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CHRONICALLY ILL AND ONLINE PEER-TO-PEER SUPPORT

ABSTRACT

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This master's thesis explored online peer-to-peer communities for chronically ill, how patients use them and how they affect their well-being. In addition to that, it was researched if the usage and effects are similar amongst Finnish narcolepsy patients.

Chronic diseases complicate life in many ways. Peer-to-peer support helps patients to understand their disease better and to feel more normal despite the disease. The amount of chronically ill patients has been increasing globally which means that there is an increasing need for peer-to-peer support.

The internet offers new ways to conduct peer-to-peer support. Online communities and social media allow patients to interact with each other regardless of their physical location.

The topic was researched with a literature review and interviews. At first, earlier studies about chronically ill and online peer-to-peer support or online health-communication were explored. After that, semi-structured interviews were conducted with Finnish narcolepsy patients. Interviews were analyzed with thematic analysis.

Finnish narcolepsy patients as well as other chronically ill use online peer-to-peer support communities mainly to discuss their own experiences and share information about their disease.

Online peer-to-peer support has many benefits: it gives a sense of connection, and helps to feel less isolated and to find new information. Chatting with peers helps to accept the disease as a normal part of one's life. Finnish narcolepsy patients had experienced similar benefits.

Online peer-to-peer support might set up too high expectations or make one take his peers' negative experiences too personally. Some patients might trust their peers too much and take poor advice from them. Finnish narcolepsy patients had not experienced these negative effects.

Keywords: Online community, social media, peer-to-peer support, chronic disease

TIIVISTELMÄ

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Tässä tutkielmassa tutustuttiin kroonisesti sairaiden vertaistukiyhteisöihin verkossa ja siihen, kuinka potilaat käyttävät niitä ja miten ne vaikuttavat heidän hyvinvointiinsa. Lisäksi tutkittiin, onko verkon vertaistukiyhteisöjen käyttö ja vaikutukset samankaltaisia suomalaisten narkolepsiapotilaiden joukossa.

Krooniset sairaudet hankaloittavat elämää monin tavoin. Vertaistuki auttaa potilaita ymmärtämään sairautta paremmin ja tuntemaan itsensä normaaliksi sairaudesta huolimatta. Kroonisesti sairaiden määrä on ollut kasvussa ympäri maailman, joten myös vertaistuen tarve kasvaa.

Internet tarjoaa uudenlaisia tapoja toteuttaa vertaistukea. Nettiyhteisöt ja sosiaalinen media mahdollistavat potilaiden yhteydenpidon riippumatta heidän fyysisistä sijainneistaan.

Aihetta tutkittiin kirjallisuuskatsauksen ja haastatteluiden avulla. Aluksi tutustuttiin aiempiin tutkimuksiin kroonisesti sairaiden verkossa tapahtuvasta vertaistuesta ja terveysviestinnästä. Sen jälkeen suomalaisille narkolepsiapotilaille järjestettiin puolistrukturoituja haastatteluja. Haastattelut analysoitiin teemoittelemalla.

Suomalaiset narkolepsiapotilaat ja muut kroonisesti sairaat käyttävät verkon vertaistukiyhteisöjä pääasiassa keskustellakseen kokemuksistaan ja jakaakseen tietoa taudista.

Verkossa tapahtuvalla vertaistuella on monia hyötyjä: se luo tunteen yhteydestä sekä auttaa potilaita tuntemaan itsensä vähemmän eristyneiksi ja löytämään uutta tietoa. Vertaisten kanssa juttelu auttaa hyväksymään taudin normaalina osana elämää. Suomalaiset narkolepsiapotilaat olivat huomanneet samanlaisia hyötyjä.

Verkossa tapahtuva vertaistuki saattaa asettaa potilaalle liian korkeita odotuksia tai saada hänet ottavaan muiden negatiiviset kokemukset henkilökohtaisesti. Jotkut saattavat luottaa vertaisiinsa liikaa ja noudattaa heiltä saamiaan huonoja neuvoja. Suomalaiset narkolepsiapotilaat eivät olleet huomanneet tämän kaltaisia huonoja vaikutuksia.

Asiasanat: Verkkoyhteisö, sosiaalinen media, vertaistuki, krooninen sairaus

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1 INTRODUCTION

The amount of chronically ill patients is increasing globally as well as life expectancy is longer than earlier due to better medicine. This means that there are more chronically ill than ever and patients live longer with their disease. Peer-to-peer support allows patients with similar issues to share their experiences and offer encouragement, hope and coping strategies with each other. Peers are equal, so support from them differs from the care doctors and other health professionals offer. Traditionally peer-to-peer support has happened for example via face-to-face support or telephone helplines, but the internet offers new ways to conduct peer-to-peer support regardless of patients' locations or time zones.

Many chronically ill describe how they enjoy support their peers give and how interacting with their peers helps them to cope with their diseases. On the other hand, some chronic diseases might make leaving outside the house and interacting with other people difficult. That is why it was interesting to explore how chronically ill use the possibilities of online peer-to-peer support and how it benefits their well-being. It was also interesting to hear concrete experiences from Finnish narcolepsy patients and to compare those with findings of earlier studies about online peer-to-peer support of chronically ill.

The goal of this master's thesis was to find out how chronically ill patients use online communities, how they affect their well-being and is the usage similar amongst Finnish narcolepsy patients. To find out answers to this question, it was necessary to answer to three other questions:

1. What kind of online communities do they use?
2. How do they use online communities?
3. How online communities affect their well-being?

These questions were studied at first by exploring earlier studies with literature review. The literature review served as a framework for the empirical part of this master's thesis.The empirical part was a series of semi-structured interviews conducted to Finnish narcolepsy patients. Collected data was analyzed with thematic analysis.

Patients with chronic disease often seek peers and support online, where they are easier to find (Mamykina, Nakikj & Elhadad, 2015). In these online peer-to-peer support communities they usually discuss their experiences with the disease and share or seek more information about it (Zhou et al., 2014; Naslund et al., 2016). Based on the literature review it can be stated that online peer-to-peer support can improve chronically diseased patients' well-being in many ways. For example they get emotional support (Mamykina et al., 2015), better access to health information (Bender et al., 2011) and even form true friendships (Zhou et al., 2014).

Finnish narcolepsy patients use online peer-to-peer support communities in very similar ways compared to other chronically ill patients. They mostly follow the discussion, but take part in if they feel like it is necessary. They discuss about living with narcolepsy and share new information about the disease. Also the advantages of the online peer-to-peer support are similar. It makes them feel more normal and gives advices. Unlike earlier research has shown, Finnish narcolepsy patients did not report having experienced any negative effects. Their online peer-to-peer community had special features because some Finnish narcolepsy patients have gotten the disease from Pandemrix-vaccine and some "naturally". This had caused conflicts in their Facebook group and they had decided to establish another group for discussion related to the vaccine.

These results are useful for designing or renewing an online community for peer-to-peer support. Hopefully the results will raise thoughts about how important peer-to-peer support is for chronically ill and how it can be conducted via internet.

The key concepts of this study are online community, social media, sense of community and chronic disease. Online community is an interesting concept, because it can mean different things to different people. Someone sees it as a positive thing that brings people together while someone else is worried about it, because it enables for example networks of hatred. In the end, an online community can be any online social space where people can come together and share for example support or information, or find company. (Preece, 2010.) Social media can be defined with two terms: web 2.0 and user generated content. Web 2.0 is a way to use the internet not only to publish content, but also to allow content to be modified by all users. User generated content summarizes the usage of social media. It describes how end-users create content in different forms and publish it. (Kaplan & Haenlein, 2010.) Chronic disease is a disease that lasts at least 3 months. In general, they can not be cured with medication or prevented with vaccines.

This study begins with literature review, which is represented in chapters two and three. Chapter two introduces theory about online communities and social media. Chapter three focuses on online communities for chronically ill. Chronic diseases, peer-to-peer support and earlier studies about health-related online communities are presented. After chapters two and three, this study mo-

ves on to the empirical part and the empirical research is introduced in chapters four and five. Chapter four focuses on the background of the empirical research, and on the research method. Results of the research are represented in chapter five. Results of the literature review as well as the empirical part are discussed in chapter six. Chapter seven concludes the study and presents limitations and suggestions for future research.

2   ONLINE COMMUNITIES AND SOCIAL MEDIA

Communities are very natural to people. Usually everyone needs other people and likes to share information and experiences and engage in discussions. For many, social relationships are essential in life. Traditionally communities have been strongly based on a location, for example villages or certain parts of a city are location-based communities. The Internet has changed communities in many ways. Online communities are often based on common goals, interests, or something else its members share. Nowadays communities can be formed regardless of the members' locations. Social media evolves communities even further. Many social media platforms provide great bases for online communities.

This chapter provides a review on online communities especially in social media. The first part of this chapter focuses on communities in general and online. At first, the concept of community is explained. Then the sense of community is introduced, and it is studied how it forms. After that it is studied if the same things apply in online communities and how the success of online communities can be measured. The second part of this chapter focuses on social media and its communities. At first, the concept of social media is explained. Then it is reviewed how people use social media in different ways. After that it is studied how social media has changed communities and online communities, and how social media communities have evolved since the beginning of web 2.0.

2.1 Online communities

Even though the internet has changed the way communities work, the basis of online communities is still in the traditional communities and there are clearly more similarities than differences. Sense of community, and interaction with other people are the most important aspects in both traditional and online communities.

According to Gusfield (1975) the term community is used mostly in two ways. The first meaning of community is the territorial and geographical community. It can be for example town or a neighborhood. The second meaning of community is relational community. It is simply a human relationship without certain reference to a location. (Gusfield 1975.) Sense of community is generally important to all people. McMillan & Chavis (1986) even state that it operates as a force in human life.

In their article, McMillan & Chavis (1986) defined a sense of community and proposed four elements of it (Table 1). According to them, a sense of community consists of four things: (1) membership, (2) influence, (3) integration and fulfillment of needs, and (4) shared emotional connection.

