedirect.com/science/article/pii/ S0002914910012142 Accessed 7 January 2015.

World Assosiation for Sexual Health. WAS Declaration of Sexual Rights. 1999. Available: http:((www.worldsexology.org(content(sexual-rights-0 Accessed 21 September 2013

World Assosiation for Sexual Health. WAS Declaration of Sexual Rights reviced 2014 2014. Available: http:((www.worldsexology.org(wp-content(uploads(2013(08(declaration_of_sexual_rights_sep03_2014.pdf Accessed 21 November 2014

World Health Organization. 2006. Defining Sexual Health. Available: http:((www.who.int(reproductivehealth(topics(sexual_health(sh_definitions(en(index.html Accessed 8 September 2013

Sairaanhoitajan antama seksuaaliohjaus kardiomyopatia- ja sydänsarkoidoosipotilaille

1. Sukupuoli *

- ◯ Nainen
- ◯ Mies

2. Ikä *

- ◯ alle 30 vuotta
- ◯ 31-40 vuotta
- ◯ 41-50 vuotta
- ◯ 51-60 vuotta
- ◯ yli 61 vuotta

3. Koulutustaso *

- ◯ peruskoulu/kansakoulu
- ◯ lukio/ ammattitutkinto
- ◯ korkeakoulututkinto

4. Asuinalue

- ◯ Etelä-Suomen lääni
- ◯ Itä-Suomen lääni
- ◯ Länsi-Suomen lääni
- ◯ Oulun lääni
- ◯ Lapin lääni
- ◯ Ahvenanmaa

5. Elämäntilanne

◯ Naimaton

◯ Parisuhteessa

◯ Avoliitossa

◯ Avioliitossa

◯ Eronnut

◯ Leski

6. Diagnoosi

◯ Dilatoiva kardiomyopatia

◯ Restriktiivinen kardiomyopatia

◯ Hypertrofinen kardiomyopatia

◯ Sydänsarkoidoosi

◯ Muu

7. Kuinka monta vuotta olette sairastanut kardiomyopatiaa tai sydänsarkoidoosia?

0-100 _____

8. Kardiomyopatia/sydänsarkoidoosi on aiheuttanut seuraavia muutoksia seksuaalisuudelleni (merkitse sopivin vaihtoehto) *

	1= täysin eri mieltä	2= osittain eri mieltä	3= en osaa sanoa	4= osittain samaa mieltä	5= täysin samaa mieltä
Minäkuvan muutoksia	○	○	○	○	○
Itsetunnon laskua	○	○	○	○	○
Kehonkuvan muutoksia	○	○	○	○	○
Seksuaali-identiteetin muutoksia	○	○	○	○	○
Ajatuksia siitä, ettei seksuaalisuus kuulu sairaan elämään	○	○	○	○	○
Arvottomuuden tai häpeän tunteita	○	○	○	○	○
Parisuhteen roolimuutoksia	○	○	○	○	○
Vaikeuksia solmia uusia intiimejä suhteita	○	○	○	○	○
Sosiaalista vetäytymistä	○	○	○	○	○
Kostumisen vaikeuksia (naisella)	○	○	○	○	○
Erektiovaikeuksia (miehellä)	○	○	○	○	○
Seksuaalista haluttomuutta jossain vaiheessa	○	○	○	○	○
Puolison seksuaalista haluttomuutta jossain vaiheessa	○	○	○	○	○
Seksuaaliseen aktiivisuuteen liittyviä pelkoja	○	○	○	○	○
Seksuaalista läheisyyttä haittaavia kipuja	○	○	○	○	○
Seksuaaliseen kanssakäymiseen liittyviä vaaroja	○	○	○	○	○
Vaikeuksia itsetyydytyksessä	○	○	○	○	○