Membership means that one has a feeling that he has invested a part of himself to become a member. Therefore, membership is a feeling of a right to belong and being a part. Another important aspect of membership is its boundaries – some people belong, and others do not belong. (McMillan & Chavis 1986.)

Influence is a concept where a member must have some influence on what group does to belong, and the group is able to influence its members. Members of a community usually feel a need for leadership. (McMillan & Chavis 1986.)

Integration and fulfillment of needs is reinforcement. Reinforcements serves as a motivator, it is rewarding to community members and it helps to maintain a secure sense of togetherness. Status of being a member and competence are good examples of reinforcers that brings members of a community closer together. (McMillan & Chavis 1986.)

Shared emotional connection has a base on a shared history of the group. In communities, the members do not necessarily have to have any part in the history, but they must at leasts identify with it. Group members' interactions for example in shared events may strengthen the community. (McMillan & Chavis 1986.)

Table 1 Elements of the sense of community

Element	Describtion
Membership	One has a right to belong and be a part of the group.
Influence	One has some influence on the group and the group has some influence on one.
Integration & fullfillment of needs	One gets reinforcement from being part of the group.
Shared emotional connection	One identifies with group's shared history.

The Internet has changed communities and the way they work – it enables people to interact in real time regardless of their locations. The buzz of online communities is not only about technology. It is also about people who have access to the internet in growing amounts and the ways they are making use of it. (Preece, 2001.) The Internet lets people create completely new kinds of social spaces where they interact with each other. Interaction can be either entertaining or informative - or both. (Smith & Kollock, 1999, p. 3-4.) It is widely popular to use online communities, which indicates that people use the internet to fulfill their objectives such as social and economic goals (Porter, 2004).

The term 'online community' is understood differently and there is not a one mutual definition. It can mean very different things to different people. For example someone might see online communities as warm groups of friends while someone else sees them as a possibility to create networks of hatred. (Preece, 2001.) Preece (2001, p. 3.) defines online communities as "any virtual social space where people come together to get and give information or support, to learn, or to find company".

There are endless amounts of different online communities. They can be small or large, international, national, or local. There are diverse types of online communities. Sometimes they are categorized based on the communication technology such as bulletin board systems or chats. Sometimes categories are based on the structure of interaction like small groups or networks. Some categories are based on a community's purpose such as interaction, support, or fantasy. Online communities could be characterized with five attributes: purpose, place, platform, structure of interaction and profit model. (Porter, 2004.)

According to Preece (2001), designing for both usability and sociability is needed to create well working online communities. We need to understand how technology supports social interactions. Sociability is about software development, policies and practices that support online interactions. (Preece 2001.) She states that good sociability consists of three key components: purpose, people and policies. Purpose is something that people in the community share. It can be for example an interest or a need that gives people a reason to belong to the community. People are interacting with each other and they have individual, social and organizational needs. Usually they take different roles in the community. Policies are protocols and language of the community. They guide how people interact and develop norms and rituals to the community. Usually there are both formal and informal policies. According to Preece (2001) usability is about how easy it is to learn to use community and how intuitive it is to us. Key issues in usability are support for dialog and interaction, information design, navigation, and access to the community.

The core of online communities is about sharing things and being a part of something no matter the physical location of its members. In its finest, the internet and online communities can help people to find other people with similar interests even if they are very specific. In good online communities people are very engaged to discussions and like to share their information and experiences.

They are also genuinely interested in other members of the community and want to learn from them.

2.2   Social media

Social media has changed internet and online communities. It offers people new ways to interact and build communities. Everyone can participate in interesting discussions, create content and comment to other users' content. The number of social media users is growing all the time all around the world. There are as many ways to use social media as there are people.

Kaplan and Haenlein (2010) define social media through two terms: web 2.0 and user generated content. Web 2.0 is a way of using the internet not only to create and publish content by individuals, but to constantly modify content by all users. User generated content sums the way social media is used. The term describes different forms of content end users create publicly. The most important aspects are that the content is publicly accessible on social media or website, that the content shows a certain amount of creative effort and that the content is created in non-professional ways. Social media is internet-based applications that are built on foundations of web 2.0, and that enable user generated content. (Kaplan & Haenlein, 2010.) There are different kinds of social media and different ways to use the social side of the online world. Kaplan and Haenlein (2010) classified different social media into six categories: collaborative projects such as Wikipedia, blogs, content communities such as Flickr, social networking sites such as Facebook, virtual game worlds such as World of Warcraft and virtual social worlds such as Second Life (Taulukko 2).

Table 2 Categories of Social Media

Social media category	Examples
Collaborative projects	Wikipedia TripAdvisor Pinterest
Blogs	Blogger Wordpress
Content communities	Youtube Flickr Slideshare
Social networking sites	Facebook Academia.edu

	LinkedIn
Virtual game worlds	World of Warcraft Minecraft
Virtual social worlds	Second life Habbo Hotel

Social media offers people an easy way to interact with each other. People use social media in growing amounts and there are many ways to use it. Someone chats with his friends, someone else tries to find a job and someone is searching for peer-to-peer support for his rare disease. Usually one person does not use social media in only one way, but has multiple different purposes to use it. For example someone might use Facebook to share updates on his life to his friends and to search for a job in professional Facebook groups. Social media has changed the way people use the internet. For example, people have usually sought health-related information privately from libraries or from the internet with search engines. Now that social media has shifted the landscape of the online world, people share more information about their health publicly. (Choudhury, Morris & White, 2014.)

There are multiple different types of social media and multiple ways to use them. Basis of social media is still the same: user-generated content and social interaction.

This study explores how chronically ill use peer-to-peer support communities online and how they affect their well-being. The empirical part of this study researched how Finnish narcolepsy patients use online peer-to-peer support and what kind of effects they think that it has on their well-being. The next chapter represents peer-to-peer support chronically ill have online, its effects and prior studies about it.

3 ONLINE COMMUNITIES FOR CHRONICALLY ILL

Peer-to-peer support is very important to people who have to live with chronic disease or diseases. Both, the diseased and their loved ones need support especially after they have gotten their diagnosis, which is a huge change in their life. Chronic disease is always long-lasting: from three months to a lifetime and it can not be completely cured with the help of medicine. Online communities and social media offer these patients an easier way to find peer-to-peer support. Some of the diseases are very rare, and some make it difficult to leave from your home or to communicate with others. For example, on social networking sites patients can interact with other patients no matter where they physically are and how often they can engage in discussions.

This chapter focuses on chronically ill, their online communities, and how these communities help their life and well-being. At first, chronic diseases and their effects on patients' life and their loved ones are briefly introduced. Then it is introduced how people use internet and online communities on health communications and peer-to-peer support. At the end of this chapter it is studied what kind of benefits and negative effects online communities have on the patients and their well-being.

3.1 Chronic diseases and peer-to-peer support

Chronic diseases are long-lasting, and they make life more difficult in multiple ways. Diseases affect patients as well as their families and friends. Luckily no one has to be alone with the disease. There are many ways to participate in peer-to-peer support.

The definition of chronic disease is that it persists for three months or more and it cannot be cured with medication or prevented by vaccines. Chronic diseases also do not just disappear and usually they become increasingly common with age. Unhealthy behaviors like lack of physical activity, poor eating habits, excessive use of alcohol and smoking are huge contributors to the most

common chronic diseases. (Medicinenet 2018.) The prevalence of the leading chronic diseases is globally increasing, and the increase is expected to continue substantially in the future. Chronic diseases are already the leading cause of death in the whole world. (Yach, Hawkes, Gould & Hofman, 2004.) In developed countries common chronic diseases are for example arthritis, cardiovascular diseases, different cancers, and diabetes (Medicinenet 2018). Increased amount of chronic diseases is a global problem that leads to growing economic costs and straining of health services (Yach et al. 2004). It is important to know the definition of chronic disease, but from a health care's and patient's point of view it is more important to know how the disease affects the diseased and his loved ones (Lubkin & Larsen 2013, p. 6).

Since there are a lot of different chronic illnesses, they might affect the patient's life in very different ways. Someone can work and live quite a normal life while someone else loses ability to work and lives with persistent pain. Even while every disease and every patient are different, there are many similarities in illness experiences. Basic strategy to cope with the problems of a chronic disease is to live as normally as possible instead of just coping with the symptoms. (Lubkin & Larsen 2013, p. 11.) A good example of this is that nonworking patients expect their illness to last longer and even report more symptoms than those patients who can go to work normally (Lubkin & Larsen 2013, p. 27). The environment has a great impact on patients' quality of life. If a patient has access to comprehensive material about the disease, and good social resources, it is easier to manage all of the problems that are created by the chronic disease even if it is disabling. Many of these problems originate in the interaction between individuals and their environments. (Scambler, 2008, p. 89.) Some problems affect everyday living. This kind of problem can be for example difficulty of self-care, mobility around home, difficulty to find work and economic problems due to that, and problems in family life and social relationships in general. Chronically ill patients tend to have an emotional burden of their illness. Psychological consequences can be for example frustration, feeling vulnerable and even depression. (Scambler, 2008, p. 90.) Chronic disease does not involve only the physical body, in many cases it changes a patient's life (Lubkin & Larsen 2013, p. 23). The whole life becomes uncertain, family relations may change, illness might affect the self-image, medical regimens require management, and the patient needs a lot of new information to cope with the disease (Scambler, 2008, p. 91-94).

It is clear that peer-to-peer support benefits patients with chronic diseases. For example, Embuldeniya, Veinot, Bell, Bell, Nyhof-Young, Sale & Britten studied literature about chronically ill and peer-to-peer support in their article (2012). According to them, peer support gives chronically diseased sense of connection and experiential knowledge, and it helps them to find new meaning in their life and feel less isolated. Peer-to-peer support lets them share their experiences, coping strategies, and feelings. It normalizes patients' conditions and builds strong relationships and communities. Peer-to-peer support helps patients by for example advising, and combating barriers and stigma of the dise-

ase. It provides them reciprocity and empowerment. Chronic diseases are more prevalent all the time and patients often seek information, peers, and support online, where it is easier to find (Mamykina, Nakikj & Elhadad 2015). Social media enables peer-to-peer communities and support also to patients who have extremely rare diseases. A patient with rare disease might be the only one in a certain area, but with the help of social media, he can find peers from all around the world.