9. Muita seksuaalisuuteen vaikuttavia muutoksia, mitä?

_____

_____

_____

10. Koen *

	1= täysin eri mieltä	2= osittain eri mieltä	3= en osaa sanoa	4= osittain samaa mieltä	5= täysin samaa mieltä
Saaneeni sairaanhoitajilta riittävästi suullista seksuaaliohjausta	○	○	○	○	○
Saaneeni sairaanhoitajilta riittävästi kirjallista materiaalia liittyen seksuaalisuuteen	○	○	○	○	○
Saaneeni riittävästi tietoa sairaanhoitajiltani kuinka saan lisätietoa seksuaalisuuteen liittyvistä asioista	○	○	○	○	○
Saaneeni seksuaaliohjausta perusterveydenhuollossa	○	○	○	○	○
Saaneeni seksuaaliohjausta keskussairaalassa	○	○	○	○	○
Saaneeni seksuaaliohjausta yliopistosairaalassa	○	○	○	○	○
Sairaanhoitajien ottaneen seksuaalisuuden puheeksi	○	○	○	○	○
Itse ottaneeni seksuaalisuuden puheeksi sairaanhoitajan kanssa	○	○	○	○	○
Sairaanhoitajilla olleen hyvät valmiudet keskustella seksuaaliongelmistani	○	○	○	○	○
Seksuaaliohjauksen käsitelleen raskauden/sukupuolitautien ehkäisyä	○	○	○	○	○
Seksuaaliohjauksen käsitelleen fyysisiä seksuaaliongelmia	○	○	○	○	○

Seksuaaliohjauksen käsitelleen seksuaalisuuteen liittyviä tunteita	○	○	○	○	○
Seksuaaliohjauksen käsitelleen parisuhdetta	○	○	○	○	○

11. Seksuaaliohjauksessa on ollut hyvää/huonoa?

_____

_____

_____

12. Koen tarpeelliseksi *

	1= täysin eri mieltä	2= osittain eri mieltä	3= en osaa sanoa	4= osittain samaa mieltä	5= täysin samaa mieltä
Sairaanhoitajien antaman suullisen seksuaaliohjauksen	○	○	○	○	○
Sairaanhoitajien antaman kirjallisen seksuaaliohjausmateriaalin	○	○	○	○	○
Sairaanhoitajien kertovan mistä löydän lisää tietoa jos minulla herää seksuaalisuuteen liittyviä kysymyksiä	○	○	○	○	○
Että saan seksuaaliohjausta perusterveydenhuollossa	○	○	○	○	○
Että saan seksuaaliohjausta keskussairaalassa	○	○	○	○	○
Että saan seksuaaliohjausta yliopistosairaalassa	○	○	○	○	○
Että sairaanhoitaja ottaa seksuaalisuuden puheeksi vastaanotto- tai hoitotilanteessa	○	○	○	○	○
Että voin itse kysyä sairaanhoitajalta mieltäni askarruttavista seksuaalikysymyksistä	○	○	○	○	○
Että sairaanhoitajilla on hyvät	○	○	○	○	○

valmiudet keskustella seksuaalisuudesta kanssani					
Että seksuaaliohjauksessa käsitellään myös raskauden/sukupuolitautien ehkäisyä	○	○	○	○	○

13. Seksuaaliohjauksessa tärkeimmät käsiteltävät asiat ovat: (Valitse alla olevasta listasta viisi tärkeintä ja laita ne tärkeysjärjestykseen niin että numero 1 on tärkein, numero 2 on seuraavaksi tärkein ja niin edelleen,)

	1=tärkein	2=toiseksi tärkein	3=kolmanneksi tärkein	4=neljänneksi tärkein	5=viidenneksi tärkein
Minäkuvan muutokset *	○	○	○	○	○
Itsetunnon lasku *	○	○	○	○	○
Kehonkuvan muutokset *	○	○	○	○	○
Seksuaali-identiteetin muutokset *	○	○	○	○	○
Ajatukset siitä, ettei seksuaalisuus kuulu sairaan elämään *	○	○	○	○	○
Arvottomuuden tai häpeän tunteet *	○	○	○	○	○
Parisuhteen roolimuutokset *	○	○	○	○	○
Vaikeudet solmia uusia intiimejä suhteita *	○	○	○	○	○
Sosiaalinen vetäytyminen *	○	○	○	○	○
Kostumisen vaikeudet (naisella) *	○	○	○	○	○
Erektiovaikeudet (miehellä) *	○	○	○	○	○

Seksuaalinen haluttomuus *	○	○	○	○	○
Puolison seksuaalinen haluttomuus *	○	○	○	○	○
Seksuaaliseen aktiivisuuteen liittyvät pelot *	○	○	○	○	○
Seksuaalista läheisyyttä haittaavat kivut *	○	○	○	○	○
Itsetyydytyksen vaikeudet *	○	○	○	○	○

14. Mielestäni seksuaaliohjauksessa parannettavaa olisi?

_____

_____

_____

APPENDIX 2

Hei Karpatioiden jäsen.
Kuten jäsenlehdessämme 3/2013 kerroimme ennakkotietona, lähetämme Karpatioiden jäsenrekisterissä oleville potilaille sähköpostitse linkin opinnäytetyön kyselyyn. Alta löydät tarkempia tietoja kyselystä. Kyselyyn vastataan anonyymisti ja osallistuminen on vapaaehtoista.

Karpatioiden hallituksen puolesta, Liisa Heino

Arvoisa vastaanottaja,

Oheinen kysely on osa Centria ammattikorkeakoulun opinnäytetyötä, jossa tutkitaan vaikuttaako kardiomyopatia tai sydänsarkoidoosi potilaan seksuaalisuuteen ja kuinka sairaanhoitajat voisivat antaa parasta mahdollista seksuaaliohjausta potilaille. Opinnäyetyö tehdään yhdessä Karpatiat ry:n kanssa ja kysely lähetetään sähköisenä Karpatiat ry:n jäsenille.

Kyselyn tietoja käytetään vain kyseisen opinnäytetyön tekoon. Kyselyyn vastataan anonyymisti ja osallistuminen on vapaaehtoista.

Pyydän vastaamaan kyselyyn viimeistään 16.3.2014.

Kyselyn löydätte oheisesta linkistä. Huomioittehan että vastaatte jokaiseen kysymykseen.

https://www.webropolsurveys.com/S/780547DD83943F58.par

Lisätiedot: katja.kosonen@centria.fi

Yhteistyöstä kiittäen,
Katja Kosonen

APPENDIX 3

OPINNÄYTETYÖ

Olen kolmannen vuoden sairaanhoitajaopiskelija Centria Ammattikorkeakoulun Kokkola-Pietarsaaren yksiköstä. Opiskelen englanninkielisellä Nursing-linjalla ja opinnäytetyöni aihe on kardiomyopatia- ja sydänsarkoidoosipotilaiden seksuaalisuus ja hoitajan rooli sen tukemisessa. Tulen tekemään tammi-helmikuun aikana Wepropol- kyselyn, jonka linkki lähetetään Karpatiat ry:n jäsenille sähköpostilla. Tutkimuksen tavoitteena on selvittää onko seksuaalisuuden kokemisessa tapahtunut muutosta sairauden myötä, olisiko hoitajien tarpeellista ohjata potilaita seksuaalisuutta koskevissa asioissa ja mitkä keinot ohjaukseen olisivat potilaiden mielestä tehokkaimpia ja luontevimpia. Tutkimukseen osallistuminen on vapaaehtoista ja kyselyyn vastataan anonyymisti. Tulokset julkaistaan opinnäytetyössä syyskuussa 2014. Lisätietoja tutkimuksesta voi kysyä sähköpostilla katja.kosonen@centria.fi.