Chronic disease can be difficult also to patients' families and other loved ones, and they might need support to cope with the disease as well. Even if the illness does not directly affect their life, it can raise great concerns and distress. Chronic diseases affect the most on others when the ill is disabled and needs help with his everyday life. Many studies have proved that caring for a disabled person is unrewarded, never-ending work even when you take care of your loved one. It takes physical and psychological commitment to cope with different problems and worries every day. (Scambler, 2008, p. 90) Even if the patient's disease does not require physical effort from his loved ones, it can be a huge emotional burden. No matter what kind of disease patient has, his family and other loved ones may need support. Peer-to-peer support benefits also their well-being. For example, loved one's cancer causes distress especially to adolescents and young adults. Their needs are usually poorly met within and outside their families. Social media provides them the possibility to access better coping resources. (Bender, Jimenez-Marroquin & Jadad, 2011.)

Chronic disease is a huge burden that affects patients' and their loved ones' physical and psychical well-being. Peer-to-peer support gives them a chance to share their experiences with other people who have similar conditions, and to find coping strategies. The Internet and social media offer whole new ways to peer-to-peer support. Support is now easier to access than ever.

3.2 Health-related online communities

People often learn about health and diseases from the internet and search health information actively. In 2013, 59 % of adults in the United States used resources from the internet to get information about health (Choudhury et al. 2014). Health related information has been searched from the internet probably since the very first search engines and online peer-to-peer support since the first web 2.0 communities. While social media and online communities have made progress, online peer-to-peer support has evolved. Online health communication and support communities have been studied from both medical and information systems science's points of view (Table 3). Online peer-to-peer support clearly benefits the chronically ill. They search and share information from everyday life with disease to various medications.

Health-related online communities and online health communications is studied only a little from an information systems science's point of view. However, it is an important research topic. It would benefit a lot of people who

suffer for example from chronic diseases to have access to good online communities. If we knew what kind of communities work best, we could create even better communities that help people as much as possible. Online communities are successful only if the design and culture of the community motivate and encourage users to share their information and learn from each other (Zhou, Si Sun & Yang, 2014). There are a lot of versatile discussions in communities where people are willing to share their experiences and new information.

Zhou et al. (2014) studied Chinese diabetic community called *Sweet Home*. They observed the community, analyzed its content, and conducted interviews to understand health management of Chinese diabetes patients. Mamykina et al. (2015) also studied the diabetes community, but their object was an international online community called *TuDiabetes*. Their study is grounded in collective sensemaking's theoretical perspective and they examined patterns of communication in the *TuDiabetes*-community. Choudhury, Morris and White (2014) studied health communication more generally. They compared what kind of health content people seek and share on social media to what they seek with search engines and studied why they choose certain platforms for online health communication.

Online peer-to-peer support and health related online communities has been studied also from a medical and psychiatric point of view. Bender et al. (2011) made a content analysis of breast cancer groups on Facebook. They studied all open breast cancer groups they found where discussion was in English and analyzed their group description, administrators, and discussions. Naslund, Aschbrenner, Marsch and Bartels (2016) studied how online peer-to-peer support communities promote wellbeing among people with serious mental illnesses like schizophrenia and bipolar disorder.

Choudhury et al. (2014) discovered that people use social media in health-related communication when they want to share information about their health status or symptoms, or when they want to share information or news about a condition. The study of Choudhury et al. (2014) concerns sharing health information in twitter, which is much more public than sharing health information for example in closed Facebook groups or in some anonymous online communities. It is possible that people seek information more openly on social media before they have a diagnosis. After the diagnosis it is easier to know which communities are the right ones for patients with that disease. Diagnosis changes life, raises a lot of new worries, and newly diagnosed patients need information and support. In their study, Zhou et al. (2014) found out that many new patients in the group *Sweet Home* join there after they have been diagnosed with diabetes in a hospital. According to Mamykina et al. (2015) patients usually come to online health communities to seek either emotional support or information.

There are a lot of different support groups about different diseases for example in Facebook. One of online communities' benefits is that it is possible to create very specific groups with different purposes. Bender et al. (2011) cate-

gorized purposes of breast cancer support groups in Facebook. According to them, support groups are established for three reasons: to support anyone affected by breast cancer, for oneself or loved one with breast cancer and for fundraisers. Bender et al. (2011) stated that there are also breast cancer groups dedicated purely to raising funds, raising awareness and promotion. They discovered that support groups had clearly more discussion than other types of breast cancer groups.

People in peer-to-peer support groups usually discuss their own experiences and search or share information related to the disease. Zhou et al. (2014) discovered that in *Sweet Home* –diabetes community users share their experiences and information. The community was originally designed to be an educational platform for patients, but eventually users used it also to exchange social support. Users often discussed and shared information about things closely related to diabetes, such as glucose values, diets, and recipes. Also people with serious mental illnesses discuss their illness experiences, and seek advice and support in their social media support groups (Naslund et al. 2016). Chronic diseases often disrupt everyday routines, so a popular discussion topic in peer-to-peer groups is advice to casual situations. For example, in Sweet Home - diabetes community users searched for substitutes for sugary foods (Zhou et al., 2014). Living as normally as possible is important to coping with a chronic disease. Diabetes in China is an interesting example of that. In China, it's common that families and friends have long, big meals together. There is also a certain wine culture, where people can be pressed to drink as much as possible. These cultural norms make a dilemma to diabetes patients, who may have to choose between being socially active and having a healthy diet. In *Sweet Home* -group the users often seek advice to cope with these chinese social eating norms. (Zhou et al., 2014.)

Since the peer-to-peer support groups are usually about one thing, the disease, that every member has in common, discussions are often deep. Users are genuinely interested about new information and others' experiences. Chronic disease is a very emotional discussion topic, so members of the community are probably emotionally engaged in discussions. In the diabetes community *TuDiabetes* users tend to engage in deep discussions. Users negotiate back and forth and seek resolutions to conflicts in their opinions. Members of the community surprisingly often valued diversity in opinions over consensus. (Mamykina et al., 2015.) Mamykina et al. (2015) discovered that most discussions in *TuDiabetes* included one to ten members and only very few had more than thirty participants. However, the discussions were deep and several of them reached over thousand replies. Mamykina et al. (2015) also noticed that most users post only once, fewer from two to six times and even fewer regularly. Successful discussions in peer-to-peer communities have a supportive and positive tone. Zhou et al. (2014) found that community support in the *Sweet Home* - diabetes community is often positive and cheerful. For example, newly diagnosed are often pessimistic about their future, but others comfort them by

saying something like that diabetes diagnosis is a right time to start living a healthier life.

Online peer-to-peer support is important to patients with chronic disease, whether it is newly diagnosed or have been persistent for a long time. People have been seeking help for their health-related issues for a long time and social media has enabled that those issues can be discussed with peers who have similar problems. Support from others, possibility to share experiences and casual discussions are important to many patients.

Table 3: Earlier studies

Study	About what	How	Who	When
Sweet Home: Understanding Diabetes Management via a Chinese Online Community	Chinese diabetic community Sweet Home and health management of Chinese diabetic patients	Content analysis and interviews	Zhous, X., Si Sun, X. & Yang, J.	2014
Collective Sensemaking in Online Health Forums	International diabetes community TuDiabetes and collective sensemaking	Analysis of communication patterns	Mamykina, L., Nakikj, D. & Elhadad, N.	2015
Seeking and Sharing Health Information Online: Comparing Search Engines and Social Media	Health content people search with search engines and seek and share on social media	Log analysis and survey	Choudhury, M., Morris, M. & White, R.	2014
Seeking Support on Facebook: A Content Analysis of Breast Cancer Groups	Breast cancer groups in Facebook	Content analysis	Bender, J., Jimenez-Marroquin, M. & Radad, A.	2011
The Future of Mental Health Care: Peer-to-Peer Support and Social Media	Social media peer-to-peer support of people with serious mental illnesses.	Literature review	Naslund, J., Aschbrenner, K., Marsch, L. & Bartels, S.	2016

3.3   Advantages and disadvantages of online peer-to-peer support

It is clear that social media and online peer-to-peer communities benefit chronically diseased. It has been studied, that patients experience the benefits themselves. In addition to them, online support promotes patients' physical and mental well-being.

Patients who belong to online communities like them or find them useful, otherwise they wouldn't use them. There are as many different reasons to enjoy being a part of a peer-to-peer community as there are community members. Some like bonding between the peers. Zhou et al. (2014) found out that in Sweet Home -diabetes community trust and sharing personal information helps establishing true friendships between members. They also develop a sense of belonging. Another reason to find a support group important is the emotional support from peers. In TuDiabetes -diabetes community users get emotional support from others, which is very important to some of them. Others valued deep discussions and different perspectives. (Mamykina et al., 2015.)

The Internet has improved ways of getting information and other resources which are important especially to newly diagnosed patients. Thanks to better information and support from other patients, chronically diseased can be healthier. Using social media support groups is associated with better access to information and resources. It raises bridging social capital and bonding social capital. This reduces anxiety and helps coping. (Bender et al. 2011.) Online communities are an easy way to promote both mental and physical wellbeing (Naslund et al., 2016). These communities help patients to know when and how to get help. Naslund et al. (2016) state that people with mental health problems were more motivated to seek formal care after discussing their concerns with peers online.

Nature of discussions in social media is a huge benefit to the chronically ill. Some patients can't fully engage in social interactions due to their disease. In online communities, people can choose themselves in which level they engage in discussion. It is ok to choose whether to post new content or not and to respond to comments as quickly or as slowly as wanted. This is a significant advantage to patients who have difficulties with social interactions. (Naslund et al., 2016.)

Online peer-to-peer support isn't completely trouble-free. Even though advantages of peer communities are greater than the risks, it is important to be aware of possible problems. The study of Nadlund et al. (2016) introduces risks like following advice from others with unknown credentials. People tend to trust their peers and Zhou et al., 2014 discovered that in Sweet Home -diabetes community users are very trusting. They trust others for getting right information and advice and often ask others about their experiences before starting a new medication. Everyone is different, and everyone's experiences of certain diseases are different. As Nadlund et al. (2016) state, learning from others' experiences may lead to unrealistic expectations, disappointments, and confusion. Generally, it's good that online communities generate meaningful relationships,

but some people may depend too much on online relationships. Too important dependency on online relationships may lead to social withdrawal in the offline world (Nadlund et al., 2016). There are also possible risks like emotional entanglement when others' problems become overwhelming. (Embuldeniya et al., 2012.)

Peer-to-peer support groups provide patients joy and benefits. Support from peers promotes their well-being and patients feel strongly belonging. In online communities patients may trust others a little too much or get unrealistic expectations, but mainly social media and peer-to-peer support benefits patients.

Finnish narcolepsy patients were studied by an empirical study, which was conducted based on the results of previously presented studies and other important matters. The next chapter introduces how the empirical study was formed.

4 RESEARCH

Narcolepsy is a chronic disease that has huge effects on patients' lives. It is also an interesting disease in Finland. Finland used Pandemrix vaccination against AH1N1 pandemic, and later it was discovered that the vaccine increased the risk of getting narcolepsy. Finnish narcoleptics have an active peer-to-peer support group Narkolepsiaan vertaistukea on Facebook. Their use of online peer-to-peer support was studied by qualitative interviews and analyzing the interviews.

Chapters 2 and 3 presented theory about social media, online communities, health related communities and peer-to-peer support. The theoretical part serves as a basis for the empirical part of this master's thesis. This chapter begins with representing starting points of the empirical research. After that, a chosen research method, semi-structured interview, is introduced. Then interviews and interviewees are presented. Finally, this chapter explains how the collected data was analyzed.

4.1 Narcolepsy in Finland

Finnish narcoleptics were chosen as the subject of research. Narcolepsy is an interesting example of chronic disease. There is no cure for it and its symptoms may vary from patient to patient. Because symptoms and their severity vary, narcolepsy effects differently on every patient's life. For example, someone may be able to work full-time and have hobbies while someone else cannot work at all and has to schedule his whole life around sleeping. Narcoleptics suffer from excessive daytime sleepiness and sleep attacks. Cataplexy is also a common symptom, but its frequency is very variable. Some have only few attacks in their whole life while others have tens of attacks every day. Hallucinations and sleep paralysis are also typical, but all patients do not have them. (Hublin, Kaprio, Partinen, Koskenvuo & Heikkinen, 1994.) Finnish narcolepsy patients have an

active online peer-to-peer support group on Facebook and Finnish Narcolepsy Association helped with recruiting the interviewees.

Narcolepsy is a chronic disorder. It effects on patient's sleep-wake cycles. Patient might feel well-rested after sleep but feel very sleepy throughout the rest of the day. This usually affects everyday life and daily activities. Patients may fall asleep unwillingly in the middle of an activity, for example watching tv, eating or even driving. Cataplexy is another common symptom. It makes patients suddenly go limp or unable to move. Patients might also have dream-like images or hallucinations and sleep paralysis. (National Institute of Neurological Disorders and Stroke, 2019.)

Narcolepsy affects men and women equally. Usually symptoms start between ages from 7 to 25, but narcolepsy can occur earlier or later. The cause of it is still unclear. Current research suggests that it may be a result of a combination of factors like autoimmune disorders, family history and rarely brain injuries. (National Institute of Neurological Disorders and Stroke, 2019.)

Narcolepsy is an interesting case especially in Finland. In 2009 Finland started vaccinations against pandemic AH1N1 with Pandemrix. Few months later excessive numbers of narcolepsy were discovered among children and adolescents. In their study Nohynek et al. (2012) found out that people between ages 4 to 19 who had had Pandemrix vaccinations had higher risk of narcolepsy compared to unvaccinated children and adolescents in Finland. In 2013 Jokinen and colleagues discovered that also Finnish adults under the age of 65 had increased risk to get narcolepsy if they had received Pandemrix vaccination. Because of Pandemrix vaccinations there has been an increased amount of narcolepsy patients in Finland since 2009.

Finnish Narcolepsy Association (Suomen Narkolepsiayhdistys ry) is a patient association for people with narcolepsy or other sleep disorders. They promote things that are important to narcolepsy patients, provide information and communicate news about narcolepsy and other sleep disorders. (Suomen Narkolepsiayhdistys ry, 2019.)

Finnish Narcolepsy Association provides peer-to-peer support. Members participate in peer-to-peer activities very actively. They arrange for example regional meetings, common weekends and courses about life with narcolepsy. They provide telephone counseling and online peer-to-peer groups on Facebook. (Suomen Narkolepsiayhdistys ry, 2017.)

The group was created October 12, 2013. May 10, 2019 it had 383 members and two of them were administrators. The group is meant for patients who suffer from narcolepsy or chronic fatigue syndrome, people who are suspected to have either of those, and patients' close ones. The discussion in the group is confidential and exclusive, and all members are expected to write a short introduction about themselves. There is another Facebook group about Pandemrix compensations and members are advised to have all conversations related to that topic there and not in Narkolepsiaan Vertaistukea group. (Facebook, 2019.)

4.2   Qualitative research method

Qualitative research method was chosen because the research data is collected from humans. Qualitative research methods provide an opportunity to study their answers in detail and to get in-depth information. The goal of the research is not to provide statistical generalizations but to narrate certain actions.

Interviews give suggesting explanations of key events and reflect interviewees' relativist perspectives. They are often used finding out answers to "how" and "why" -questions. (Yin, 2018.) Interviews were chosen as a research method for this research, because the goal of this research is to increase understanding of how Finnish narcolepsy patients use online peer-to-peer support communities and how they help with their well-being.

Different interview methods can be divided in three categories: (1) structured interview, (2) semi-structured interview and (3) unstructured interview (DiCicco-Bloom & Crabtree, 2006). Differences between their interview methods can be seen in Table 4. Interviewing method for this research was chosen between semi-structured and unstructured, because qualitative methods suit best for this research. Structured interviews generally produce quantitative data. In semi-structured interviews the discussion is formed around a set of predetermined open questions. Other questions might emerge during the dialogue between interviewer and interviewee or interviewees. Semi-structured interviews are the most used interviewing method in qualitative research. In an unstructured interview, the discussion resembles guided conversation. (DiCicco-Bloom & Crabtree, 2006.) It was decided that a semi-structured interview method is best for the research. Because interviews will be based on predetermined questions, the interviewer can be sure that the interviewees tell their views on all issues that are relevant to the study. In semi-structured interviews the interviewees can freely tell their sentiments about the topic and the interviewer can ask clarifying questions if needed.

Table 4: Interview methods

Interview method	Description	Usual use of the data
Unstructured interview	Unstructured interviews resemble guided conversations (DiCicco-Bloom & Crabtree, 2006).	Unstructured interview is conducted with observational data (DiCicco-Bloom & Crabtree, 2006).
Semi-structured interview	In semi-structured interviews discussion is formed around predetermined open questions. Other questions might	Semi-structured interview is often the only data source in a qualitative research (DiCicco-Bloom & Crabtree, 2006).

	emerge during the discussion. (DiCicco-Bloom & Crabtree, 2006.)	
Structured interview	Structured interview is like a survey. Interview is conducted using a structured questionnaira. (Yin, 2018.)	Structured interviews usually produce data for quantitative research (DiCicco-Bloom & Crabtree, 2006).

Semi-structured interviews can be conducted either with an individual or in groups. Group interviews are usually formed around focus groups, which means that each group represents one entity within different groups, and all participants have experience or knowledge on a certain topic. In a group interview gathered data is from a wider range of experience, but individuals usually do not want to share as deeply as in individual interviews. Individual interviews provide data about social and personal matters. (DiCicco-Bloom & Crabtree, 2006.) Individual interviews were chosen for this research, because the topic is quite sensitive. Deep information about interviewees views on online peer-to-peer support is useful with searching answers to the research question.

There are few possible problems in the semi-structured interviewing method. For the interviews to succeed, it is crucial that the interviewer develops a positive relationship with the interviewee. Interviewee should trust and respect the interviewer and the interview's environment should be comfortable and safe. In the worst-case scenario interviewee might not talk at all, if the relationship is not positive. Positive relationship encourages interviewee to share a lot of information in his or her own words and to answer possibly sensitive questions. Another important aspect of interviews is to avoid directive questions. (DiCicco-Bloom & Crabtree, 2006.) For example, instead of asking "Does that make you feel sad?", the interviewer should ask "How does that make you feel?". It is important to remember that interviews are always verbal reports. Everything interviewees tell can be biased, articulated inaccurately or poorly recalled. (Yin, 2018.)

The collected data is assumed to serve this research well. Purpose of this empirical research is to find out how Finnish narcoleptics use social media communities and how it affects their well-being. Interviews provide qualitative data and allow interviewees to tell in-depth information. With semi-structured interviewing method the interviewer can make sure that interviewees answer the right questions and ask clarifying questions if it seems like that there is more that the interviewee can tell about the topic.

4.3 Interviews

Interviewees were recruited with the help of Finnish Narcolepsy Association. In Finland there are only circa 500 people in Finland who are diagnosed with narcolepsy (Suomen Narkolepsiayhdistys ry, 2017). There are even less narcoleptics who use online peer-to-peer support, so it was known that recruiting interviewees would be difficult. A representative of the Narcolepsy Association posted an invitation to participate in interviews on Facebook group *Narkolepsiaan Vertaistukea* in spring 2018. After that four people contacted the interviewer and told that they would be interested to be interviewed. Two months later the invitation was posted again in order to get more interviewees. After that four more people contacted the interviewer. Eventually interviews were scheduled with six people. Interviews were conducted between March of 2018 and May 2018.