Terveisin Katja Kosonen

Centria
AMMATTIKORKEAKOULU

OPINNÄYTETYÖSOPIMUS

Opinnäytetyön tekijä/t Katja Kosonen	Aloituspäivämäärä 1.5.2013
Koulutusohjelma Degree programme in nursng	Yksikkö Kokkola-Pietarsaaren yksikkö
Koulutusohjelman yliopettaja Anita Hollanti	Opinnäytetyön ohjaaja Pia Hagqvist/Anita Hollanti

Opinnäytetyön työnimi (aihe)

CARDIOMYOPATHY AND HEART SARCOIDOSIS PATIENTS´ SEXUALITY AND NEED FOR SEXUAL GUIDANCE

Tutkimusongelma/kehittämistehtävä

1) **How has the sexuality of the patients changed due the disease? Kuinka seksuaalisuus on muuttunut sairauden myötä?**

2) **What kind of guidance related to sexuality and sex have the patients received from nurses during their process of illness? Millaista seksuaalisuuteen ja seksiin liittyvää ohjausta potilaat ovat saaneet hoitajilta sairauden aikana?**

3) **What kind of sexual guidance the patients need? Millaista seksuaaliohjausta potilaat tarvitsevat?**

Opinnäytetyön tavoite ja rajaus/tutkimustulokset

Tarkoituksena on selvittää kokevatko kardiomyopatia- ja sydänsarkoidoosipotilaat tarvetta seksuaaliohjaukselle ja millaista ohjausta he tarvitsevat. Tavoitteena on, että hoitajat saisivat tietoa ohjauksen tarpeesta ja voisivat antaa sitä parhaalla mahdollisella tavalla.

Centria
AMMATTIKORKEAKOULU

OPINNÄYTETYÖSOPIMUS

Opinnäytetyön alustava aikataulu (pvm:t kuukauden tarkkuudella)

Aloituspalaveri (ohjaaja, työn tekijä, työelämäohjaaja) [1/2014]
Toteutussuunnitelman esittäminen [1/2014]
Väliraportointi [3/2014]
Ohjaajan tarkastus ja/tai loppupalaveri [5/2014]
Opinnäytetyön hyväksyttäväksi jättäminen [6/2014]
Opinnäytetyön seminaariesitys [9/2014]
Kypsyyskoe [10/2014]

Toimeksiantajan yhteystiedot (yritys, yhteyshenkilön nimi, osoite, puhelin, sähköposti)

Karpatiat Ry, Liisa Heino/ Eija Suominen, Oltermannintie 8, 00620 Helsinki, 0400 602 878, toimisto@karpatiat.net

Tämä sopimus on laadittu kolmena kappaleena. Sopimuskappaleet toimitetaan opinnäytetyön tekijälle, toimeksiantajalle sekä työn ohjaajalle. Keski-Pohjanmaan ammattikorkeakoulun opiskelija sitoutuu tekemään toimeksiantajan toimeksiannosta edellä mainitusta aiheesta opinnäytetyön 31.10.2014 mennessä.

Toimeksiantaja sitoutuu antamaan opiskelijan käyttöön työssä tarvittavaa tietoa sekä arvioimaan opinnäytetyön valmistuttua sen hyödynnettävyyttä toiminnassaan. Toimeksiantaja maksaa
materiaali-, postitus-, matka- ym. mahdolliset kulut laskun mukaan. Toimeksiantaja voi maksaa opinnäytetyön tekijälle palkan.

Tämän sopimuksen osapuolet ovat velvolliset pitämään salassa kaiken, mitä he toimeksiannon yhteydessä ovat aaneet tietoonsa asioista, joita voidaan pitää toisen sopijapuolen liikesalaisuutena. Opinnäytetyö käydään läpi ammattikorkeakoulun opinnäytetyöseminaarissa ja se on julkinen asiakirja. Toimeksiantajan tulee erikseen pyytää työn salausta.

Ammattikorkeakoulu ei vastaa opinnäytetyön tekijän mahdollisesti aiheuttamasta haitasta tai vahingosta.

Päiväys
14.2.2014

Työelämäohjaajan allekirjoitus

Opiskelijan allekirjoitus

Opinnäytetyön ohjaajan allekirjoitus

APPENDIX 4/3