Interviewees for the research were recruited from Finnish Narcolepsy Association's Facebook group called Narkolepsiaan Vertaistukea (peer-to-peer support for narcolepsy).

At the beginning of each interview the interviewer told briefly about the study and that the interview would be voice recorded, transcribed and translated into English. She also reminded that the interview will be confidential and that no one else would hear the record of the interview.

First questions were about interviewees' backgrounds. There were only a few background questions. They were narrow, because narcolepsy is quite a rare disease so it was made sure that interviewees will not be recognizable. Background questions were:

- How old are you?
- How old were you when you got the diagnosis?
- How does narcolepsy affect your life?

Age is the only demographic that was asked from the interviewees. It does not make interviewees recognizable, but it provides information about the stage of interviewees' life. Second background question was about how old interviewees were when they got the diagnosis of narcolepsy. Answers to this question tells how long interviewees have lived with the diagnosis and at what point of their life they got it. Last background question is "*How does narcolepsy affect your life*?". It provides a lot of information. For example, it tells how severe interviewees' narcolepsy are, if they have had to give some things up because of the disease and how the disease has affected their life choices. All of these things might affect the support the interviewees need.

After the background questions interviews proceeded by themes. There were three themes: (1) online peer-to-peer communities interviewees use, (2) how they use online peer-to-peer communities and (3) the impact online peer-to-peer support has had on them. Each theme had one question and multiple

possible supplementary questions. Supplementary questions were asked if the interviewee did not cover them in their other answers.

First theme started with a question "What online peer-to-peer communities do you use?". Purpose of the question is to find out what peer-to-peer communities interviewees use related to narcolepsy or other things and why. Answers to this question also provide information about how many online peer-to-peer communities interviewees use and if narcolepsy is the only thing they seek online peer-to-peer support to or are there also some other things. If interviewee mentioned peer-to-peer communities that were not related to narcolepsy, the interviewer specified that interview questions will be about narcolepsy communities. Supplementary questions for this theme were:

- When did you join the community?
- Why did you join there?
- What kind of expectations did you have about the community?
- Do you feel that you are part of a community? Why?

Second theme started with a question "How do you use online peer-to-peer communities?". Purpose of this question was to get an understanding on how different interviewees behave in the community and how they feel about the community and its members. Supplementary questions for this theme were:

- How often?
- How actively do you participate in discussions?
- What kind of discussions do you have? About what topics? What do they feel like?
- How does discussions online differ from face-to-face discussions?
- What kind of information do you share with others?
- What kind of information do you seek from the community?
- How trustworthy is the information others share? Do you take their advice?
- What kind of policies the community has? Do they affect how you use the community?

Third theme started with a question "What kind of impact online peer-to-peer support has had on you?" Purpose of this theme was to find out what kind of benefits and negative effects online peer-to-peer support has had on interviewees' life and well-being. Supplementary questions for this theme were:

- Have you noticed benefits to your well-being?
- Has the community had negative effects on your life?
- What kind of information have you gotten from the community?
- Does your life with narcolepsy feel different now than it did before you joined the community? How?
- How does it feel to read about others' problems?
- How does it feel to read about others' successes?

- Has discussing in the community had an impact on your social life? How?

4.4 Interviewees

Six interviewees were interviewed for the research. Four of them are female and two are male. At the time of the interview they were aged from 22 to 51. One of them did not yet have a diagnosis for her sleep disorder and the rest had had narcolepsy diagnosis for from a couple of months to eight years. Summary of interviewees can be seen in table 5.

Second question was how old interviewees were when they got diagnosed with narcolepsy. I1 told that she had gotten the diagnosis in 2010. I2 was diagnosed in 2015. I3 got her diagnosis a little over two years before the interview, but she told that she had had symptoms for over ten years. I4 had gotten her diagnosis a few months before the interview. I5 was diagnosed in 2012. I6 did not yet have a diagnosis for her sleep disorder, but she had had symptoms since the year 2010.

Last background question was how narcolepsy affects interviewees' life. All interviewees described how the disease has a significant effect on their life. They told either that it affects everything or that it affects their life daily. I1 told that the disease affects everything. She had quit her studies in university with a half-done master's thesis. She was not able to work and did not know if she ever will be. I2 told that narcolepsy had changed his life totally and that a lot of things are left undone. He had been in disability pension since 2016. I3 told that narcolepsy makes life a lot more difficult and that she does not have as much time to do things as she did before. She had to reduce her exercise and work. She is on a partial disability pension. I4 told that she is constantly tired and most of her days go by sleeping. She has lost two jobs, has difficulties to focus and gets frustrated easily. I5 said that narcolepsy affects his everyday life. He has to live according to the disease and schedule his day around sleep. I6 told that her sleep disorder affects her life especially when the fatigue is higher. She must schedule her day so that she can take a nap. She studies and works but told that it is difficult. She is not able to work normal days and can not work sitting down if she wants to stay awake.

Table 5: Interviewees' backgrounds

Interviewee	Age	Gender	Year of Diagnosis	Effects on Life
I1	35	Female	2010	Had to quit studies, cannot work.
I2	51	Male	2015	Is on disability pension.

I3	46	Female	2016	Is on partial disability pension.
I4	22	Female	2017	Has lost two jobs and has problems with focusing and self-control.
I5	34	Male	2012	Has to plan days according to the disease
I6	24	Female	Not yet diagnosed, symptoms since 2010.	Has difficulties to work and study, cannot work normally.

4.5 Analysis of the data

Results of the interview are not directly used as the results of this research. Interviews were analyzed and conclusions of the analysis are presented as the results. Results are represented in chapter 5. When a community is viewed with empirical study, it comprises an unique focus group. Finnish narcoleptics are also an unique group so the results are not necessarily generalizable to other groups.

All interviews were voice recorded and transcribed. Because interviews were conducted in Finnish, transcriptions were translated from Finnish to English before analyzing the data.

Interviews were analyzed with thematic analysis method. Thematic analysis is an encoding process for qualitative information. Code for encoding can be for example a list of themes like in this research. Themes can be directly observable in the data or they can be underlying. Thematic analysis allows researchers to use qualitative data more systemically. It increases accuracy in understanding views about situations, events, people and organizations. Thematic analysis also helps to see patterns in information that might seem to be random. (Boyatzis, 1998, p.4-5.) Thematic analysis method was chosen because research questions and interview questions were already based on certain themes. With thematic analysis it can be ensured that all of the questions are answered and all themes are covered.

Although thematic analysis might seem to be a simple way to analyze data, it is not. According to Boyatzis (1998, p.12-13) there are three common factors that may affect the analysis:

- Researcher's projection,
- Researcher's sampling, and
- Researchers mood and style.

It is important to make sure that these factors affect results as little as possible.

Projection is a natural defense mechanism. It means that the researcher projects his or hers thoughts or values onto the people from whom the data has been collected. Sampling the data can affect the results, because the researcher might not be aware of all variables and might leave something important out or put it in a different theme than someone else would have. Also researchers mood and style may have an effect on how he or she views the data. (Boyatzis, 1998, p.13-15.)

Data was read through multiple times and themes were picked based on the topics interviewees talked about. Interview questions were already divided into three themes: (1) online peer-to-peer communities interviewees use, (2) how they use online peer-to-peer communities and (3) the impact online peer-to-peer support has had on them. Naturally these themes were discussed in the interviews and were also big themes in the data. In addition to them, two more themes came up in the interviews. First one is a sense of community and how other members of the community are viewed. Second one is duality in the community. Four of six interviewees talked about how there are two kinds of narcoleptics: those who have gotten it "naturally" and those who have gotten it because of the Pandemrix vaccine.

After the themes were discovered, the data was organized under them. Transcribed and translated interviews were read once again and parts where interviewee talked about certain themes were picked from each interview. This way data formed new sets around the themes and themes could be analyzed.

Next chapter presents and opens above described empirical research's results verbally and graphically. Conclusions of this research are presented in chapter 6.

5   Results

The interviewees use Finnish narcolepsy peer-to-peer support group *Narkolepsiaan vertaistukea*. Their usage of the group was quite typical, they mainly follow the discussion and sometimes participate. However the peer-to-peer support that the group offers had helped them to cope with their disease.

As stated in chapter four, there are 5 themes that came up in the interviews. Themes are (1) online peer-to-peer communities interviewees use, (2) how they use online peer-to-peer communities, (3) the impact online peer-to-peer support has had on them, (4) sense of community and other members of the community, and (5) duality in the community. Summary of the results by themes can be seen in table 6.

This chapter introduces each theme of the interviews and what came up related to them. Results of the interviews presented in this chapter and results of the literature review presented in chapters 2 and 3 are formed into conclusions which are used to answer the research questions. They are presented in chapter 6.

5.1   Use of online peer-to-peer communities

First two themes (1) online peer-to-peer communities interviewees use and (2) how they use them are based on the interview questions. First theme concerns what narcolepsy-related online peer-to-peer communities interviewees use and why. Second theme is about how interviewees behave in the community or communities they use and how they feel about it.

All of the interviewees were in Facebook in the Finnish narcolepsy peer-to-peer support group *Narkolepsiaan vertaistukea*. None of the interviewees mentioned other online communities related to Narcolepsy. Some of them were also in other peer-to-peer support groups, but they were related to other things. For example interviewee I6 was also in an endometriosis peer-to-peer support group and interviewee I3 was also in a hypothyroidism peer-to-peer support

group. Based on the interviews it can be stated that the majority uses the group mainly by just following discussions there. Some of them follow the group frequently and some more rarely.

> I1: The Facebook group is not the forum for me. I mainly check it if something pop ups in my Facebook feed and I remember that the group exists. I rarely follow it.

> I2: I follow it daily. I see every time someone posts something, and I read it almost immediately.

Although most of the interviewees told that they mainly just follow the discussion or that they are not very active in the group, many of them also said that they comment every time if the post or other comments are relevant to them. All of the interviewees said that they comment sometimes. Interviewees I2, I3, I5 and I6 told how they comment their own experiences and answer to others' questions if the discussion is relevant to them or if they have information about the topic.

> I3: Mostly I just follow it. But if I have something to ask or comment, I ask or comment. People often ask questions in there and I answer if I have information about the topic.

> I5: I'm not very active there or in Facebook at the first place. I'm some active, like if someone posts something new, but I don't participate in a daily conversation. If I have something to say about some topic or if I can give advice to someone, I will write. I mostly read it.

> I6: I comment every time if the post is relevant to me or my experiences. But I don't comment if there's nothing I can say. So, in moderation.

> I2: Sometimes there is something, which is close to my own situation or someone asks how something is with others. I have commented my own story in every site, and it helps others, when I tell it and how I have gotten things to work.

Interviewee I1 told that she had had some negative experiences with other group members after commenting in the group. She told for example that someone had name-called her just because her narcolepsy is not caused by the Pandemrix-vaccine. That is why she does not comment very often and is careful with what she writes there.

> I1: So, I carefully comment about very neutral topics – Like the disability pension and other neutral topics.

Many of the interviewees told that they used the group more frequently right after they had joined there, when they had ongoing physical examinations, or if there had been recent changes for example in their medication. Based on this, it could be stated that online peer-to-peer support is important when there is something new related to the disease.

> I3: I followed the group more frequently at first, it was daily. Every time I went to Facebook. I still follow it multiple times in a week.

> I6: At the beginning I used it a lot more often, especially when my medication was changed and so on. I read also old posts weekly. But now, let's say couple of times in a month. Depending on are there new posts. I get a notification every time someone posts, and I read it and comment if it's relevant or if I know something about it. So more than once a month.

Based on what the interviewees told, the discussions and their topics on the group vary a lot. There are discussions for example about everyday life, experiences with the disease, and coping with the disease.

> I2: There is a whole spectrum of discussions. People tell very openly, their daily news and so on, what kind of things have happened. Many ask information, for example how others have experienced something and how some people have gotten something that others haven't. It goes on very well, I feel like it has been useful for many people.

> I4: For example, about what kind of experiences people have about medicine. Job opportunities, financial aid, examinations. As a woman, how it effects on pregnancy or having children. We talk a lot about successes and failures in everyday life. Like what problems people face. There are all sorts of discussions.

Most of the interviewees were in the group to learn new information and to hear about other narcoleptics' experiences. Some of them seek also peer-to-peer support and understanding.

> I1: Actually I have given up my hope to find peer support from there, but maybe I seek support to practical things.

> I3: Well, I have asked for example about medications and then about the symptoms. Because sometimes it's a little unclear which symptom are caused by which disease since I have other diseases as well. Those kinds of things.

> I4: I wanted to get answers to my questions and experiences. (…) But I also seek relief, like how someone lives their everyday life normally.

I5: Of course, I wanted to read other diseased people's experiences.

I2: For example, this medicine thing. One drug may work for someone and not at all for someone else. So for example how some drug has worked.

I6: Maybe advices and tips, because there are people who have had the disease for a very long time. I have also been tired and so on for a long time, but they have dealt with the disease longer. Maybe help with accepting the disease and understanding to finding my own limits. Like you can say "no" if you really can't. Or maybe the pain, because I'm still very young and many things are left undone because I'm so tired or I have to limit. Like how you can take it into account in everyday life, so you can be prepared. So, advice and tips from people who have had the disease for a longer time.

I2: I was curious and wanted to hear other peoples' stories. No one understood me at home, because they couldn't even imagine what it can be.

I3: I needed peer support. It is quite rare disease, I myself didn't know much about it and all the doctors didn't know much. I got help, support and understanding in there.

Based on the interviews, there is a lot of variation of what members of the group want to share about themselves or their experiences to other group members. Some do not want to share anything while others share everything they can if they feel it might be helpful to others. Some share only their knowledge about the disease or other things related to it.

I1: I don't feel that the group is the forum for me to share, but it probably is associated with personalities. It's part of my personality that I don't share much of my own things.

I3: I haven't really shared anything there. I have mostly asked questions if I have posted something.

I2: Well, I have shared everything there has been for now. Everything I know is worth trying, for example with loss of earnings compensations and so on.

I6: Also, quite personal things, but mostly about coping. Or if I have had some examinations, I share how they went. Or if someone asks experiences like "did you went to examinations in Uniklinikka Helsinki?", I will tell how my case went there. Mostly things like that. There really isn't discussion about other things than fatigue and so on, so not much about your life otherwise.

I5: Well, I have lived with this disease for almost six years. I share what I have learned about living with this. For example, about sleeping or dreams.

Some of the interviewees felt like they do not want to share too personal things with a big group of people. For example, interviewee I4 told that it would be helpful to share more personal things, but the Facebook group is not the right forum for that.

> I4: If you feel depressed or something, you don't want to take part in a group, or you don't want to share it with many people. But from there you sort of get support if you want to ask for example experiences about medication, working or studying and you will get answers. But you don't want to share much of your personal things there. I wish there was somewhere to share also them.

5.2 Effects of online peer-to-peer support on well-being

Third theme (3) the impact online peer-to-peer support has had on the interviewees is based on the interview questions. It handles the benefits as well as negative effects online peer-to-peer support has had on the interviewees' well-being and life in general.

When asked, one interviewee, I1, said that she had not noticed any remarkable benefits on her well-being.

> I1: You can't choose who to talk with in a Facebook group, so I don't feel like I have gotten much out of it. Mostly some practical things.

Other interviewees had noticed that online peer-to-peer support had been good to their well-being. Mostly they had learned to cope with the disease better and accept it as a normal part of their life. Many of them had found it helpful to get to know other people with the same condition.

> I2: I have understood more, what it's all about. Then I have learned perspective, when I have noticed that my narcolepsy is not the worst.

> I4: Peer-to-peer support has been a big part in a way. If you want to ask or want to hear other people's experiences or share your own. In a way, when you read about other people's things, you feel like you are not alone.

> I5: Well, maybe when you read about other people's symptoms and the disease, they are very similar. How could I say it? I can identify with them.

> I6: I don't know anyone who has anywhere near similar situation. I have gotten a lot of help with my coping and really living with this. The disease isn't me, but it's a part of me. It has been a huge help with accepting this.

In the discussion most of the interviewees told how being part of the Facebook group had changed the way they feel about having narcolepsy and helped them accept that they cannot do everything like healthy people. Based on this, it could be stated that online peer-to-peer support helps to see narcolepsy as a normal thing and to accept the disease.

> I1: Maybe sometimes when I read posts, I feel like I should be more gracious to myself. It's kind of a reminder of that when I read other peoples' stories. It's funny how when I read other's stuff, I just wonder how they cope. And about my own problems I'm just like "I'm okay, it's fine." When you read about someone else's life with narcolepsy you are like "that's terrible." So it's a reminder that I should forgive myself more and stress less about housekeeping too little or napping too much etc.

> I2: Now I have learned to take it as something I can't change. It will be with me for the rest of my life.

> I4: If I had to cope without this little big easily accessed support, I would feel much worse about what this is, and it would be more difficult to understand this disease.

> I6: I got a name and a reason to why I feel like this. It felt like doctors just guessed if it could be this or that. It hasn't yet clarified, but I feel like I have a same situation than someone else. There's a sense of community and relief. Like this is normal and people can live with this.

Some of the interviewees had had also concrete benefits because of the online peer-to-peer support group. For example, interviewee I3 had noticed that her medication was improper because there is a lot of discussion related to medications in the group.

> I3: It has probably had big impact on me after I ran in to the group. The place where my narcolepsy is currently treated has quite weak knowledge about all this, so I have gotten many advices from the group. I have also read a lot about medications and so on from the group. Then I have asked more from the Uniklinikka just in case. I have had some mistakes in my medication, which I wouldn't even know about without the group.

Two of the interviewees, I3 and I4, told that they have gotten valuable information about the disease from the group. Some of the interviewees mentioned that they already had a lot of information when they joined the group, but they estimated that they would have gained useful information if they had joined the group right after the diagnosis.

> I3: Then I have gotten a lot more information about the daily scheduling and all that, than I would have ever gotten from my doctors.

I4: I have gained a lot of knowledge about this disease based on the studies and what people tell.

Most of the interviewees told that they had not noticed any negative effects of online peer-to-peer support. Interviewee I1 said that she had had negative experiences with some of the group members and it affected the way she uses the group.

I1: Once there was a study about hereditary of narcolepsy and the researchers wanted siblings to participate. The study was in California and I asked do they want to study children who have narcolepsy or adults. I have a brother who doesn't have narcolepsy and I wanted to know if we could take part. I don't think I could leave my children and travel, but this would be a nice reason to do so. Then someone crazy messaged me in private. At first, he commented something like "just play with your brother there" and I was like "Excuse me?". Then he messaged me "Have you gotten narcolepsy from the vaccine?" And I told him no. "Where did you get it from?" "I don't know why I have fallen sick" "Well you can go to hell then" I was like okay and messaged the administrator. There is very good administration and this one had caused trouble also in other groups, so they deleted him from the group.

I1: I can't get these people to think about their views again, so it's better to be quiet.

Interviewee I6 told that she had been disappointed because she did not get as much support as she expected, but she understands that. Also, interviewee I4 told that she understands that and that she does not take discussions in the group personally.

I6: Maybe I was kind of disappointed at first, when I didn't get as much answers as I expected. But now I have understood that it might be because, I myself often read something and think that I will comment later, but don't remember to do so.

I4: Not really. I don't think it has. You take every discussion in a different way. Or you know, they don't have time to affect me much.

It could be problematic to read about your peers' problems or successes. Some people might take other peoples' problems very seriously or feel jealous if someone else succeeds while they don't. All of the interviewees described how they are very empathetic towards others. They told that other people's problems make them feel bad, but none of them seemed to take them too heavily.

I1: Sometimes I feel hopeless for others. Especially if someone has financial problems. I'm lucky, because I don't have to worry about money. I would like to get into wor-

king life because of myself, but I would also cope without a job. I'm lucky to have my financial things secured. But then there's people in difficult situations. They can't work, but they don't get sick pension. I feel terrible and hopeless for them. How do you cope with that, when you have no way out? You should work, but you can't, and no one will hire you, but you also don't get sick pension. It's terrible to read about that.

I2: I feel bad about kids and adolescent. Some of them have such bad condition they can't study or anything. They have been in primary school and then you should start to build your own life. The base is all gone, you can't do anything, state bounces you around and you get no compensations or anything. There are many, who have studied, lived on their own and then are forced to move back at their parents. Also, the parents have to use their time to take care of their child. I know that there are people, who haven't gone out in a couple of years. Practically they are asleep the whole time. There are many kinds of situations. That's why I feel bad about how state has handled this.

I4: Well, I identify with many problems. I also feel bad, if others feel bad. But you share the same feelings. If you notice something that has gotten better or would get better over time, you try to be supportive.

All of the interviewees told that reading about other peoples' successes make them feel good. Instead of being jealous they are happy and also hopeful about their own situation.

I4: It's meaningful when you notice someone else succeed and living normal life. It's the greatest thing and it's also the biggest thing I need from the group.

I2: It feels good. I notice it myself, there are many who seek peer support. When something has gone wrong or succeeded. You feel good, when someone has gotten their things better.

I3: Of course, you are happy for them. You don't want anything else for others.

I6: It's wonderful, if someone has for example finally gotten a diagnosis or helped own coping with a diet. We fight with almost the same things, so it's wonderful to see, if someone succeeds or if someone's life gets better, because you know what it's like.

5.3   Sense of community and other people in the community

Fourth theme (4) sense of community and how other members of the community are viewed is not based on the interview question, but it came up frequently in the discussions with the interviewees. The theme is about how well the interviewees feel like they are a part of a community and how they feel about other members of the community.

All of the interviewees except for interviewee I1 told that they feel like they are a part of a community in the Facebook group. Some felt like the group is a very close community and some felt like the disease puts them in the same boat together.

> I1: I don't feel that I belong there. There are certain people, whose posts I comment more and feel like there is real conversation.

> I2: It's easy to belong when you know what you are talking about. You know that everyone has similar situation, so there is fellowship in the group.

> I3: I feel like that in the peer-to-peer support group all understand what it's like and they have information. I feel like it's quite close community.

> I4: You share same things, like experiences and the disease, which is quite rare. Other people, who don't have the disease, can't understand how the constant fatigue feels like or how it feels like when your feet just sweep off if you laugh or how it feels when you suddenly start to fall asleep easily. So yes, in small level. I'm not very active there in comparison to others, but I still feel like we are in the same boat.

> I6: Now I feel like, yes. At the beginning it was different, because I didn't have all the typical symptoms. I didn't have cataplexy, I didn't fall asleep in every place. Then I felt like I was a little outside, because I didn't have diagnosis. But it's for all who suffer from sleep disorders, so now I feel like I'm welcome.

Based on the interviews there are many kinds of people in the narcolepsy peer-to-peer support Facebook group. Interviewees I1, I3 and I6 told that there had been some problems in discussions between some of the group members. Most of the interviewees thought that the discussion is mainly smooth and supportive, and majority of the group members behave well.

> I4: There are all kinds of people. Different ages. There are also people whose family members have narcolepsy, there are people who have narcolepsy. There are younger people and older people, there are parents of small children. Many people fit in there as well as many people fit in apartment house.

> I5: Well, they are like any one of us. I don't think I can say anything more based on Facebook conversations. They are like anyone else without the disease. You can't really categorize people or notice anything from the conversations.

> I1: There are lovely persons, but also few who aren't tolerant about other people's views.

> I3: Of course, there are many kinds of members, but I think that they are mostly quite well-behaved, and everyone supports each other. Of course, sometimes someone says something incorrect and then someone who knows better corrects him and

people might start to argue. But there is only a little that kind of conversation. Mostly people have good agreement and you get support, understanding and answers.

I6: It varies, but most of them are nice and open, and they answer on posts, even though more people could answer if someone asks something. Nowadays there has been more about that discussion needs to be moderated and topics need to be intervened.

All of the interviewees told that they trust other group members, but with skepticism. They do not think that anyone would lie there on purpose, but they are critical for example if someone generalizes their personal experiences.

I1: I'm critical. There is for example a lot of discussion about drugs like "not in any case, I got terrible side effects, so you shouldn't take it." I believe that someone has gotten side effects, but I don't base my decisions on that, because they are personal things.

I4: I trust them with common sense skepticism. Like all the things don't work with all the people in a same way, for example medication. Everyone is unique and symptoms can be unique. If someone tells me he has these symptoms, I believe he has them. But I can't trust that I would have similar symptoms that something happens to me because it happened to someone else.

I5: I trust what people tell there. I don't think that anyone had a reason to make up things there. I trust mostly. Of course, if something is told, I like to learn more about that. But mostly I trust.

I6: I take it critically. I study social services and health care. Many ask there about health and medication, what people have had. And it's really personal how they effect on different people. But you get a lot of valuable information about user's experience, for example common side effects. I take them quite trustingly, but with a little criticism. Same thing with applying financial aid and things like that. Many have experience on that and they now how it goes, what you should write and what comes straight back. You get trustworthy information quite well from there.

5.4 Polarization between vaccinated and natural narcoleptics

he last theme (5) duality of the community is about how the interviewees view the two types of narcoleptics in their community. Four of the six interviewees mentioned two different types of narcoleptics, which are narcoleptics who have gotten narcolepsy "naturally", and narcoleptics who got it because of the Pandemrix vaccine.

Narcoleptics who have fallen ill because of the vaccine have somewhat different situations than the other narcoleptics. For example, they get compen-

sation from the Pharmaceutical Insurance pool. Based on the interviews they sometimes do not remember that and that had caused some issues in the group.

> I1: I have noticed that many who have gotten it from the vaccine sometimes forgot that it's not the case with everyone. For example, if someone asks about compensations like disability pension the answer is always "You should contact Pharmaceutical Insurance pool". The pool doesn't help us at all, and it has nothing to do with us.

> I6: It's quite biased, it feels a little bit like there are two opposites. There are these, who have gotten narcolepsy naturally and then there are these, who have gotten it because of the vaccine. Between them there's issues like it isn't allowed to discuss about the vaccine compensations. I think it's quite stupid, because we can't do anything about it if someone has happened to get narcolepsy from the vaccine.

Problems between Pandemrix vaccinated narcoleptics and other narcoleptics got so bad that they decided to found another group. In the *Narkolepsiaan vertaistukea* group there is common discussion related to narcolepsy. In the other group there are discussions mainly about the Pharmaceutical Insurance pool's compensations and other things that are related to narcolepsy and Pandemrix vaccine.

> I2: Because of that, we have two separate groups. There's narcolepsy association's group and then there's group for the ones who got narcolepsy because of the vaccination. Compensations caused a lot of nerve. In the vaccination group we talk mainly about the compensations and so on, because these so-called natural narcoleptics haven't gotten any compensations. That's why the separate group was founded, so we can tell more about the compensations and so on.

> I3: They just ruled out discussions about the vaccination and compensations. I haven't gotten narcolepsy because of the vaccination. They made a different group for discussions about that. It made it a little bit easier.

Table 6: Results of the interviews

Theme	Results
Online peer-to-peer communities interviewees use	• All interviewees were in the narcolepsy Facebook group *Narkolepsiaan vertaistukea*. • No one mentioned other narcolepsy-related online communities. • Two interviewees were also in other online peer-to-peer support groups.

How interviewees use online peer-to-peer communities	• Most of the interviewees said they mainly just follow the discussion. • All interviewees said that they comment sometimes and 4 said they comment every time they see something relevant to them. • Many of the interviewees had used the group more frequently when they had something new related to the disease, for example examinations or medication. • Discussions and their topics vary a lot. • Most of the interviewees seek new information and other narcoleptics' experiences. • Some of the interviewees seek peer-to-peer support and understanding. • Some of the interviewees do not want to share anything personal while others share everything they can if they feel that it helps others.
Impacts online peer-to-peer support has had on the interviewees	• Only 1 of the interviewees had not noticed any benefits on their well-being. • Mostly interviewees had learned to cope better with the disease. • 2 interviewees had gotten new information about the disease. • Only 1 interviewee had had negative experiences in the group. • All of the interviewees told that reading about others' problems make them feel bad, but they do not take it too heavily. • All of the interviewees told that reading about others' successes make them feel good and hopeful.
Sense of community	• 5 of 6 interviewees told that they feel like they are a part of a community in the group. • Most of the interviewees told that the majority of the group members behave well and that the discussion is smooth and supportive. • 3 interviewees had had some problems in discussions. • All interviewees trust other group members with skepticism.
Duality in community	• Pandemrix vaccinated narcoleptics have somewhat different situation compared to other

	narcoleptics and it had caused some issues in the group. • They found another group for discussions that are related to narcolepsy and Pandemrix vaccine.

6 Discussion

In this chapter, it is reviewed what kind of conclusions can be made based on the results of the interviews presented in chapter 5, and what kind of entity the interviews form. In addition, it is represented how these conclusions are in line with literature and earlier studies which are presented in chapters 2 and 3.

6.1 Used Online Peer-to-Peer communities

Interviewees for the empirical part of this study were recruited from the Finnish Facebook group *Narkolepsiaan vertaistukea*, so it is natural that all of them used that group. There are endless amounts of different kinds of online communities. An online community can be large or small, local or international, and they can be based around a certain purpose. (Porter, 2004.) *Narkolepsiaan vertaistukea* is a rather large community with 383 group members. It is a national community, because its purpose is to offer peer-to-peer support for narcolepsy to Finnish people. Like online communities usually, the group is also a relational community. It does not matter where group members are physically, because the group is formed around human relationships. (Gusfield 1975.)

There are endless amounts of different peer-to-peer support communities on the internet. However, *Narkolepsiaan vertaistukea* and its sister group for pandemrix-vaccinated narcolepsy patients were the only narcolepsy-related online community mentioned in the interviews. Couple of the interviewees mentioned other peer-to-peer support groups related to other diseases such as endometriosis.

6.2 How Online Peer-to-Peer Communities Are Used

Mostly the interviewees just follow the discussion on the *Narkolepsiaan vertaistukea* group. This is in line with the study of Mamykina et al. (2015) who

found out that most group members post only once, fewer post from two to six times, and even fewer post regularly. Some of the interviewees told they follow the group more frequently and some of them quite rarely. However, all of the interviewees stated that they comment on others' posts for example every time they know the answer to a question or if their own experience is relevant to the topic. Also earlier studies have shown that peer-to-peer community members usually discuss about their own experiences and share information about their disease (Zhou et al., 2014; Naslund et al., 2016). Interviewees described common discussion topics on the group. Many of them mentioned topics about everyday life, experiences with the disease, and coping with the disease.

It is common that new members of a peer-to-peer support community are newly diagnosed. In that situation patients are usually curious to find support and more information about the disease. (Zhou et al., 2014.) Based on the interviews it could be stated that also the group *Narkolepsiaan vertaistukea* is important to its members every time there is something new related to the disease. Many of the interviewees described how they used the group more frequently right after they joined there, when they had new physical examinations, or if their medication had been changed.

Mamykina et al (2015) found out that patients with a chronic disease usually seek information, peers, and support online. Also most of the interviewees told that they are in the group *Narkolepsiaan vertaistukea* to hear about other narcoleptics' experiences and to learn new information. Some of them said that they also seek understanding and peer-to-peer support.

It can be stated that it varies a lot how much people want to share about themselves in an online peer-to-peer support group. Some of the interviewees told that they do not want to share personal things in a big group and some told that they share everything they can if they feel like it helps others.

6.3   Impacts of Online Peer-to-Peer Support

Peer-to-peer support benefits chronically ill patients. It can for example give a sense of connection and experiential knowledge, help to find meaning in life and to feel less isolated (Embuldeniya et al, 2012). Many of the interviewees described how online peer-to-peer support had helped them to learn to better cope with narcolepsy, and to accept it as a normal part of their life. Some of them also felt that it had helped to know other people with the same condition.

Most of the interviewees stated that being part of *Narkolepsiaan vertaistukea* had changed the way they feel about the disease. Many of them mentioned that now they see narcolepsy as a normal part of their life, and that they have accepted that they can not do everything like healthy people. Feeling normal is a meaningful aspect of peer-to-peer support. Patients who live their life as normally as possible usually view their disease more positively (Lubkin & Larsen 2013, p.27).

Earlier studies have shown that online peer-to-peer support groups are linked to better access to information related to the disease which makes it easier to manage all the problems caused by the disease (Bender et al., 2011; Scambler, 2008, p. 89). Also the interviews revealed that some of the interviewees had had concrete benefits or valuable information from the group *Narkolepsiaan vertaistukea*.

None of the interviewees had noticed that online peer-to-peer support would have had any negative effects on their well-being. Some of them had not gotten as much support as they had wanted or had had some negative encounters with other group members, but they had not taken it personally. Possible negative effects of online peer-to-peer support are that patients shut off their offline relations or that they are too trusting with advice they read online (Naslund et al., 2016; Zhou et al., 2014). Some patients can take others' problems very seriously and feel bad about reading them or feel jealous if they read about others' successes. None of the interviewees had not had problems with that.

6.4   Sense of community

Five out of six interviewees felt like they are a part of a community in the group *Narkolepsiaan vertaistukea*. This is very natural with online peer-to-peer support groups, because usually they are formed around one thing, the disease (Mamykina et al., 2015). Some of the interviewees described how the group is a very close community and some felt like the disease is the reason they are all in it together. This is in line with prior studies. Mamykina et al. (2015) found out that chronic diseases are a very emotional topic and it brings community members together. Discussions are often deep and members are genuinely interested in each other.

Based on the interviews, discussion in the group is mainly smooth and supportive. Although there had been some problems between group members, the majority of the group members behaved well.

6.5   Duality in the community

Finnish narcoleptics are in an unusual situation where some of them have gotten the disease "naturally" while others have gotten it from the Pandemrix vaccination. This has caused some issues in the group *Narkolepsiaan vertaistukea*. It could be stated that there is duality in the community because the two kinds of narcoleptics have very different situations. Interviewees mentioned for example that pandemrix-vaccinated assume that all of the narcoleptics get the same compensations as they do and that all of the "natural" narcoleptics do not want to read discussions about the vaccine or about the compensations.

There are no earlier studies about this phenomenon, but it is studied that online communities might have very different meanings to different people. For example Preece (2001) stated that some see online communities as warm groups of friends while others see possibilities to hatred-based groups. However Mamykina et al. (2015) found out that in the international diabetes support group *TuDiabetes* members value all opinions even if they can be very diverse.

7   CONCLUSIONS

This master's thesis consists of literature review and empirical research. At first, chapter 2 presents information about online communities and social media. In chapter 3 earlier studies about chronically ill and online peer-to-peer support are introduced. Empirical research and research methods are explained in chapter 4. Chapter 5 presents results of the empirical research and in chapter 6 they are discussed and compared to earlier studies. In this chapter the results of this study are reviewed and discussed. After that, the reliability and validity of this study are reviewed. Finally, this chapter introduces limitations of this study and proposes topics for future research.

7.1   Online Communities as Channels for Peer-to-Peer Support

Research question of this study was 'How chronically ill patients use online communities, how they affect their well-being and is the usage similar amongst Finnish narcolepsy patients?'. To find out answer to this question, it was necessary to find out answer to three sub-questions:

What kind of online communities do they use?
How do they use online communities?
How online communities affect their well-being?

These questions were studied at first by reviewing literature and earlier studies about the topic. After that empirical research was conducted based on the literature review. In the empirical part of this study six Finnish narcolepsy patients were interviewed.

Based on the literature review it could be stated that there are many ways chronically ill patients can use online communities. Mostly they share their experiences and information, and seek support. Empirical research suggests that Finnish narcolepsy patients use their social media community in a very similar way.

Literature review showed that online communities have many benefits on the well-being of chronically diseased as well as possible disadvantages.

Probably the most important finding of the literature review was that chronically diseased feel like online peer-to-peer support benefits their well-being. They get emotional support and online peer-to-peer support makes their life with the disease feel more normal. There were also other important aspects. Peer-to-peer support enables better access to health information and peer-to-peer support online communities might help patients to know when and how to seek help for themselves. Some chronically ill may have difficulties in fully engaging in social interactions, and online peer-to-peer support offers a way to have social connections where people can engage in whatever level they feel like.

Empirical research showed that Finnish narcolepsy patients had gained similar benefits from online peer-to-peer support. Mostly it had helped them to better cope with narcolepsy and to take it as a normal part of their lives. Some of the interviewees had learned valuable information from their peers online.

Literature review revealed that online peer-to-peer support has also negative aspects. Patients can for example be a little bit too trusting towards their peers and they might take some poor advice from people they do not know in real life. Some patients might take other peers' posts too seriously and begin to worry about others or get expectations that are unrealistic for themselves.

Based on the interviews, Finnish narcolepsy patients had mainly not experienced any negative effects of online peer-to-peer support. One interviewee told that she had had negative encounters with her peers and other told that she had been disappointed for the small amount of support. Interviewees told that they feel bad about their peers' problems, but based on the interviews they did not seem to take them too seriously. None of them had gotten unrealistic expectations, but more hope for themselves.

To summarize, it could be stated that there are endless amounts of different online peer-to-peer support communities and chronically ill use them very diversely. Online peer-to-peer support has clear benefits on their well-being, but it can also have negative effects. Online peer-to-peer support usage and benefits are similar amongst Finnish narcolepsy patients with some special features.

Results of this study can be used when it is thought whether an online peer-to-peer community is useful to establish or not. Results are also useful when an online peer-to-peer community is founded or renewed. These results helps discussion about online peer-to-peer support communities for chronically ill.

7.2 Limitations

This research has a couple of key limitations. Probably the biggest limitation is that the interview count is quite low. Although originally the goal was to interview ten to fifteen Finnish narcolepsy patients, there were only six interviews. Recruiting interviewees proved to be difficult. At the time of the study there were only 383 members in the group *Narkolepsiaan vertaistukea* (Facebook, 2019) and they live all around Finland so it was challenging to find enough people who were interested to participate in the study and could arrange time for the interview. The disease is a very sensitive topic to talk about to a stranger, which also could have limited the amount of the interviewees, although it was stated that the interviews would be confidential. Although there were only six interviewees, they were quite diverse. they were aged between 22 and 51, and both male and female. Some of them had gotten narcolepsy from the pandemrix vaccine and some without it. The disease affected all of their lives differently. If even one of the interviewees would forget to mention something important, it could affect the results because of the low amount of interviews.

Another limitation is that the interviews were conducted in Finnish, transcribed and translated to English. Even though transcriptions and translations were made carefully, some information could have been lost in translation.

This study can be considered successful. It met its objectives and all of the research questions were answered to. Research also gave a lot more information which might be useful considering future research. Results of this study can be used as a framework when online peer-to-peer support communities for chronically ill are discussed.

7.3 Future research

This study brings up a few interesting topics for future research. It would be useful to study more specifically how online peer-to-peer support groups should be constructed so that they are as beneficial as possible. Another interesting topic would be how different group policies and administration of the group affect the usage and benefits of online peer-to-peer support.

Because the empirical part of this study was researched with a qualitative method, it would be interesting to research the topic further with quantitative methods to see if the findings of this research are generalizable.

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